

Commonwealth Mental Health Programs Monitoring Project

Tracking transitions of people from PIR, PHaMs and D2DL into the NDIS

FINAL REPORT
September 2019



THE UNIVERSITY OF
SYDNEY

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Benevolent Society	Mental Health Foundation ACT
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Breakthru	New Horizons
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CoHealth	Star Health
EACH	TeamHEALTH
Eastern Melbourne Primary Health Network	Uniting Care
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- Helen McCosker for permission to use your artwork that sends a powerful message about the importance of getting NDIS and mental health services ‘right’
- Rob Ramjan for assistance with contextual interpretation of findings

Abbreviations

ARF	Access Request Form
ASGS-RA	Australian Statistical Geography Standard-Remoteness Area classification
CoS	Continuity of Support
CMO	Community managed organisations
D2DL	Day to Day Living Commonwealth Program
MH	Mental Health
MHR-CS	Mental Health Respite – Carer Support
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisations
NPS	National Psychosocial Support
NPSM	National Psychosocial Support Measure
PEP	Psychosocial Extension Program (also called Psychosocial Transition Program)
PHaMs	Personal Helpers and Mentors Commonwealth Program
PHN	Primary Health Networks
PIR	Partners in Recovery Commonwealth Program
RA1	Major Cities of Australia (ASGS-RA)
RA2	Inner Regional (ASGS-RA)
RA3	Outer Regional Australia (ASGS-RA)
RA4	Remote Australia (ASGS-RA)
RA5	Very Remote Australia (ASGS-RA)
SF	Support Facilitator
SPMI	Severe/Serious and Persistent Mental Illness
SW	Support Worker
TSP	Transition Support Program

Executive Summary

Background

While the NDIS presents an opportunity for some people living with serious mental illness to access supports that may have previously been unavailable, a range of existing mental health programs and supports have been terminated in order to fund the NDIS. Only with a robust, publicly accessible 'picture' are we able to assess whether alternative funding (Continuity of Support¹) for those not applying or not eligible for NDIS is adequate. Equally, ongoing data is needed in order to assess the adequacy of the recently implemented up to 12-month extended transitional funding² to assist those people commencing or in the process of applying for the NDIS.

Community Mental Health Australia (CMHA) and The University of Sydney have, over an 11-month period, collected, analysed and reported³ on national data regarding the NDIS transition, or otherwise, of clients living with serious mental illness from three Commonwealth funded programs: Partners in Recovery (PIR), Personal Helpers and Mentors (PHaMs) and Support for Day to Day Living (D2DL). All three programs have now been discontinued.

Data Collected

Community-based organisations providing PIR, PHaMs and D2DL programs were invited to participate by providing non-identifiable data about the transition of their clients. Both qualitative and quantitative data were collected and reported in three iterative phases. In total **138 datasets** were provided by **84 PIR, PHaMs or D2DL programs** from **41 community-based organisations** spanning all states and territories. Data were captured for **3,138 individuals living with mental illness in Phase 1, 8,162 in Phase 2, and 6,005 in Phase 3**. Quantitative data were provided on numbers of clients at various points of transition or not. Qualitative data were provided to assist in a deeper understanding of the results.

Summary of Findings

This report evidences **that there are a high proportion of people who have not applied and a high proportion of people who have applied and have been found ineligible**. These data raise concerns about the adequacy of alternative funding. Equally the data in this report provide insights that raise concerns about the adequacy of the up to 12-months of extended transitional funding to assist those people commencing or in the process of applying for the NDIS.

Stage of Transition:

- Consistently across the study, approximately **half of people within these programs had submitted an application to the NDIA to test their eligibility for NDIS**. (49% in Phase 1, 51% in Phase 2, 44% in Phase 3).

¹ Department of Social Services (DSS). (2018). *Continuity of support for clients of Commonwealth disability program*. Retrieved from the DSS website: https://www.dss.gov.au/sites/default/files/documents/08_2018/d18_802800_final_fs_-_budget_2018-19_-_continuity_of_support_for_clients_of_commonwealth_disability_p_1.pdf

² Department of Social Services (DSS). (2018). *Extension of Commonwealth programs transitioning to the National Disability Insurance Scheme (NDIS)*. Retrieved from: <https://www.dss.gov.au/disability-and-carers-transitioning-to-the-ndis/extension-of-commonwealth-programs-transitioning-to-the-national-disability-insurance-scheme-ndis-frequently-asked-questions>

³ Commonwealth Mental Health Programs Monitoring Project: Tracking transitions from PIR, PHaMs and D2DL into the NDIS. Interim reports for Phases 1 and 2. <https://cmha.org.au/publications/>

- Around **one quarter of people had commenced the process of gathering evidence required to submit an application to the NDIA** (22% in Phase 2 and 27% in Phase 3).
- Around **one fifth of people had not commenced gathering evidence required or did not intend to test their eligibility for NDIS** (19% in Phase 2 and 22% in Phase 3).

Outcomes for those who had applied:

- Consistently across the study, **over a quarter of people who had applied were assessed as ineligible for the NDIS** (28% in Phase 1, 28% in Phase 2, 27% in Phase 3).
- Comparing outcomes between PiR and PHaMs, **a greater proportion of PHaMs clients who had applied were assessed as ineligible for NDIS** (38% in Phase 2 and 32% in Phase 3, compared with 24% in Phase 2 and 27% in Phase 3 for PIR clients)
- Of all people assessed as ineligible, **more than half of people did not appeal or re-apply** (data only collected in Phase 3).
- The **proportion of people who had applied for the NDIS and were assessed as eligible reduced across the study** (60% in Phase 1, 47% in Phase 2, 33% in Phase 3). However, this is likely to be in large part because of the increasing proportion of people who had applied and were still awaiting to hear the outcome of their application (12% in Phase 1, 25% in Phase 2, 40% in Phase 3).

Understanding the high proportion of people not applying:

Consistently across all phases the qualitative data showed that the most frequent reasons given for why **“clients will not/are not applying”** for the NDIS were: clients are fearful of the application process; clients’ mental health is too poor or too unstable; clients are dealing with more urgent priorities (e.g., housing and poor mental health); clients don’t trust government related agencies; inability to obtain the evidence required by the NDIA (due to transience and limited contact with services).

“... [they are] unable to apply [for NDIS] as the effort required has been too overwhelming, the information required too hard to gather and the process of navigating the NDIA too complicated (PIR WA)”

Understanding the challenges in gathering the evidence needed to apply:

A range of data in this report provide insights into the high proportion of people still in the process of gathering evidence to apply and perhaps reasons for the high proportion of people assessed as ineligible because the level of evidence required was not met within applications.

Most frequently reported challenges included: nature and impact of client’s psychosocial disability made obtaining evidence hard/impossible; clients did not accept/identify as having a ‘disability’; clients became too unwell to continue with the process; specialists/GPs/psychiatrists – lack of knowledge/understanding of NDIA requirements; costs of GPs, psychiatrists and other specialists (preclude collection of needed evidence); and additional challenges for rural and remote communities and for clients who need language interpreters.

“There have been many participants who have limited expert evidence on record to help support an application. Many do not have a regular GP and have not access health service in many years so gathering functional evidence has been difficult” (PIR NT)”

Understanding the high proportion of NDIS plans deemed inappropriate by providers

While it is important to acknowledge the range of work that the NDIA is doing to address many of the issues raised in this and previous reports, the data indicates an inconsistent approach to NDIA assessment and appeals and providers continue to report inconsistent NDIA staff understanding of psychosocial

disability and these impacted on the appropriateness of plans. Providers assessment of the proportion of inappropriate NDIS plans for their clients increased (28% in Phase 2, 35% in Phase 3).

The most frequent reasons given for inappropriate plans included: lack of, or insufficient support coordination; inadequate funding for needs to be met; insufficient mentoring at the planning phase; not enough capacity building – only core supports included; lack of NDIA understanding of psychosocial disability; lack of inclusion of transport needs (both for client and for services); additional rural and remote complexities, and culturally inappropriate plans.

“Planners don’t understand that people with Psychosocial disabilities need support coordination as a must. The plan will not be used if there is no support coordination because participants are generally too unwell to organise an NDIS plan” (PIR NSW)

Further, challenges were raised in actioning plans even when deemed appropriate. A **lack of services available to action plans** was most commonly reported and this was a greater problem for people living in rural and remote communities. Finally, a number of providers expressed concerns about **plans for clients being reduced in the review process because they were ‘underutilised’**.

Discussion and Reflections

Those who have not yet applied for NDIS:

These data suggest that **many people not applying are in fact those most in need of a high level of support and it is the severity and complexity of their mental illness that is precluding them from engaging in the complex and stressful process required** to apply or re-apply. Close and ongoing monitoring of the adequacy and appropriateness of time-limited extension funding to support these people to apply for the NDIS is needed. Data in this report indicates that a **12-month extension of transition funding is unlikely to be adequate**. Equally, the level of support provided through this funding needs to be monitored to ensure it avails this vulnerable population the amount and quality of assistance required to engage with what is a complex and demanding application process.

Those who are now NDIS participants:

It is very evident that **for many who have been assessed as eligible, the NDIS has been life changing**. However, as with all major social reforms, there are still many areas in need of improvement and work needed to better align the Scheme with the needs of people with psychosocial disability, and to reduce the barriers and complexities of NDIA and NDIS. This includes **ongoing psychosocial disability training for NDIA staff and continual improvement in the consistencies of communication and practices** within NDIA and with people trying to access the Scheme. The high proportion of plans that are deemed to be inappropriate by providers, and the repeated reporting of plans being reduced because of ‘underutilisation’ both evidence the need for increased NDIA staff training in psychosocial disability. **Rather than underutilisation reflecting a lack of need, providers told us it was more commonly because of the episodic nature of mental illness, because people had been too unwell to activate them, they had long periods in hospital, didn’t have the support coordination to enact their plans, or were unable to find anyone to provide services within the plan.**

Those who will fall outside of the NDIS:

These data also evidence that **a high proportion of previous PIR, PHaMs and D2DL clients do and will continue to fall outside the NDIS** – either because they do not apply, or because they apply and are found ineligible. This highlights the need to closely monitor the alternative supports and services provided for people living with serious mental illness who fall outside of the NDIS (currently **greater than 50% of PIR, PHaMs and D2DL clients**) to ensure they continue to have access to the range of

psychosocial supports that meet their individual needs and that they are not worse off as a consequence of the roll out of the NDIS. **Until the final number of people who transition from these programs into alternative support programs has been established, it is unclear if the alternative to NDIS is adequate and replaces the supports previously provided through PIR, PHaMs and D2DL programs.**

Providers expressed concern that without at least equivalent supports, this group of people would be at **risk of end up depending upon more expensive acute and clinical mental health services and be at greater risk of ending up in the justice system.**

“The ceasing of PHaMs [presents] a great risk to local and regional communities with a potential for increased need on the local justice and health systems” (PHaMs QLD)

1. Project Background and Aims

“When making a major complex system change, by all means throw out the bathwater but keep your eye on the baby” – Fastcompany.com

Context

The National Disability Insurance Scheme (NDIS) is the largest reform of disability services in a generation. The NDIS legislation was passed in 2013 and the scheme is anticipated to be fully operational by 2023 providing support for approximately 460,000 people with disabilities and amongst those approximately 64,000 people with primary Psychosocial Disabilities⁴.

In the planning for the rollout of the NDIS a number of Commonwealth and State/Territory disability programs were scheduled for cessation, with the undertaking made through the Council of Australian Government (COAG) that the people being assisted through those programs would obtain at least equivalent, and hopefully better support through the NDIS.

Based on feedback from the mental health sector, in October 2018 the Government announced the implementation of a *Psychosocial Disability Stream* to assist people with serious mental health issues⁵ to have improved access and support in the NDIS. This initiative is part of the NDIS Pathway Reform agenda.

The NDIA June Quarter 2019 National Performance Report to the COAG Disability Reform Council⁶ shows that nationally, of the participants entering in the June quarter, 12% had a primary disability of Psychosocial Disability compared with 8% (cumulatively) in previous quarters. There was an increased proportion of participants who joined the Scheme in the quarter with psychosocial disability, particularly in Tasmania and South Australia. Overall the proportion of active Psychosocial Disability participants with an approved plan is 9% (25,192 participants).

This project was developed to understand the transition of clients from Commonwealth programs to the NDIS. The project was conducted in an uncertain environment where it was not clear what ongoing supports would be available to consumers accessing three Commonwealth programs offering psychosocial supports (Personal Helpers and Mentors (PHaMs), Partners in Recovery (PIR) and Day to Day Living (D2DL), as program funding was scheduled to cease as of 30 June 2018. Acknowledging the slower than forecasted transition of people with psychosocial disability into the NDIS, the programs were extended to 30 June 2019 and since, further transitional funding has been made available to support⁷ the wholesale transition of program participants.

In partnership, Community Mental Health Australia (CMHA) and The University of Sydney have over a 11-month period, collated, analysed and reported⁸, on data available regarding the transition of

⁴ National Disability Insurance Agency (2017) *Attachment A: Key Data on Psychosocial Disability and the NDIS - as at 31 March 2017*. <https://www.ndis.gov.au/medias/documents/hda/h2c/8804425367582/Attachment-A-Key-Data-on-NDIS-and-Psychosocial-Disability.pdf>

⁵ Pathway reform Media release from the Minister Media release from the Assistant Minister (10th October 2018): <https://www.ndis.gov.au/news/400-government-announces-improved-ndis-mental-health-support>

⁶ Quarterly NDIA Reports to COAG Disability Reform Council: <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

⁷ Extension of Transition Support: <https://www.dss.gov.au/disability-and-carers-transitioning-to-the-ndis/extension-of-commonwealth-programs-transitioning-to-the-national-disability-insurance-scheme-ndis-frequently-asked-questions>

⁸ Commonwealth Mental Health Programs Monitoring Project: Tracking transitions from PIR, PHaMs and D2DL into the NDIS. Interim reports for Phases 1 and 2: <https://cmha.org.au/publications/>

PHaMs, PIR and D2DL clients to the National Disability Insurance Scheme (NDIS). To establish a national dataset, this project was designed to engage directly with service providers working with these clients and to develop, with them, an understanding in 'real time' of the outcomes and challenges for this cohort transitioning into the NDIS.

This study is an important contribution to inform key decision makers and the sector of the number, the rate of transition and the systemic issues contributing to or impeding the process. The Australian Government has made a commitment to the 'principle of no disadvantage' through the bilateral agreement between the Commonwealth and state governments⁹. Accessible national data will make accountable this commitment to ensuring that 'no one will be worse off' because of the roll out of the scheme.

The changing funding and service delivery landscape

Within the short space of time that this study has been conducted, the national context has changed with numerous funding changes and policy announcements as the Australian Government has been making adjustments in line with sector signals, and a series of formal reviews and enquiries including the Joint Standing Committee on the NDIS.

In late 2018, the Australian Government announced two new funding streams intended to address the needs of people who are not eligible for the NDIS and who may 'fall through the gaps', the National Psychosocial Support (NPS) Measure and Continuity of Support (CoS) funding. These two planned funding streams are for people with a severe mental illness who have reduced psychosocial functional capacity, who are not already more appropriately supported through the NDIS, and or are not eligible or who are yet to test their eligibility for the NDIS. These funds are managed by Primary Health Networks, so it is important to note that there are variations in how these funds are being administered across regions. These various funding streams and eligibility to access each are demonstrated in Figure 1 and detailed below¹⁰

Psychosocial Transition/Extension Program

In March 2019, the Australian Government announced purpose specific funding of \$121.29 million over 12 months to support remaining PIR, PHaMs and D2DL clients, transition to the NDIS or CoS support streams. The Psychosocial Extension Program will be provided for a period of up to 12 months to support existing clients of PIR, D2DL or PHaMS who have not yet tested eligibility for the NDIS, or who are waiting to receive an access decision or approved support plan for the NDIS.

Continuity of Support (CoS)

CoS¹¹, provides clients previously in PIR, D2DL or PHaMs programs, who are found to be ineligible for supports under the NDIS, with supports to 'achieve similar outcomes to those they received in the previous programs. In the 2018-19 Federal Budget the Government announced \$109.8 million for CoS. From

⁹ Agreement regarding the Principle of No Disadvantage:

https://www.coag.gov.au/sites/default/files/agreements/Intergovernmental%20Agreement%20for%20the%20National%20Disability%20Insurance%20Scheme%20%28NDIS%29%20Launch_unsigned%20doc.docx

¹⁰ PHN Commissioned Psychosocial Programs:

[https://www1.health.gov.au/internet/main/publishing.nsf/Content/2A58F6131FE16440CA2583C40014ABF6/\\$File/Fact%20Sheet%20-%20NDIS%20transition%20PHNs-%2003.04.19.pdf](https://www1.health.gov.au/internet/main/publishing.nsf/Content/2A58F6131FE16440CA2583C40014ABF6/$File/Fact%20Sheet%20-%20NDIS%20transition%20PHNs-%2003.04.19.pdf)

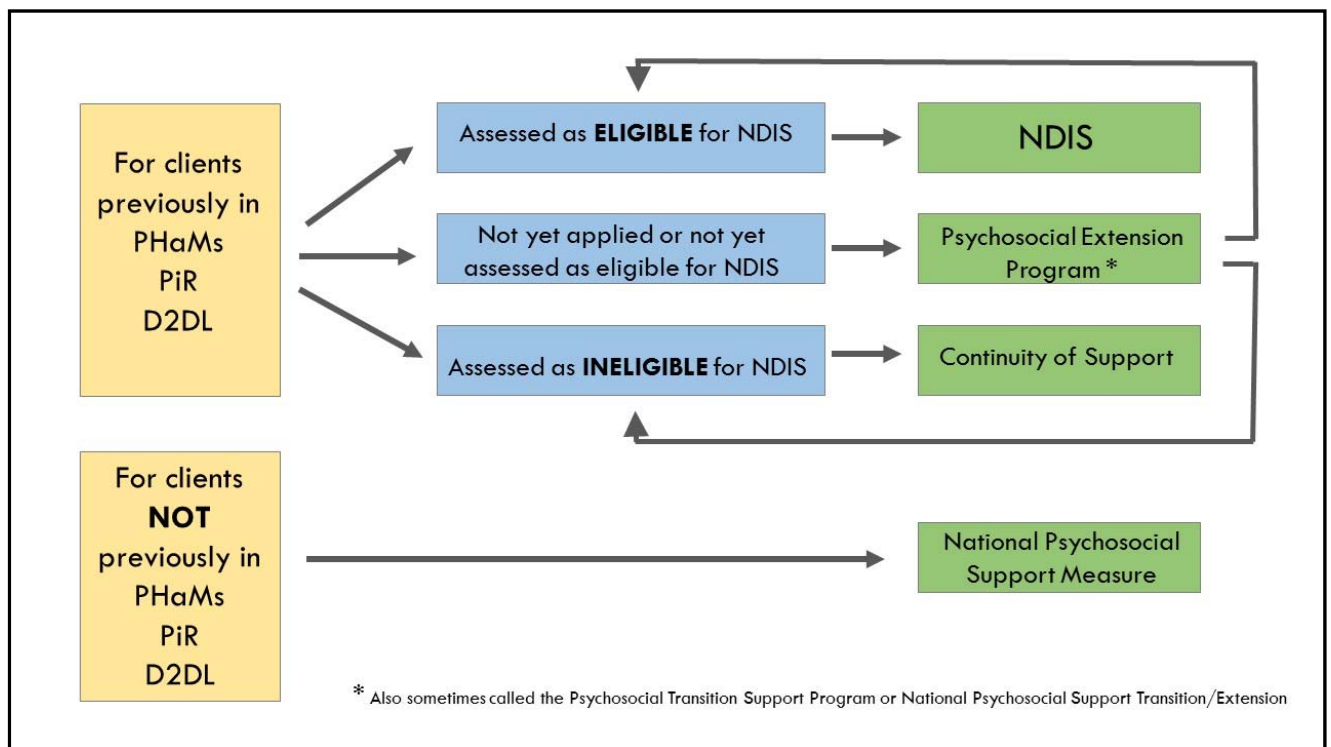
¹¹ Department of Social Services (DSS). (2018). *Continuity of support for clients of Commonwealth disability program*. Retrieved from the DSS website: https://www.dss.gov.au/sites/default/files/documents/08_2018/d18_802800_final_fs_-_budget_2018-19_-_continuity_of_support_for_clients_of_commonwealth_disability_p_1.pdf

1 July 2019 CoS provides ongoing funding, ensuring CoS clients have access to long-term, responsive support.

National Psychosocial Support (NPS) measure

NPS measure¹² aims to help people with severe mental illness who are not more appropriately funded through the NDIS and not actively engaged with the Commonwealth funded programs, to increase their ability to do everyday activities through a range of non-clinical community-based support. In the 2017-18 Budget the Government committed \$80 million over four years for the NPS measure.

Figure 1. Flow chart of psychosocial program pathways



Scheme improvements for people with a psychosocial disability

As detailed in reports from NDIA to COAG, significant ongoing work has been undertaken by the NDIA¹³ to improve the participant experience, in consultation with participants, families, carers, providers and sector representatives, including a service stream for psychosocial disability to deliver targeted support to provide participants with an experience more suited to their specific needs.

From 30 April 2019, streamlined access for people with psychosocial disability became available to prospective participants in all States and Territories. As part of the streamlined access process, prospective participants can:

- verbally begin their access request with a support worker or a trusted other person
- provide consent for their support worker or a trusted other person to be the NDIA contact for the duration of the access process
- re-test access to the NDIS with the support of a trusted person (where required).

¹² National Psychosocial Support measure: <https://www1.health.gov.au/internet/main/publishing.nsf/Content/mental-n-national-psychosocial-support-measure>

¹³ Quarterly NDIA Reports to COAG Disability Reform Council: <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

The streamlined access process aims to support the high proportion of prospective participants with mental health conditions that the NDIA has not been able to contact and/or has not received requests for access.

To support the NDIA's aim for greater consistency, fairness and reliability in access and planning decisions, an Independent Assessment Pilot ran from November 2018 to April 2019. Its purpose was to better understand and assess the impact of disability for people accessing the NDIS (including those with psychosocial disability), to improve the consistency, accuracy and reliability of access and planning decisions. Given the timeframes and limitations of this pilot, it would be fair to assume that any benefit or impact of streamlined access is not reflected in the data in this report.

2. Methods

Recruitment

This project involved three iterative phases. Initially four phases were planned, however phases 3 and 4 were combined to reduce provider burden. In each of the three phases, provider organisations from the three programs (PIR, PHaMS, and D2DL) across all states and territories were identified and invited to participate as partners in the project. Organisations were identified and invited by state and territory peaks – noting that Community Mental Health Australia (CMHA) is a coalition of these peaks. Participating organisations and programs submitted non-identifiable data to the research team regarding active PIR, PHaMS, and D2DL clients who were transitioning, or otherwise, to the NDIS. Efforts were made to ensure that participating providers were broadly representative and included both metropolitan, regional and rural programs across all states and territories.

Data collection and analysis

In each phase, participating programs were provided a data collection spreadsheet/table. Findings from the first phase were reported in December 2018³. In this pilot phase an initial understanding of NDIS transition was gained and the most accessible, least burdensome methods for programs to provide data to the research team in following phases established. In the second phase, reported in April 2019* a greater body of national data confirmed and built on the initial findings. The reports from Phases 1 and 2 were made publicly available and fed back to participating programs for reflection and engagement in planning for the following phase. After each phase, discussion within the team and with participating programs lead to refinements and change in some areas of focus. This final report draws together and synthesises the results from Phases 1, 2 and 3 to provide a robust national picture of changes over time as well as consistent themes or findings.

The University of Sydney team collected, collated and analysed the data. A summary of the data sought from each program across each of the 3 phases is provided below. Quantitative data were analysed using simple descriptive statistics. Where data were incomplete, or discrepancies existed, programs were contacted directly to gain clarification or review. Where there was too much missing data because a program was unable to access and provide robust figures for a question, all data from that program were removed for that specific analysis. Thus, prior to the reporting of each of the results, the number of programs and clients included in the analyses are detailed. Qualitative data were analysed thematically and NVIVO software was used to manage the qualitative data set.

DATA COLLECTED ACROSS THE THREE PHASES:

- The number of active clients in the program during that phase
- The number of those clients who had applied for the NDIS/chosen to test their NDIS eligibility
- For those who had applied –
 - Length of time from application to determination
 - Outcomes (numbers who have been deemed eligible, ineligible and were still awaiting outcome)
- For those assessed as eligible for NDIS –
 - Appropriateness or not of plans – number and reasons (phases 2 and 3)
 - Length of time between submitting application and receiving outcome
 - The number for whom plan dissatisfaction led to a request for plan review
- For those assessed as ineligible –
 - Reasons provided for ineligibility (phase 1)
 - The number of appeals/reapplications submitted for those who were assessed as ineligible (phases 2 and 3)
 - Length of time between appeals being lodged and reviewed
 - Outcomes of those appeals
 - Alternative referrals/pathways provided and reasons for these
- For clients who chose not to/declined to apply for NDIS support –
 - Reasons why
 - Alternative referrals/pathways provided and reasons for these

ADDITIONAL DATA COLLECTED IN THE FINAL PHASE:

In the final phase, participating providers were also invited to provide additional qualitative commentary throughout and to provide final reflections.

3. Findings

These findings are a synthesis of data collected over 11 months for the following three time periods:

Phase 1: 1st August 2018 – 31st October 2018 (3 months)

Phase 2: 1st November 2018 – 28th February 2019 (4 months)

Phase 3: 1st March 2019 – 30th June 2019 (4 months)

3.1 An Overview - Organisations, Programs and People

Across three data collection phases that spanned 11 months, **41 organisations** provided **138 datasets** for **84 PIR, PHaMs or D2DL programs** spanning **all states and territories**. A large number of individual people living with serious mental illness were reported on across the phases of this study: **3,138 in phase one; 8,162 in phase two; 6005 in phase three**. In each phase there were elements of data sought that some programs couldn't access/provide. Therefore, to maximise transparency, the number of people included in each analysis is provided. 17 programs were able to participate across all three phases, 29 participated in two, and 38 in a single phase.

A breakdown of participation by each program type within each phase and the overall proportion of metropolitan and regional participation are reported in the tables below.

Table 1. Number of organisations, programs and individuals reported on across the project

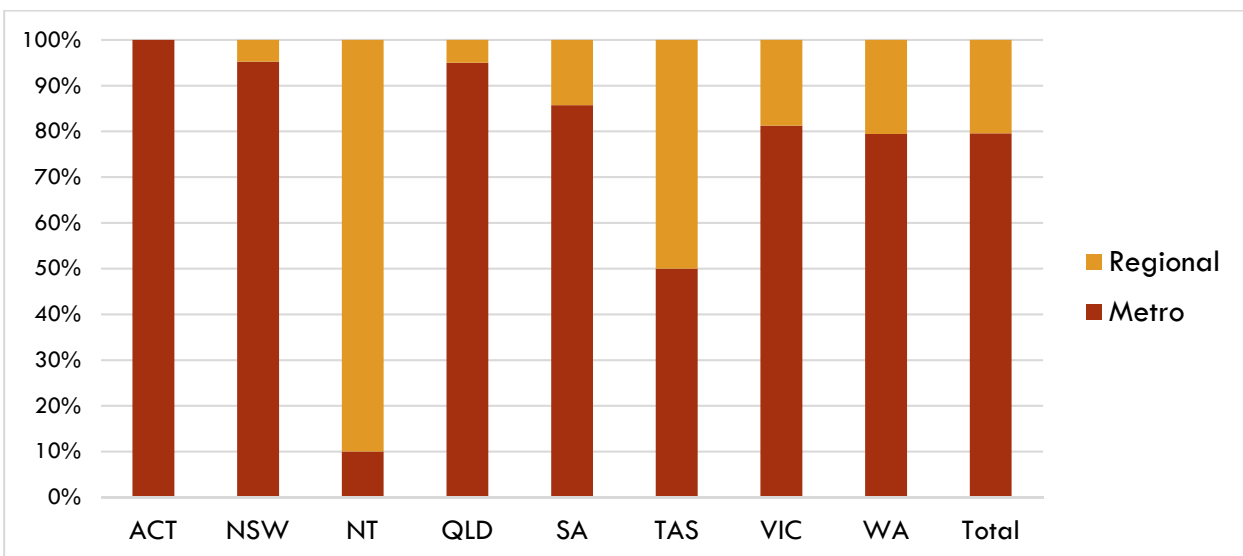
PHASE	Number of ORGANISATIONS	Number of discrete PROGRAMS for each program type	Number of INDIVIDUALS reported on	TOTAL number of INDIVIDUALS reported on
1	22	PIR: 17	2,464	3,138
		PHaMs: 8	493	
		D2DL: 3	181	
2	31	PIR: 27	4,760	8,162
		PHaMs: 26	2,257	
		D2DL: 11	1,145	
3	27	PIR: 17	3,109	6,005
		PHaMs: 23	2,261	
		D2DL: 6	635	

Table 2. Overall number of regional and metropolitan datasets for each state and territory

STATE	METRO #	REGIONAL #
ACT	7	0
NSW	20	1
NT	1	9
QLD	19	1
SA	6	1
TAS	3	3
VIC	26	6
WA	27	7
Total	109 *	28 *

Notes: # Metro includes RA1 and/or RA2 (major cities and inner regional Australia). Regional includes a combination of RA3 (outer regional Australia), RA4 (remote Australia) and RA5 (very remote Australia). Website: <https://www.health.gov.au/resources/apps-and-tools/health-workforce-locator/health-workforce-locator> * these are the number of data sets rather than number of programs. Some of the 84 participating programs provided data across more than one data collection phase.

Figure 2. Overall proportion Metropolitan and Regional datasets for each State and Territory



Note. Data is based upon number of program datasets rather than number of individuals reported on.

Program participants reported on

All people reported on were adults living with mental illness and, at the time of reporting, current active participants of PIR, PHaMs or D2DL programs. There were more females than males within the total datasets for both Phase 2 and 3. Psychiatric data presented suggests that many individuals had more than one psychiatric diagnosis, and this is an under-estimation of multiple diagnoses given that many programs, particularly D2DL programs, only kept primary diagnoses in their records. Equally, very few programs reported non-psychiatric co-morbidities, but this ranged between 30-50% of people when it was reported. Common non-psychiatric comorbidities included acquired brain injury, intellectual disability and a range of chronic physical conditions.

Gender

Table 3. Gender representation across 3 Phases

Phase	Individuals data provided for	Males	Females	Other/not reported
1	3138	1098 (35.0%)	1531 (48.8%)	509 (16.2%)
2	6845	2829 (41.3%)	3962 (59.9%)	54 (0.8%)
3	5010	2173 (43.4%)	2803 (55.9%)	34 (0.7%)

Psychiatric Diagnoses

Table 4. Psychiatric diagnoses known for individuals reported on across 3 Phases

Phase	Individuals data provided for	Schizophrenias	Mood Disorders	Anxiety Disorders	PTSD	Other	TOTAL
1	Insufficient data provided						
2	6062	1650 (27.2%)	2736 (45.1%)	1508 (24.9%)	544 (9.0%)	1269 (20.9%)	*127.1%
3	4421	1202 (27.2%)	2022 (45.7%)	1436 (32.5%)	583 (13.2%)	862 (19.5%)	*138.1%

Notes. * Percentages add to greater than 100% because more than one diagnosis was reported for some people; Mood Disorders = depression, major depression, bipolar disorder; Anxiety Disorder = anxiety, obsessive compulsive disorder, agoraphobia; PTSD = Post Traumatic Stress Disorder; Other = diagnoses that programs were unable to align with other categories including autism, borderline personality disorder, multiple personality disorder.

3.2 Peoples' Stages of Transition

At each of the three data collection points, we asked program providers to tell us how many of their currently active clients had applied for NDIS and how many had not. In the second and third phase we asked for more detail about those who had not applied. We asked how many were in the process of preparing an application and how many were not planning to apply or had not started applying. Program providers were encouraged to say 'unknown' for any clients that they had lost contact with or who they believed might be applying with support outside of their program.

Consistently across all three phases, close to 50% of currently active clients had submitted an NDIS application. There was a slight reduction in the proportion of active clients who had applied, and this might be expected given that programs were in the process of preparing to close down and refer clients elsewhere or were transitioning to alternative funding and service models.

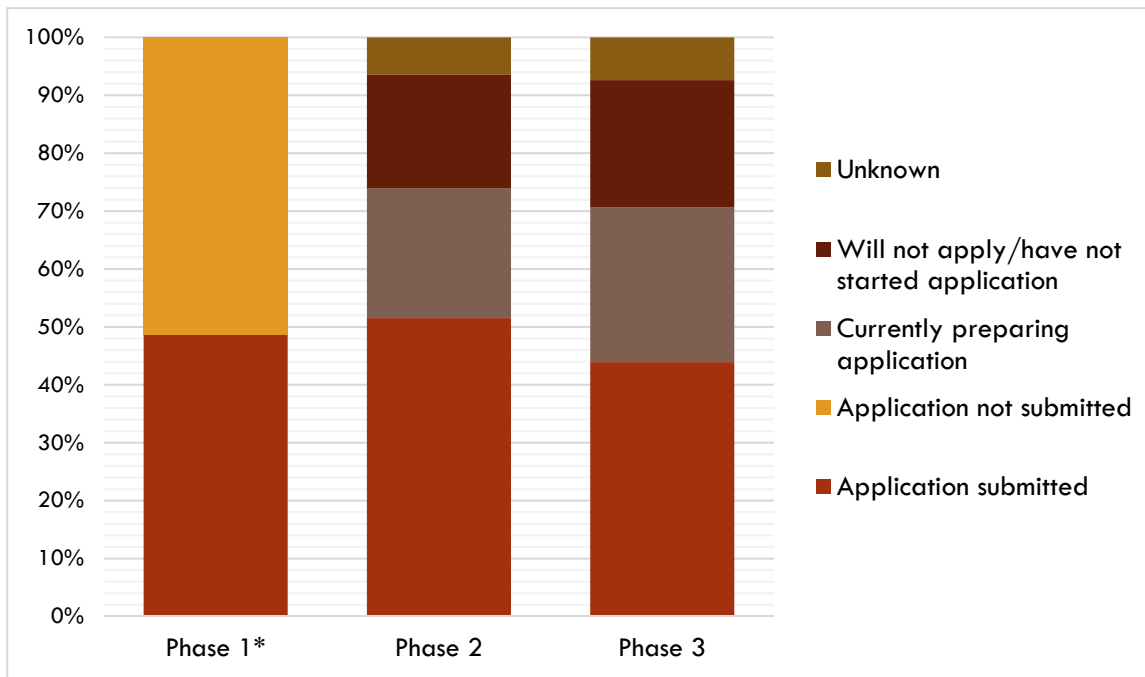
In Phases 2 and 3, more detail was sought regarding people who had not submitted an NDIS application. They were asked to provide data on who had commenced the process of gathering evidence (Table 5. Currently preparing to apply), and who had not commenced the process whether they had intention to do so in the future or not (Table 5. Will not/had not started to apply). Of those who had not submitted an application, **close to equal numbers had, and had not, commenced the process of applying** (see Table 5 below). People who had not commenced the process of applying (gathering evidence etc.), included those who had zero intention of ever applying, those who are too unwell to consider it at present and those who are undecided. More detail for this group is provided later in the report given this is a critical group that needs to be understood as alternatives for PIR, D2DL and PHaMs who are not NDIS participants are being developed and rolled out.

Table 5. Overall transition data across the 3 Phases

STAGE OF TRANSITION	PHASE 1	PHASE 2	PHASE 3
TOTAL NUMBER with transition data provided	3138	8002	4948
Applied (1st or 2nd time)	1528 (48.7%)	4118 (50.5%)	2174 (43.9%)
Currently preparing to apply (1st or 2nd time)	1610 (51.3%)	1790 (21.9%)	1321 (26.7%)
Will not/had not started to apply	Note. Not separated in Phase 1	1578 (19.3%)	1086 (22.0%)
Unknown	0 (0.0%)	516 (6.3%)	367 (7.4%)

Note. Some individual will be reported on across more than one phase

Figure 3. Proportions of people at different stages of transition across 3 Phases



Note. * In Phase 1, data did not differentiate between ‘Currently preparing application’ and ‘Will not/have not started application’ – this data was combined into ‘Application not submitted’

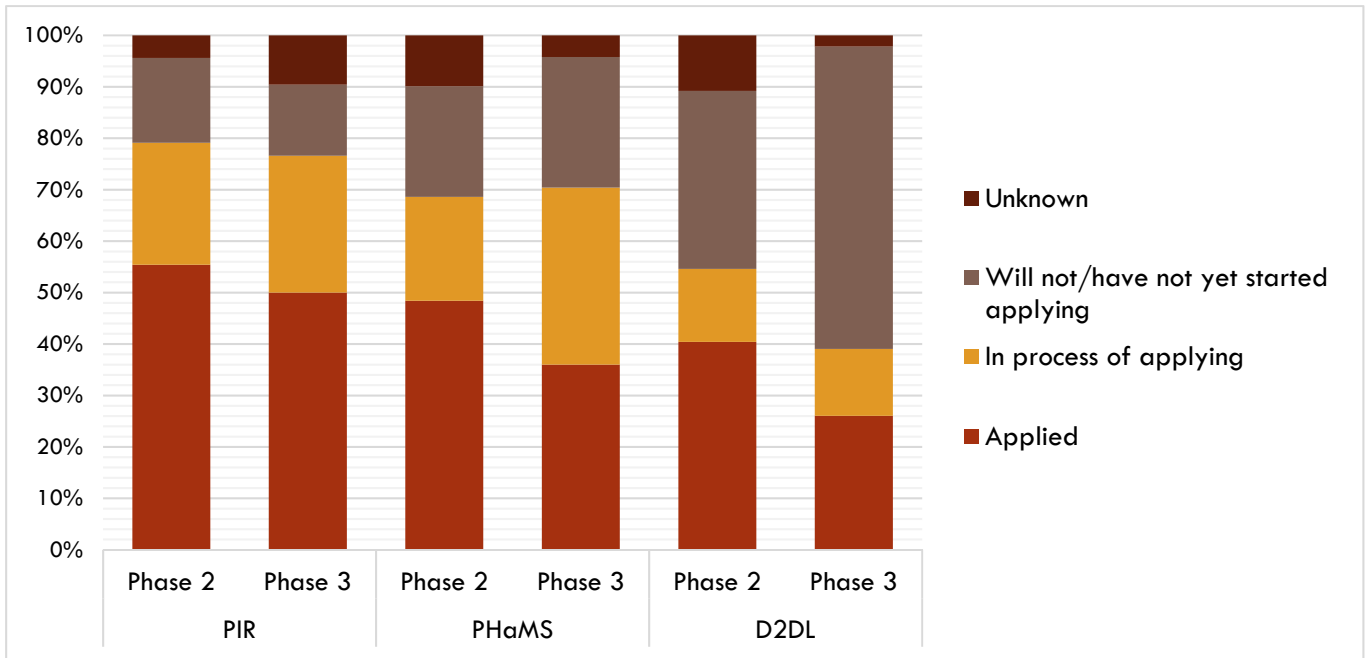
3.3 Transition data – comparing across PIR, PHaMs and D2DL Programs

There was less consistency between the data from program types. However, caution is needed in any major interpretation of this data given the much greater proportion of data provided by PIR and PHaMs programs.

Table 6. Transitional data for each program type across Phases 2 and 3

	Phase	Data provided for # program/ people	Applied (%)	In process of applying (%)	Will not/have not started applying (%)	Unknown (%)
PIR	2	27/4760	55.4	23.7	16.5	4.4
	3	17/3109	50.0	26.6	13.8	9.6
PHAMS	2	26/2257	48.4	20.2	21.5	9.9
	3	20/1301	36.0	34.4	25.4	4.2
D2DL	2	11/1145	40.4	14.2	34.6	10.8
	3	5/538	26.0	13.0	58.7	2.2

Figure 4. Transitional data per program across Phases 2 and 3



3.4 Outcomes for People who have Applied for NDIS

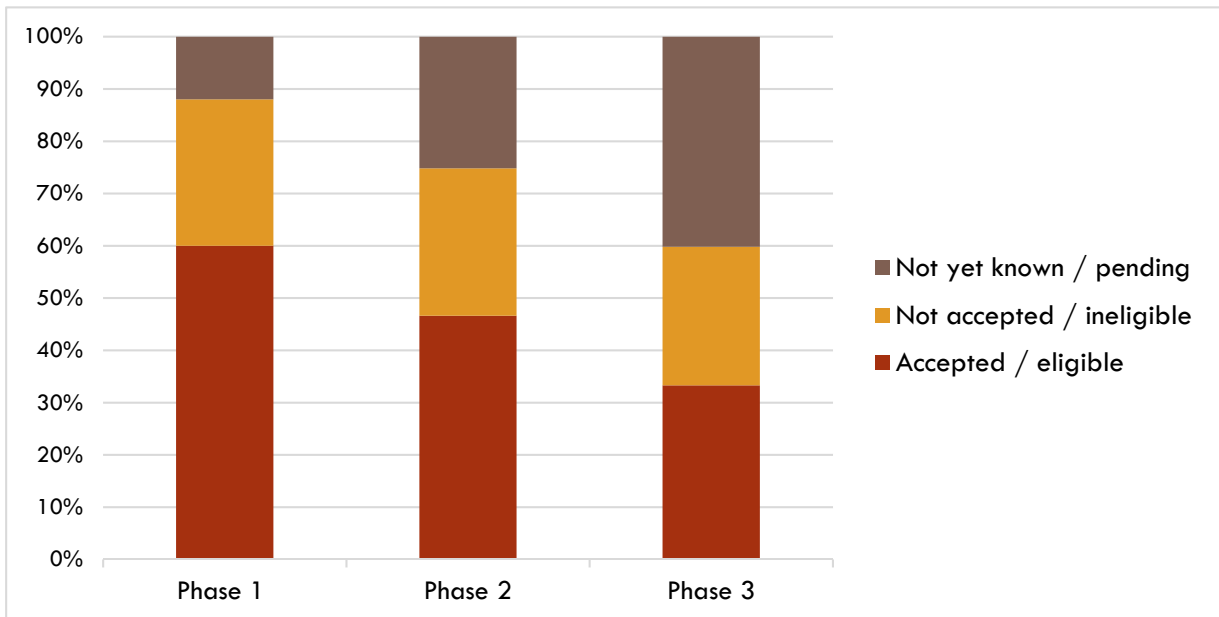
The data presented in the figure and table below show the number and proportion of applications to the NDIA that have resulted in the following outcomes ‘eligible for NDIS’ , ‘ineligible for NDIS’ as well as the proportion of applicants who are still waiting to hear the outcome. In each phase, data were based on only currently active PIR, PHaMs and D2DL clients.

Table 7. Outcomes of NDIS applications

Outcome of applications	Phase 1**	Phase 2	Phase 3
Number of people data was provided for*	1335	3796	1155
Accepted/eligible	797 (60%)	1769 (46.6%)	385 (33.3%)
Not accepted/ineligible	378 (28%)	1073 (28.2%)	306 (26.5%)
Not yet known/pending	160 (12%)	956 (25.2%)	464 (40.2%)

Notes – * while a greater number of people had applied, outcome data was reported for this number of people; data for **Phase 1 was only provided from PIR programs and acceptances have been higher for PIR programs across all 3 phases.

Figure 5. Proportional outcomes from NDIS applications



Note. data for Phase 1 was only provided from PIR programs and acceptances have been higher for PIR programs across all 3 phases.

The trend patterns in the data reported in Table 7 and depicted in Figure 5 are informative. First, **over the three phases consistently around 26% to 28% have been deemed ineligible.** Second, **the proportion of NDIS applicants who have been deemed eligible has decreased over time, from 60% to 33.3%.** This appears in large part to be because of the **greater proportion of NDIS applicants who are still waiting to hear the outcome of their application (12% in Phase 1, 25.2% in Phase 2, and 40.2% in Phase 3).** Additionally, as noted above, data from Phase 1 was only for PIR programs and this program appears to have greater proportion of clients assessed as eligible across all three phases.

3.5 Outcomes – comparing across PIR, PHaMs and D2DL Programs

Comparing the overall trends in terms of outcomes across PIR and PHaMs clients is informative. The data reflects the combined data above that suggests the proportion of NDIS applicants who have received an assessment of 'eligible for NDIS' has reduced over time. Again, this appears to relate to the greater proportion of people still waiting to hear the outcome of their application. Outcomes for D2DL clients for Phase 3 were based on a very small number of programs (3), so this unusual finding needs to be interpreted with caution. It also suggests that a greater proportion of PIR than PHaMs clients are being assessed as being eligible for NDIS. The more frequently positive outcomes for PIR clients was also noted by a few providers:

There needs to be recommendations that apply specifically for PHaMs clients under 65 that allow them to be considered for NDIS in the same way that PIR clients have now been and are entering NDIS with a lower threshold of evidence (PHaMs VIC)

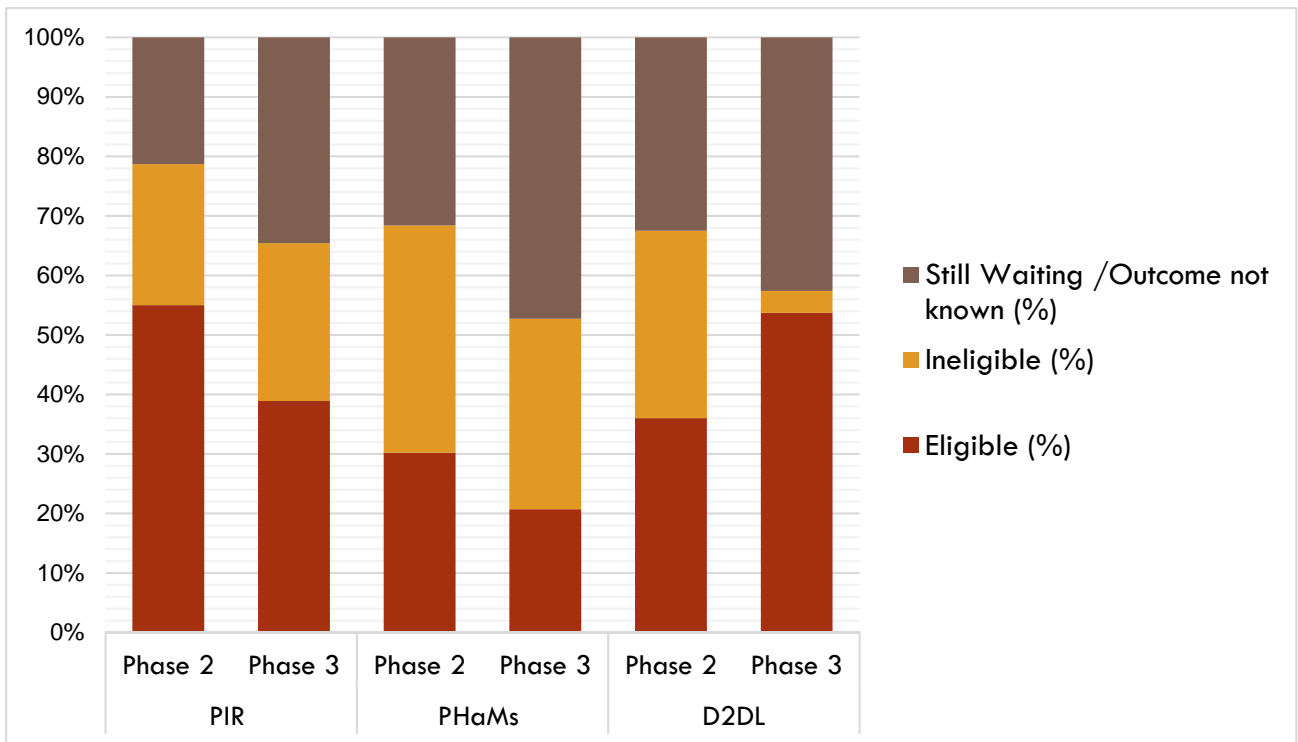
Due to the nature of diagnosis (mood and anxiety predominately), it has been consistently difficult to get PHaMs clients an NDIS package (PHaMs NSW)

Table 8. Comparison of outcomes by program type across Phases 2 and 3

Program	Phase	Data provided for # program/ people	Eligible (%)	Ineligible (%)	Still Waiting /Outcome not known (%)
PIR	1*	16/1335	60	28	12
	2	23/2397	55	23.7	21.3
	3	14/607	38.9	26.5	34.6
PHaMs	2	27/980	30.2	38.2	31.6
	3	18/440	20.7	32.0	47.3
D2DL	2	10/419	36	31.5	32.5
	3	5/108	53.7	3.7	42.6

Note. Outcomes for D2DL clients for Phase 3 were based on a small number of programs (5), so this unusual finding needs to be interpreted with caution; * Phase 1 data only provided by PIR programs

Figure 6. Comparison of outcomes by program type across Phases 2 and 3



Note. Outcomes for D2DL clients for Phase 3 were based on a very small number of programs (5), so this unusual finding needs to be interpreted with caution.

3.6 Stages of Transition and Outcomes Combined

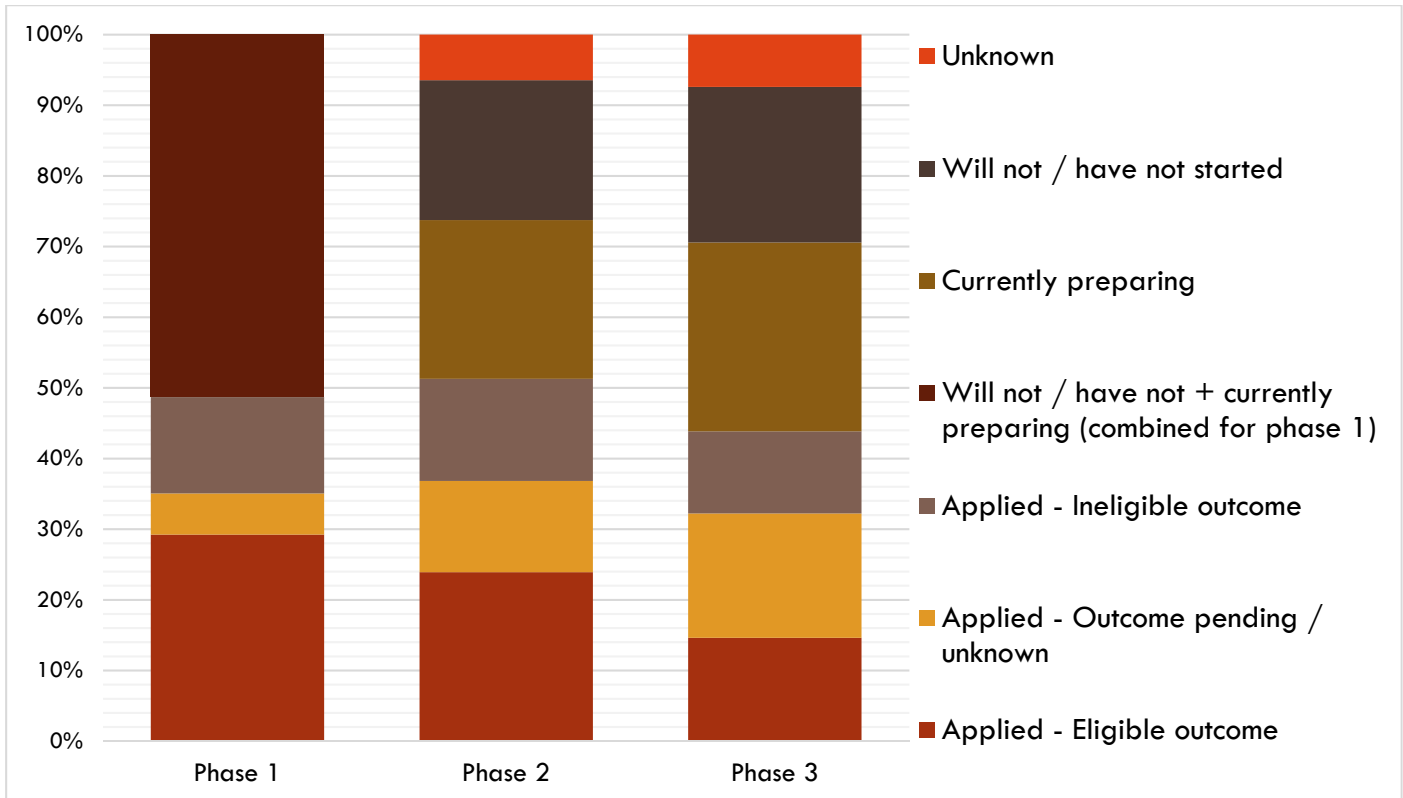
Drawing together data about people’s stage of transition AND data regarding the outcomes for those who have submitted an NDIS application provides a critical national overview. When reviewing the eligible, ineligible and pending data below, note that these percentages differ to those presented in Table 8 because here they are presented as the proportion of the whole dataset, not just those who had submitted an application.

Table 9. Overall stage of transition or otherwise

Transition Stage	PHASE 1		PHASE 2		PHASE 3	
	Transition	Application Outcomes	Transition	Application Outcomes	Transition	Application Outcomes
TOTAL data provided (programs) people	(27) 2464	*(16) 1335	(64) 8162	(60) 3796	(46) 4948	(37) 1155
Have applied	1528 (48.7%)	Eligible 29.2%	4118 (50%)	Eligible 23.3%	2174 (43.9%)	Eligible 14.6%
		Ineligible 13.6%		Ineligible 14.1%		Ineligible 11.6%
		Pending 5.9%		Pending 12.6%		Pending 17.7%
Currently preparing application	1610 (51.3%) Note. Not separate d in Phase 1		1790 (21.9%)		1321 (26.7%)	
Will not/have not started application			1578 (19.3%)		1086 (22.0%)	
Unknown			516 (6.3%)		367 (7.4%)	

Note. * only PIR data was robust enough to include in phase 1 analyses of outcomes

Figure 7. Overall stage of transition or otherwise



Across the three phases, (see Table 9 and Figure 7 above), **a relatively consistent proportion of active clients had submitted an application** for NDIS – just under 50%. However:

- There is an **increasing proportion of people awaiting outcomes** for applications submitted. Likely to be a consequence of this, **the overall proportion of current clients who had been assessed as eligible by NDIA reduced, from around 30% in Phase 1 to under 15% in the final Phase.**
- The overall proportion of clients who had applied and were **found ineligible** for the NDIS was relatively consistent across each phase, ranging from around 14% in phases 1 and 2 to 11.6% in Phase 3.
- At the end of Phase 3 (June 30th, 2019), **85% of current clients were not in the NDIS** (total of people who have not applied or have applied and are ineligible or are awaiting outcome – see Figure 7).
- At the end of Phase 3 (June 30th, 2019), **almost 50% of current PIR, PHaMs and D2DL clients had not submitted an application.**
- At the end of Phase 3 (June 30th, 2019), **22% of current PIR, PHaMs and D2DL clients had either not commenced the NDIS application process or did not intend to do so.**

Collectively these data raise important questions about the adequacy of future funding for the large proportions of people still trying to gather the evidence required to submit an application and the large proportion who have either not started or have no intention of applying for the NDIS.

Qualitative comments from providers also highlighted concerns about whether future supports would match the amount and quality of supports provided through PIR, PHaMs and D2DL programs. Again, while these were consistently raised, only a few sample quotes are provided.

Providers described the significant time and skill required to establish trust and rapport in order to be able to support, guide and advocate for each person as they considered and then engaged in the complex and often stressful process of gathering evidence in order to apply for the NDIS. They also needed to invest time in the education of GPs and other specialists in order to get the expert evidence required by NDIA. They were concerned about the reduced funding and time-limited nature of transition support funding and believed people would not get this needed support and advocacy. Example quotes:

I have participants who require a high level of communication between myself and their clinical treatment teams. How will this be handled in future? (PIR ACT)

Clinicians have no knowledge around the NDIS and SF [support facilitator] having to educate them in the language which is [needed] to provide in the application” (PIR WA).

High level of function[al] impact hinders people’s ability to complete the process on their own, causing high levels of stress and unwellness with no funding in place to cover this gap. Block funding programs are ‘bearing the brunt’ and stepping up to fill these gaps for individuals without this people would have no ability to navigate the NDIS application system (D2DL WA)

it usually takes several months for a new client to settle into the program, complete all the Assessments & Action Plan processes and establishing sufficient rapport between staff & participant before they are able to commence the [NDIS] application (PIR NSW)

Much support is provided to individuals to apply for the NDIS, without these high levels of support people have stated that they would be unable to navigate the NDIS process (D2DL WA)

Although there were providers who had been blocked by NDIA staff from attending and advocating or supporting clients at planning and assessment meetings, many had managed to negotiate this and said:

Past PIR consumers not having someone available to go to their plan reviews to help advocate for their needs. This will be very difficult for some of our consumers (PIR SA)

Due to our role, many of our clients in PIR have been well supported to transition and gather appropriate evidence for the NDIS, however without that support [they] may have experienced different outcomes (PIR WA)

The NDIS process can be difficult for clients to undertake without support due to associated stress and lack of clarity and understanding of processes (PIR WA)

As well as expressing concerns about the adequacy of transitional supports, providers were concerned about the adequacy of additional programs of support outside of the NDIS designed to replace supports provided through PIR, PHaMs and D2DL as they are terminated.

The funding is grossly insufficient for NPSM, ETS and CoS services moving forward. PIR clients will not receive the same level of support (as promised by the Federal Government) under these programs (PHaMs NT)

I'm not sure that Continuity of Support is available to people who have decided not to apply (PIR ACT)

We are not sure how long we are allowed to work with someone through the extended transition if they are unsure about whether or not they wish to apply for the NDIS (PIR SA)

If access to COS funding is dependent upon a person having engaged in the NDIA application process, this will exclude arguably the most vulnerable, and most in need of support group of people. Repeated evidence demonstrates that applying for NDIS is currently a complex and stressful experience for people living with serious mental illness, and for these and other reasons, many are choosing not to, or are unable to apply. For more detail, please see the following section.

DISCUSSION POINT 1 – TRANSITIONS AND OUTCOMES

Consistently large proportion of people assessed as ineligible

The consistent proportion (27-28%) of people who have been assessed as ineligible for the NDIS raises concerns about the adequacy of the NDIA assessment process (discussed further in DISCUSSION POINT 2) and the adequacy of the CoS funding being provided for people outside of the NDIS (discussed further in DISCUSSION POINT 4).

High proportion of people requiring future support to apply for NDIS

The data in this report evidences a high and somewhat increasing proportion of people who are at some stage in the process of gathering the evidence required prior to submitting an application for NDIS eligibility. Around half of people assessed as ineligible plan to re-apply or appeal the outcome (see page 40). There is also a high proportion who have not yet commenced the process. All of these individuals will require future supports to engage with and continue the process of gathering the level of evidence required to submit an application.

PIR, PHaMs and D2DL have now ceased operation and the supports for people in the process of applying or re-applying is now provided through psychosocial extension funding delivered through PHNs. This extension or transition support funding has not always been allocated to the previous PIR, PHaMs or D2DL program meaning that while for some people the support staff member will remain

consistent, for others, this will involve a change in support organisation and the reestablishment of trust and rapport with a new individual worker.

While the psychosocial extension funding will support people in the application process, this funding stream is time limited and will cease in July 2020. Data in this report indicates that there is a high risk of many people not having completed the process of gathering evidence, submitting an application and being informed of the outcome before the funding ceases.

While service providers are familiar with the application process, greater complexity with preparing applications appears to be impacting on transition rates. Gathering evidence and preparing clients with more complex needs or experiencing poorer mental health presents additional challenges in gathering evidence from multiple sources, slowing the process down. As service providers have reported continuing challenges with gathering evidence for applications, it appears unrealistic to expect all clients to be transitioned before the extension funding ends.

Outcome variability and inconsistencies

Providers repeatedly described variability and inconsistencies between program types, geographic location, different providers and different NDIS assessors and planners.

Historically PiR, PHaMs and D2DL were designed with different referral or inclusion criteria and provided varying levels and types of support. For example, PiR was designed to support case coordination that arguably aligns better with the supports required to gather evidence from various sources or agencies, whereas PHaMs was designed to provide personalised one-on-one support rather than linking and connecting to other services/agencies. Therefore, differing client characteristics and differing program supports provided by PiR, D2DL and PHaMs could explain some of the variances in eligibility rates between program types with the proportion of eligible clients being the highest for PiR clients and the lowest for D2DL clients.

However, while there are differences between program types, there are also inconsistencies between individual programs of the same type. This inconsistency has not changed between phases of data collection. This suggests that there is also variance in individual NDIA staff and/or individual provider processes, skills and understanding of psychosocial disability and the requirement of the NDIA. It appears highly improbable for example that almost all clients attending one PHaMs program do not have psychosocial disability while almost all attending another PHaMs program do. Much more likely is that: 1. there is inconsistency of program staff in terms of the knowledge, skill, time and resources needed to assist a person through the complex application process, and/or 2. there is inconsistency in the assessment skill and understanding of psychosocial disability between individual NDIA assessors.

Although steps have been taken by NDIA to alleviate the issue of NDIA assessor inconsistencies, the recency of this data suggests that this matter needs further and ongoing attention. It is also highly likely that staff in individual transition support programs that will continue to assist people to apply for NDIS require greater resources, training and support in order to give the best support and guidance possible to people as they engage in the arduous process of building evidence to apply.

4. The NDIA and NDIS Applications

4.1 Current Challenges with the Application Process

In Phase 2, providers gave commentary around the greatest challenges experienced in supporting clients to prepare and submit an application to the NDIA to test their eligibility for NDIS. The most common challenges or barriers as well as the percentage of programs reporting that challenge are reported in the table below.

Table 10. Common challenges with collecting evidence for applications across **all** program types (Phase 2 data)

Challenges or Barriers	Number *	Percentage
GP/specialist's – lack of understanding of NDIS/client/psychosocial disability	39	76
Limited/lack of evidence available due to limited service engagement	34	67
Clients fluctuating mental health and thus ability to manage application process	24	47
Cost of gaining expert evidence	22	43
Barriers/time delays in accessing data from other services	13	25
Resource limits of program to support collecting evidence	3	6

Note. * A total of 51 programs responded to this question

In Phase 3, providers were invited to review the Phase 2 results and provide additional commentary about any ongoing challenges with supporting clients to prepare and submit NDIS applications. 21 (46%) of the providers submitted further commentary. Data were analysed thematically and only those themes reported by more than half of providers are detailed below. Themes from this dataset are consistent with the issues and challenges raised earlier. To facilitate a deeper understanding of these challenges, a selection of direct provider quotes is included.

a. Nature and impact of client's psychosocial disability made obtaining evidence hard/impossible

Providers repeatedly explained that the fluctuating nature of people's mental illness, their transience and limited or sporadic engagement with mental health services collectively resulted in a lack of available evidence that would meet NDIA requirements. An established and ongoing relationship with GPs was also often absent which created challenges for gathering evidence:

[difficulty with] Individuals remembering all the services they have been involved in (PIR WA)

Not currently linked to a treating health professional (PHaMs NSW)

There are clients who due to their mental health condition have been unable to have a stable long-term GP and therefore have no long-term medical evidence. GP clinics now often have a rotating roster whereby our clients will not always see the same GP every time they go so there is no relationship built so disclosure is becoming less. Client will disclose more to their support workers yet that evidence for access is not as heavily weighed (PHaMs QLD)

Homelessness, transient nature of Mental Health (D2DL WA)

Some clients are undiagnosed or do not have a medical person who knows them or their condition well enough (PIR SA)

There have been many participants who have limited expert evidence on record to help support an application. Many do not have a regular GP and have not access health service in many years so gathering functional evidence has been difficult (PIR NT)

b. Clients became too unwell to continue with the process

While some clients had commenced the process, their mental health had deteriorated, and they were no longer able to continue with their applications.

Participants' fluctuating mental health: there were times where the application process had to be delayed [in order] to address their situation(s) instead (PHaMs ACT)

Participants being in crisis and applications being put on hold to support with that (PHaMs WA)

Participant became homeless and chaotic in mental health symptoms (PIR ACT)

c. Clients were distressed and traumatised by the application process

Providers across all phases of this project repeatedly told us that the application process remains complex and distressing for many clients.

Clients have also reported that the stress and unsettling process ... is difficult and creates many other challenges for them (PHaMs SA)

The process of the NDIS application is leaving people with triggered trauma responses, the NDIS needs to consider being a Trauma Informed Service that causes no further harm to vulnerable individuals. This process is traumatic for many individuals due to the uncertainty, lack of support in application process, revisiting historical events, having no rapport/trust with planners, lack of understanding of their personal mental health challenges, and the fact that trusted known providers that have the information and relationship are unable to advocate for them as they have done in the past prior to the NDIS (D2DL WA)

Some clients find the process re traumatizing, they may have had multiple visits to doctors/Psychiatrists and feel they are "going over" things (PIR SA)

Lack of sensitivity of some NDIS staff when speaking with them over the phone can create significant distress for the client (PIR SA)

A rigid process which does not accommodate the client's barriers such as significant mental health symptoms, trauma (PIR SA)

Many, many psychosocial clients are receiving NDIS letters, when advised they would not, which is causing large amounts of distress and frequent phone calls of inquiry (PHaMs WA)

d. Clients did not accept/identify as having a 'disability'

Again, reiterating comments from earlier phases, providers in Phase 3 said that some clients either did not have insight into their mental illness (an inherent part of some mental illnesses), or did not equate their experience as a disability or illness.

Client's may not identify as having a mental health condition (PIR SA)

The NDIS also presents a barrier to people who do not identify as having a disability which is common within mental health and local communities where people experience high levels of stigma based on their circumstances (PHaMs QLD)

e. Specialists/GPs/psychiatrists – lack of knowledge/understanding of NDIA requirements

A challenge that almost all providers reported was that many GPs or health professionals, upon whom clients depend for expert assessment evidence for NDIA applications, had poor understanding of evidence and language required by the NDIA. This resulted in multiple visits, additional cost to the client, distress and lengthy time delays.

One challenge has been getting GPs to fill out the ARF or Evidence of Psychosocial form. GPs have not known about the NDIS and have found the paperwork difficult – some not knowing what a psychosocial disability is (PIR NT)

Use of language used by clinicians contradicting what the NDIS understand as terms of impairment [and not] receiving information from clinicians in a timely manner (PIR WA)

Some GPs and Psychiatrists do not understand the NDIS process, sometimes multiple visits are required which can be stressful for the client (PIR SA)

Clinician's lack of knowledge and awareness is the major barrier to completing the transition process. Most clinicians don't have an understanding [of] the difference [between] the functional impact of a disability and a diagnosis (PHaMs WA)

The predominant challenges that clients came across were accessing evidence, the lack of understanding of the NDIS from their current or historical clinical supports and also the fluctuating nature of their diagnosis (PHaMs NSW)

Clinicians not having an understanding around NDIS criteria and requirements. For example, being unwilling to sign off on permanence because it doesn't align with the recovery model (PHaMs WA)

The biggest difficulty is gathering evidence from GP's who won't give their time to assist and then clients who struggle with the constant rejection (PHaMs VIC)

f. Costs of GPs, psychiatrists and other specialists

Beyond GPs and other specialists' lack of understanding of NDIA requirements, costs of appointments to get these assessments were prohibitive for many. Some programs had funding to cover the costs of specialist assessments, others did not.

Finding cost effective means to gather evidence. Specialist costs are well above affordability for clients (PIR QLD)

Psychiatrist charging to complete access request forms (PIR WA)

The medical system aren't paid to provide the evidence so they don't (PIR NSW)

We were lucky in that we had some excess funds which we used to fund assessments for consumers who had an access not met decision. In many cases, someone who had not met access, who reapplied with an assessment (e.g. OT, Neuropsych), met access the second time with this additional evidence. Going forward we will not have the funding to support these assessments which have proven vital for some access requests (PIR SA)

Challenges around clients unable to afford obtaining further supporting medical evidence/ reports which... require a fee with the treating health professional (PHaMs NSW)

The final two themes were not raised by the majority of providers but are included because of the importance of understanding issues specific to rural and remote communities and those people for whom English is a second language.

g. Additional challenges for rural and remote communities

Many of the challenges already described were heightened for rural and remote participants because of distance, lack of local providers, GPs or specialists, consequent additional costs, and less education about NDIS and NDIA provided to these communities.

Other barriers have been for Participants who live in remote Communities. It's hard to smoothly process an application when the Participant is over 80kms away and has no phone/not willing to talk on the phone (PIR NT)

We have had to fly in MH specialists to assist with the information gathering, which is a huge cost (PIR NT)

[no] local GP - rural area (PIR WA)

Travel to and from client/appointments (PHaMs SA)

A huge barrier is the resource limits, as staff need training in order to submit the applications. We have very high turnover of staff in the NT, if they are not trained properly to submit applications it is likely the applications will not be of the standard required (PHaMs NT)

Majority of community is unaware or very confusion by impending changes and this makes initial stages of conversation quite difficult (PHaMs WA)

h. Additional challenges for clients who need language interpreters

Two providers highlighted the additional challenges for clients whose first language was not English.

There is also an issue around language. For some participants, English is a second or third language and interpreters are required. It is difficult to try and facilitate a VAR (Verbal Access Request) when an interpreter is required. The other alternative is to do an ARF, which slows the process down incredibly (PIR NT)

Language barrier – CALD clients (PHaMs NSW)

4.2 Current Waiting Times from Application Submission to Receiving Outcome

In each phase, participants were asked to provide details about the lengths of time people waited after submitting their application before they heard the outcome – eligible or ineligible for NDIS. The two figures below show the shortest and the longest waiting time recorded within each phase. 28 programs were able to provide this data in phase 1, 42 in phase 2, and 34 in phase 3. These data demonstrate a great variance in waiting times. This variance occurred across states and territories and across PIR, PHaMs and D2DL programs. Long waiting times created distress for people who had applied. Providers gave qualitative data to facilitate interpretation of these waiting times and this is reported below the figures.

Figure 8. Shortest waiting times (weeks)

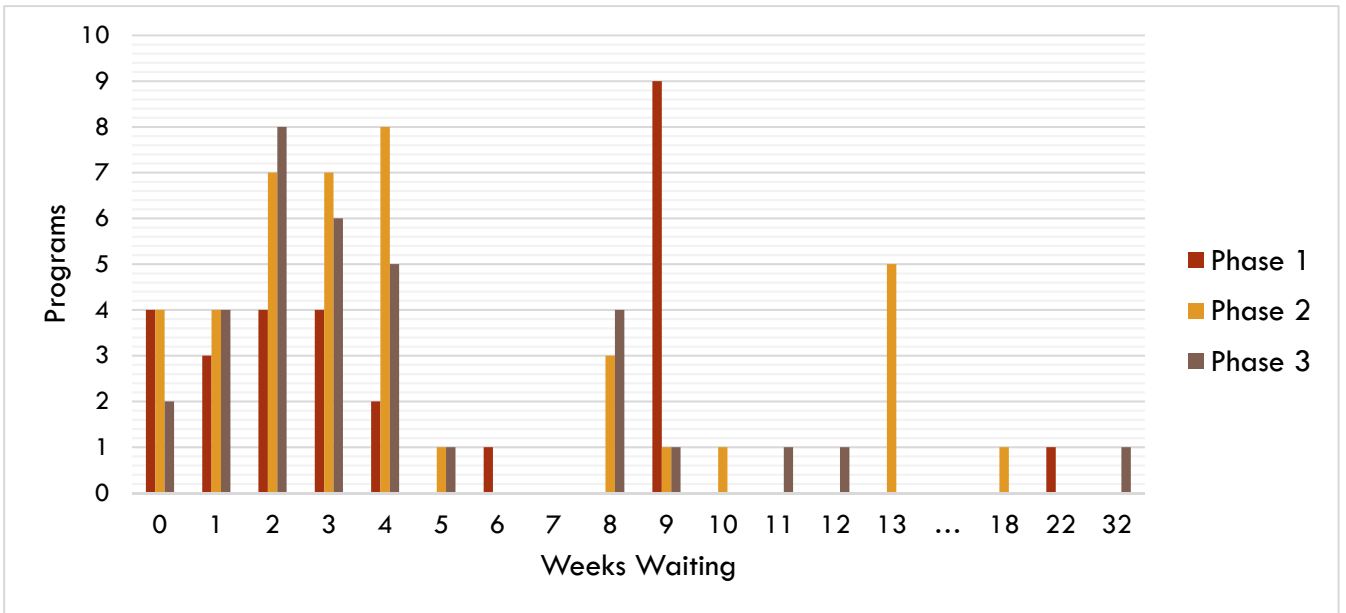
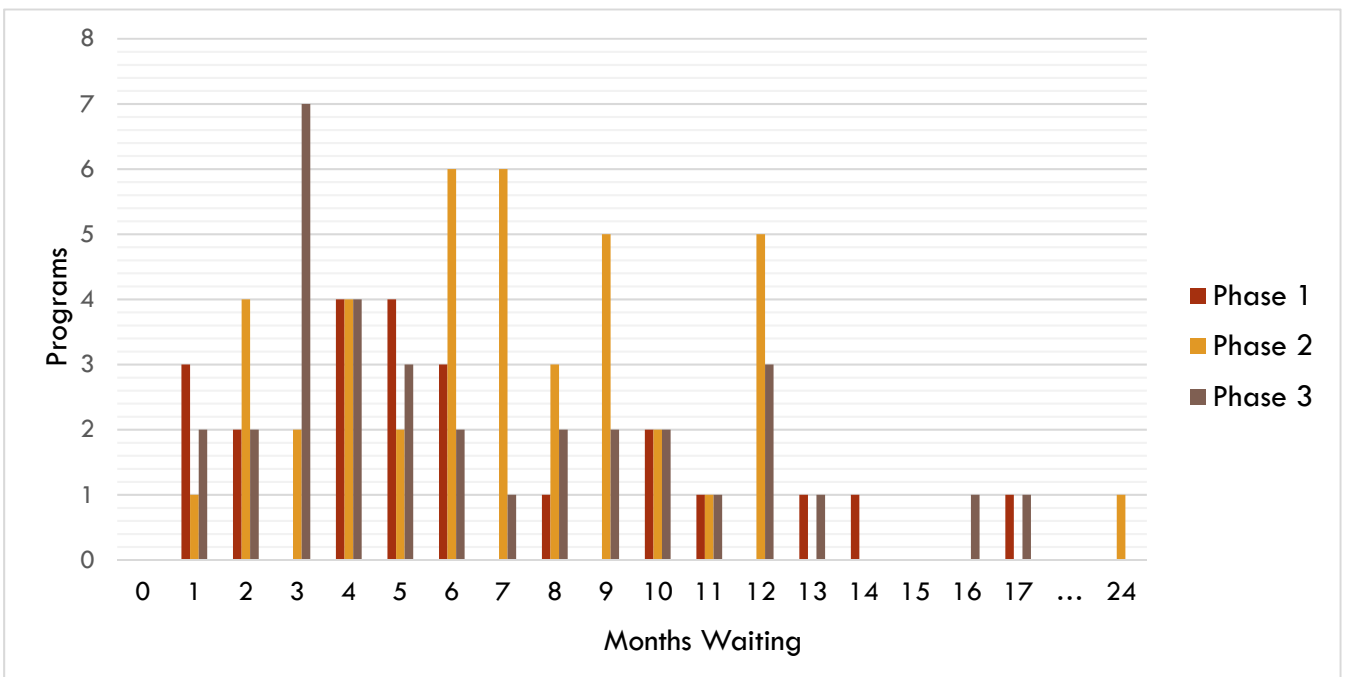


Figure 9. Longest waiting times (months)



What providers told us about waiting times

19 (41%) of programs in Phase 3 provided qualitative comments about waiting times and these have been thematically analysed. Themes are reported below with a sample of quotes only to provide illustration.

a. Diversity of waiting times within and across programs

As clearly evidenced by the data above, participants described an unexplainable range in client waiting times between the submission of an application and the outcome being provided.

They are very random and there seems to be no rhyme or reason why some clients get outcomes quickly and others take forever (PHaMs VIC)

One client had a plan waiting on the system for 4 months which required urgent attention due to hospitalisation. It was only after the advocacy around urgency that the plan was approved (PIR WA)

Some of them get quick responses from NDIS and others wait for long time (PHaMs SA)

Wait times are dependent on the assessor. Not sticking to the 21-day timeframe – saying they don't have capacity to do this. Some assessors are very fast and have told us they're working weekends and nights now (PHaMs WA)

Waiting times are inconsistent- some appear to happen quite quickly while others are left for ages. There isn't really a given turn over time, or it isn't communicated consistently (PHaMs NSW)

b. Communication failures within NDIA extend waiting times

Providers said that waiting times were extended when communication channels broke down within the NDIA, as explained in the following quote examples:

Numerous instances of NDIA not having any record of applications, even though receipt of application was received. [We would] call back and speak to a different staff member and they found applications with no issue (PIR SA)

Instances whereby assessment team would inform that the application was sitting with a different team, when contacting that team, they informed that it was sitting with assessment team (PIR SA)

When following up with NDIS, you only get the information that is its pending and they will put a note on it to push the application through which does not happen. No communication between departments (PIR WA)

c. Lost letters informing of outcomes extend waiting times

Waiting times were impacted upon because outcome letters were lost or never received by some people.

Anecdotally many of our clients' disregard many 'official' looking letters they receive, especially if they have been found ineligible previously... [They] do not expect to just to receive a letter if they are successful in being eligible for an NDIS plan. This also makes it difficult to gain accurate information around the client's status or progress in transition to supports (PHaMs SA)

For participants that have chosen to use their home address, they have sometimes misplaced correspondence they receive. Therefore, we have to call the NDIA and ask for the letter to be re-sent. This can reflect badly on NDIS waiting times when in fact it is the participant that has lost the correspondence. Where possible we put down our organisations address and email for all correspondence so that we can monitor this (PHaMs NT)

d. Waiting times remain inconsistent and long

Providers continued to discuss the issue with long waiting periods, and the inconsistencies of these, particularly Western Australia. Many areas of Western Australia have only this year commenced roll-out of NDIS, and many are transitioning from the state scheme (WANDIS). They consistently described long and unacceptable waiting periods

when told that you will receive an outcome within 21 days... people with anxiety-based disorders are experiencing severe distress when this is not met by the NDIA and severe waits are occurring without communication from anyone (PIR WA)

The timeframes involved in submitting and testing eligibility and then having an active plan in place have been a huge barrier to ensuring that people's needs are met (PIR WA)

There has been a back log in the process, meaning that no plans for PIR applications have been processed during the data capture period (PIR WA)

Waiting times were not just from NDIA, it also included waiting for evidence from clinicians and GPs:

"The other problem that has been noticed by the team is waiting for evidence from the clinics and mental health clinicians, which is delaying the applications. FOI also taking a while to come through (PIR WA)

there is a lot of inconsistency with ... waiting periods for applications, appeals and application (PHAMS NSW)

e. The good news – waiting times have reduced overall

While the overall view was that waiting times remained too long, some providers said that waiting times were reducing.

Some are far too long – but they are definitely getting better (PHaMs WA)

Most participants towards the end only had short waits (PHaMs QLD)

It has been more expedient leading to June 30th prior to determinations of COS funding (PHaMs VIC)

DISCUSSION POINT 2 – THE APPLICATION PROCESS

Continues to be a complex and distressing process for many

The consistently high proportion of people across all three phases of the study who have not yet applied for an NDIS assessment because they are either unable yet to commence the process or are still working to gather evidence required by NDIA speaks to the complexity of the application criteria and the barriers that continue to exist for this population. The many and complex barriers reported throughout this study are consistent with those that have been reported repeatedly elsewhere^{14 15 16}

¹⁴ Mental Health Australia (2018). Optimising Psychosocial Supports Project Report. Mental Health Australia, Canberra. https://mhaustralia.org/sites/default/files/docs/optimising_psychosocial_supports_project_report_final_web.pdf

¹⁵ Smith-Merry, J, N. Hancock, A. Bresnan, I. Yen, J. Gilroy, G. Llewellyn (2018) Mind the Gap: The National Disability Insurance Scheme and psychosocial disability. Final Report: Stakeholder identified gaps and solutions. University of Sydney: Lidcombe. <http://sydney.edu.au/health-sciences/documents/mind-the-gap.pdf>

¹⁶ Joint Standing Committee Report; Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition. https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Report

Recent introduction of a specialist psychosocial disability stream/pathway

Efforts are continuing to be made by NDIA to improve the application process, and this is being done in partnership with those who understand psychosocial disability to make them appropriate, accessible and safe. The recent commencement of a specialised psychosocial disability stream or pathway evidences that the NDIA are aware of the unique needs and challenges of this population and are engaging with the expertise available within the sector. In practice this pathway should be accessible across the country and ongoing monitoring of alignment with the needs of people with psychosocial disability is needed. At a minimum this pathway should enable:

- ongoing expert support for people preparing applications to NDIS,
- education and upskilling of GPs/ specialists regarding the specific evidence required by NDIA,
- the employment of specialised assessors and planners,
- enhanced linkages between mental health services and NDIA staff, and
- focus on recovery-focused planning and episodic needs to enhance the proportion of plans that are appropriate to the needs of people living with psychosocial disability.

As the pathway is progressively implemented, if successful we will see increasing numbers of clients applying for NDIS and a reduction in the challenges described throughout this report.

Diversity of waiting times between application submission and outcomes

The great variance in time to process applications has been raised again and previously and suggests that there is variance in NDIA standards or practices across the country. This is an area that is also expected to improve as the new Psychosocial Disability Stream is implemented.

While these data merely provide an indication of waiting times, they are consistently diverse across all phases of the study and raise questions:

- Why are the waiting periods so varied between programs irrespective of whether they are PIR, D2DL or PhaMs?
- Why would any application take more than a few months to assess?
- What are the mental health implications for people with mental illness who are waiting for long periods of time to hear the outcome of their application?
- Is there way to minimise any distress for people while their applications are being assessed – particularly if it is going to take months and potentially more than a year?

There are a number of possible explanations for the diverse and sometimes very long waiting periods. It is possible this could be because the 'easy to assess' clients and the clients with easily accessible evidence to compile submitted their applications earlier on and were, at an earlier point, more quickly assessed as eligible.

Another explanation may be that the assessment criteria for psychosocial disability has changed over time and may be more complicated and hence more time consuming for NDIA assessors to make decisions. There is likely to have been a lag in building capacity in appropriately trained assessors with skills in psychosocial assessment. There has been a continuing focus on improving supports for people with psychosocial disability, including foundational psychosocial disability awareness training for planners and LACs. This training focuses on making sure staff are better able to support participants with psychosocial disability. Nationally, around 3,460 service delivery staff and partners have received this training and all new staff complete this as part of their standard induction training.

Currently however there still seems to be a lack of a consistent national approach for assessment. Jurisdictional variation of bi-lateral agreements and scheme maturity may be another contributor to the increase in the number waiting for an outcome as Queensland and Western Australia came 'online' to the scheme over the course of this project and states like Tasmania and South Australia have taken

an age cohort approach to the scheme, with the age group considered to have the highest representation of psychosocial disability only coming into the scheme over the past 6 months.

Regardless of the interpretation, given there appears to be an increasing proportion of people waiting to hear the outcomes of their application and funding to support their transition is time limited, further investigation is needed.

5. About People Eligible For NDIS

The report is dominated by issues, concerns and recommendations raised by providers. This is perhaps to be expected as those with expertise share on-the-ground insights in order to enhance the potential of the still somewhat new roll-out of the NDIS as well as identifying emerging broader consequences and impacts. However, one program provided positive feedback that demonstrates the value of NDIS when all is working as intended, and we share this in its entirety:

An enormous amount of work has been done in the NDIS space to increase the access of people with a psychosocial disability and we have appreciated these endeavours. We are also heartened that measures have been put in place to ensure that nobody loses out on support in our area with NPS extension and COS funding coming through. We have already noticed the huge difference an NDIS package can make in the life of a person with mental health struggles and this has made transition incredibly rewarding work for our staff (PIR QLD)

5.1 Plans deemed appropriate or inappropriate by providers and plan review requests lodged

In Phases 2 and 3, programs were able to provide data regarding their assessment of the appropriateness or otherwise of NDIS plans. In Phase 2 this provider assessment was given for 959 eligible people – (50% of the potential data set). In Phase 3 this assessment was provided for 256 eligible people (67% of the potential data set). The findings suggest that over time, rather than seeing an improvement in the proportion of appropriate plans, providers are reporting a greater proportion of plans they believed were inappropriate. Across both phases, around one third of plans were deemed inappropriate.

The proportion of plans deemed appropriate ranged dramatically across individual programs/services irrespective of program type (PIR, PHAMS or D2DL) with some deeming all plans to be inappropriate and others deeming all to be appropriate. This inconsistency of ‘satisfaction’ between programs existed across both phases.

Equally disparate was the proportion of people from services who were submitting requests for plan **reviews**. No requests for plan reviews were submitted by unsatisfied clients of some services, and all unsatisfied clients in other services had submitted a request for a plan review.

There is an important limitation to this data – that it is based upon the opinion of mental health staff rather than clients themselves. However, in the absence of data collected on client perspectives and the absence of government provided data on the proportions of people who have submitted requests for review of their plans, these findings provide valuable insights.

Table 11. Assessment of perceived appropriateness of plans – comparison across Phases

	PHASE 1	PHASE 2	PHASE 3
Data available for each phase	Data not sought in this phase	42 programs/959 people	32 programs/256 people
Deemed Appropriate		695 (72.5%)	166 (64.8%)
Deemed Inappropriate		264 (27.5%)	90 (35.2%)

Table 12. Review requests lodged for plans perceived to be inappropriate (Phase 3)

		PHASE 3	
Data available (programs/people)	32/256		
Deemed Appropriate	166 (64.8%)		
Deemed Inappropriate	90 (35.2%)		
Action taken for plans Deemed Inappropriate	No action taken	75 (72.8% of inappropriate plans)	
	Plan review request lodged	28 (27.2% of inappropriate plans)	

Figure 10. Assessment of appropriateness of plans and review requests lodged

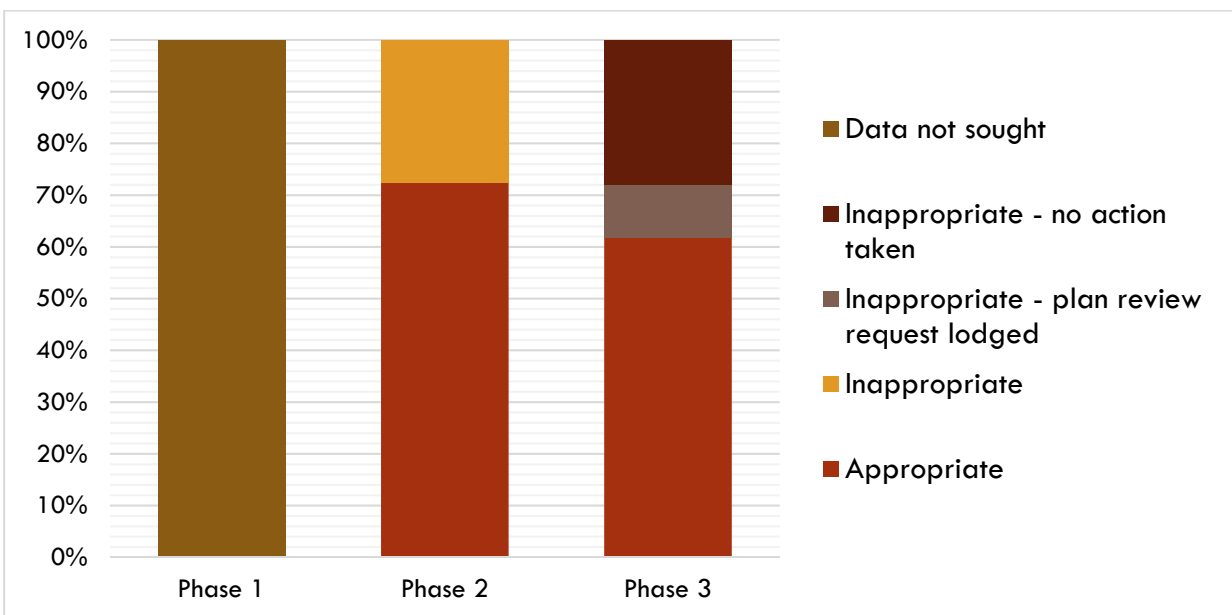


Table 13. Why plans were considered inappropriate (themes) – data from Phase 2

Themes	Number *	Percentage
Plan does not align with psychosocial support needs	24	96
Number of hours in the plan is inadequate	22	88
Lack of needed Support Coordination in the plan	7	28
Funding amount in the plan is inadequate	4	16
Persons support needs and goals have changed in interim	4	16
Admin errors - service booking to wrong org etc	3	12
Important supports omitted in the second plan	3	12
Support coordination was not outlined as in-kind	3	12
The ultimate plan does not align with planning meeting decisions	2	8
Transport related – limited or not appropriate type	2	8
Inappropriate process - phone call out of blue	1	4

Note. * A total of 25 programs responded to this question

To gain a deeper understanding of the issues with plans that were raised in Phase 2, during Phase 3 providers were also invited to provide commentary. 23 (50%) of providers did so. These qualitative data were thematically analysed and themes with example quotes are provided below.

a. Lack of, or insufficient, support coordination

The most frequently described plan limitation was inadequate amount of, or a lack of, support coordination in people’s plans. The implications of limited or lack of support coordination were also frequently reported. Without support coordination, providers said that many people were overwhelmed, unable to coordinate their own plans and services required, leaving their plan unable to be used.

The Planners don’t understand that people with Psychosocial disabilities need support coordination as a must. The plan will not be used if there is no support coordination because participants are generally too unwell to organise an NDIS plan (PIR NSW)

Support Coordination hours are minimal and insufficient for participants and are varied (D2DL NT)

Lack of Support Coordination hours – participants plan had a number of support services that needed coordination, and none was included in the plan (PHaMs WA)

No Support Coordination received either. Therefore, he may never use the funds in his plan (PHaMs VIC)

While PIR, PHaMs and D2DL programs remained, staff from these programs have been filling this gap by helping people to organise the NDIS plan supports and services without payment for their time.

Clients are unable to access the LAC regularly for plan activation and understanding. This means that in most instances, no Support Coordination is in plan and Service providers are assisting at no charge to assist clients link to appropriate services and supports (PHaMs QLD)

b. Incorrect pricing guide/Inadequate funding for need to be met

Both administrative errors and overall limitations in the funding within people's plans left clients without the resources required to meet their needs.

Participants plans have been built with the incorrect price guide, causing delays with the plan having been sent back to NDIA to be amended (PIR NT)

Insufficient funds to support client goals (PHaMs SA)

Not enough funding / hours to support their needs (PHaMs VIC)

In WA, services reported reduced funding in the transfer from WANDIS:

transfer from WANDIS to NDIS plans not being straight changeovers and less hours being approved (PIR WA)

c. Insufficient mentoring at the planning phase

The quality of the planning meeting was critical to appropriate plans. Providers described clients receiving inappropriate and inadequate plans when they were confused, overwhelmed, not adequately informed about what was available through the NDIS and were unsupported in planning meetings.

Preplanning was not pushed in some of the service areas as clients felt that the NDIA/LAC would understand the client's needs and provide appropriate plans for their needs, unfortunately often clients were not aware of the realms of the NDIS and what to discuss (PHaMs QLD)

There was insufficient 1:1 in-kind mentoring put into participants plans – only 2 participants received this support (PIR NT)

The planning meeting was completed over the phone... this may be the reason for the lack of Support Coordination in the plan (PHaMs WA)

d. Not enough capacity building – only core supports included

Providers felt strongly about the importance of Capacity Building supports within plans for many people living with psychosocial disability and said that for many that this was an inappropriate plan omission. They also described the inconsistency of messaging from NDIA regarding the availability of Capacity Building supports for people with psychosocial disability.

Appropriate levels of capacity building funding is not being built into participants plans. For e.g. a participant who has issues of social anxiety and social isolation was not provided any capacity building supports to help them manage this- they were only provide with core supports (PIR NT)

The NDIS/NDIA must support the evidence that states that those with a mental illness can live in recovery, and this is done by supporting clients to build their own capacities. If Capacity Building is not incorporated into the plans of people with psycho-social disability, they will further be disabling these people (PHaMs VIC)

Limiting their opportunities to gain further strategies that assist in staying well, enhancing coping, resilience and gaining transferable skills that they can use in their lives, therefore leading to healthier communities (D2DL WA)

A participant with complex psycho-social support needs, with very little informal supports, was not provided with Capacity Building in his plan, only Core Supports. We were advised... that no applicants with a mental illness will ever receive an NDIS plan with Capacity Building (PHaMs VIC)

e. Lack of NDIA understanding of psychosocial disability

Providers explained that, in large part, it was NDIA assessors and planners lack of psychosocial disability expertise/understanding that resulted in important plan omissions and inappropriate plans that didn't align with needs of people living with psychosocial disability.

And lack of understanding about psychosocial needs (PHaMs VIC)

lack of understanding of psychosocial support needs resulting in insufficient hours (PIR WA)

The person was well at the planning meeting and now has deteriorated (PHaMs NT)

Participants need to not have their funding reduced in the second year, mostly this will be underspent because of the time it takes for people to get used to the new scheme and purchase supports (PHaMs QLD)

One provider said that inappropriate plans also stemmed from their own support staff not knowing how to advocate for people with psychosocial disability at planning meetings.

The staff at the planning meeting do not understand or have lack of training how to advocate for an appropriate plan (PHaMs NT)

f. Lack of inclusion of transport needs (both for client and for services)

Lack of assessor/planner understanding of psychosocial disability also resulted in transport assistance being excluded from people's plans and this led to some people not being able to implement their plans. Providers also described the impact of services not being paid for travel time.

No transport funding when necessary (D2DL QLD)

Transport has not been included as planners have deemed psychosocial disabilities don't impact catching public transport (PIR WA)

Lack of transport funding in plans. We are hearing that the NDIA are taking this out of plans. (PIR ACT)

Lack of adequate transport funding meant that NDIS plans were not able to be actioned. (PHaMs VIC)

g. Additional rural and remote complexities and culturally inappropriate plans

Providers supporting rural and remote communities and individuals raised additional complexities both in terms of the appropriateness of plans and the ability to action plans. They described a lack of services (thin markets) available to action NDIS plans and questioned the cultural appropriateness of the NDIS model for remote communities. Quotes relating to the particular challenges facing rural and remote communities and individuals are provided earlier on page 27.

5.2 Lack of Services to Action Peoples' Plans

Although they were not asked about actioning of plans, six providers in a space provided for any final reflections described issues with a poverty of service providers needed to action people's NDIS plans. This lack of available providers to action plans has been referred to as 'thin' markets. While thin markets were highlighted as a particular issue within rural and remote regions and communities, providers in major cities also described the lack of services available to engage or action people's NDIS plans. Example quotes:

Supports and services in the market that can actually provide services under clients' NDIS plans. The market is still catching up – There are clients who cannot use some of their plan as there is no one providing that particular support in SA (PIR SA)

From our experience it will take some time for the market to adjust to the need driven by the NDIS. We are hoping to see more mental health specialists' services in the landscape (PIR QLD)

5.3 Lack of NDIA understanding about why plans are sometimes 'under-used'

Many providers in this study would not have clients who had yet experienced an annual NDIS plan review, because they were in more recent NDIS roll-out areas, and therefore no information was requested regarding reviews. However, five providers, in their final reflects, expressed concerns about seeing reductions in people's plans at review. They believed that these reductions were because NDIA assumed lack of need based upon under-utilisation in the previous year. Providers believed that this demonstrated a lack of understanding of psychosocial disability. In contrast to lack of need, providers said that reasons for under-utilisation included periods of hospitalisation, periods of acute illness as well as inability to find/access services to action plans.

NDIS system does not account for the episodic nature of psychosocial disability. Needs to be some work around this so that supports can be increased at times of increased need. Additionally, consumers should not be punished (by reducing plan funding) at the plan review stage for underutilisation of their plan. Underutilisation may occur due to it being a time of low need time for the consumer, but this does not mean they won't need the higher level of supports in the future (PIR SA)

In addition, many of clients work with us episodically- we have many long-term clients that we know will engage in a cyclical way, which we support as part of the recovery model. We work with clients to build their independence. When our clients are in crisis or have insight to see things in their life that might become overwhelming, they re-engage. There for we have clients that may not have much activity or engagement for a period of time but then may require support again soon (PHAMS SA)

DISCUSSION POINT 3 – THE EXPERIENCES OF ELIGIBLE PEOPLE WITH AN NDIS PLAN

Many plans deemed inappropriate by providers

This study has only explored the perspective of service providers in relation to the appropriateness or otherwise of people's NDIS plans. It is critical that the experiences and perspectives of NDIS participants themselves are examined and we are aware of a number of studies that have commenced to fill this gap. Notwithstanding the limitations of seeking provider perspectives, their collective wisdom provides important indicators of what is needed to enhance the appropriateness of plans for people living with psychosocial disability as well as their ability to action these plans. Providers highlight the importance of support coordination so that people are helped to action their plans. They also highlighted the need to review exclusions to capacity building supports within people's plans. Anecdotally we have heard that these are both currently being given attention to by the NDIA. The thin markets or lack of available services to action people's plans was also a problem – particularly for those living in rural and remote regions. Linked to this, a lack of understanding about the psychosocial related barriers to using public transport for many with psychosocial disability adds to the challenge in actioning plans.

Misunderstanding of reason behind underutilised plans

As described above, numerous barriers still exist for people in being able to action their plans. A number of providers expressed concerns about plans for clients being reduced in their annual review process because they were 'underutilised'. Rather than underutilisation reflecting a lack of need, providers told us it was more commonly because of: the episodic nature of mental illness, because people had been too unwell to activate them, they had long periods in hospital, didn't have the support coordination to assist them to enact their plans, or were unable to find anyone to provide services within the plan. It is hoped that this understanding is developed within NDIA reviewers as the specialist pathway continues so that people's plans are improved to provide the supports needed rather than being inappropriately reduced over time.

6. About People Ineligible for NDIS

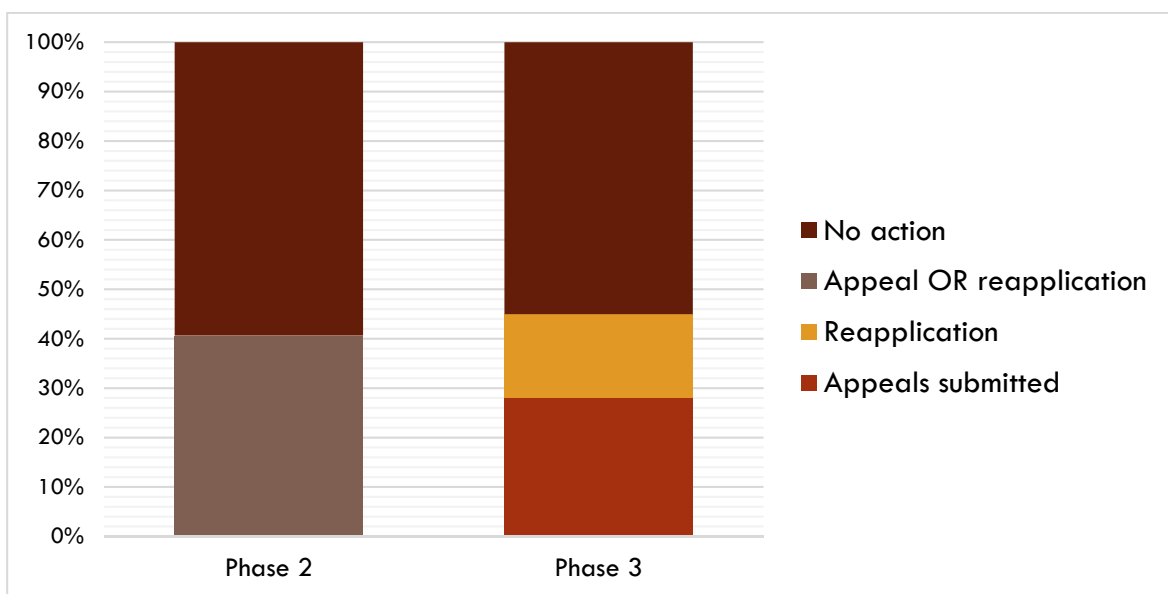
6.1 Actions Taken – None, Appeals and Reapplications

As our understanding of the number of people being found ineligible grew, we asked for increasingly specific data from providers at each phase of this study. Initially in Phase 1 providers were not asked about actions taken for people found ineligible. In Phase 2 providers were asked if appeals or re-applications were submitted and in Phase 3 appeals and re-applications were asked about separately. Consistently over 50% of people found ineligible did not appeal or re-apply. While providers told us often in qualitative comments that they had been advised by NDIA to re-apply rather than appeal to reduce waiting times, overall, they reported more frequently supporting people to appeal rather than re-apply. Importantly the practice or choice to appeal or re-apply was dramatically inconsistent across individual programs. All ineligible clients in some programs appealed the ineligible outcome, all clients reapplied rather than appealed in others. There were also noticeable trends across program types. All (100%) of the D2DL clients reported on submitted an appeal. Two thirds of PIR clients appealed rather than reapplying. In contrast, two thirds of PHaMs clients reported on had decided to reapply rather than appeal.

Table 14. Actions taken for/by people whose application was assessed by NDIA as INELIGIBLE

	PHASE 1	PHASE 2	PHASE 3
Total number of people data provided for	Data not sought in this phase	874	306
No further NDIA-related action		519 (59.4%)	168 (54.9%)
Appeals submitted		355 (40.6%) data was not separated in this phase	86 (28.1%)
Reapplication for the NDIS			52 (17.0%)

Figure 11. Actions taken for/by people whose application was assessed by NDIA as INELIGIBLE



6.2 Experiences and Reasons for Action Taken

In Phase 3, we also invited providers to provide commentary around decisions regarding actions/no actions taken when clients had received the news that they have been assessed as ineligible for NDIS. 24 PIR and PHaMs providers provided commentary. Data were thematically coded and are outlined below with example quotes

a. Client is too overwhelmed to try again

Being too stressed or overwhelmed by the initial application process was the most frequent reason provided for why clients chose to accept ineligibility rather than to submit an appeal or to re-apply.

The whole application process is too stressful for a lot of participants so the thought of doing it all again is too over whelming and they will not appeal (PIR NSW)

Individuals who have been deemed ineligible have experienced a decline in their mental health due to the amount of stress involved in applying so they generally decide not to appeal (PIR WA)

The deficit-based language and the nature of being deemed ineligible has generally placed clients in a stressful disillusioned place; questioning their faith in a system that is supposed to support their psychosocial needs (PHAMS NSW)

For some clients with anxiety related disabilities, the added stress related to appeals is far too overwhelming, clients feel the stress not worth the effort (PHAMS QLD)

b. Client will reapply – faster than appealing

Providers repeatedly said that they encouraged clients to submit a new application rather than appealing an 'ineligible' outcome because appeal processes took too long. Sometimes this was based upon their own experience/assessment.

The appeal process takes a ridiculous amount of time. We have a Participant who has waited 2 months and their application hasn't even been viewed yet (PIR NT)

Appeals can take an indefinite amount of time as there is no legislation around this (unlike DSP for example). Staff only appeal generally after a second failed access request as a reapplication is always quicker (PHaMs WA)

Many of our staff found that appeals take too long, and therefore the preference has been to submit a new access request rather than appealing the decision (PIR SA)

Sometimes they said that NDIA had recommended that they get clients to submit a new application rather than an appeal to save time.

Advice given to staff that the review and appeal process is too long and it is best to wait 3 months for a new NDIS Access Request (PIR VIC)

We have been advised never to appeal but to re-apply (PHAMS NT)

The NDIA staff are usually informing our staff not to appeal as it's quicker to wait 3 months and re-apply (PHaMs VIC)

Most of advice from NDIA says that it is better to submit a new application rather than waiting to appeal. Most of the clients want to reapply instead of appeal (PHaMs WA)

c. Poor NDIA communication/Lack of information about processes and why they were assessed as ineligible

Beyond the variable NDIA messaging about whether clients should appeal or resubmit, six providers described poor NDIA communication about ineligibility, and an overall confusion about the processes of appeal/re-submission.

The letters that are sent back to say the participant is ineligible does not give enough information as to why the application was rejected. The SF has to ring the planner or NDIS to find out exactly what is wrong with it (PIR NSW)

Lack of communication- it is often the worker who needs to follow up with the NDIA or else "they generally never hear back from the NDIA (PHAMS NSW)

Workers have found it very difficult to navigate the process with clients as different advice and process have been followed (PHAMS SA)

7. About People Who Will Not/Are Not Applying

In both Phases 2 and 3, around **20% of clients across the three federal programs were either not going to apply for the NDIS or had not started gathering evidence in order to do so.** Understanding the reasons behind this large number is important in informing future service delivery, supports and funding allocation. In Phase 2 providers gave qualitative data regarding the most common reasons why people had not applied for the NDIS. The reasons (themes), frequency and percentage of programs that described each is listed below.

Table 15. Reasons for not applying (data from Phase 2)

REASONS (Themes)	Frequency	Percentage*
Clients are paranoid about or don't trust the system	10	52.6
Clients are currently too mentally unwell	10	52.6
Clients are overwhelmed by the process of collecting evidence	9	47.4
Clients are still deciding - not sure if they want or need to	8	42.1
Clients are unwilling to identify as disabled	7	36.8
Clients are older or close to 65 years	7	36.8
Evidence Needed by NDIA doesn't exist - lack of consistent service use	6	31.6
Clients are not interested or don't want to	5	26.3
Clients have other more urgent things to sort out	4	21.1
Clients are new to program or attendance is intermittent	4	21.1
Evidence available is not strong enough to meet NDIA requirements	3	15.8
Health professionals/specialists are unable to provide adequate reporting/evidence	3	15.8
Clients live out of NDIS area	3	15.8
Clients are not yet Australian Citizen	3	15.8
Clients prefer to use others supports - e.g., family	2	10.5
Clients do not think they would be eligible	2	10.5

Note. * based upon proportion of the 19 programs who provided data for this question.

In Phase 3, providers were asked to reflect on the list of reasons provided in Phase 2 for why people were either not planning to apply or had not started the process, and to provide any further comments about why clients had either decided not to or were unable to apply for NDIS support. 19 providers provided further commentary, and these were analysed thematically, and themes are reported below with example quotes provided for each.

a. Clients are fearful of the application process – re-traumatising, stressful and overwhelming

Providers reported that many clients were not applying because they were fearful and overwhelmed by the complexity of the process and what would be involved.

... unable to apply as the effort required has been too overwhelming, the information required too hard to gather and the process of navigating the NDIA too complicated (PIR WA)

The system is asking people to focus on how unwell they are which is contradictory to the strength-based recovery model implemented by most organisations working in community health. At times this can trigger self-stigma and relapse of mental health (PHaMs VIC)

Too overwhelming, not emotionally ready (PHaMs QLD)

A number of providers reported that consumers were not applying for fear of being re-traumatised if they had to revisit prior traumatic experiences in order to gain the evidence needed for eligibility.

Fear of having to discuss trauma and other aspects of their life to enable them to receive supports or to provide evidence again. Some clients in a recovery process become re-traumatised when constantly revisiting areas of their life that may be a trigger (PHaMs QLD)

Traumatic past – don't/can't cope with the information on file (PHaMs SA)

Don't think they can deal with the process due to fears it will be re-traumatising (PIR VIC)

b. Clients' mental health is too poor or too unstable

Many providers said clients were not applying because they were currently acutely unwell, or their mental illness was too severe for them to be able to engage in the application process.

Most of the time, people are choosing not to apply because they are too unwell (PIR NSW)

Crisis or mental health too severe to engage in the application process yet (PHaMs WA)

Mental Health acuity. Mental illness is currently more severe/acute. Some hospitalised in inpatient unit due to acuity. Others while still living in the community are too unwell to contemplate or understand the actual concept of the NDIS let alone have the cognitive or mental capacity to undertake the task of working through Application process (PIR NSW)

They are too unwell and are unable to manage the process (PIR SA)

Regular hospitalisation therefore challenging to "make time" to do application (PHAMS NSW)

c. Clients are dealing with more urgent priorities

For many clients with complex needs, particularly homelessness, applying for the NDIS was a lower priority that was put aside until these more pressing needs were addressed.

Homelessness / housing instability. Numerous participants are currently experiencing homelessness... When basic fundamental needs remain unmet – participants cannot muster the mental focus or willingness to undertake what can be a seemingly over-whelming task (PIR NSW)

They are often dealing with other priorities such as addressing homelessness or family breakdown. They need to get these basic needs met before they can consider the NDIS (PIR SA)

When people come to our organisation, they usually have many priorities e.g. need to gain housing or deal with a crisis situation. Therefore, applying for the NDIA is not appropriate at the time, often this can go on for quite a while and there are always other priorities that the participants want to deal with (PHaMs NT)

Experiencing other issues that take priority such as homelessness, suicidal (PHaMs QLD)

d. Clients don't trust government related agencies including NDIA

Providers described the mistrust that some clients had with government agencies because of previous negative experiences and a fear of personal information being shared with other agencies. This fear and mistrust led to clients choosing not to apply.

Lack of trust of systems/services/the government (PIR SA)

Reluctant / reticent to engage in govt systems. Numerous participants have been on the receiving end of complex and seemingly callous medical and govt systems all their lives. Particularly for those [who] may have been in State Care (Wards of the State) as children or perhaps suffered abuse in Institutional Out-of-Home Care (such as Sexual Abuse etc) these people can often have deeply entrenched suspicion of government systems & their corresponding bureaucracies such that they often tend to withdraw from society & do not wish to engage in mainstream supports, services & systems. (PHaMs NT)

There is some mistrust of the NDIS which Participants haven't reconciled yet. There are also Participants who haven't been approached yet for NDIS plans (PIR NT)

Some clients are frightened/mistrustful of the Scheme and feel in danger of losing benefits/pensions (PHAMS VIC)

Concerns around privacy and information sharing amongst govt agencies (PHaMs WA)

e. Inability to obtain the evidence required by the NDIA

For clients who were homeless, transient and had limited or only sporadic engagement with mental health services, the level of evidence required by the NDIA was not available.

Participants have had limited engagement with clinical services and unable to collect enough evidence (PIR ACT)

Lack of evidence exists for an NDIS application (PIR NSW)

Not connected to any services or clinicians (PIR WA)

Records belong to correctional services (PHaMs SA)

Lack of evidence, currently trying to link in with clinical supports (PHaMs WA)

People whose Transition Status was Unknown

In the final data collection phase, providers were invited to provide commentary regarding the clients whose stage of transition or otherwise they did not know. Almost invariably they described having lost contact with these clients because they had moved, had disengaged, become unwell and retracted from services.

Person became unwell and is currently not engaging with services (PIR ACT)

remain enrolled in the program – however experience a period of less intense contact and interaction due to their own choice or capacity (PIR NSW)

participants who are listed as unknown have not had recent contact with support workers. We will continue to attempt to contact these individuals (PHaMs SA)

We have been unable to locate a few participants due to their transient lifestyle (PHaMs WA)

This applies to clients who have ceased to engage and cannot be contacted by their Support Worker (PHAMS VIC)

DISCUSSION POINT 4 – PEOPLE NOT ELIGIBLE OR NOT APPLYING FOR THE NDIS

High rates of ineligibility

The high rate of NDIA assessment of ineligibility for people with a psychosocial disability was first recognised with the trial sites and has been an acknowledged ongoing concern, particularly for the Joint Standing Committee for the NDIS. Data in this report suggests it remains the case. The consistently high proportion of applicants from PIR, PHaMs and D2DL who have been assessed by NDIA as ineligible for NDIS is of concern. Across all three phases this has been between 27% and 28% of applicants. Given that these programs, in particular PIR, were only provided to people with serious and persistent mental illness and additional complex needs, these high rates of ineligibility make limited sense and require investigation.

Further, rates of eligibility were inconsistent across the country with programs that achieved 100% eligibility rates and others with no client assessed as eligible. As stated above in DISCUSSION POINT 1, this requires detailed investigation going forwards to ensure all people have equal opportunity irrespective of the program providing support to apply and irrespective of the individual NDIA staff involved in their assessment.

Is funding sufficient under COS for ineligible NDIS applicants?

The data in this report indicates that it is highly likely that a significant number of people with serious and severe mental health issues will not ultimately receive support through the NDIS. These include people: who do not apply for NDIS (up to 22% depending on how many of these people do in time decide to test their eligibility); those already found ineligible (12% of the total cohort and 28% of those who have applied); and the proportion of people preparing to apply (27%) or are still waiting to hear their outcome from NDIA (18% of the total cohort and 40% of those who have applied) and are ultimately assessed as ineligible in time.

Further investigation is needed on the number of previous PIR, PHaMs and D2DL clients who are not NDIS participants either because they were found ineligible or because they chose not to apply.

While this report provides some indication as to the proportion of clients moving into NDIS, it remains unclear whether CoS has the funding needed to provide an adequate level of replacement support. D2DL, PHaMs and PIR support packages varied from \$1850 to \$7000 with NDIS providing average packages for psychosocial support of \$30,000. While this is the largest publicly available national dataset that we are aware of, without a complete national data reporting on the numbers of clients who remain ineligible or do not apply for the NDIS over time, it will be impossible to determine whether CoS is an adequate ongoing replacement and that 'no one will be worse off'.

Appropriate and effective continued assistance to help people with a psychosocial disability apply for and get support from the NDIS will clearly reduce the numbers of people dependent on CoS. Given the inconsistencies in regard to ineligible applications, there is also a question regarding the

clients in CoS who would be better suited to NDIS and how they may be encouraged to reapply or appeal.

Access to CoS without applying for NDIS

A high proportion of people reported on in this study have not started or do not intend to apply for the NDIS. The current Commonwealth Department of Health flowchart models show that in order to access Continuity of Supports, people are required to have applied for NDIS and been deemed ineligible¹⁷. This requirement appears problematic given the consistent evidence regarding the barriers to NDIS application for people with a serious mental illness. Repeated evidence, both within and beyond this report, demonstrates that the process of applying for the NDIS can be traumatising, costly, and the level of evidence required is not possible to obtain for very many people living with serious mental illness. How for example is a person who is homeless, has no connection with primary or clinical care and is experiencing ongoing psychosis, expected to gather evidence from experts to prove that they have a permanent disability? Even with support, the process is costly, requires focus and determination an acceptance themselves that they have a disability, and enough functional capacity to navigate and attend an ongoing series of meetings and appointments.

While we are anecdotally aware that some PHNs are not strictly applying this criterion, the key question remains. Will people previously supported through PIR, D2DL and PHaMs who for various reasons, many of which are detailed throughout this report, choose not to go through the NDIS application process be excluded from CoS supports? If so, this appears inconsistent with both the principles of choice and control and the principle of nobody being worse off as a consequence of the roll-out of the NDIS.

¹⁷ PHN Commissioned Psychosocial Programs:

[https://www1.health.gov.au/internet/main/publishing.nsf/Content/2A58F6131FE16440CA2583C40014ABF6/\\$File/Fact%20Sheet%20-%20NDIS%20transition%20PHNs-%2003.04.19.pdf](https://www1.health.gov.au/internet/main/publishing.nsf/Content/2A58F6131FE16440CA2583C40014ABF6/$File/Fact%20Sheet%20-%20NDIS%20transition%20PHNs-%2003.04.19.pdf)

8. Future issues to consider

8.1 Future supports for people who will not be in the NDIS

Providers described being concerned about the clients who would not be eligible for or would choose not to apply for NDIS (noting this is the vast majority of current clients). They spoke specifically about the limited supports that would be available to them and the expected flow on impact on clinical mental health services and the justice system.

One provider described the need for ongoing services and supports outside of the NDIS in detail:

“When the Commonwealth Govt received numerous feedback and advice from PIR, PHaMs & D2DL programs PLUS Peak Bodies (such as Community Mental Health Australia) and advocacy groups (such as MH Carers Australia) [they] pledged funding for TWO distinguishable cohorts via the 2017-18 AND 2018-19 Federal Budgets:

a) People who applied for NDIS & were found ineligible but still have a severe & persistent mental illness which may be profound & sustained through their life-span.

b) People who experience severe & persistent Mental illness of a more episodic nature which can be totally debilitating in high acuity – requiring either a MH inpatient admission/hospitalisation AND subsequent intensive community-based support once they are discharged OR those whose MH challenges do NOT meet eligibility for NDIS AND may not require hospitalisation but nevertheless still require significant support to function in everyday life, engage in community and partake in social inclusion on an on-going basis – regardless of acuity. (ie their baseline functioning requires support).

There will ALWAYS be a multiple of people within these two cohorts who do not ‘fit the mould’ of the NDIS and cannot be assumed to be living functional healthy lives without some measure of on-going support that is tangible and predictable.

Therefore, there will ALWAYS be need for block-funded services to be kept in place as a safety net for the many people who will not qualify for NDIS but yet experience severe & debilitating episodic mental illness”

(NSW PIR)

Concerns regarding quality of future supports

Providers however described concerns that needed services outside of the NDIS were being severely reduced and this was placing people with severe and persistent or episodic mental illnesses at risk.

Without the likes of such programs, these clients are typical of those who fall through the cracks; not receiving the adequate supports within the community (NSW PIR)

[The] funded program for new participants (NPS) who previously would have been referred to PHaM or D2DL, is grossly underfunded and will not be enough to service the demand (PHAMS NT)

Just because they have not met [NDIS] access, does not mean that these people will not require ongoing supports. Majority will need some sort of psychosocial assistance lifelong, even if it is episodically (PHAMS QLD)

Concerns about future flow-on impacts on health and justice systems

Rather than these service reductions ultimately saving the governments money, providers believed that without the level of previously accessed community-based supports, people would end up using more costly crisis, acute hospital and clinical services and/or end up within the justice system.

Majority will now place an additional burden on emergency services and the health system if they lose their support workers which will cost the government more, rather than investing in them to manage their mental health to where they are able to function in the community (PHAMS QLD)

The ceasing of PHaMs presents a great risk to local and regional communities with a potential for increased need on the local justice and health systems. PHaMs provides people with simple access to tailored support that is not determined on their diagnosis (PHAMS QLD)

Confusion about eligibility for various schemes

In the final phase of data collection, providers were asked about plans being made for people who were ineligible or had not applied. While providers described a range of supports potentially available to people not within NDIS after June 2019, many were **confused about the inclusion criteria for various schemes**. While COS is intended for people who have tested their eligibility for NDIS and been found ineligible, a number of providers said that they would be referring people who did not want to apply for NDIS to COS programs for support. Others asked the question about where they could refer these clients.

I don't know. I'm not sure that Continuity of Support is available to people who have decided not to apply (PIR ACT)

We are not sure how long we are allowed to work with someone through the extended transition if they are unsure about whether or not they wish to apply for the NDIS (PIR SA)

Concerns about limited extension funding

Several providers said that they had been given extended funding through the Psychosocial Extension Program (PEP) to continue providing support to people considering/in the process of applying. However, the **length of program extension provided through PHN funding varied from 2 months to 16 months**:

Remain within PIR for a two-month program extension period (PIR NSW)

Additional NPS extension funding has been provided through the PHN's initially for 6 months with options to continue if there are still some people requiring support into 2020 (PIR QLD)

People who are yet to submit an access request, or those wishing to reapply, will be supported through the extended transition phase of PIR. This is allowing us 1 additional year to finalise the access process for consumers (PIR SA)

Some providers expressed **concerns about their ability to support people adequately** within the reduced COS funding and limited timeframe for transitional supports.

After June 19 we are reliant on PHN funding for transition and CoS, which is limited (PHaMs NT)

Funding very limited with time constraints (D2DL WA)

They will remain working with a support facilitator - although this may not be the same person due to reduced budget (PIR SA)

Some clients would be able to continue with the same support workers or programs because those programs had new federal funding. Other clients would lose this continuity because programs were no longer funded to support them.

Providers described a range of alternative supports/services that they would be referring people who were ineligible or not applying for NDIS support to. These included state/territory funded programs, mental health clinical supports, employment services, mental health care plans, psychologists, family-focused supports, neighbourhood centres etc.

8.2 Concerns and suggestions regarding future transition-related processes and practices

Providers also raised concerns relating to the NDIA and NDIS, relevant to clients who will apply for and/or be eligible for NDIS in the future.

Anticipating less support for people applying or reapplying after June 2019

Providers described the skill and time needed to establish rapport and trust and to support and guide each person as they consider and then engage in the complex and often stressful process of gathering evidence in order to apply for the NDIS. They were concerned about the reduced funding and time-limited nature of transition support funding and believed people would not get this needed support and advocacy.

I have participants who require a high level of communication between myself and their clinical treatment teams. How will this be handled in future? (PIR ACT)

The funding is grossly insufficient for NPSM, ETS and CoS services moving forward. PIR clients will not receive the same level of support (as promised by the Federal Government) under these programs (PIR SA)

Much support is provided to individuals to apply for the NDIS, without these high levels of support people have stated that they would be unable to navigate the NDIS process. Again, block funding is providing much of this, as the NDIS funding brackets do not cover this role as it is prior to plan eligibility and no funding has yet been allocated and no guarantee that individual will receive a plan (D2DL WA)

Advocacy and service integration needs to be valued/enabled

Although there were providers who had been blocked by NDIA staff from attending and advocating or supporting clients at planning and assessment meetings, many had managed to negotiate this. Providers described the value of advocacy from those with knowledge of and known by clients and the variability with whether NDIA staff permitted this advocacy to occur. They repeatedly recommended changes to NDIA and the NDIS business model that facilitated and valued greater advocacy, service integration, collaboration and cross-agency communication systems in order to enhance experiences and outcomes for clients.

The NDIS process can be difficult for clients to undertake without support due to associated stress and lack of clarity and understanding of processes (PIR WA)

Past PIR consumers not having someone available to go to their plan reviews to help advocate for their needs. This will be very difficult for some of our consumers (PIR SA)

[there is a need for] the freedom for support workers to be able to attend (for example) a Case Conference convened by MH Services (Local Health District staff etc) WITHOUT the requirement to bill their time to an NDIS line-item! Services need to collaborate to achieve best outcomes in people's lives and this cannot be achieved under this current NDIS business model (PIR NSW)

Connecting to new services/workers will require a warm handover for many of our clients. [We have] concerns around this being implemented without PIR worker support (PIR SA)

There needs to be an easier process for staff to speak to the NDIA on the participant's behalf without them present. It would be beneficial for the NDIA to get a "consent to enquire" form similar to Centrelink... We have had very mixed information from the NDIA – even them telling us if we want to enquire, we need to be nominated and have to come into the NDIA and provided 100 points of ID, our workers should not have to do this (PHAMS WA)

There should have been more of a collaborative approach for access with these participants between their service provider and NDIS in the assessment of their eligibility for NDIS (PHAMS QLD)

Improved NDIA consistencies and communication needed

Providers described ongoing NDIA process inconsistencies, and this does not appear to have improved with recently introduced processes.

The NDIA at times can be challenging to work with due to inconsistency... Having worked with transition and roll outs in different areas, my experience is that there is a lot of inconsistency with communication, changes to NDIS policies etc and also waiting periods for applications, appeals and application (PHAMS NSW)

We have not seen any better or faster outcomes for clients who applied for the NDIS through the Streamlined Access Process (PHAMS VIC)

The range of recent changes to extend the period of support for people applying for NDIS have created confusion and providers said these changes were poorly communicated and thus poorly understood.

Communication around the transition post June 30 has been disappointing (PIR ACT)

Due to the psychosocial disability of the participants, the process of transition is really hard for them to understand (PIR VIC)

Concerns for the transition phase and staff being able to manage ... transitioning and mentoring clients (PHAMS WA)

Need for more/better mental health specialist NDIA assessors and planners

Providers continue to report on the negative impact of NDIA staff inconsistencies and lack of mental health training/understanding, and an ongoing need for this to be addressed. Stories of NDIA assessors overriding expert assessments was repeated by a number of providers. Repeatedly inconsistencies were deemed to be because of NDIA staff's lack of, or variable understanding of psychosocial disability. While raised broadly, this was a particularly heavy focus of Western Australian providers

There is no rhyme or reason as to how people are deemed eligible or ineligible and lots of our existing clients want to be in the NDIS but their psychosocial disability is not understood by the NDIA (PHAMS VIC)

Continued education [is needed] for people within the NDIA on barriers faced by people with a psychosocial disability and how they affect individuals differently (PIR WA)

People living with mental health issues have hit barriers in having their needs fully met through a lack of understanding of the impact on an individual's functioning (PIR WA)

The NDIA needs to employ mental health competent assessors who understand the complexities of episodic illness. We have found that there has been a huge lack of understanding around the nature of mental health. For example, we have had access requests rejected on permanence for BPD because someone hasn't engaged in DBT. This is despite the psychiatrist writing a strong letter advising that the person's illness is considered permanent. We do not believe the assessors personal opinion should override the treating doctor's medical opinion (PHAMS WA)

Need to address additional future rural and remote complexities

Providers supporting rural and remote communities and individuals questioned the sustainability of the current NDIS model for their clients. They described a lack of services (thin markets) available to action NDIS plans and questioned the cultural appropriateness of the NDIS model for remote communities.

Rural and Remote regions are significantly disadvantaged - E.g. Kangaroo Island... does not have anywhere near enough service providers who can service clients via their NDIS plans, particularly psychosocial supports. There are also no other psychosocial supports on the island (PIR SA)

Providing NDIS supports in remote communities is not a culturally appropriate model, and the financial constraints of NDIA funding means that services in these areas are not feasible (thin markets) (PHAMS NT)

Additionally, lack of adequate transport funding meant that NDIS plans were not able to be actioned in rural and remote areas.

Transport/travel funding in country regions makes providing services unviable (PHAMS SA)

They reported that current funding was insufficient to make service delivery viable in these areas – both within NDIS itself and within the alternative and transitional federal funding schemes.

In some parts of the Territory there is no other service that provides psychosocial supports, therefore it is not realistic to expect participants to be picked up by other services, when NPS has reached capacity. For example, we have referrals for participants living in Adelaide river 120 KMs from Darwin, there is no other non-clinical mental health supports available for these people (PHAMS NT)

Centre-based supports – not sustainable/viable within regional and remote regions (D2DL NT)

Concerns on viability of centre based programs under the NDIS into the future, the low levels of funding diminish the sophistication of these programs. Outlying areas are already negatively affected with centres closing and many clients unable to attend (D2DL WA)

Relying on the NDIA for centre based supports is providing challenging. Given the nature of our clientele, many are unable to remember what time or day they should attend for particular activities. Many of them have very sporadic attendance, which causes issues for a fee-for service model (D2DL NT)

A need for greater organisational support and training was also highlighted by rural and remote providers.

Besides Flinders Transition Support Project, there is no other training opportunities for our staff to learn how to apply for the NDIS, therefore organisations are having to wear this cost and manage their own internal training (PHAMS QLD)

Nationally there is limited training available for organisations around the NDIS. One option is Disability Services Consulting who are very good, however they are costly and do not travel to Darwin regularly (PHAMS NT)

8.3 Concerns about the future mental health workforce – within and beyond the NDIS

The rapid and constant changes across the community mental health service system, both within and beyond the NDIS is having a major impact on the mental health workforce and provider organisations. Providers reported that many staff are burning out and leaving the sector.

Most if not all clients of mental health programs require... consistency of carers/support workers – not the high staff burn-out & turn-over we have seen in the sector since the NDIS was introduced (PIR NSW)

The release of alternative funding (CoS / NPS and TSP) which has been funnelled through the PHN's was so late in the planning stages that staff have been negatively affected. It was too late to give organisations time to plan (PHAMS VIC)

The uncertainty of contracts has resulted in challenging environments to retain quality staff to facilitate this process (PHAMS WA)

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