

# Submission to the Review of the National Disability Insurance Scheme (NDIS) Act and the new NDIS Participant Service Guarantee

## Introduction

Mental Health Australia, Community Mental Health Australia and the Mental Illness Fellowship of Australia welcome the Government's intention to review the National Disability Insurance Scheme (NDIS) legislation and develop a NDIS Participant Service Guarantee. The mental health sector has advocated for, and worked with the National Disability Insurance Agency (NDIA) on, an improved experience of the Scheme for people with psychosocial disability since its introduction.

However, we anticipate the Participant Service Guarantee, as proposed in the discussion paper, will not be able to be realised without changes to the legislation, rules and practices of the NDIS and NDIA. This submission proposes such changes designed to assist the NDIA to realise its proposed Participant Service Guarantee, clarify the original policy intent of the NDIS and align it more closely with recovery-oriented practice. None of the proposed changes are intended in any way to widen the scope of the Scheme.

## NDIS Legislation and Rules

Since introduction of the NDIS Legislation and Rules, the mental health sector has raised concerns about the use of the term 'permanent' to describe an impairment related to a psychiatric condition (see Section 24 of the *National Disability Insurance Scheme Act 2013*). This terminology is opposed to recovery-oriented practice,<sup>1</sup> widely accepted as good practice in psychosocial disability work.

Despite this advice, an Independent Review of the NDIS Act by Ernst and Young in 2015,<sup>2</sup> concluded the need for an impairment to be permanent in the context of mental illness should not be changed, because changing this language could potentially widen the scope of the Scheme. Ernst and Young found the legislative framework already accommodated some of the sector's concerns around allowing for fluctuating impairments and the evidence at the time didn't indicate this aspect of the legislation had an impact on Scheme participation by people with psychosocial disability.

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<sup>1</sup> The National Framework for Recovery-Oriented services states that recovery-oriented practice "refers to the application of sets of capabilities that support people to recognise and take responsibility for their own recovery and wellbeing and to define their goals wishes and aspirations." (p15)

<sup>2</sup> Ernst & Young (2015) Independent review of the NDIS Act

In practice Government has shown some good intention to adjust the operation of the Scheme, within current legislative restrictions, to more closely align it with recovery-oriented practices. For example the Council of Australian Governments (COAG) Disability Reform Council recently announced the “establishment of a Psychosocial Disability Recovery Framework, with a strong focus on recovery and supporting episodic needs...”<sup>3</sup> The NDIA has also established a working group with Mental Health Australia focussing on how to improve the experience of the Scheme for people with psychosocial disability, outlined in more detail below.

However, feedback from service providers suggests the permanency provision remains incompatible with recovery-oriented practice as this requirement in the legislation flows into practice within the NDIA. For example, the NDIS (Becoming a Participant) Rules state that NDIS applicants with disability are required to prove that there are “no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment.” While this measure of permanency may be adequate for some other disabilities, it does not recognise that people with mental illness will receive ongoing clinical, medical and other treatments and psychosocial services to aid their recovery, potentially (sometimes episodically) over the course of their lives. It fundamentally fails to acknowledge the episodic nature of psychosocial disability.

To resolve this issue, in 2017, Mental Health Australia, Community Mental Health Australia and the Mental Illness Fellowship of Australia provided advice to the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme, including suggestions for changes to both the NDIS Act and the Rules. The key elements of this submission relevant to the current NDIS Legislation Review are:

- NDIS Act section 24:
  - replacing the word ‘permanent’ with ‘ongoing, enduring or chronic’
  - replacing references to ‘psychiatric condition’ with ‘psychosocial disability’
- NDIS (Becoming a Participant) Rules:
  - Stating that rule 5.4 (which requires proof that all treatments that would be likely to remedy the impairment had been explored) does not apply to psychosocial disability
- NDIS (Supports for Participants) Rules:
  - Recognising that a recovery-oriented approach will be taken by the NDIA in determining support needs for people with psychosocial disability.

The full submission is at Attachment A for reference.

In response, the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme recommended:

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<sup>3</sup> COAG Disability Reform Council (2019) Meeting of the COAG Disability Reform Council, Sydney – 9 October 2019, (p1)

- that the NDIS Act is reviewed to assess the permanency provisions in Section 24 (1) (b) and the appropriateness of the reference to 'psychiatric condition' in 24 (1) (a)
- a review of the NDIS (Becoming a Participant) Rules 2016 be considered to assess the appropriateness and effectiveness of clarifying that Rule 5.4 which dictates that a condition is, or is likely to be permanent, does not apply to psychosocial disability, to reflect that people with mental health conditions will receive ongoing treatments to aid recovery.

Mental Health Australia, Community Mental Health Australia and the Mental Illness Fellowship of Australia continue to support the Parliamentary Joint Standing Committee's recommendations. We welcome the opportunity presented by the current NDIS Legislation Review for further assessment of these recommendations.

### Recommendation

The Australian Government:

- revises Section 24 (1) (a) and (b) of the *National Disability Insurance Scheme Act 2013*, in consultation with key stakeholders across the mental health sector to better align these sections with recovery-oriented practice
- makes changes to the NDIS (Becoming a Participant) Rules 2016, Rule 5.4 so that it does not apply to people with psychosocial disability
- includes reference to recovery-oriented supports in the NDIS (Supports for Participants) rules 2013.

### Participant Service Guarantee

As noted above, the mental health sector has advocated for, and worked with the NDIA on, an improved experience of the Scheme for people with psychosocial disability since its introduction. Mental Health Australia, Community Mental Health Australia and the Mental Illness Fellowship of Australia therefore support the Government's intention to formalise a NDIS Participant Service Guarantee. This will provide an opportunity for consumers and carers to understand what they have a right to expect of service provided through the Scheme. It will also provide an objective measure, against which to guide service provided by NDIA and partner staff.

However, as the Scheme currently stands, the NDIA will have difficulty in realising the Participant Service Guarantee for people with psychosocial disability. In order to do this, the NDIA will need to fundamentally change the way the Scheme is operationalised for people with psychosocial disability.

The NDIA has already made significant inroads on this work through engaging Mental Health Australia in 2018 to run consultations in relation to the design of an NDIS Psychosocial Pathway. This was in response to significant and varied

concerns raised by the mental health sector in relation to the response of the Scheme toward people with psychosocial disability.

Mental Health Australia's consultations resulted in the provision of 29 recommendations to the NDIA in the form of Mental Health Australia's National Disability Insurance Scheme Psychosocial Disability Pathway Report (see Attachment B for the full report). Key recommendations included:

- improvements to assist people with psychosocial disability to access the Scheme including assertive outreach, personalised NDIS engagement support and better communications
- improvements to the skills, knowledge and experience of NDIA and partner staff to work with people with psychosocial disability
- creating better linkages and referral for people who are ineligible for the Scheme.

In October 2018, the Minister for Families and Social Services announced that the NDIA would establish a psychosocial stream for the NDIS including:

- staff with specialist skills who understand psychosocial disability
- better linkages between mental health services and NDIA staff and partners
- a focus on recovery-based planning and episodic needs.

The NDIA subsequently established a NDIS Psychosocial Stream working group with mental health sector stakeholders to work through Mental Health Australia's recommendations paying particular attention to:

- supporting people with psychosocial disability to prepare to access the Scheme
- responding to the episodic nature of psychosocial disability
- creating better linkages and referral for those who are ineligible for the Scheme.

The NDIS Psychosocial Stream working group's advice has been provided to the NDIA. Subsequently, the COAG Disability Reform Council has announced a range of initiatives designed to improve the experience of the Scheme for people with psychosocial disability as well as managing the interface with mainstream services.<sup>4</sup>

Each of the reforms outlined above will be an integral component underpinning the success of the NDIA, or otherwise, in realising its proposed Participant Service Guarantee in practice for people with psychosocial disability. With effective collaboration having been undertaken through the NDIS Psychosocial Stream working group, and robust advice having been received by Government, we are now at a critical juncture to ensure change is implemented. Accordingly, it will be important for both the COAG Disability Reform Council and the NDIA to enact swift and comprehensive communications campaigns about the specific changes they intend to make in order to improve the experience of the Scheme for people with

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<sup>4</sup> See the Council of Australian Governments Disability Reform Council Communique of 9 October 2019.

psychosocial disability, including the timeframes over which these changes will be implemented.

## Recommendations

In order to realise the proposed Participant Service Guarantee:

- the NDIA should:
  - continue to work collaboratively with the sector to improve the experience of the Scheme for people with psychosocial disability
  - embark on detailed communications with the sector about its plans to improve the experience of the Scheme for people with psychosocial disability, based on its recent work with the NDIS Psychosocial Stream working group.
- the COAG Disability Reform Council should publicly release a detailed implementation plan in relation to the work program it has proposed in its communique of 9 October 2019.

## Conclusion

The recommendations outlined in this submission are intended to assist the NDIA to realise its proposed Participant Service Guarantee, clarify the original policy intent of the NDIS and align it more closely with recovery-oriented practice. The recommendations are not intended, in any way, to widen the scope of the Scheme.

It is clear that NDIS is on the cusp of exciting changes, which should improve Scheme effectiveness and experience for people with psychosocial disability. It is important this momentum is seized by governments and the advice developed by or in collaboration with the sector is acted on. This should include changes to the legislation, rules and operations of the NDIS and NDIA as outlined above. These actions will underpin the NDIA's success in realising the proposed Participant Service Guarantee.



**Mental Health  
Australia**

### About Mental Health Australia

Mental Health Australia is the peak, national non-government organisation representing and promoting the interests of the Australian mental health sector and committed to achieving better mental health for all Australians. Mental Health Australia members include national organisations representing consumers, carers, special needs groups, clinical service providers, public and private mental health service providers, researchers and state/territory community mental health peak bodies.

### About Community Mental Health Australia

Community Mental Health Australia (CMHA) is a coalition of the eight state and territory peak mental health organisations. Through them CMHA has a direct link and provides a unified voice for several hundred nongovernment organisations who work with mental health consumers and carers across the nation.

### About the Mental Illness Fellowship of Australia

Mental Illness Fellowship of Australia (MIFA) is a federation of long-standing member organisations, established in 1986. Our members deliver specialist services for individuals living with severe mental ill-health and their carers, friends and families, out of nearly 60 'front doors' in metropolitan and regional areas, to over 20,000 people each year. Our membership has a strong focus on building community, valuing peer support and lived experience, and supporting recovery.



# Attachment A

## Options for achieving recovery oriented psychosocial support in the NDIS

Supplementary submission to the Joint Standing Committee on the NDIS inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition

This supplementary submission has been prepared for the Joint Committee on the National Disability Insurance Scheme in response to its question on what needs to change for the Scheme to have a recovery focus for people with psychosocial disability. We believe the issue, which is the subject of widespread stakeholder concern, has arisen in part because the Scheme was initially designed for people with physical disability, with psychosocial disability a late addition.

Our recommendations are informed by the principles in the *National Framework for Recovery-Oriented Mental Health Services*, endorsed by the Australian Health Ministers' Advisory Council in 2013. A recovery-oriented approach aligns with the objective of the NDIS to maximise independence and social and economic participation at the individual level. A recovery orientation is also consistent with the Scheme's emphasis on choice and control.

The options presented are intended to clarify the original intended cohort for the Scheme – i.e. people with the greatest need for disability support – not to expand the Scheme's reach. We do not recommend a relaxation in access criteria or their application, but instead to make improvements in order to assist the right people to access the NDIS as easily as possible.

### Legislation

We recommend the following amendments to section 24 of the *National Disability Insurance Scheme Act 2013*:

- Remove references to *psychiatric condition* and replace with *psychosocial disability*. Using a validated assessment tool, a full assessment of a person's functional capacity to undertake activities of daily living can preclude the current requirement that a *psychiatric condition* be demonstrated by medical certification.
- Replace the word *permanent* with *ongoing, enduring, or chronic*
- Consider incorporating into 24.1 (b): *the impairment or impairments are ongoing, or likely to be ongoing without the person receiving supports intended to build their capacity.*

While a change to the legislation is necessary, we believe the urgent priority is to ensure the operation of the Scheme is recovery-oriented for people with psychosocial disability.

## Regulation

Amendments to NDIS Rules will give the NDIA greater flexibility to implement the Scheme for people with psychosocial disability based on recovery principles. We recommend the following amendments to the Rules:

Amend the *National Disability Insurance Scheme (Becoming a Participant) Rules 2016* to:

- Include the principle of recovery-oriented practice for psychosocial disability.
- Remove the requirement that psychosocial disability must be, or likely to be, permanent. (Subrule 5.1.(e) requires that a person is likely to require support under the NDIS for their lifetime, which adequately covers the longevity of the impairment.)
- Clarify that Rule 5.4 does not apply to psychosocial disability, to reflect that people with mental illness will receive ongoing clinical, medical and other treatments and psychosocial services to aid their recovery.

Rule 5.4 An impairment is, or is likely to be, permanent (see paragraph 5.1(b)) only if there are no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment.
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- Recognise that medical evidence obtained for the purposes of gaining the Disability Support Pension is sufficient in confirming both the medical fact of and the enduring nature of a psychosocial disability.

Amend the *National Disability Insurance Scheme (Supports for Participants) Rules 2013* to:

- Recognise that a recovery-oriented approach will be taken by the NDIA in determining support needs for people with psychosocial disability.
- Require that a validated assessment tool is used for assessing reasonable and necessary supports for people with psychosocial disability, which would ensure equity for these NDIS participants while enabling the NDIS to operate according to insurance principles with timely investment to minimise lifetime costs.

## Operational processes

The universal model of the NDIS is admirable. However, unique needs can and should have tailored approaches, such as that which has already occurred with early childhood. Recovery-oriented practice can be applied to the operational aspects of the Scheme for psychosocial disability.

Given the philosophical differences between the recovery-oriented assessment of and planning processes for people with psychosocial disability and those with other disabilities, the organisational structure of the NDIA should accommodate a specific psychosocial disability stream and NDIA staff (including staff involved in assessment and planning) should have expertise in psychosocial disability.



Other options for recovery-oriented practice in NDIS processes are set out below.

#### Assessment process

- Remove the requirement for people with psychosocial disability to produce medical evidence of the psychiatric condition and a medical testament to its permanence. This administrative practice to truncate individualised assessment of functional capacity is not a recovery-oriented approach to providing psychosocial supports services for people with mental illness.
- Adopt a validated assessment tool that is fit for purpose to assess the eligibility of people with psychosocial disability that focusses on their impairment and functional capacity to undertake activities of daily living.
- Assessment of people with psychosocial disability should be undertaken by a person with the right professional expertise. This can be done within the NDIA or outsourced, noting that the professional expertise largely exists in community based mental health service provider organisations and mental health professionals working with people with psychosocial disability.

#### Planning process

- Participants' plans should be oriented to capacity building supports to aid recovery, wherever possible.
- The planning process should be based on evidence of what constitutes effective and recovery-oriented packages of support for psychosocial disability.

#### Pricing

- Prices for psychosocial supports services should reflect the costs of a recovery-oriented services, i.e. not simply assistance with activities of daily living.

Since rollout commenced, mental health providers have repeatedly highlighted that the price of supports is set well below the hourly rate for psychosocial support work currently delivered by suitably qualified people. There is no hourly price for psychosocial support services in the NDIS Price Guide, and mental health providers have had no involvement in the process to set prices for different support types.

#### Background

The *National Framework for Recovery-Oriented Mental Health Services* was developed by the Australian Health Ministers' Advisory Council in 2013 and is formal government policy. The Framework acknowledges that "Words and language are critically important in the mental health field where discrimination, disempowerment and loss of self-esteem can cause people to battle with self-stigma". This is why the use of the term "permanent" in the NDIS legislation presents such a big barrier to the cohort for whom the Scheme is intended to support. It is why so many stakeholders have made this point in their submissions to Parliamentary inquiries, review of the NDIS legislation and to the Productivity Commission.

In 2015, reporting on its review of the *National Disability Insurance Scheme Act 2013*, Ernst and Young recommended that the government conduct another review of the Act in two to three years given that the "legislative framework will be exposed to more participants, more

locations and more sources of stress”.<sup>1</sup> Ernst and Young noted that the [second] review will “help government ensure that the legislative framework is ‘fit for purpose’ for full Scheme”.

### Eligibility assessment tool

In its advice for implementing the NDIS for people with mental health issues<sup>2</sup>, the NDIS Independent Advisory Council found there was “no commonly accepted and used instruments for assessing functional impairments and indicating support needs related to disability due to a psychiatric condition”. The Council highlighted the risk of inconsistent approaches in both eligibility and support needs being determined by the NDIA.

The issue remains unresolved and the Council has recommended, in its submission to the Parliamentary Joint Standing Committee on the NDIS, that the NDIA “invest in the development of a validated instrument for identifying an evidence-based approach to the determination of functional impairments and support needs for people with an impairment related to a psychiatric condition”. It is unclear what has prevented the NDIA from: a) developing an NDIS specific tool; b) modifying the existing assessment tool for physical disability to assess psychosocial disability; or c) purchasing the licence for an existing psychosocial assessment tool.

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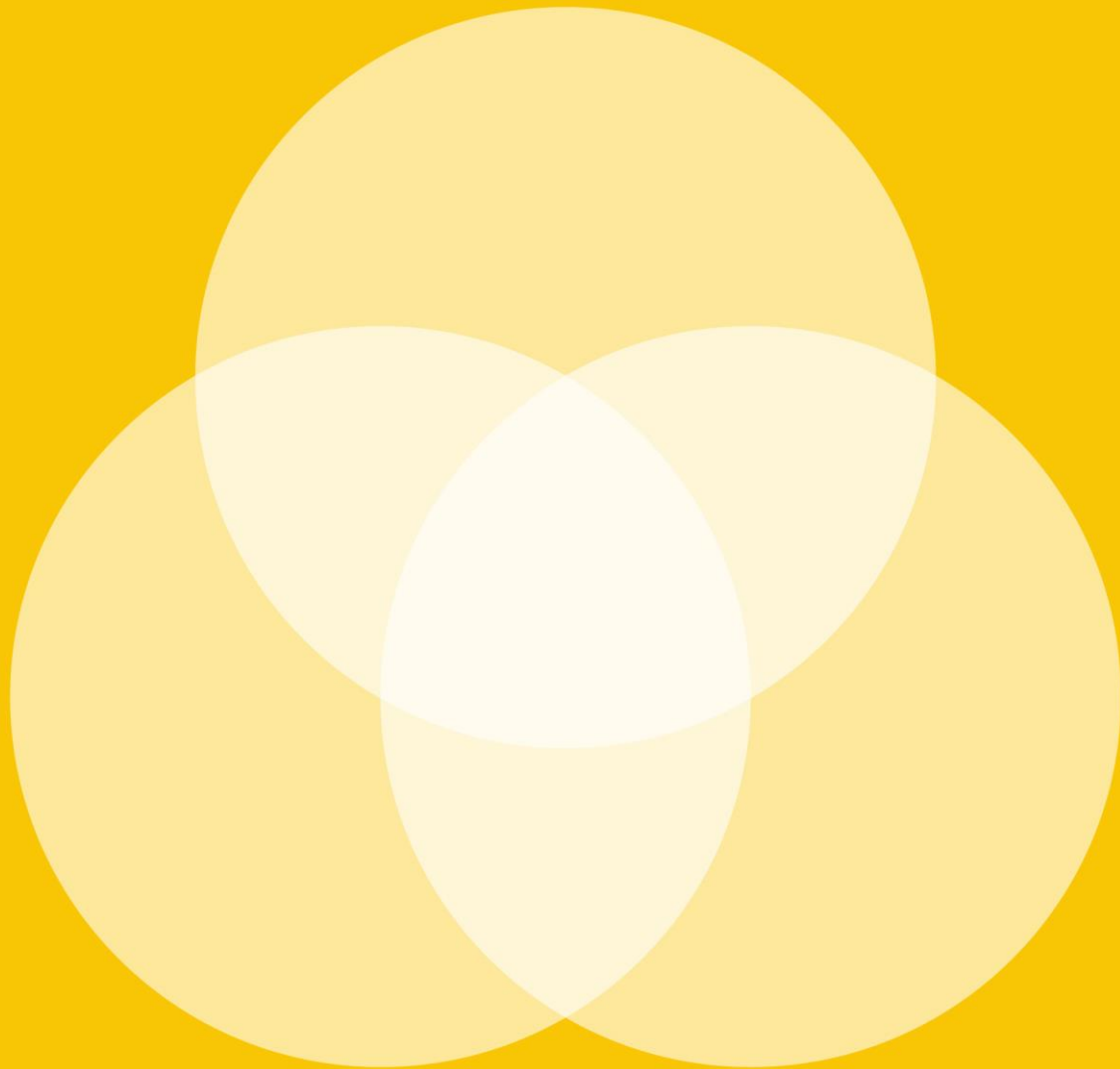
Liz Crowther  
President  
Community Mental Health Australia



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<sup>1</sup> Ernst and Young, *Independent review of the NDIS Act*. December 2015. Page 3.

<sup>2</sup> Independent Advisory Council for the National Disability Insurance Scheme, *IAC advice on implementing the NDIS for people with mental health issues*, 2014



**National Disability Insurance Scheme:  
Psychosocial Disability Pathway**

**MAY 2018**

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# Key messages

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During February, March and April 2018, Mental Health Australia conducted a series of consultation workshops with stakeholders to hear how NDIS participants with psychosocial disability, their carers and providers experience the National Disability Insurance Scheme (NDIS). Mental Health Australia held five face to face workshops involving over 170 participants and one after-hours teleconference with health professionals. Thanks to the generous engagement of the workshop participants, Mental Health Australia is able to propose to the National Disability Insurance Agency (NDIA) a series of important reforms to improve the experience of the scheme for people experiencing psychosocial disability.

Provided below are the key messages arising from the consultations. More specific descriptions around pain points and corresponding recommendations are provided at Chapter 7.

1. Psychosocial disability differs from most other forms of disability, especially because it directly affects and is affected by the individual's NDIS service experience
  - » the individual's mental health fundamentally shapes their NDIS experience
  - » poor experiences with access and planning (for example long wait times and decisions that are inconsistent with individual needs) can degrade NDIS participant and carer wellbeing.
2. The psychosocial disability journey begins well before 'Phase 1' of the NDIA's current pathway, requiring:
  - » assertive outreach
  - » personalised NDIS engagement support
  - » resources for the community.
3. The skills, knowledge and experience of front line staff are crucial:
  - » NDIA and partner staff who work with people experiencing psychosocial disability should have psychosocial disability specific skills, knowledge and experience. Administrative process and arrangements should support the practical application of those skills and experience.
4. Access, planning and review processes need to be consistent, fair and transparent
  - » there is an urgent need for a validated, psychosocial disability specific, access assessment tool
  - » NDIA needs to provide routine opportunities to people with psychosocial disability and their supporters to check and confirm decisions and the evidence on which they are based

- » family and carers have a crucial role. For example, family and carers often hold crucial information about a participants' support needs, which the participant may not articulate themselves as a part of assessment or planning processes.
5. The NDIA has a responsibility towards people experiencing psychosocial disability who do not access the NDIS including:
- » those who are 'hard to reach' who may not be in contact with services, which could assist them to access the NDIS
  - » those who may for a variety of reasons – often reflective of their psychosocial disability – be reluctant to seek to test their eligibility
  - » those found to be ineligible or those who assume they would not be eligible.

The NDIA could improve the assistance it provides to people in the above-outlined situations through referrals ('warm handovers') to effective and appropriate mainstream services, for example: as a part of strengthening the Information, Linkages and Capacity Building component of the NDIS.

It is also important that the pathway reforms take account of new service offerings for people who will not be eligible for the NDIS, likely to come online over the next 12-18 months at both a State/Territory and Commonwealth level.

6. Certain support types should be discussed in every planning conversation with NDIS participants with psychosocial disability:
- » support coordination
  - » capacity building
  - » carer support and respite
  - » provision for urgent and unplanned needs, due to episodes of illness and disability.
7. Implementation of reforms to the psychosocial disability pathway should be collaborative and subject to transparent evaluation, this would mean:
- » major design elements to be tested with participants and through piloting
  - » the NDIA to ensure close engagement with the mental health sector including mainstream systems and stakeholders
  - » regular, targeted reporting on outcomes for people seeking access to the scheme and the content and effectiveness of psychosocial disability plans.

Implementing an effective response to psychosocial disability presents not just a significant operational challenge to the NDIA (involving changes to how the NDIA and its partner organisations operate in their interactions with people experiencing psychosocial disability), but also a major strategic challenge. This is because issues for people experiencing psychosocial disability arise and are fundamentally shaped by their experience outside the NDIS. People with psychosocial disability often experience the inherent vulnerabilities which result from a personal history of mental health hospital admissions and potentially involuntary treatment, including seclusion and restraint. This can make it difficult to navigate an often fragmented mental health sector. In addition, mental health services are generally poorly resourced, operating in an environment where there are major gaps in service provision across the country and ongoing uncertainty about the provision of psychosocial support both within and outside the NDIS. These strategic challenges for providers have a major impact on the supply side of the market and make the NDIA's role as 'market steward'



more complex. Addressing those issues will require effective partnerships and coordination with mainstream service systems and engagement and investment from all Australian governments, which have ultimate responsibility for the mental health system and the NDIS.

In short, minor adjustments to existing NDIS pathways will not result in the change required for the NDIA to appropriately engage people with psychosocial disability; instead the NDIA must develop a comprehensive psychosocial response if improvements in outcomes for the cohort are to be sustainable and the NDIS is to deliver on its promises.

Mental Health Australia therefore recommends the NDIA develop an overarching psychosocial disability strategy to address the range of issues articulated by participants, carers, providers, advocacy groups and other stakeholders through these consultations. Such a strategy would include but not be limited to:

- reforms to the NDIS pathway for participants with psychosocial disability
- improvements in the skills, knowledge and experience of NDIA and partner staff to work with people with psychosocial disability
- reforms to reference packages for psychosocial disability to ensure substantial improvement in the quality of plans, building on a major project already initiated by eight psychosocial providers, supported by the National Mental Health Commission and managed by Mental Health Australia to develop alternative typical support packages for psychosocial disability
- a Communications Strategy to ensure mental health stakeholders are given the best opportunity possible to understand how improvements to the NDIA's work with people with psychosocial disability are working in practice.

# 1. Introduction

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Mental Health Australia is pleased to present this report to the NDIA on the outcomes of a series of consultation workshops held during February, March and April 2018.<sup>1</sup> The workshops considered the NDIS 'pathway' for people experiencing psychosocial disability, and how that pathway can be improved.

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*I'm thankful for being able to talk about the good and the bad of the NDIS  
and all the services involved.  
Workshop participant, Melbourne*

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There were five face-to-face forums in Melbourne (2), Sydney, Perth and Townsville and one teleconference. The workshops comprised part of a wider initiative by the NDIA to develop its new participant pathway and to examine options for addressing the needs of specific groups who may need tailored support and assistance in dealing with the scheme. Issues around mental health and psychosocial disability arise throughout the NDIA's participant pathway initiative, including by:

- individuals with complex needs
- Aboriginals and Torres Strait Islanders
- people from culturally and linguistically diverse (CALD) backgrounds
- people in rural and remote locations.

There were more than 170 participants in the psychosocial disability workshops, including people with psychosocial disability, family members, carers, providers of psychosocial supports and health services, peak bodies, and NDIA staff, managers and board members. The team also conducted a workshop with the NDIA's Mental Health Sector Reference Group, and worked in close consultation with senior staff in the NDIA including the NDIA's Mental Health Special Adviser.

This report is the result of the generous contributions of all the participants in the workshops. It provides advice from Mental Health Australia on the broader strategic issues facing the NDIA as it seeks to ensure the NDIS fulfils its promise as a key element in the wider system of mental health supports and services across Australia. Details of 15 'pain points' identified by workshop participants are provided at Chapter 7, together with 29 recommendations to address those pain points.

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<sup>1</sup> Working closely with the Mental Health Australia team, the workshops were facilitated by Ms Kim Koop and outcomes were recorded by ThinkPlace consultants. Documentation (workshop materials and reporting) was undertaken by Dr Russell Ayres.

To put the 'pain points' in context and to provide a set of specific responses for the NDIA's consideration, this report provides:

- a rationale as to why a different approach is required by the NDIA for people with psychosocial disability than for people with other disabilities
- the key elements of a psychosocial response for the scheme
- the principle design features which would bring these elements to life within the NDIS pathway context, including a new engagement phase for people with psychosocial disability ('Phase 0').

Chapters 5 and 6 of the report address the challenges faced by the NDIA in responding effectively to people experiencing psychosocial disability, with a focus on four key factors underpinning successful implementation of a NDIS psychosocial pathway:

- building psychosocial disability competencies among staff within the NDIA and its partners
- strengthening the role of health professionals, community mental health workers and peer workers in relation to the NDIS
- redefining typical support packages for participants with psychosocial disability
- engaging governments as the stewards of both the NDIS and mainstream service systems, to undertake a more holistic and systematic approach to addressing the complex and challenging needs of people with psychosocial disability.

## 2. Why is psychosocial disability different?

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The inclusion of mental health and psychosocial disability has been a challenging issue for the NDIS, for governments and for policy analysis and advice. The fact that the Productivity Commission (PC) did not include mental health as part of the proposals in the draft report on the NDIS in 2011 meant that many of the fundamental design features of the scheme were developed without reference to the needs of this population.<sup>2</sup> More recently, the PC's report on its study into NDIS costs<sup>3</sup> and the Parliamentary Joint Standing Committee (JSC) inquiry into the NDIS' implementation of psychosocial disability supports<sup>4</sup> seek to address some of the shortcomings in implementation of the scheme to date. The PC's costs report, for example, recommends that a 'psychosocial disability gateway' be established for the NDIS,<sup>5</sup> and the JSC recommends the development of a validated assessment tool for psychosocial disability.<sup>6</sup>

Unique approaches to policy and implementation are needed because psychosocial disability differs from most other forms of disability in key respects. How someone who has a psychosocial disability experiences the world – including their experience in this case of the NDIS – can directly and substantially affect their mental health and therefore their psychosocial disability. This can also vary over time, depending on fluctuations in the individual's mental health condition.

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*Empathy and understanding [are] important for this group.  
Workshops participant, Melbourne*

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Workshop participants indicated the NDIS experience has frequently been a negative one, resulting in additional and unnecessary trauma and distress. This represents an added level of risk for people with psychosocial disability, and an added level of responsibility for the NDIA and its partners. It puts a premium on getting the experience right through well trained and competent staff and clear and transparent procedures, which can materially contribute to the individual's wellbeing and their capacity to deal with the effects of their condition.

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<sup>2</sup> Productivity Commission. (2011). *Disability Care and Support*. Canberra: Commonwealth of Australia.

<sup>3</sup> Productivity Commission. (2017). *National Disability Insurance Scheme (NDIS) costs*. Canberra: Commonwealth of Australia.

<sup>4</sup> Joint Standing Committee on the National Disability Insurance Scheme. (2017). *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*. Canberra: Parliament of Australia.

<sup>5</sup> Productivity Commission (2017), recommendation 4.4.

<sup>6</sup> Joint Standing Committee on the National Disability Insurance Scheme (2017, recommendation 4.

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*The small, positive experiences that contribute to a sense of self and agency are not incidental or minor; they are fundamental to being able to engage in the NDIS.*

*Workshop participant, Melbourne*

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Psychosocial disability can also have a direct impact on a person's ability to navigate the complicated access and planning processes. Some impacts relate to the mental health condition or disability, such as difficulty processing information or fluctuations in mood. Some impacts are secondary, such as the effect of a person's previous traumas, including from a history of being treated involuntarily and subjected to restrictive practices. Some traumas may precede the mental health condition (and psychosocial disability), such as childhood or life traumas.

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*It's important to understand that it's about staying alive.*

*Workshop participant, Melbourne*

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The impact of psychosocial disability can fluctuate, both as a consequence of the mental health condition and in response to factors in the individual's life. There can also be psychological impacts that are secondary to the mental health condition, such as lack of confidence, grief and loss.

In terms of the service response, understanding the social determinants of health is essential to responding effectively to mental health and psychosocial disability. The concept of wellbeing is key. Staff working in the NDIA and for scheme partners should seek to use a person-centred approach to improve, or at least not make worse, the wellbeing of people with psychosocial disability. For example, 'languishing while waiting' for services to commence is often very detrimental to a person's wellbeing.

It is also important to see the individual in the context of their family, carers and support network, which can vary considerably in strength and capacity to provide the support the individual needs. Individuals may also vary in their acceptance of family supports. Families experience the illness in their own way and this should not be underestimated. Equally, individuals and their families should not be blamed for responding to the effects of mental illness in diverse ways.

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*The participant's journey is the [carer/support] network's journey.*

*Workshop participant, Melbourne*

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Staff who do not understand psychosocial disability and mental illness and their impacts can:

- fail to recognise behaviours and responses as part of the mental health condition or psychosocial disability
- perceive individuals as 'failing' to progress, when in fact there are barriers to their progression – this can be unconscious and unintentional but very powerful and disempowering for everyone involved

- fail to engage in effective problem solving
- due to general misunderstandings about psychosocial disability and mental illness that exist in the broader community, perceive an individual to be 'difficult' or 'challenging' rather than seeking to understand how the psychosocial disability and mental illness impact on and are impacted by a person's existing functioning, informal supports, environment and circumstances
- fail to recognise the primary and secondary impacts of the illness as outlined above.

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*High turnover of staff damages [the participant's] experience.  
Workshop participant, Sydney*

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It is therefore crucial that staff have psychosocial disability specific skills, knowledge and experience and that they bring to the task of working with people experiencing psychosocial disability a high degree of sensitivity and empathy.

It is equally important that processes and arrangements allow and ensure the application of these skills at all stages as participants progress through the system.

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*It's not just a difficult or challenging process, the fact is that it's personally  
and emotionally traumatic.  
Workshop participant, Sydney*

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# 3. Elements of a psychosocial disability response

An individual’s experience of the NDIS is a function of the many complex interactions and processes that take place in all three phases of the participant pathway (see

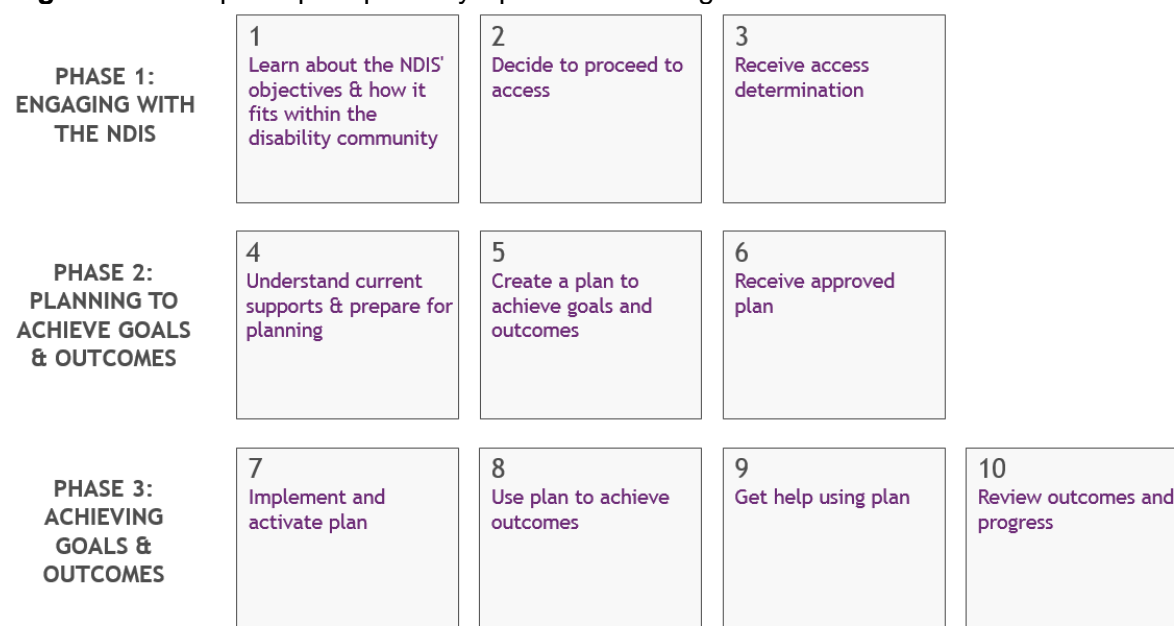
Figure 1):

- Phase 1 – Engaging with the NDIS
- Phase 2 – Planning to achieve goals and outcomes
- Phase 3 – Achieving goals and outcomes

These stakeholder consultations strongly indicated that the period before the NDIS experience formally begins (which will be referred to in this report as ‘Phase 0’) is crucial to the success or otherwise of the individual’s outcomes.

Taken together, interactions and processes throughout the phases (including Phase 0) constitute the NDIS psychosocial disability response. The effectiveness of that response should be seen first from the perspective of the individual who approaches the scheme and seeks and gains access and becomes a participant (or does not). It should also be analysed from the perspective of carers and providers. The response can then be seen from the perspective of the NDIA, as the Agency responsible for working with the individual to ensure the experience of the scheme is as positive as possible.

**Figure 1:** NDIS participant pathway - phases and stages



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*What is the role of mental health assessment instruments in the eligibility or access process?*  
*Workshop Participant, Melbourne*

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The scheme's responsibility to ensure that people with psychosocial disability have equal opportunity to gain access to this scheme as people with other disabilities is significant and complex. Discrimination in accessibility occurs if the NDIA does not allow for the impact of psychosocial disability and mental illness on an individual's ability to access the scheme.

Extreme ends of the spectrum of responses should be avoided, i.e. a paternalistic 'cotton wool' treatment that denies the individual any real agency, and at the other end a one-size-fits-all, cost-driven service delivery that can cause distress and aggravate participants' mental health issues.

There is also a significant responsibility towards people who do not access the scheme, but who need careful and supported referral to non-NDIS services.

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*The NDIS is not for everyone, we need to consider other support options for these people.*  
*Workshop Participant, Melbourne*

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For people with severe mental illness, the NDIS psychosocial disability response is not merely a matter of good 'customer service'. The experience of the NDIS, its people and its processes directly affect the individual's wellbeing and mental health status. That experience must make a positive contribution to their efforts to deal with the effects of psychosocial disability, and must not cause a deterioration in their condition.

To achieve this, the individual's NDIS experience should comprise:

- human, face-to-face interactions, where the individual is met 'on their own terms', wherever possible in locations they feel comfortable, and at a pace they set with processes with minimal stress and according to the needs of their circumstances and condition
- assertive and empathetic listening by assessors and planners who build and sustain rapport
- close involvement of family and carers in meetings and discussions, where agreed with the individual
- active assistance in helping the individual pursue their recovery goals, adjusted to their individual capacity and flexibly applied depending on the fluctuations in their mental health condition
- minimal changes in personnel
- 'warm handovers' (i.e. in person, and with appropriate documentation) between staff and services where required (including for referrals to non-NDIS services and to the Information, Linkages and Capacity Building element of the NDIS, especially for people who do not access the scheme)

- record keeping that minimises the individual needing to repeatedly tell their story (which can risk adding to trauma and distress)
- clear and consistent notification of key process steps ('no surprises')
- documentation that is in clear, plain language
- clear communication of rights and responsibilities, including appeal and review rights
- timeframes that allow the individual adequate time to consider draft or proposed decisions, collect relevant information and evidence, and consult with their family, carers and/or advocates.

In the light of how the NDIS experience can best respond to the needs of individuals experiencing psychosocial disability, the NDIA needs to ensure the scheme has:

- NDIA and partner staff who are:
  - » able to deal sensitively and patiently with people experiencing serious mental health issues, as well as with their families and carers
  - » knowledgeable about the impact of mental illness and psychosocial disability, the recovery model, and about local service providers' capacities and capabilities (including any gaps in supply)
  - » skilled in active listening and guiding constructive conversations
  - » patient, persistent and proactive in maintaining contact and progressing the process
  - » available for face-to-face contact, especially when conducting assessments and planning processes
  - » alert to opportunities to reinforce and contribute to the individual's capabilities and self-confidence
  - » willing and enabled to work with peer workers wherever possible and appropriate

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*Planners need the skill to engage no matter who sits in front of them.  
Capacity to personalise the approach has been wonderful to watch in a lot  
of cases.*

*Health professionals teleconference participant*

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- access and planning forms, documentation and processes that are:
  - » fair, with consistent assessment tools and planning processes (including the use of relevant typical support packages)

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*Need a tailored screening tool, the questions are wrong and insulting.  
Workshop participant, Sydney*

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- » systematic, with each step made clear to the individual (and their family and/or carer) in advance

- » transparent, providing information about processes, documentation, eligibility criteria

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*There's no process to see if people agree on plans.  
Health professionals teleconference participant*

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- » stepped, with opportunities to review and clarify draft or proposed decisions before finalising
- » well documented, with plain language forms and guidance, and assistance for the individual where required

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*The language remains brutal "you are ineligible due to this part of the Act".  
Instead, give a liaison point with a clinician to understand.  
Health professionals teleconference participant*

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- » flexible, with multiple modes for conveying information (e.g. written, oral, online, audio-visual, etc), so as to adapt to the individual's preferred modes for receiving and understanding information
- » co-designed in close consultation with people with lived experience of psychosocial disability, their families and carers.

In effect, these elements (i.e. those from the individual's point of view and those from the NDIA's point of view) constitute the basis for performance or progress measures as the NDIA pursues actions to improve the psychosocial disability pathway.

The key design features of a NDIS psychosocial pathway consist of what happens before someone accesses the NDIS (referred to as 'Phase 0' below) and the design features once someone commences their access journey (outlined above and in the recommendations).

# 4. A psychosocial disability pathway ‘Phase 0’

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*New participants of the NDIS don't know where they are going to go. They have complete control of their own destiny, very different to what they were used to.*

*Workshop participant, Melbourne*

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A key challenge for the NDIA arising from the psychosocial disability pathway workshops is that what happens in the individual's life before they even consider approaching the NDIS can fundamentally shape their experience of the scheme.<sup>7</sup> As noted above, this ‘Phase 0’ comes before the NDIA's phases 1, 2 and 3, and it lays the foundations for the success or otherwise of those phases and potentially of the participant's longer term wellbeing.

Getting Phase 0 right will ensure that individuals experiencing psychosocial disability who are likely to benefit from participating in the scheme approach the NDIA. It can also help them to be better prepared for the access and planning processes that can in turn reduce the intensity of effort required on the part of the NDIA and its partners. For example, the potential participant would be more able to obtain and present the evidence needed for access assessment.

A well-executed Phase 0 approach would also make it less likely for individuals who are not eligible for the scheme to seek access. Supported referrals could be provided to services that better meet these individuals' needs. This could help to reduce the risk of the individual's disability deteriorating to the point where they become eligible for an NDIS package at a later date.

The Phase 0 experience would also provide an opportunity to include and respond to carers and family in a more assertive and sustained manner.

## Who is the ‘Phase 0’ response for?

There are three main cohorts of people with psychosocial disability who will engage with the NDIS access process:

- people receiving supports through transitioning programs

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<sup>7</sup> See ‘Designing operational reforms at a time of uncertainty’ below for a discussion of the strategic challenges arising from ‘Phase 0’ and mainstream service gaps.

- people not currently receiving supports through any programs
- people who, in future, would have qualified for a transitioning program, but for who such programs will no longer exist. In these cases transitioning programs will no longer exist to provide access support.

Mental Health Australia understands that organisations delivering Commonwealth transitioning programmes (Partners in Recovery, Personal Helpers and Mentors and Day to Day Living) have a contractual obligation to support their existing clients to access the NDIS. However, there is no formal access support for people who are not receiving any psychosocial support services to access the NDIS. While NDIS Local Area Coordinators have responsibility to support people with psychosocial disability to engage with the NDIS, that assistance often falls far short of the 20 hours one on one support, which community mental health organisations advise it takes to assist someone through the NDIS access and planning process. In addition, those who are unconnected to services may not find out about the NDIS unless assertive outreach is in place to actively engage them. Workshop participants said that Phase 0 activities are essential to helping people with psychosocial disability to engage with the scheme.

## The Phase 0 response

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*[Need] Time, trust, belief in me and hanging in there when things go wrong, because they DO and WILL.  
Workshop participant, Sydney*

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In the broadest terms the Phase 0 response requires:

- assertive outreach
- personalised NDIS engagement support
- resources for the community.

The skills, experience and knowledge required to deliver the majority of these services already rest within the community mental health sector and in some instances with the NDIA or its partners.

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*Get pre-engagement right by empowering the specialist community mental health sector to the greatest possible. This will in turn flow through to a better experience with access and planning, which will lead to better participant outcomes.  
Workshop participant, Sydney*

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## Assertive Outreach

This Phase 0 service would include people with psychosocial disability specific skills, knowledge and experience undertaking the following tasks:

- mapping places where people with psychosocial disability who would normally be considered 'hard-to-reach' are likely to be in their local area.



- conducting site visits to these places to engage with people with psychosocial disability, carers and service providers in locations where they feel comfortable and discuss what the NDIS has to offer for them.
- working with local community and public mental health services (including mental health facilities, hospitals, GPs, community services, etc.) to upskill them in identifying and providing information and advice about the NDIS to people experiencing psychosocial disability.
- providing a “warm referral” to the personalised support service outlined below for those who indicate they are interested in applying for NDIS access.

## Personalised NDIS engagement support

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*Quality [of plans] ranges from fantastic to appalling. [The] factor that determines the quality is the person who advocates for the person with a disability. An informed parent, a professional, or someone who can draw up a plan you're more likely to get a good plan.  
Health professionals teleconference participant*

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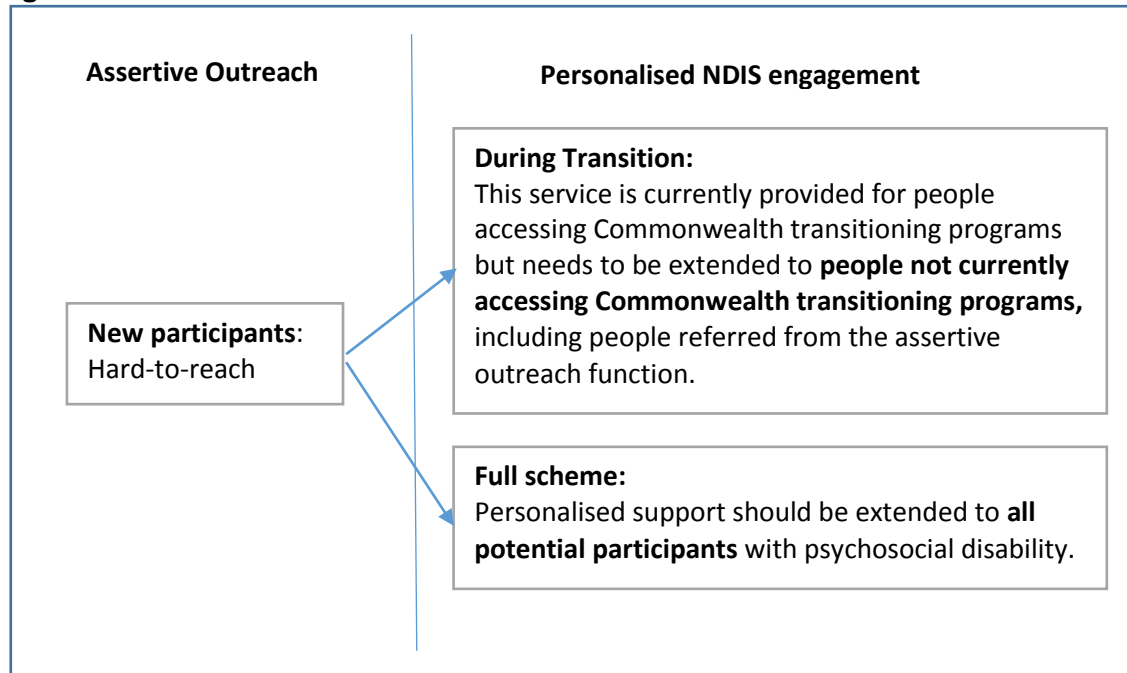
This Phase 0 service would include people with specific skills, knowledge and experience with psychosocial disability undertaking the following tasks:

- assisting the potential NDIS participant to understand the NDIS
- providing consistent guidance and capacity building support to the potential NDIS participant throughout the NDIS access and planning process
- conducting safe, trauma informed conversations with the potential NDIS participant at critical transition points in their NDIS journey (e.g. receiving an access determination and receiving their plan)
- assisting the (now) NDIS participant to activate their plan through either providing a warm handover to a support coordinator or if no support coordination is funded through the plan, assisting the NDIS participant to find suitable service providers and enter into service agreements
- where someone is found to be ineligible or chooses not to engage with the NDIS, assisting the person to access non-NDIS services as appropriate
- identifying individual and local barriers for people with psychosocial disability accessing the scheme and proactively managing change to remove the barriers.

The assertive outreach and personalised NDIS engagement support functions are modelled on the Partners in Recovery Support (PIR) Facilitator role, which is recognised as very effective for this high need, hard to reach cohort and was consistently mentioned by stakeholders as a model for best practice and delivering strong outcomes for individuals navigating the service system (see [Attachment A](#)).

The intended participants in the assertive outreach and personalised support functions is shown in Figure 2 below.

Figure 2



## Resources for the community

Workshop participants also advised that community-wide resources would be useful. However, they stressed that people with psychosocial disability can have difficulty accessing web based resources for a number of reasons, emphasising the importance of one-on-one personalised NDIS engagement support and assertive outreach.

The NDIA could undertake to:

- provide resources targeted specifically at general practitioners and health and mental health professionals to explain their role in the NDIS access and planning processes and provide detailed information about how to support people with psychosocial disability to access the scheme (including through referrals to the above-mentioned personalised NDIS engagement support).
- provide online supports and referrals for individuals, their families and carers, to be available for those who prefer using such technologies and pathways, including information about local NDIS and non-NDIS services that can assist with face-to-face follow-up. Workshop participants mentioned the reimagine website ([www.reimagine.today](http://www.reimagine.today)) as a useful resource.
- deliver substantive information about the NDIS and its role in relation to people experiencing mental health issues and psychosocial disability, to the community in general through mainstream services using multiple platforms (e.g. mainstream media, social media, printed materials, information sessions, etc.) including its links and relationships with non-NDIS services and programs.

The assertive outreach and Personalised NDIS Engagement support functions offer benefits to the operation of the NDIS and also work to resolve some of the issues related to the fractured nature of the mental health system as a whole.

# 5. Key success factors for the psychosocial disability pathway

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There are several factors that will be key to the success of any reforms the NDIA puts in place to improve the scheme's psychosocial disability pathway.

## Building psychosocial disability staff competencies within the NDIA and its partners

An overriding theme of stakeholder feedback pointed to a lack of psychosocial disability specific skills, knowledge and experience held by NDIA and partner staff. The NDIA should therefore work to increase the psychosocial disability specific skills, knowledge and experience of NDIA and partner staff who work with people with psychosocial disability.

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*Employ more peer workers and staff that understand what people have been going through. Walk in people's shoes.  
Workshop participant, Sydney*

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The aim should be that staff who deal with people experiencing psychosocial disability are able to relate to participants, their families and carers with empathy, compassion and patience, applying with energy and skill their knowledge and expertise about mental illness, psychosocial disability and the recovery model. These specialist front line staff should form a community of practice both among themselves and with other skilled and knowledgeable service providers in the mental health system. They should be supported by practice leaders who can provide professional supervision. They should be recognised for their specialised skill and knowledge, and they should be provided with appropriate administrative supports, decision-making procedures and reporting arrangements that recognise, support and reward working effectively with people experiencing psychosocial disability. This means having monitoring and reporting arrangements that emphasise the quality of interactions and the effectiveness of outcomes, rather than throughput and the number of applicants or participants dealt with or 'processed'.

The people in these roles would provide 'front line' services (e.g. interviewing and developing a plan) that form the foundation of a service relationship through which the NDIA starts the process of building trust and confidence. However, NDIA and partner staff are not covered under the NDIS Practice Standards or the National Standards for Mental Health Services 2010, nor are they necessarily covered by standards of particular professions, for

example the Australian Association of Social Workers Practice Standards for Mental Health Social Workers 2014. It is even more important therefore that NDIA and partner staff have the pre-requisite competencies to ensure both quality service provision and, at a minimum, do no harm to people with psychosocial disability. This is an issue, which should be considered by the NDIS Quality and Safeguards Commission once established.

As a point of reference, Mental Health Victoria (formally Psychiatric Disability Services of Victoria) and the Mental Health Coordinating Council of NSW (MHCC) have both offered training to NDIA and partner staff to increase their understanding of psychosocial disability and the recovery oriented approach. This is useful and necessary, but not sufficient.

Mental Health Australia suggests the NDIA urgently commences the development of an aspirational psychosocial disability competency framework to develop the skills, knowledge and experience of NDIS Local Area Coordinators, assessors and planners who work with people with psychosocial disability. The NDIA should co-design this framework with Mental Health Victoria and the MHCC and mental health professional bodies, which hold the expertise on development of mental health competencies. Carers have also produced some guidance material to support their engagement in service support processes and this material should be considered in development of a competency framework<sup>8</sup>. It should be noted here that competencies specifically related to psychosocial disability do not exist, however, the NDIA may wish to draw on Mental Health Victoria and MHCC's expertise to identify which core competency units included in the Mental Health Certificate IV and the Mental Health Peer Work Certificate IV are most relevant to the roles of NDIS Local Area Coordinators, assessors and planners.

Training offered to date by both Mental Health Victoria and MHCC to support NDIA and partner staff to understand psychosocial disability will assist but more is needed to build the level of competency required. The type of work being undertaken by NDIA and partner staff also necessitates:

- detailed knowledge about psychosocial disability, including understanding the complex interaction between the disability, co-existing conditions and environmental factors and a recovery oriented approach
- skills in implementing trauma-informed care and a recovery oriented approach
- the personal attributes and aptitude to be able to embed these into practice.

These three factors should be underpinned by values and attributes aligned to the delivery of recovery oriented practice. It will also be critical to develop appropriate indicators of success in this area of work that supports and encourages effective work practices. There will be medium to longer term outcomes that should be measureable, such as fewer appeals and higher satisfaction among this cohort of scheme participants. Shorter term indicators might be positive feedback from participants, family, carers and clinicians.

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<sup>8</sup> For example see: A practical guide for working with carers of people with mental illness, March 2016, Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia.

## ***Rationale for building psychosocial disability specific staff competency***

Feedback from workshop participants indicated some NDIA and partner staff did not appear to understand:

- the impact of psychosocial disability on a person's social and emotional functioning
- the impact of psychosocial disability on a participant's ability to navigate NDIS processes
- the interaction between psychosocial disability and other types of functional impairment
- the types of supports best suited to people with psychosocial disability.

At best, according to participants and carers consulted, this can result in difficulty in navigating the process and plans that did not meet the participant's needs. At worst, this can result in deterioration of a participant's disability or mental health condition either through poorly managed interactions with the participant or the removal of critical services.

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*Process of access can have a detrimental impact.  
Workshop participant, Sydney*

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Clinicians reported similar concerns, and in some instances noted among NDIA staff and Local Area Coordinators a lack of knowledge and about psychosocial disability and a lack of respect for or understanding of clinical expertise hampering access and planning processes. These issues are considered in more detail in 'The role of health professionals' below.

## ***Redefining typical support packages***

NDIS participants, carers and service providers provided much commentary on the balance (or rather imbalance) between core and capacity building support items in plans for people with psychosocial disability. With core items largely predominating especially in certain regions, stakeholders reported that there was a large gap between the potential for the scheme to invest in people's ability to participate socially and economically and the current reality for many participants.

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*Plans [are] skewed towards care support and little capacity building support.  
Workshop participant, Melbourne*

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For their part, providers are keen to deliver capacity building support but report being hamstrung by plans which do not match the needs of participants. Often these needs only become apparent after working with a participant for some time (the simplistic or mechanistic application of goal-based planning was broadly seen as unhelpful and often counterproductive), although there are not always the right kinds of investments at the capacity building level, including support coordination, to allow this to happen. Many

stakeholders regarded getting a good plan as something of a 'lottery', depending on which planner in which location a participant happened to be allocated to.

To some extent, solutions to these problems can be seen to be national and systematic:

- improvement of the competencies of NDIA planners,
- tightening up expert oversight over the plans that people with psychosocial disability receive, and
- providing a greater level of information and support (including peer support) for people with psychosocial disability at the pre-planning stage.

These all remain valid ambitions and need to be pursued, however, improvements in these areas will not have the impact required to improve plans for people with psychosocial disability without action to improve typical support packages for this group of people.

Workshop participants provided a loud and clear message about several support items they feel would support people with psychosocial disability.

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*Mental health issues are cyclical, plans must include 'built in' flexibility.  
Workshop participant, Sydney*

*Carer activities /respite not available if participant has a plan.  
Workshop participant, Melbourne*

*Support coordination should be an automatic plan item.  
Workshop participant, Sydney*

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Accordingly, Mental Health Australia recommends that certain support types should be discussed in every planning conversation with NDIS participants with psychosocial disability, including:

- » support coordination
- » capacity building
- » carer support and respite
- » provision for urgent and unplanned needs, due to episodes of illness and disability.

Mental Health Australia is currently managing a project on behalf of eight large national providers of psychosocial support through the NDIS to develop alternative typical support packages. The project is also supported by the National Mental Health Commission. The objectives of this program of work are to:

- reorient the planning of supports for NDIS participants with psychosocial disability away from a welfare-oriented model and towards an investment-driven approach
- describe additional supports not currently in the NDIS Price Guide, and appropriately price these and any other supports already in the Price Guide but not already appropriately priced

- produce one or more alternative typical support packages, with strong links to outcome-based evidence where possible, for the Scheme Actuary to integrate into the NDIA's reference packages for participants with psychosocial disability.

Mental Health Australia will be working with consumers, carers and other experts through a Delphi process to refine a set of alternative typical support packages. The starting point will be existing evidence, including empirical service use and outcomes data held by providers.

Mental Health Australia is keen to work with the NDIA to optimise this important opportunity for partnership. The potential outcomes for participants would include:

- NDIS plans that can be implemented in ways which are consistent with individual needs much more effectively than at present
- access to more intensive NDIS-funded support, based on a person-centred approach, particularly in the first one to three years of a plan
- greater capability to participate in the community in the medium to long term, and even to exit the NDIS either temporarily or permanently, as a result of the supports received through the NDIS.

For governments and the community, the potential outcomes would include:

- more effective and efficient use of taxpayer investments in disability support services, especially from a lifetime perspective
- much lower utilisation of NDIS-funded services that participants don't value
- the ability to refine and test a new, evidence-based and expert-informed approach with near to real-time data as the scheme matures
- greater economic participation and less reliance on welfare by this cohort in the medium to long term as a result of investment-driven NDIS-funded support
- increased ability for the NDIA to redirect investment within its \$22 billion envelope in the interests of people with psychosocial disability (e.g. filling data gaps, assertive outreach, reduction in both stigma and discrimination).

## The role of health professionals

Health professionals consulted by Mental Health Australia identified many of the same issues with pre-access, access, pre-planning, planning and reviews that were identified in the face-to-face workshops, but from the perspective of the clinical impact on consumers. Most notably, they all reflected that for people with psychosocial disability:

- the NDIA engagement does not accommodate their disability
- the NDIA lacks a recovery-oriented and strengths-based approach, instead focussing on core supports, which generates long term dependence (and costs) on the NDIS
- when mismanaged, NDIS processes can undermine wellbeing rather than promote recovery.



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*One of the NDIS people was too clinical and made things confronting and used big words. So, the client said she wasn't going to bother with this and didn't want to go through this again.*

*Health professionals teleconference participant*

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Many health professionals' interactions with the NDIS occur at the access stage, although clinicians would prefer a much stronger care partnership beyond that point.

Health professionals can make an important contribution to the success of the NDIS, as advocates for consumers and as clinical experts to maximise the benefits the NDIS offers people with psychosocial disability. In fulfilling their duty of care to consumers, health professionals have sought to understand the eligibility requirements of the NDIS and how their clinical expertise can inform consumers' access and subsequent packages.

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*We need to recognise that for NDIS to run efficiently, there needs to be an investment in educating about the NDIS. GPs come in contact with participants throughout their lives.*

*Health professionals teleconference participant*

*GPs need to be briefed on how to provide evidence for consumers of psychosocial nature. Open source information, localised capacity building is needed.*

*Workshop participant, Sydney*

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Instead, their interaction with the NDIA has been one way. Health professionals have experienced:

- inconsistent information and advice about the eligibility criteria for people with psychosocial disability
- a disregard for their professional responsibility to participants
- questioning of their motives in advocating for participants.

Health professionals' engagement with the NDIS could be improved by:

- helping them to understand the NDIS, providing consistent advice and a local NDIA contact
- recognising that health professionals' reports can support the planning process, including informing the recovery goals of participants and the supports needed to achieve those goals
- providing feedback to clinicians about how well their reports supported the NDIA to make an access decision and undertake pre-planning
- working with health professionals to personalise the approach for individuals, and to amend plans (without review) when the participant's situation changes.

The health professionals consulted through this process had (almost by definition) a strong interest in the NDIS and its future success. However, they emphasised that many of their



clinical colleagues (particularly GPs and psychiatrists) are not well informed about the scheme, are by nature very busy, and continue to receive inconsistent advice from NDIA staff. Future communications by the NDIA need to take into account the diversity of knowledge and engagement among and within individual health professionals if knowledge and collaborative partnerships are to grow.

Over 2018 and 2019, Mental Health Australia will be undertaking a project to gather evidence about barriers for people with psychosocial disability to NDIS access in clinical and primary care settings. This project, to be funded through the NDIS Sector Development Fund, will produce:

- a communications strategy and/or practical tools for clinicians to facilitate access to the NDIS for people with psychosocial disability and raise the awareness of health care providers about what the NDIS offers people with psychosocial disability, as informed by consultation and other evidence
- advice to the NDIA on refinements to the psychosocial pathway and other processes that could benefit people with psychosocial disability
- advice to the Department of Social Services on matters of policy that affect this cohort, whether or not they are NDIS-eligible, particularly where they relate to the intersection of the NDIS and clinical systems.

Mental Health Australia anticipates that successful completion of this project will make a significant contribution to improving pathways through health and mental health settings to NDIS access for people with psychosocial disability.

## 6. Designing operational reforms at a time of uncertainty

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Taking effective action to address psychosocial disability is a complex operational challenge for the NDIA and its partners. Complicating the operational challenge for the NDIA is a broader strategic challenge: building effective interface arrangements with mainstream services, such as health and Commonwealth, state and territory government funded community mental health services. All this is occurring as services outside the NDIA (especially Commonwealth funded services being devolved to Primary Health Networks) are simultaneously being restructured.

The extent of this strategic challenge is increased because of the ongoing gaps between mainstream services. These gaps create a risk that the NDIA could find itself being drawn into areas of need that in principle should be addressed by mainstream service systems. The conceptualisation, design and implementation of any response to Phase 0 would therefore need to recognise and manage that risk, and where possible offer closer integration across service offerings and supports. The same applies to actions to address the needs of people experiencing psychosocial disability who do not access the NDIS.

Even as this report is being written, the mental health sector is keenly awaiting further news of bilateral negotiations regarding additional psychosocial services for people who will not access the NDIS. The scale, scope and nature of these services are all unknown, though the Australian Government's own contributions have been announced in broad terms. Similarly, the mental health sector, including consumers and carers, are yet to hear in any detail relating to continuity of support arrangements announced in the 2018 Budget, including exactly what services will be on offer for people currently accessing services through transitioning programs who are not NDIS eligible. Just one year from Full Scheme, these critical questions remain unanswered.

The NDIA is embarking on its pathway design, in fact, it is rolling out the entire scheme, even while these major uncertainties remain. The complexity of the task cannot be underestimated. If the NDIA is to be successful in implementing its objectives, it will need to work closely with governments. Implementation of a Phase 0 response by the NDIS should include a clear and explicit articulation of the nature and extent of the need for action, and the dependencies on interfaces with other systems. It should also include a progressive roll out that manages the risks and demonstrates the benefits for people with psychosocial disability (and their families and carers), for service providers, for regulators, and for funders. It should be supported by nationally consistent information and advice, including online and digital services, referrals and advice.

Complementing this national response, there must also be a local level strategy, with ‘on the ground’ arrangements that take into account regional variations in mainstream service systems and local community needs. Interfaces with Primary Health Network and Local Health Network commissioned services will vary considerably across the country. This would accord with the strongly articulated desire by NDIS participants and carers who participated in the psychosocial disability workshops for contact with people with strong expertise (including where possible lived experience) to help them navigate what can be a confusing maze of services (or lack thereof). Among the NDIS population, the special needs of groups such as LGBTIQ, CALD, Aboriginal and Torres Strait Islander people, people with intellectual disability, and others should also be identified and responses developed.

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*Interface between NDIS and other services not clear.  
Workshop participant, Melbourne*

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NDIS partner governments and funders will be key stakeholders in this strategic response. Improving the experience and outcomes of people with severe psychosocial disability would help reduce cost pressures on the scheme by ensuring individuals are more ‘access ready’ when they approach the scheme, thereby reducing appeals and reviews. It could also help the effectiveness and efficiency of non-NDIS service systems, for which NDIS partner governments are also responsible, including high-cost clinical services, such as hospitals and health facilities. This is because individuals (and their families and carers) would be better informed and prepared in their engagement with a range of services, not just the NDIS.

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*Now seeing a backlash – e.g. Carer goes on holiday, respite not included in Plan, they move into the acute hospital ward.  
Health professionals teleconference participant*

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Delivering on these potential benefits of reform is complicated by the policy and operational context. Fragmented governance, decision-making and funding across the various service systems, tends to work against a broader consideration of the long-term benefits of early interventions of this type. Program design and service delivery decisions tend to be made on narrow cost considerations rather than system wide and long-term outcomes and costs. This results in poor or even negative outcomes for individuals experiencing psychosocial disability, for their carers and families, and for service providers.

It is a clear and fundamental responsibility of all Australian governments to exercise their collective responsibility for the NDIS and for mainstream mental health services. This includes improving governance, coordinating policy-making and program design, and providing the level of funding required. The NDIA has an important role to play in informing these deliberations

Mental Health Australia – indeed, the whole mental health sector – stands ready to assist in encouraging and supporting governments as well as the NDIA in this crucial endeavour. The extent and quality of engagement in the psychosocial disability workshops at such very short notice shows that the many people experiencing psychosocial disability, and their families

and carers, are also central to developing and implementing the strategic response to this challenge.

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*When it works, amazing things happen to people.  
Health professionals teleconference participant*

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# 7. Psychosocial disability ‘pain points’ and recommendations

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The key messages arising from the psychosocial disability workshops are outlined above. The following sections detail the specific ‘pain points’ identified by participants in the workshops, and provides recommendations to address those pain points.

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***Pain Point 1:*** *People experiencing psychosocial disability face specific and particular challenges and issues when dealing with the NDIS. Mental ill health can be greatly exacerbated or ameliorated, depending on the quality of the individual’s experience with a complex and demanding scheme such as the NDIS.*

**Recommendation 1:** The NDIA should develop an overarching psychosocial disability strategy to address the range of issues articulated by participants, carers, providers, advocacy groups and other stakeholders through these consultations. Such a strategy would include but not be limited to:

- » reforms to the NDIS pathway for participants with psychosocial disability
- » improvements in the skills, knowledge and experience of NDIA and partner staff to work with people with psychosocial disability
- » reforms to reference packages for psychosocial disability to ensure substantial improvement in the quality of plans, building on a major project already initiated by eight psychosocial providers, supported by the National Mental Health Commission and managed by Mental Health Australia to develop alternative typical support packages for psychosocial disability
- » a Communications Strategy and supporting arrangements to ensure mental health stakeholders are given the best opportunity possible to understand how improvements to the NDIA’s work with people with psychosocial disability are working in practice.

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**Pain Point II:** *The psychosocial disability journey begins at 'Phase 0', well before the individual approaches or potentially even hears about the NDIS. This is in part because people with psychosocial disability can have highly negative perceptions and experiences of government agencies, clinicians and providers. It is also because the nature and strength of the client's existing support network is a significant determinant of their capacity to engage with the NDIS and its forms and processes, and because many people experience a range of life barriers which may need to be addressed before the NDIS can contribute in any significant way to their wellbeing and recovery.*

**Recommendation 2:** That the NDIA establish a sustained assertive outreach capacity (using the example of Partners in Recovery), to identify and work with people who experience psychosocial disability (and the services that support them), to inform them about the scheme, and to encourage them to test their eligibility. This role would work closely with services – such as GPs, hospitals, homeless services, and drug & alcohol services – to identify and work with individuals, especially in making the transition from clinical or intensive support to community and disability support service systems, and in identifying people out of touch with or on the margins of traditional service systems.

**Recommendation 3:** That people with psychosocial disability be provided as early as possible – i.e. before they approach the NDIS – with personalised and ongoing support initiation and coordination services. Such services should be delivered by people with psychosocial disability specific skills, knowledge and experience, working alongside the person and in partnership with their family, carers and/or advocates to help navigate the options in the local community mental health system, including the NDIS.

**Recommendation 4:** That a strong and sustained information campaign be undertaken, to ensure mental health consumers, families, carers and providers are aware of the NDIS and its role in providing supports for people who experience psychosocial impairments, including referring people who may not be eligible for the NDIS to appropriate psychosocial support (such as the new National Psychosocial Support Program, state/territory equivalent programs, and Continuity of Support arrangements).

**Recommendation 5:** That the NDIA develop consistent national and local level resources (online and print as necessary) providing information about the NDIS and psychosocial supports, local providers of support services, and the supports and services identified in NDIS participants' plans at the local, state and national levels. This will help address information gaps.

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**Pain Point III:** *NDIA and partner frontline staff dealing with people experiencing psychosocial disability often do not have psychosocial disability specific skills, knowledge and experience. At worst, this can mean they risk exacerbating the person's condition, creating distress for highly vulnerable people.*

**Recommendation 6:** The NDIA should urgently develop an aspirational psychosocial disability competency framework to develop the skills, knowledge and experience of NDIS staff and partners who work with people with psychosocial disability. The NDIA should co-design this framework with Mental Health Victoria and MHCC NSW and other relevant stakeholders.

**Recommendation 7:** The framework should include the establishment of a cohort of NDIA and partner staff who have relevant psychosocial disability specific skills, knowledge and experience.

**Recommendation 8:** Peer workers – especially those with experience of the NDIS’ psychosocial disability supports – should be employed wherever possible to provide support to individuals approaching and dealing with the NDIS, as well as throughout the access, planning and plan implementation processes (see Phase 0 related recommendations above).

**Recommendation 9:** The NDIA should subject itself to the oversight of the NDIS Quality and Safeguarding Commission. This would allow it to apply the same practice standards that apply to partner organisation to apply to its own staff.

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**Pain Point IV:** *Families, carers and advocates are critical to successful outcomes for many people experiencing psychosocial disability. Failure to engage and support them can lead to applicants being denied access to the scheme or receiving insufficient plans.*

**Pain Point V:** *Carers (formal and informal) can also experience significant stress and fatigue through the NDIS process, placing at risk their own mental health and capacity to undertake their crucial role.*

**Recommendation 10:** That consumers’ families/carers/advocates are acknowledged and supported, including – where agreed with the consumer – involvement in all relevant meetings and discussions.

**Recommendation 11:** That governments ensure carers be provided with adequate respite arrangements, including crisis respite.

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**Pain Point VI:** *Many health professionals are not fully aware of the NDIS, or are not convinced of its value, which can further impair the individual’s capacity to gather relevant evidence.*

**Recommendation 12:** That the NDIA ensures that health professionals dealing with people with mental health issues are well informed about the NDIS, its role in relation to psychosocial disability supports and services and health professionals’ roles, particularly in relation to the access process.

**Recommendation 13:** That appropriate incentives and resources are provided for health professionals (e.g. GPs and psychiatrists) to assist them to provide supporting evidence for NDIS access requests.

**Recommendation 14:** That the NDIA establish an ongoing health professions forum to improve the interface between mainstream health systems and the NDIA.

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**Pain Point VII:** *People experiencing psychosocial disability can have greater difficulty ensuring all relevant evidence and information is taken into account in access and planning decisions. Some mental health conditions (and some medications used to treat such conditions) can significantly impair the individual’s cognitive capacity, undermining their ability to gather and present evidence and to put forward a coherent and full case.*

**Recommendation 15:** That administrative practices and delivery standards in relation to people with psychosocial disability ensure iterative, progressive assessment and planning processes that provide opportunities for NDIS participants (and trusted others) to check and confirm the evidence base for access and planning decisions.

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**Pain Point VIII:** *People experiencing psychosocial disability can often fail to progress through the NDIS process because of inadequate handovers between staff and from one step or phase to the next. This means that at each point where there is a transition between staff there is an inherent risk that the participant may disengage.*

**Recommendation 16:** That staff dealing with people experiencing psychosocial disability always ensure they provide 'warm handovers' (i.e. in person) as a person passes through the NDIS phases or stages.

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**Pain Point IX:** *Access and eligibility processes and outcomes for people experiencing psychosocial disability are inconsistent, lack transparency and can be complicated by the presence of other disabilities and barriers.*

**Recommendation 17:** That the NDIA implement as a matter of urgency a validated, agreed and transparent assessment tool for determining the severity, impact and likely persistence of psychosocial disability. Rollout of the tool should occur alongside an appropriate stakeholder communication strategy.

**Recommendation 18:** That the NDIA ensure that people experiencing psychosocial disability undertaking the NDIS access and eligibility process are provided with clear and unambiguous information about the process, documentation requirements, assessment tools and questionnaires and options for review.

**Recommendation 19:** That the NDIA amend its documentation and administrative arrangements to ensure that where an applicant experiencing psychosocial disability is being assessed, the impairments arising from that disability are given due weight, relative to any other (more apparent) disabilities that they may also have.

**Recommendation 20:** That the NDIA implement a regime of randomised audits of access and planning decisions for people experiencing psychosocial disability, along with targeted case study analysis, to help ensure decisions (a) meet objective standards of appropriateness and (b) are consistent across consumers with similar forms and levels of impairment and needs. The outcomes of those audits should be made public in summary form, to help alleviate existing stakeholder anxieties regarding the access and planning processes. These processes should engage with stakeholders outside the NDIA to constantly review practice.

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**Pain Point X:** *There can be undue delays in access and planning decisions and therefore delays in receiving supports. For people with psychosocial disability, these delays can lead to a deterioration of their condition.*

**Recommendation 21:** That the NDIA provide participants, carers and providers with clear information about process steps and anticipated wait times throughout the access and planning processes in particular. That the NDIA streamlines administrative processes for people with psychosocial disability.

**Recommendation 22:** That the NDIA establish an interim support service to ensure consumers are not without service while awaiting planning decisions.



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**Pain Point XI:** *People experiencing psychosocial disability who do not access the NDIS lack clear referral pathways for ongoing support, including capacity building. This creates risks for consumer wellbeing as well as for crisis services if early and effective supports are not available, and for the NDIS, if the individual's condition deteriorates to the point where they seek and gain access to the scheme, due to a lack of earlier intervention and support options.*

**Recommendation 23:** That governments with responsibility for community mental health services outside the NDIS ensure those services are adequately resourced and commissioned to provide people experiencing psychosocial disability with the supports they need.

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**Pain Point XII:** *NDIS plans for participants experiencing psychosocial disability often lack elements that most of these participants will require, especially for the first one to three years. In addition, when there is a change in circumstances (for example, a crisis) there is not a facility for supports to be quickly scaled up or down to reflect this.*

**Recommendation 24:** Certain support types should be discussed in every planning conversation with NDIS participants with psychosocial disability:

- a. support coordination
- b. capacity building
- c. carer support and respite
- d. provision for urgent and unplanned needs, due to episodes of illness and disability

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**Pain Point XIII:** *A psychosocial disability can impact on a person's ability to initiate their NDIS plans and navigate the process of identifying and negotiating service agreements with providers.*

**Recommendation 25:** That the NDIA institute a system of monitoring and informal review during the first six months of the first plan for participants experiencing psychosocial disability, to identify early where the participant may be struggling to initiate or fully utilise their plan.

**Recommendation 26:** That the NDIA ensure that participants experiencing psychosocial disability have access to support and advice in finding and negotiating service agreements with providers of supports under the NDIS plan.

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**Pain Point XIV:** *Reviews of NDIS plans for participants experiencing psychosocial disability can sometimes result in undue reductions in funding levels, not because the participant does not need them, but because the participant's condition is episodic and they have not needed them in the review period or because the person has a strong desire for independence and does not recognise that they are unwell*

**Recommendation 27:** That decision making about changes to plans at review is based on rigorous analysis of the participant's ongoing need drawing on information from multiple sources, including from the participant, family and carers (including the option of a carers statement) and service providers.

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**Pain Point XV:** *Reforms to disability and other social services are often carried out in a way that is detrimental to the needs of people experiencing mental health issues. Implementation of the psychosocial disability pathway should take into account the complexity of the exercise and the needs of the individuals affected and the capacities of the service providers.*

**Recommendation 28:** That the psychosocial disability pathway be introduced progressively, with 'early win' changes implemented as soon as possible and more complex changes that require changes to resourcing priorities, timeframes and service offerings be implemented according to a systematic schedule.

**Recommendation 29:** That implementation be carried out in an open and transparent manner, with relevant data and information on progress published on a regular basis.

# Attachment A: Partners in Recovery support facilitators

## *Program Guidelines for the engagement of Partners in Recovery Organisations 2012-13 to 2015-16 (Extract)*

Support Facilitators will be engaged by the PIR organisation to undertake day to day tasks in supporting the role of the PIR organisation. In delivering the benefits of system collaboration to clients, the Support Facilitator could:

- receive and review referrals that come to the PIR organisation and assess referred individuals against defined inclusion criteria (this could include facilitating the verification or arranging for the diagnosis of a severe and persistent mental illness if this is not immediately apparent or available through existing records);
- following referral, undertake an assessment of the needs of PIR clients (which may involve reviewing previous assessments and require the engagement of appropriately trained specialists to determine the client's clinical needs);
- in collaboration and with the commitment of regional PIR partners (and carers and families as is appropriate), develop, monitor and regularly review a PIR Action Plan that will guide the necessary engagement and integration of required services identified in the needs assessment (the Plan should sequence and prioritise efforts to gain access to services and supports so as to ensure a coherent and logical pathway through the service delivery system);
- engage with existing case managers that may have a role in the care of the client, and ensure their support facilitation/coordination focus is maintained and not shifted to a case management focus. Where sufficient or effective case management functions do not exist for the client, Support Facilitators could under the case management role on an interim basis, with a view to establishing this function and identifying a substantive case manager early in the implementation of the PIR Action Plan;
- in the main, be a coordinator of the service system, not a 'service deliverer' in the traditional sense;
- in working to improve the system response to a PIR client, engage with and chase up services and supports, build service pathways and networks of services and supports needed (wherever possible, the Support Facilitator should try to secure access to existing services and supports, reinforcing the expectation of existing services and supports being available and accessible to assist PIR clients);
- be a point of contact for PIR clients, their families and carers when service arrangements are not working or the client becomes disconnected from required supports;
- maintain the necessary reporting and information provision to PIR organisation management to ensure effective administration of governance arrangements; and
- have a role in the collection of data for the purposes of monitoring, reporting and evaluation of the initiative.

# Mental Health Australia



Mentally healthy people,  
mentally healthy communities

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