

Joint Standing Committee on the National Disability Insurance Scheme:

the provision of services under the NDIS for
people with psychosocial disabilities related to
a mental health condition

Partners in Recovery Tasmania Consortium Submission

2/27/2017



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1. About Partners in Recovery Tasmania's submission

About the Partnerships in Recovery Tasmanian Consortium

Partners in Recovery (PIR) assists people with severe and persistent mental illness and complex needs to access required supports and services. Where these supports are unavailable or inaccessible, PIR works to build capacity by identifying and addressing gaps and barriers.

PIR can also assist people with psycho-social disabilities to understand the new National Disability Insurance Scheme (NDIS), and to access that scheme if they meet the eligibility criteria.

PIR employs Support Facilitators in every Local Government Area of Tasmania. They work with sensitivity and flexibility with each person, their family, friends, carers and other services to facilitate a coordinated response to both clinical and community living needs. Support Facilitators assume that the people they work with are the experts in their own lives. When people are accepted and respected in this way, they make better choices and assume more control of their lives, and are therefore more likely to reach their full potential.

PIR Tasmania is a consortium between five agencies: Anglicare Tasmania, Colony 47, Richmond Fellowship Tasmania, Relationships Australia Tasmania and Wellways.

The ultimate objective of Partners in Recovery is to improve the system's response to, and outcomes for, people with severe and persistent mental illness who have complex needs by:

- Facilitating their access to the National Disability Insurance Scheme
- Facilitating better coordination of clinical and other supports and services to deliver 'wrap around' care individually tailored to each person's needs
- Strengthening partnerships and building better links between various clinical and community support organisations responsible for delivering services to the target group
- Improving referral pathways that facilitate access to the range of services and supports needed by the Partners in Recovery target group
- Promoting a community-based recovery model to underpin all clinical and community support services that is delivered to people experiencing severe and persistent mental illness with complex needs.

How we developed our submission

Through Anglicare Tasmania's Social Research and Action Centre (SARC), we undertook:

- a survey of PIR Consortium members to identify the main issues of interest to the Joint Standing Committee
- further conversations with partner delivery organisations within the Consortium

- a survey of Anglicare staff to identify the main issues of interest to the Joint Standing Committee
- conversations with staff members working within community mental health services across the state and at all levels from senior management to case worker
- conversations with state peak bodies relevant to this area.

2. Our bird's-eye view

"As our experience in the NDIS grows, so too will our understanding of the challenges and benefits."

PIR Consortium member, Consultation, January 2017

Learning from Tasmania's experience

The NDIS policy framework and implementation systems are still developing. This is a crucial time to pause and consider how the scheme is being governed, resourced and implemented to avoid the impact of current problems multiplying as the scheme rolls out.

Due to Tasmania's involvement in the NDIS trial since July 2013 and the incremental way the roll out is occurring in this state, the PIR consortium can offer some valuable insights into how the system is working so far for consumers living with complex and severe mental health conditions, their carers and families and for organisations working with them.

- Tasmania has been part of the NDIS trial, 'road testing' the system for young people. Since 1 July 2013, NDIS has been available for young people aged 15 to 24, with the addition of 12 to 14 year olds since 1 July 2016. We can provide particular insight into how young people, their carers and families and the services that support them are experiencing NDIS and other mental health service responses in ways that enable, or inhibit, a contributing life.
- As a whole state trial area, Tasmania has had an initial insight into potential State Government mental health funding and support responses for those both eligible and ineligible for NDIS support services.
- Unlike some other jurisdictions, Tasmania is in the fortunate position to be incrementally introducing NDIS by age cohort up to July 2019 (see Table 1). Tasmanian consumers, communities and service organisations have the opportunity to learn, reflect and adjust practice as we go.

Table 1: Phased age-based roll out of NDIS funding in Tasmania and participant estimates

Introduction date	Tasmanian Age cohort
1 July 2013	15 to 24 year olds
1 July 2016	12 to 14 years olds
1 January 2017	25 to 28 year olds
1 July 2017	4 to 11 year olds

1 January 2018	29 to 34 year olds
1 July 2018	3 years 35 to 49 year olds
1 January 2019	50 to 64 year olds

As such, our submission offers insights into how the system is tracking and could be adapted to ensure consumers living with complex and severe mental health conditions are positively enabled to socially and economically participate within their communities. The National Disability Insurance Agency (NDIA) has stated that:

We are committed to ensuring that recovery and hope-restoring recovery practice are supported for participants with psychosocial disability through the design and implementation of the NDIS.

(NDIA, 2016)

Given this commitment, our consortium's observations are focused on effectively working within the recovery framework.

About the fundamentals: designing holistic policy that works

In developing our submission, key overarching questions have emerged for us that we feel the Committee should consider in relation to the terms of reference.

These questions concern how we ensure all consumers living with mental health conditions have access to the types of supports they find useful to enhance their social and economic participation, who is responsible for ensuring this happens and how community services can be effectively and responsively resourced to deliver this by Commonwealth and State Governments.

In putting together these questions, we have drawn not only on our own consultations, but also the thoughts of Mental Health Australia (MHA 2017). These core policy design and resourcing issues colour our responses to the Committee's specific terms of reference. Our overarching questions are:

- Who is overseeing mental health services and who's accountable for coherent consumer services and outcomes?
- How can the recovery model of mental health services effectively shape NDIS planning and support?
- Is the NDIS engagement and planning system resourced adequately for this point in the roll out?

Q.1: Who's overseeing mental health services and who's accountable for coherent consumer services and outcomes?

Despite ongoing efforts by governments and service providers, many people who experience severe and complex mental illness still do not receive the supports they need. Achieving a regionally integrated service system that reduces fragmentation, poor coordination of services and duplication of roles will provide a crucial platform for improving the lives of people with severe and complex mental illness and their families... Current and unfolding reforms provide an opportunity for governments to work together to address the fragmentation and lack of coordination of services for people with severe and complex mental illness...

Governments will work together to develop a set of national guidelines that will support jurisdictions to deliver care pathways for people with severe and complex mental illness that are coordinated and integrated, and bridge the gaps between clinical and non-clinical services to offer person-centred wrap-around care for consumers.

These guidelines will provide PHNs and LHNs (as the respective bodies tasked with co-planning, co-design, and potentially co-commissioning services) with the policy mandate to agree and implement integrated care pathways and clinical information sharing protocols in their respective regions to ensure there is no 'wrong-door' for people with severe and complex mental illness to receiving the right amount of clinical and community support at the right time.

This work will need an agreed common vision, clarity around what the changes will mean, and strategies that will help ensure a smooth transition for all consumers. A focus will need to be on ensuring clinical services required for both mental and physical health are in place, as well as ensuring a seamless interface with the NDIS as its roll-out responds to changes on the ground. These are complex changes that will require governments and delivery agencies to be prepared to learn what works and what does not, through an open and collaborative process with clear governance and coordination arrangements.

(Department of Health 2016, *Draft Fifth National Mental Health Plan*:26-29)

As Mental Health Australia's submission to the Committee highlights (MHA 2017), there is currently no one body overseeing how people living with mental health conditions are supported at a clinical and community level. As such, no one body is accountable for ensuring services are relevant, holistic and adequate to meet the needs of a range of consumers living with moderate to severe mental health conditions. This is a fundamental omission to the design of mental health services and is leading to unintended – and unaddressed – gaps in Commonwealth and State Government funded support. As highlighted in the draft Fifth National Mental Health Plan (Department of Health 2016), the complexity and inconsistency of support is currently problematic; it risks both not engaging clients who need support and disengaging clients from services that support them, exacerbating personal and social costs:

The diversity and fractured coordination of government funding, policy frameworks and service systems can hinder the ability of services to adequately address need. This may leave consumers to navigate a system that is often complex, uncoordinated, and not tailored to their needs. This can result in vulnerable people being caught in cycles of prolonged illness and dependence, with serious repercussions for a person's relationships, education, housing and employment, and an over-reliance on support from families and carers to fund and resource recovery-based care. The cost to families, carers and the wider community, both in direct service provision and in lost productivity, can be very high.

(Department of Health 2016:27)

The Consortium welcomes the aim within the draft Fifth National Mental Health Plan to coordinate regional planning and service delivery to deliver 'a service system that works in an integrated way at the regional level to plan and deliver services that are tailored to the needs of consumers and carers, is easier for consumers and carers to navigate, and is delivered in the most effective and efficient way possible' (Department of Health 2016:4). The Plan points to Primary Health Networks potentially fulfilling this role. Although it is worth noting that many states, although not Tasmania, have local Mental Health Commissions that are well placed to co-ordinate the health and NDIS systems. Whichever body fulfils this crucial regional coordination function, there may still need to be a need for a national oversight forum to oversee consumer outcomes and ensure there are no gaps in clinical and non clinical services.

Introducing another national scheme into the mental health space in the form of NDIS for psychosocial disabilities should be welcomed. However, without a coherent suite of clinical and community mental health services for those with complex and severe mental health conditions, NDIS has the potential to exacerbate the gap between those consumers who can access coherent support and those who can not.

To ensure NDIS adds value to mental health support services for consumers and that no-one is left behind through the funding and implementation of NDIS, there are three key questions an oversight / governing body needs to address:

Support for all NDIS eligible participants with psychosocial disabilities

Given NDIS modelling has under-budgeted for individuals with psychiatric disorders (57,000 nationally, compared to the 280,000 individuals with severe and persistent mental illness who are estimated to need support) (MHA, 2017:6), which systems, funded by whom, are responsible for the remaining 229,000 consumers with complex and severe mental illness who need clinical and community support?

Support for people living with mental health conditions who are not eligible for NDIS funding under psychosocial disability

In Tasmania, it has been agreed that the vast majority of Commonwealth and State Government community mental health funding is being cashed out to fund NDIS, but not all those Tasmanians living with mental health conditions are eligible for NDIS Individual Funding Packages. So, which systems, funded by whom, are responsible for ensuring those Tasmanians with mental health conditions who are not eligible for NDIS packages receive the clinical and community support services they need?

Support for carers

Nationally, at least half of current Mental Health Respite: Carer Support (MHR-CS) funding is being cashed out to provide NDIS funding (MHA 2017). Support for carers of NDIS eligible participants may be included within a participant's Individual Funding Package (IFP), if the participant chooses to include it. But it is not clear if there will be any way for such carers to access a support package directly. Nor is it clear what accessible support there will be for

carers of consumers who are not eligible for NDIS funding, once current MHR-CS funding has been cashed out to fund NDIS. So which systems, funded by whom, are responsible for carer policy and funding?

For more on the consequences and impacts, see what we have to say about:

Section 2: Eligibility

Section 3: Outreach

Section 4: Information, Linkages and Capacity Building Framework

Section 5: Transition

Q.2: How can the recovery model of mental health services effectively shape NDIS planning and support?

We welcome NDIS' policy aim to work within the recovery model of mental health, as endorsed by the Australian Health Ministers' Advisory Council (AHMAC 2013a and b). And our consortium members support NDIA's stated approach (see p.6.).

However, our consortium organisations are finding that the NDIS policy, assessment, planning, line items and pricing frameworks do not currently work for supporting a recovery model of mental health. On the contrary, the frameworks often work against this model, leading to many of the implementation issues we are flagging as needing attention in our submission.

There are three fundamental policy positions that could be considered in ensuring that people with severe and permanent psychosocial disabilities are better served by services under a recovery model. These options are:

- a) **investment in improvements to the existing NDIS scheme** design and roll out that improve the outcomes for people with a psychosocial disability;
- b) **redesign of the NDIS scheme** to address the specific needs of the people with a psychosocial disability within the recovery framework; or
- c) **the exclusion of people with a psychosocial disability from the NDIS** and the design of a system to support services that better aligns with the needs of people with a psychosocial disability.

We favour option b: the redesign of the NDIS system to address the specific needs of a psychosocial disability within the recovery framework. In particular:

- The creation of a specific psychosocial gateway service for people with a psychosocial disability that converts the concepts of permanent disability to a system that supports recovery;

- The creation of a psychosocial assessment and planning system that embraces the concept of recovery for people with a psychosocial disability;
- The creation of a psychosocial service and pricing system that better reflects the recovery concepts;
- The adoption of psychosocial service standards that reflect the National Mental Health Service Standards; and
- The adoption of psychosocial outcomes measurement systems that aligns with the recovery of people and their increasing contribution and engagement in the community.

The main system design issues that need adjustment to support people to live a contributing life within the recovery framework as described above are:

Eligibility: 'permanent' disability and the concept of recovery

The need for psychosocial disability to be both severe and permanent does not fit well with the concept of recovery. Many consumers – particularly young people – are reluctant to sign up to their condition being 'permanent' and clinicians are reluctant to diagnose young people with a lifetime illness. This is inhibiting access to NDIS support for many potential participants.

Assessment and planning processes

Many successful mental health services delivered by our consortium members (such as PIR, the Personal Helpers and Mentors Scheme [PHaMs] and Day 2 Day Living [D2DL]), rely on developing a trusting and meaningful relationship between the consumer and service providers. These relationships take time to develop and need to be ongoing to continually engage consumers in active recovery. For example, within PHaMs, it is our members' experience that developing an Individual Recovery Plan (IRP) can take months, as the first stage is for a specialist service provider to build a rapport with a consumer.

Within our consortium members' experiences, NDIS planning is often conducted by Local Area Co-ordinators (LACs) who do not have specialist knowledge or understanding of mental health issues; the planning is often conducted via a one off phone discussion. The assessment and planning tools are not specific enough to capture the needs of Tasmanians living with psychosocial disability. Consequently, where eligibility for NDIS support on the basis of psychosocial disability is confirmed, this compressed planning process is often leading to inadequate plans and goals for participants, which then has a knock on effect on the relevance and types of support participants might access.

Appropriate services for psychosocial disability

Given that the assessment and planning tools are not specifically designed to capture needs related to enabling people living with mental health conditions to access social and economic participation, many NDIS line items are not specifically tailored to cater for enabling a contributing life. Our consortium members' PIR Support Facilitators and PHaMs Recovery Mentors are finding themselves transitioning from working with or providing enabling services under the recovery model, to working with or providing activity-based 'services' for participants. For example, in response to a client needing support with household tasks, rather than supporting them to manage cleaning themselves as would be the case through PHaMS, under NDIS line items, service providers are able to offer a cleaner; a member's client who was formerly enabled to use public transport to attend TAFE on their own is now being escorted to TAFE. Such a change in approach to support is potentially undermining significant achievements consumers may have made in living a contributing life; it seems to work against NDIA's stated approach to working within the recovery model.

Additionally, to build a contributing life there is often a need for both clinical and community supports. For example, it is essential that NDIS participants have access to therapeutic conversations that assist people to overcome issues that are a barrier to participation resulting from mental illness. In contrast to existing mental health programs that provide facilitation or support, such as PIR and PHaMS, such a combination of support is not facilitated through NDIS line items. Accessing occupational therapy for an autistic child may be a crucial part of building a contributing life; Cognitive Behavioural Therapy may support a young person to deal with anxiety related to interacting in an educational or social setting. Although such services may be therapeutic, as clinical services, it's likely that these services would not be permissible under the current NDIS framework.

Appropriate standards and pricing for mental health services

As highlighted by the Mental Health Council of Tasmania in their submission to the Committee (MHCoT 2017), consortium members are finding that NDIS line item costings are not viable for sustaining the quality of services required within *the National Mental Health Service Standards*. Our consortium members are losing about 50% an hour on any given NDIS line item, or having to compromise on the service offer. For example, one member is either offering participants a less qualified worker, or half the hours of service specified in their plan with a specialised worker. (Current pricing is based on SCHADS 2, which is commonly used within the general disability sector, rather than SCHADS 4, which is more commonly offered for specialist mental health support workers.) Longer term, this may lead to either a significant decline in the quality of mental health services, or market failure and severe consequences for community-based rehabilitation, as the Mental Health Council of Tasmania has flagged to the Committee (MHCoT 2017):

Members stressed that there is a high risk of seeing significant market failure across the sector. Community Mental Health Australia rightly points out that, “A range of highly successful community managed mental health services will no longer be funded in various jurisdictions as the NDIS moves to full implementation. These services are primarily focused on community-based rehabilitation and their disappearance means that people will no longer have access to the services that help them to reduce the disabling impacts of their mental illness.” (CMHA 2017) Consequently, the NDIS may potentially be faced with an exponentially growing level of disability while at the same time community-based rehabilitation services are experiencing loss of funding, loss of qualified mental health staff and the capacity to provide services commensurate with need. The potential loss of existing skilled and qualified staff and a de-skilling of the workforce means that that organisations are unable to offer services to people with NDIS Plans as well as those without.

MHCoT 2017

Flexibility of the planning and review process

NDIS participants who have been confirmed as having both a severe and permanent psychosocial disability need responsive support. Their symptoms may fluctuate and change rapidly and often, or may be episodic. This means that their support needs may change equally rapidly and often. To work within the recovery model, their package of support needs to be flexible to adapt with a participant's changing needs, as is possible within PHaMS and through PIR Support Facilitators. Our consortium members are finding that the rigidity of the NDIS planning and review process, as well as long delays in accessing reviews, do not allow for responsive plans and support to be put in place for participants.

We are finding that, when crises occur, participants and their families cannot get any additional support in an effective timeframe. This leaves them to deal with changing circumstances and crises largely alone, which can have catastrophic outcomes.

For more on the consequences and impacts, see what we have to say about:

Section 2: Eligibility, planning and review

Section 3: Outreach

Q.3: Is the NDIS engagement and planning system resourced adequately for this point in the roll out?

We support NDIA's endeavours to develop meaningful plans and set swift and responsive targets to review them.

A repeating theme in the feedback from our consortium members has been that compromises are being made in how NDIS services are implemented, due to NDIA being under-resourced for the current volume of business. This has had particular impacts on the adequacy of outreach and engagement and the appropriateness and timeliness of the planning and review processes.

We have already flagged the need to consider appropriate planning processes that allow time for LACs to build relationship with participants, understand their needs and allows time for participants to both trust in the process and consider their plans. Under current resourcing levels, it may be a challenge for NDIA LACs to offer such a service.

Consortium members are also reporting concerns about the responsiveness of NDIA review periods. Although operational guidelines suggest NDIA has 14 days to decide to review a plan, Anglicare Tasmania have examples of cases where reviews have not been resolved for up to seven months. In all cases we have been involved with, timeframes have been very lengthy and involved a huge amount of follow up from families or workers.

Given that mental illness may be episodic and support needs may change quickly, an agile review process is crucial to ensuring that participants have continuity of appropriate support.

With the significant demands in NDIA's planning and review services persisting and being likely to increase as more cohorts become eligible for NDIS funding, how do we ensure that NDIS participants with psychosocial disabilities can access support to identify their community support needs, plan their support, and choose and access appropriate services?

For more on the consequences and impacts, see what we have to say about:

Section 2: Eligibility, planning and review

Section 3: Outreach

Recommendation 1:

In accordance with the draft Fifth National Mental Health Plan, Commonwealth and State Governments need to ensure there is co-ordinated national as well as regional oversight of planning and outcomes for mental health services to ensure there are no gaps in clinical and community services for consumers with complex and severe mental health conditions, their carers and their families. This national and regional oversight needs to consider both those who are NDIS eligible and those who are not.

Recommendation 2:

In order to work within the recovery model of mental health services and offer appropriate and responsive support for participants to lead a contributing life, NDIS needs to develop a specific mental health 'stream'. This might include:

- The creation of a specific psychosocial gateway service for people with a psychosocial disability that converts the concepts of permanent disability to a system that supports recovery. Practically, this may include NDIA Community Engagement staff and Local Area Coordinators (LACs) who are specifically trained in understanding the needs of mental health consumers and appropriate service responses within the recovery model, to ensure engagement, planning and reviews are timely and relevant for participants.
- The creation of a psychosocial assessment and planning system that embraces the concept of recovery for people with a psychosocial disability. Practically, this may

include incremental, timely and responsive planning and reviews, with a clear offer for participants to undertake this face to face with a LAC, or via phone.

- The creation of a psychosocial service and pricing system that better reflects the recovery concepts. Practically, this may include service line items specific to the needs of participants and service providers working within the recovery model of mental health services. These services to include any activities that may assist a participant to overcome challenges to social and economic participation, to ensure that support is coherent and comprehensive. These services need to include access to therapeutic clinical, as well as community, services such as Allied Health Professionals.
- The adoption of psychosocial service standards that reflect the National Mental Health Service Standards; and
- The adoption of psychosocial outcomes measurement systems that aligns with the recovery of people and their increasing contribution and engagement in the community.

Recommendation 3:

NDIA is fully resourced during the roll out of NDIS to cope with the demands of conducting appropriate engagement, planning and reviews.

3. Eligibility, planning and review

A reoccurring theme in conversations with our consortium members about challenges for psychosocial disabilities within NDIS has been that mental health is being retrospectively fitted into a disability scheme. As mental health is a specialist area of disability, it requires a specialist workforce from assessment through to service delivery and specifically designed operational frameworks. It is our members' experience that such specialisations are yet to be embedded into NDIS.

Eligibility and the planning and review processes are clear examples of where the existing system needs to be redesigned in order to be fit for purpose. We have already outlined how we suggest the system could be adapted to fit more closely within the recovery model of mental health services (see Section 1). Here, we highlight more detailed aspects of NDIS eligibility and the planning process that need adaptation for the purpose of accommodating people with psychosocial disabilities.

Unclear eligibility guidance

Mental health conditions are not as clear cut to diagnose as many physical disabilities may be. The lack of clarity in NDIA's guidance on what qualifies as a psychosocial disability for the purposes of NDIS is currently leading to inconsistent assessments. Our consortium members are seeing participants with ostensibly very similar needs present with vastly different levels of ISPs.

There is a degree to which this is due to some consumers and their families having varied levels of self-advocacy skills (see more on this below). However, it is our members' experience that these discrepancies are mainly due to issues with the NDIS assessment tools not being sensitive enough to pick up psychosocial disability and consequent needs appropriately and LACs not having specialist knowledge in this area (see Section 1).

In our members' view, there is an urgent need to review current NDIA assessment and planning guidance to ensure it provides a clearer framework for LACs to make decisions around both NDIS eligibility and support needs.

Permanency and the recovery model

*"Getting diagnoses testifying permanency continues to be very difficult."
PIR Consortium Member, SARC 2017*

One of the challenges for people accessing NDIS for psychosocial support is providing medical evidence that an impairment is likely to be permanent, as well as it having impacts on everyday life (NDIA 2015). This is particularly an issue for younger people, who our members have now been working with for a significant period through the NDIS process. Professionals are reluctant to both diagnose and label symptoms as a specific illness and to

confidently state that this is a permanent condition. And many young people living with mental health conditions are likely to be reluctant to buy into their condition being 'permanent', given the recovery model's emphasis on positive improvements.

So not only is there likely to be a growing gap in comprehensively covering support services for those with diagnosed and undiagnosed mental health conditions as NDIS rolls out, but the reluctance for clinicians to label a disability as 'permanent' and 'persistent' is likely to exacerbate this gap. This leaves a significant number of vulnerable Tasmanians, often living with comorbid and complex support needs outside of NDIS support.

Lack of clarity on future services for consumers who will not be NDIS eligible

Consortium staff report that many people with severe mental illness currently supported by Commonwealth and State Governments' community support programs, such as PIR, PHaMs, or D2DL are unlikely to be eligible for the NDIS. Many people who need support to manage their mental illness are not experiencing a 'permanent' disability under the terms of the NDIS (Independent Advisory Committee for the National Disability Insurance Scheme 2014). Or they may not have a diagnosis, or clinicians are reluctant to diagnose their condition as 'permanent'. Yet their needs are often urgent and significant.

We do not have data that tells us how many Tasmanians have severe and persistent mental illness and complex needs that means they may be included or excluded from funding under the NDIS model. The consortium has estimated that around 72% of current PIR clients either have or would be likely to obtain a diagnosis that would qualify them for NDIS support on the grounds of psychosocial disability (see Table 2). That leaves 28% of those currently receiving support through PIR whose future support is unclear: 9% who our consortium members feel would not qualify for NDIS and nearly a fifth for whom our members are unsure.

In our experience, some of the issues with securing eligibility for NDIS amongst those living with mental health conditions are:

- Clients being transient, so not having secured a diagnosis to date
- Clients having old diagnoses, so having challenges in obtaining the evidence to back this up
- The 'permanency' issue, as described in Section 1, working against concepts of recovery
- People living with mental health conditions may be slow to grasp the benefits of NDIS and reluctant to surrender their privacy
- NDIS application and planning processes not creating space for trust and relationships to develop with planners.

Table 2: Mental Illness Diagnosis Status – PIR Consortium Participants

	PIR participant No by age cohort and Tasmanian region		Total PIR participant No	Total PIR participant %	PIR participant % with a likely diagnosis
	0 – 35 years	35 – 65 years			
Number of individuals with mental illness diagnosis considered to be ongoing	22 14 19	48 44 68	215	60	74
How many of remainder do you think would get a diagnosis?	5 5 1	13 9 9	42	12	15
Number of individuals remaining unlikely to have a mental illness diagnosis?	9 1 1	8 12 1	32	9	11
Number of individuals unable to say at this time	6 2 1	5 12 42	68	19	-
TOTAL	86	271	357		
%	24	76		100	100

11 January 2016 Region: S, N, NW

The lack of clarity about the future support available for consumers living with mental health conditions who will not be eligible for NDIS is an unacceptable position for governments, for consumers and for service providers. It is urgent that the Commonwealth and State Governments work closely with the health and community sectors to get a firmer understanding of such data to enable strategic service planning and costing. (See Section 6 for more details).

Appropriate planning processes

“Currently we have experienced challenges in relation to the timeliness and clarity of information provided and the functionality of the systems in place.”

PIR Consortium Member, SARC 2017

Our consortium members identified elements of the planning process that are working well for them and participants:

- Planning processes are now clearer and members feel better informed.
- Packages that give sufficient hours are working out well for some participants.

However, there are a number of challenges within the planning process specific to participants with psychosocial disabilities that need to be tackled. We have already outlined some of those adaptations in Section 1, namely:

- an incremental planning process between participants and LACs that enables a trusting relationship to be developed
- participants routinely to have the options of face to face or phone interactions
- specialist mental health trained LACs
- specifically targeted line items that meet the needs of participants with psychosocial disabilities, including access to clinical therapeutic services, including Allied Health

Professionals, costed at levels that are sustainable for providing a market in specialist mental health services;

- a more flexible review process that can respond to changes in participants' support needs in a more agile manner.

Below, we've provided details and examples of further issues that our consortium members have flagged as needing adapting within the planning and review processes to ensure that participants can lead a contributing life and effectively participate socially and economically.

Unfunded activities

Transport

Transport is a crucial facilitator of social and economic participation for people living with mental health conditions and an important cost for service providers reaching out in their support work. Its importance is exacerbated within regional and rural areas, where travel to social activities, education, training and employment and clinical and community services may be longer and a significant cost.

Under current Commonwealth funded mental health programs, such as PIR, PhaMs and D2DL, transport costs for both service providers and for clients are funded as part of the grant. Within NDIS, it is a participant line item. There are a number of issues to address here. Firstly, if transport funds within an ISP run out, this creates a potential barrier to participation in planned activities. Without a responsive review process, this is a challenge to resolve in a timely manner. Transport costs for service providers are no longer funded, so participants living in regional and rural areas are likely to cost more to provide services for. This raises issues of equity and viability in pricing.

Supporting effective applications

Support to access services is a key part of current PIR activities. This service both helps to ensure that people are maximising their support entitlements and helps to address equity of access to services for all consumers, which might otherwise be out of kilter due to some people / families having more effective advocacy skills.

Given problems with the appropriateness of current NDIS planning processes and line items, it is our staff's experience that consumers with effective advocacy skills or families with such advocacy skills are likely to gain the most from their plans.

Within NDIS, there is no universal support for making applications. Supporting both existing clients of other Commonwealth funded mental health services to 'transition' to NDIS and community members who have not engaged previously with services to make a new application to NDIS are not funded activities. Although the Information, Linkages and Capacity Building Framework is looking to encourage more consumer engagement in

applications, it does not look like it will offer support for individuals to get their diagnosis and submit NDIS applications.

Consortiums such as ours support our existing clients to obtain a diagnosis, if they do not have one already, and encourage them to make their NDIS applications. But this is an 'off the side of the desk' activity which will not be sustainable as NDIS rolls out.

Not providing support for NDIS applicants is likely to exacerbate inequality of access to NDIS and is another layer of challenge which is leading to participants presenting with vastly different levels of support.

Experienced mental health service providers, like those within our consortium, are well placed to support applications both from mental health clients who are engaged in existing Commonwealth and State funded mental health programs and from people who have not previously engaged with services and may not even have a diagnosis. To ensure equality of access to services, such support is crucial.

Disproportionate spending on administration of plans

As we have outlined within Section 1, current delays within the plan review process require significant follow up to ensure continuity of relevant support for participants. To expedite this, participants are drawing on our Coordinator of Supports to submit a participant's plan for review. This review support is funded from the participant's plan. Given that significant follow up is required – well beyond the 14 days of review time specified in guidance – participants are spending more of their funding than should be the case if NDIS was operating within stated service standards.

Participants who change states

There is a national commitment to ensuring continuous support for NDIS participants across Australia. But as the roll out of NDIS looks different in each state, so too will the packages of support arranged for consumers with psychosocial disabilities. An emerging issue here is Tasmania is that there is no body / process responsible for transitioning NDIS participants' ISPs when they move states. This is possibly a procedural oversight due to the relative newness of the system.

For Tasmania, that means we are seeing consumers with 'out of age group' ISPs and plans that are for longer than the 'normal' 12 month plans in this state. Currently, there is no formal mechanism to ensure that NDIS participants arriving in Tasmania are 'transitioned' to local support services. In our consortium members' experiences, this means that continuity of support relies on either participants proactively coming forward themselves (which has led to one case of a participant having a 6 month gap in support whilst they worked out how to navigate their way into a new support system), or a proactive service provider in the area a participant is leaving informing a destination state service provider that an NDIS eligible participant is transferring.

To ensure that such a policy oversight does not continue and amplify as the NDIS rolls out further, we need clarity on who is responsible for ensuring that those NDIS participants who change states receive a continuous package of appropriate support.

Recommendation 4:

Review NDIA eligibility guidance to provide a clearer framework for LACs to make more consistent decisions around psychosocial disability.

Recommendation 5:

Timely, well written, easy to access NDIA resources and descriptions of eligibility / processes / procedures specific to psychosocial disability for consumers and for service providers.

Recommendation 6:

Consideration could be given to funding / resourcing NDIS applications and reviews outside of a participant's plan funding, so that spending on this is not impacted by delays in NDIA administration processes.

Recommendation 7:

Clear operational processes are needed to transfer packages for participants who are moving from one state to another.

Recommendation 8:

There needs to be a clear and urgent focus on the funding and information needs for those not eligible for NDIS on the grounds of psychosocial disability.

4. Outreach,

"Leveraging off existing services / programs (e.g PIR) and using the profiles / reputations of organisations who have rapport with consumers."

PIR Consortium Member, SARC 2017

To engage more participants within NDIS, there is a need to understand where consumers are coming from and meet them on their terms. In our members' experience, NDIA Engagement Officers are not specifically thinking about how to reach consumers with mental health conditions. And, as we have previously flagged in Section 1, staff may not have expertise in this area and current processes do not work well within accepted mental health engagement practices.

Relationship is crucial to engaging people living with mental health conditions in planning for and working on developing and maintaining a contributing life. Our members believe that this can be successfully achieved by utilising the networks of existing specialist mental health service providers, who already have valuable relationships within communities and with clients, carers and families, and who work within recovery models of mental health services.

But to engage more potential NDIS participants, we need clearer, specific information for those eligible and ineligible for NDIS, so that fear of the uncertain and lack of clarity about future support do not interfere with engagement.

Recommendation 9:

For more effective outreach, engage existing service providers for:

- strengthened relationships and collaboration with referring providers and services
- proactive, well written, easy to access information briefings on:
 - how to assist people to access NDIS
 - how to help them prepare for eligibility and subsequent planning interviews.

5. Information, linkages and capacity building framework

"A longer funding timeframe for existing services will be required (i.e. past June 30 2019) so that the full impact of the NDIS can be assessed and it is clearer which services will need ongoing support through ILC funding."

PIR Consortium member, SARC 2017

At this stage, it is unclear how the Information, Linkages and Capacity Building Framework will cover gaps which will emerge as the NDIS is implemented. As the Mental Health Council of Tasmania highlight in their submission to the Committee, this funding was expected to meet some of the needs created by how NDIS has been constructed for people living with mental health conditions, such as:

- **Support for those not eligible for NDIS funding on the basis of psychosocial disabilities:** We have outlined our thoughts in Sections 1, 2 and 6. Our members are keen to highlight that clear information on future services for those not eligible for NDIS funding on the grounds of psychosocial disability is crucial.
- **Support for carers, families and communities:** The loss of psycho-social program funding to support individuals and families will also make it more challenging to address intergenerational mental health issues that often co-exist with other issues and cluster in communities of disadvantage. We know that for every person who has a complex mental illness, at least five family members or friends will be affected (SANE 2016). Anglicare works with many people living with mental health conditions through Housing Connect, Drug and Alcohol services and other services, such as financial counselling. Increased pressure on other family and community support services is likely to be exacerbated by NDIS's funding model, as funding packages are targeted towards individuals. As such, it is not designed to address the impacts of mental health on a community, carer, or family level
- **Support for making applications and reviews to NDIS:** It is not clear whether ILC will fund individual engagement. See Section 2.

The key issue will be the level of funding for the ILC. It is unclear to the sector what the long term vision for ILC funds will be and on what basis the allocation of funds has been made, given the clear evidence that there would be a significant number of people who would be ineligible for the level 3 packages.

"[We] will need to focus on providing timely, clear messages for our consumers that are unable to access NDIS support. We will also need to focus on securing funding for our services and programs designed for consumers that are unable to access NDIS funding."

PIR Consortium member, SARC 2017

Recommendation 10:

ILC needs to have a longer timeframe and be responsive to emerging needs that become apparent as NDIS rolls out.

6. Transition of commonwealth and state government mental health funding

Fig: 1 – Bilateral Agreement on Continuity of Support

5.0 Continuity of Support Arrangements

The NDIA and Governments will agree on a process to give effect to the arrangements set out in Schedule D: Continuity of Support Arrangements in Tasmania.

Deliverable: Governments and the NDIA will develop and implement working arrangements to provide continuity of supports for existing Tasmanian and Commonwealth clients who are ineligible for the NDIS.

Agreed Action:

5.1 The Tasmanian Government, in consultation with the Commonwealth, will identify existing clients (people and programs) in Tasmania that do not meet the NDIS access requirements.

5.2 To give effect to Schedule D: Continuity of Support Arrangements, the Tasmanian Government, in consultation with the NDIA and the Commonwealth, will develop working arrangements for continuity of supports that include:

- A process to inform the Tasmanian and Commonwealth Governments when an existing client is found ineligible for the NDIS;*
- A Government approach to maintain supports where existing supports do not meet the NDIS definition of reasonable and necessary; and*
- An agreed approach for communicating NDIS decisions to ineligible people to ensure continuity of supports.*

Timeframe: Quarter 3, 2015-16.

Extract from Operational Plan Commitment between the National Disability Insurance Agency (NDIA), Tasmanian Government and Commonwealth Government for Transition to the National Disability Insurance Scheme (NDIS), 2016-9

Psychosocial support under the NDIS has been funded by transitioning funding from existing Commonwealth funded mental health programs (MHA 2017), such as:

- 100% of Personal Helpers and Mentors (PHaMs) funding,
- 70% of Partners in Recovery (PIR) funding,
- 50% of Day to Day Living (D2DL) funding, and
- 35% of Mental Health Respite funding.

On 15 December 2015, the Commonwealth and Tasmanian Governments signed a bilateral agreement for the transition to and full roll out of the National Disability Insurance Scheme (NDIS) (COAG 2015). The Council of Australian Governments' Disability Reform Council provides a forum for Commonwealth and State Governments to continue to discuss issues

relating to reform in disability, including refining and further developing the National Disability Insurance Scheme. Paragraph 54 enables that, *'This Agreement may be amended at any time by agreement in writing by the Tasmanian Premier and the Commonwealth Minister for Social Services'* (COAG 2015).

The Operational Plan Commitment between the Commonwealth and Tasmanian Governments specifies a number of commitments to find out the number of people ineligible for NDIS on the grounds of psychosocial disability and a commitment to continuity of support (see Fig.1). But the commitment stops short of specifying who is responsible for leading these data gathering and funding initiatives. As such, we still do not understand the 'gap' that needs to be addressed in the mental health sector between those in and outside of NDIS.

It is worth noting that the bilateral agreement only commits to continuity of support for those clients who are with an existing mental health program at the time that NDIS rolls out for their cohort. It does not specifically mention those people living with complex, severe and/or persistent mental health conditions who are not engaged in support services at the time NDIS rolls out – i.e. potential consumers not engaged with any services and any future consumers.

This issue relates back to our first recommendation: that there needs to be a lead agency ensuring that such coordination of data, planning, services and outcomes happens.

For consumers

"For those ineligible, the horizon is dark."

"Uncertainty, concern, distress about their future – possibly exacerbating existing mental health issues."

PIR consortium members, SARC 2017

We simply do not know and are not able to inform many Tasmanians living with mental health conditions what support they are likely to receive once their age cohort becomes part of the NDIS. This uncertainty has consequences for consumers, as well as for service providers. Our consortium members are particularly seeing many consumers feeling they may be left without services and some consumers feeling frustrated and let down. They do not have information about how to handle this and such uncertainty may exacerbate mental health issues for many.

More certainty is needed in the holistic provision of mental health services if we are to continue to engage people who are currently a contributing life, and to reach those who are not.

"Need to create a sense of hope for those not eligible for NDIS. More secure and longer term funding arrangements."

PIR consortium member, PIR Consultation, Feb 2017

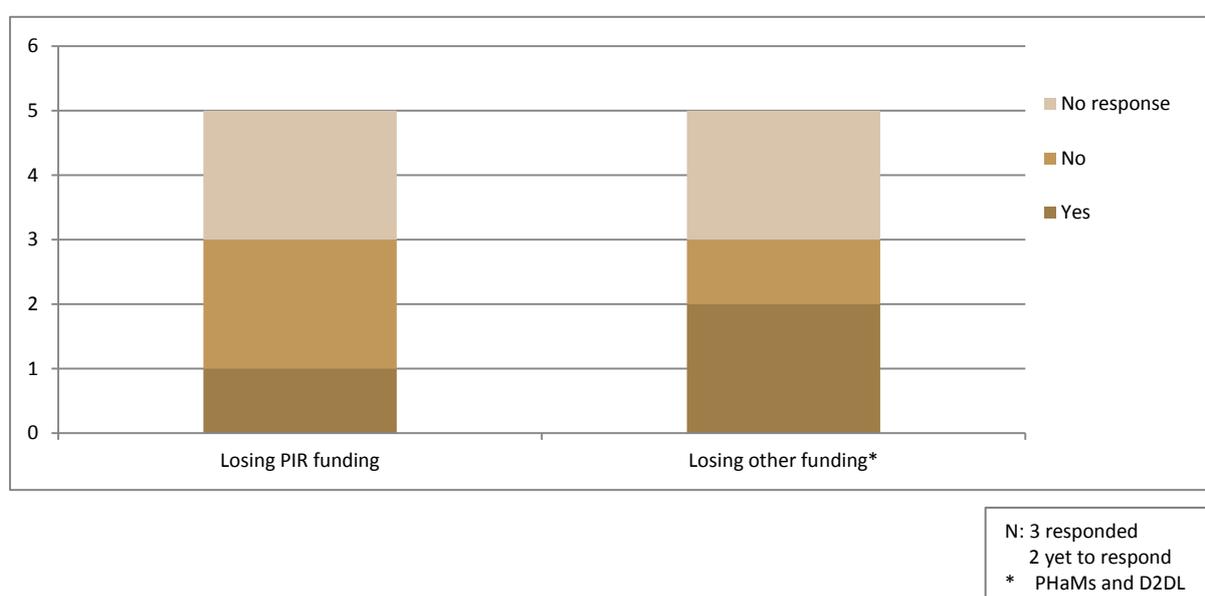
For Organisations

"Many things will be lost in the transition - We will be picking up pieces for decades."

We are able to support these consumers through our other services and programs however funding for these may be at risk."

PIR Consortium Members, PIR Consultation, Feb 2017

Fig 2: Number of PIR Tasmania Consortium members losing existing mental health services funding as a result of funding transitioning to the NDIS



Within the PIR Consortium, we estimate that approximately between 10 and 30% of existing clients will either not be eligible for NDIS due to psychosocial disability, or are unable to predict (see Table 2). Two more of our organisations will be losing other mental health services funding – PHaMs and D2DL. These programs currently support consumers with severe and persistent – but not necessarily permanent – psychosocial disability and they do not require a diagnosis to access support. We have outlined in Section 2 some of the reasons for consumers either not having or not seeking a permanent diagnosis. We have also highlighted why some clinicians are reluctant to diagnose a condition as ‘permanent’. But we are unclear whether there will be replacement funding to facilitate support for such consumers.

We are maintaining support for those ineligible for NDIS through drawing on other relevant programs, focusing on comorbid needs such as alcohol and drugs or counselling. But this is not sustainable. We have concerns that once funding for psychosocial services through programs such as PIR, D2DL and PHaMs is entirely transferred to NDIS, there will be a significant number of individuals, families and communities who have no access to

supports that promote their ability to lead a contributing life and engage in developing their potential.

Using Anglicare Tasmania as a case study, the organisation provides services for 400 individuals through PIR, 200 through D2DL and reaches a further 400 people through family support within PHaMs. Funding under these programs is gradually being transferred into NDIS. For example, Anglicare had a 16% decrease in PHaMs funding this year, as the cohort under 25 transferred to NDIS for psychosocial support. Additionally, State Government funded recovery and residential services are being cashed out, such as Anglicare's Recovery programs and Curraghmore Residential and Recovery Support Service. To date, only a small proportion of young people in the NDIS age cohort have been assessed as eligible for NDIS funding, leaving the remainder unable to access NDIS or Commonwealth funded support programs. Due to Anglicare's integrated services model, it has maintained support for those ineligible for NDIS through drawing on other relevant programs that focus on comorbid issues. But this is not sustainable.

The assumption has been that NDIS will pick up support for those living with mental health conditions who previously received support under such programs. However, as the Mental Health Australia states, 'Emerging evidence reinforces concerns that... the NDIS could unintentionally result in a shortage of services for those people who will remain outside the NDIS' (MHA 2016, p. 11).

For those Tasmanians without a permanent diagnosis but who have comorbid and complex support needs directly and indirectly related to their mental health, withdrawing direct mental health support is likely to put more pressure on already stretched clinical and acute mental health support and intensive family support. This is a much more expensive and resource intense model of support for the State Government longer term. It is also a distinct move away from investing in preventative support highlighted in the State's mental health strategy, ReThink (DHHS 2015c).

On a workforce level, the insecurity of mental health funding means insecurity of employment for many specialist mental health workers. If they choose to leave their current positions, we risk losing important mental health expertise within the sector. This would be damaging for the quality and choice of mental health services within Tasmania. On an organisational level, we are also facing an uncertain future in terms of service planning and provision.

The services gap will reach a crisis point in July 2019 when existing funding for mental health programs outside of NDIS will finally be completely withdrawn. Ahead of this date, it is imperative for the State Governments to be talking with and agreeing with Commonwealth Government who will take responsibility for funding support for people with mental health conditions not eligible to receive NDIS funding in the short and longer terms. A longer term agreement may, of course, be guided by this Parliamentary Inquiry into Mental Health in the NDIS (Parliament of Australia 2016). But a shorter term agreement between State and Commonwealth Government is needed to bridge support over the coming financial years while the Inquiry is conducted, reported upon and any

recommendations considered and actioned. This would enable any State Government / partnered funding and resourcing to be allocated in a timely manner in forthcoming Commonwealth and State Budgets.

Given the current development of the Fifth National Mental Health Plan (DoH 2016b), the role of Primary Health Networks in providing support will also need consideration and clarity within any revised agreement.

Recommendation 11:

As a matter of urgency, Commonwealth and State Governments need to liaise to clarify:

- how many people living with mental health conditions will not be eligible for support under NDIS – both those with severe and persistent conditions who currently receive mental health services under PIR, PHaMs and D2DL, and an estimate of future numbers
- what support will be available for consumers not eligible for support through and post-transition.

Recommendation 12:

As a point of urgency, keep consumers not eligible for NDIS engaged in leading a contributing life through committing to clear pathways of support.

Summary of recommendations

Recommendation 1:

In accordance with the draft Fifth National Mental Health Plan, Commonwealth and State Governments need to ensure there is co-ordinated national, as well as regional oversight of planning and outcomes for mental health services to ensure there are no gaps in clinical and community services for consumers with complex and severe mental health conditions, their carers and their families. This national and regional oversight needs to consider both those who are NDIS eligible and those who are not.

Recommendation 2:

In order to work within the recovery model of mental health services and offer appropriate and responsive support for participants to lead a contributing life, NDIS needs to develop a specific mental health 'stream'. This might include:

- The creation of a specific psychosocial gateway service for people with a psychosocial disability that converts the concepts of permanent disability to a system that supports recovery. Practically, this may include NDIA Community Engagement staff and Local Area Coordinators (LACs) who are specifically trained in understanding the needs of mental health consumers and appropriate service responses within the recovery model, to ensure engagement, planning and reviews are timely and relevant for participants.
- The creation of a psychosocial assessment and planning system that embraces the concept of recovery for people with a psychosocial disability. Practically, this may include incremental, timely and responsive planning and reviews, with a clear offer for participants to undertake this face to face with a LAC, or via phone.
- The creation of a psychosocial service and pricing system that better reflects the recovery concepts. Practically, this may include service line items specific to the needs of participants and service providers working within the recovery model of mental health services. These services to include any activities that may assist a participant to overcome challenges to social and economic participation, to ensure that support is coherent and comprehensive. These services need to include access to therapeutic clinical, as well as community, services such as Allied Health Professionals.
- The adoption of psychosocial service standards that reflect the National Mental Health Service Standards; and

- The adoption of psychosocial outcomes measurement systems that aligns with the recovery of people and their increasing contribution and engagement in the community.

Recommendation 3:

NDIA is fully resourced during the roll out of NDIS to cope with the demands of conducting appropriate engagement, planning and reviews.

Recommendation 4:

Review NDIA eligibility guidance to provide a clearer framework for LACs to make more consistent decisions around psychosocial disability.

Recommendation 5:

Timely, well written, easy to access NDIA resources and descriptions of eligibility / processes / procedures specific to psychosocial disability for consumers and for service providers.

Recommendation 6:

Consideration could be given to funding / resourcing NDIS applications and reviews outside of a participant's plan funding, so that spending on this is not impacted by delays in NDIA administration processes.

Recommendation 7:

Clear operational processes are needed to transfer packages for participants who are moving from one state to another.

Recommendation 8:

There needs to be a clear and urgent focus on the funding and information needs for those not eligible for NDIS on the grounds of psychosocial disability.

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For more effective outreach, engage existing service providers for:

- strengthened relationships and collaboration with referring providers and services
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 - how to assist people to access NDIS
 - how to help them prepare for eligibility and subsequent planning interviews.

Recommendation 10:

The Information, Linkages and Capacity Building Framework needs to have a longer timeframe and be responsive to emerging needs that become apparent as NDIS rolls out.

Recommendation 11:

As a matter of urgency, Commonwealth and State Governments need to liaise to clarify:

- how many people living with mental health conditions will not be eligible for support under NDIS – both those with severe and persistent conditions who currently receive mental health services under PIR, PHaMs and D2DL, and an estimate of future numbers
- what support will be available for consumers not eligible for support through and post-transition.

Recommendation 12:

As a point of urgency, keep consumers not eligible for NDIS engaged in leading a contributing life through committing to clear pathways of support.

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