

St Vincent's Mental Health Submission

NDIS Participant Service Guarantee

This submission is made on behalf of St Vincent's Mental Health NDIS Committee. St Vincent's Mental Health is a program of St Vincent's Hospital Melbourne which is in turn part of St Vincent's Health Australia.

St Vincent's Mental Health

St Vincent's Mental Health is an adult mental health service for people aged between 16-64 years who live in the inner urban east area of Melbourne and provides assessment, treatment and care to people with severe mental illness. These services are delivered in hospital (acute inpatient), sub-acute, bed-based clinical rehabilitation services and in community ambulatory settings. Underpinned by a recovery oriented approach, these services are aimed at people experiencing mental illness and associated disability, including acute and long-standing psychotic disorders, mood and anxiety disorders, or severe personality disorder. In addition, St Vincent's Mental Health manages specialist state-wide, regional and hospital services which focus on providing and improving services for groups with special needs.

St Vincent's Mental Health NDIS Committee

St Vincent's Mental Health NDIS Committee's role is to oversee and guide the establishment of an effective operational interface between our mental health service and the NDIS, with the aim of improving eligible consumers' access to and experience of the NDIS pathway.

In preparing this submission the Committee acknowledges the existing and concurrent work in understanding and improving outcomes for people with psychosocial disability, including

- Psychosocial Supports Design Project
- The Productivity Commission Inquiry into NDIS Costs
- Joint Standing Committee on the NDIS: Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition
- The Evaluation of the NDIS
- The McKinsey Independent Pricing Review of the NDIA
- The Psychosocial Pathways Project
- The Royal Commission into Victoria's Mental Health System
- The Productivity Commission Inquiry into the Social and Economic of Improving Mental Health
- The Optimising Psychosocial Support Project (and the supporting Literature Review)

and welcomes the opportunity to provide input into the NDIS Participant Service Guarantee and share the experiences of the vulnerable populations with mental health issues that we serve, for whom service engagement is difficult and who otherwise are unable to contribute to these discussions.

*“Critical to the discussion is the fact that the current understanding of met and unmet needs and consumer preferences is based largely on individuals with some degree of service engagement. **There is a potentially large and particularly vulnerable and marginalised cohort of people whose needs are not adequately reflected in current conjecture.**”*

p.14 Optimising Support for People Psychosocial Disabilities Participating in the NDIS Literature Review 2018
https://mhaustralia.org/sites/default/files/docs/optimising_psychosocial_supports_-_literature_review.pdf

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This submission draws on the experience of

- St Vincent's mental health clinicians supporting consumers and their family/carers along the NDIS pathway, and
- committee members who have contributed to NDIS related projects including
 - *Self-Advocacy for the NDIS (Mental Health)*: Independent Mental Health Advocacy <https://www.imha.vic.gov.au/about-us/news/support-for-people-with-mental-health-conditions-to-access-ndis>
 - *Practice advice for mental health clinicians*: North East Healthy Communities (formerly North East Primary Care Partnership) <https://www.nehc.org.au/ndis-for-mental-health-clinicians/>
 - *Specialist Clinical Mental Health and NDIS Collaboration Project*: funded by the Victorian Department of Health and Human Services through the Commonwealth Government Sector Development Fund <https://providers.dhhs.vic.gov.au/sites/default/files/2019-02/ndis-resources-for-clinical-mental-health-services.docx>.
 - *Parenting, psychosocial disability and the NDIS: A tool to support consumer parents preparing for an NDIS planning meeting* Families where a Parent has a Mental Illness (FaPMI Program) a Victorian Government initiative <https://www.bouverie.org.au/support-for-services/fapmi> , aligned with the national initiative www.copmi.net.au / www.emergingminds.com.au.
 - *Psychosocial Pathway Project* :Mental Health Australia consultations <https://mhaustralia.org/our-projects/ndis-psychosocial-pathway-project>
 - *NDIS Workforce Development (Psychosocial Capabilities) Project*: Mental Health Victoria <https://www.mhvic.org.au/policy-projects2/current-projects/368-ndis-workforce-development>
 - *Scheme Dreams*: Victorian Mental Illness Awareness Council podcast for consumers to assist them in understanding and engaging with the NDIS around their psychosocial disability support needs <https://www.vmiac.org.au/services/ndis/>
 - *NDIS Communications Steering Committee*: neami national's strategy to inform participants about NDIS roll-out in Northern Eastern Melbourne, including eligibility, services and access.

Key points

1. In 2011 the Productivity Commission recommended that people with psychosocial disability be supported through the NDIS and determined "any people with significant and enduring psychiatric disabilities have the same day-to-day or weekly support needs as people with an intellectual disability or acquired brain injury."

This determination does not reflect the experience and outcomes for people with psychosocial disability, particularly when it comes to interacting with the Scheme. The Act Review's focus of "removing red tape and making the participant experience better" for vulnerable populations with serious mental health illness, **requires a significant co-design process with clinical mental health services and key stakeholders**. We submit *Ways of Working with the NDIS* (Attachment A), part of the work we undertook as part of the Specialist Clinical Mental Health and NDIS Collaboration Project, as an example.

2. The 2011 Productivity Commission report also recommended coordination of supports between NDIS and clinical services for good outcomes. Currently **communication with NDIS is a barrier to coordinated care**, and often experienced as adversarial rather than collaborative, with limited

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transparency on what can be expected when communicating with NDIS and what action can be taken when calls, emails or requests are not responded to.

Much work has been done locally and internationally on coordinated and integrated care for people with complex needs. We submit

- a. the *Yarra Mental Health Alliance submission to Royal Commission into Victoria's Mental Health System* (Attachment B) which identifies what works and illustrates a cooperative approach that enables members to hold risk and work with great complexity for better consumer outcomes, and
 - b. *The NDIS Pathway Timelines: Response times and follow up action for clinical mental health services* (Attachment C) which was developed to clarify communication and follow up processes.
 - c. *Effective Partnership Models* (Attachment D): considers the established mechanisms currently supporting the provision of integrated care and service coordination for mental health consumers through the mental health and NDIS interface, successful models of partnership to support an effective interface between specialist clinical mental health services and the NDIS and the key issues and barriers impacting the establishment of effective partnerships with key NDIS stakeholders to support this service provision
3. The 2011 Productivity Commission report is referenced heavily here as it informed the development of the NDIS, and therefore had an important role in the development of the Act. The 2011 report and subsequent 2017 review of Scheme costs address the importance of managing down the total cost of disability over a participant's lifetime for the financial sustainability of the Scheme but fail to acknowledge the intergenerational impact of psychosocial disability.

A 2017 report¹ found that children of parents in receipt of Disability Support Pension for mental illness were 2.5 times more likely to receive Disability Support Pension late in life. Up to 45% of consumers accessing clinical mental health services are parents and their children are twice as likely to have poorer social, educational, developmental and mental health outcomes across their childhood, and are over represented in all service sectors. These outcomes are not inevitable. The likelihood of these outcomes can be reduced by parents getting the supports they need to parent well and look after their own wellbeing. NDIS's approach of "investing in people with disability early to improve their outcomes later in life" is commendable, but does not recognise the impact of disability on dependent children nor the benefits of investment in parent participants in reducing disability associated with mental illness in their children.

Changes to the Act and Rules and the NDIS Act and accompanying Rules need to incorporate addressing

- **the intergenerational impact of psychosocial disability, and**
- **the unforeseen negative consequences of the NDIS's individualised approach on families of people with psychosocial disability.**

Response to Discussion Paper questions

Which of the principles do you think are important for the NDIA to adhere to, and why?

¹ Cobb-Clark, Dahmann, Salamanca and Zhu (2017) *Intergenerational Disadvantage: Learning about Equal Opportunity from Social Assistance Receipt*, Melbourne Institute Working Paper No. 28/17 October 2017

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We agree with all of the principles below as they align closely with the outcomes identified in *Ways of Working with the NDIS* (Attachment A)

- i. The NDIS process will be easier to understand and use, enabling decisions about access, planning and review to happen promptly.
- ii. The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes.
- iii. NDIA staff have a high level of disability training and understand the impact particular disabilities have on people's lives. They understand what supports are most effective for a person's disability.
- iv. The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services.
- v. Participants, their families, carers and other support persons feel valued in their interaction with the NDIS, and know where to go if they need further assistance.
- vi. Decisions are based on merit: NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.
- vii. All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive for Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and other individuals.

In your experience with the NDIA, do you think they fulfilled the above principles? If not, how are they falling short?

- *All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive* – 50% of the people we work with and are likely to be eligible choose not to engage with NDIS, largely due to difficulty understanding and navigating the NDIS. For every NDIS plan that is working well, one is failing/at risk of failing. For the majority of consumers with significant mental illness and functional impairment the process asks too much of them – is too difficult, drawn out, demanding, unclear and intrusive. For many ongoing situational crises and life events for consumers establishing rapport and trust are barriers
- *NDIA staff have a high level of disability training and understand the impact particular disabilities have on people's lives. They understand what supports are most effective for a person's disability* - The same functional impairments that make consumers NDIS eligible are the reasons they struggle to interact with NDIS, in our experience has been this has been poorly understood and/or accommodated by NDIA staff.
- *The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services* – persistent issues related to NDIA administrative errors and poor/inconsistent communication regarding requests for further mental health information on applicants. NDIA communication and engagement issues; NDIA do not proactively and efficiently engage with treating service throughout the access process, particularly when additional mental health information is required. Often no indication of what information is required when more information requested. Request for more information is going to consumer not to clinician (although clinician contact details always provided, and communication invited). NDIA administrative errors include - incorrect details in correspondence details so no communication sent to consumer, cut and pasting into proforma letters, wrong disability, diagnoses that were never included in evidence, incorrect gender and names.
- *Processes will be easier to understand and use, enabling decisions to happen promptly.*

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Psychosocial disability service stream improvements are still not meeting needs of people we work with and information has improved but still not fit for purpose.

What other key principles are important for the NDIA to follow, that could be included in a Participant Service Guarantee?

The *Ways of working with NDIS* (Attachment A) identifies outcomes for participants and carers (consumers and carers) along the NDIS pathway, and what clinical mental health staff will be doing to support these outcomes. It was developed following a co-design process with area mental health services, consumers and carers and staff from the NDIA and the LAC partner. We submit this as a useful model and approach for NDIA to consider in developing the Participation Satisfaction Guarantee.

One way to measure these principles is through a set of 'Service Standards'. Do you think these Service Standards are fitting? Are there other standards you believe should be included?

We agree with the standards below regarding timeliness and responsiveness and submit *The NDIS Pathway Timelines: Response times and follow up action for clinical mental health services* (Attachment C) and would welcome similar information that clarifies timelines and actions and contact details when timelines are exceeded.

The NDIA makes decisions in a timely and responsive manner:

- Once the NDIA has appropriate information, Access requests are made in XX days.
- Participants are offered a planning meeting within XX days of receiving their access met decision.
- First plan approvals take less than XX days after their access decision.
- Plans are approved within XX days of their final planning meeting, following the provision of all necessary evidence.
- Plan amendments are considered within XX days of the request.
- Plans involving SDA or AT requests are made within XX days of the information being provided.
- Participants who request an internal review of decision are contacted within XX days of the request

We also support a Service Standard on partnership and integrated care and submit the *Yarra Mental Health Alliance submission to Royal Commission into Victoria's Mental Health System* (Attachment B) which identifies what works and illustrates a cooperative approach that enables members to hold risk and work with great complexity for better consumer outcomes.

Factors that facilitate this include

1. A common cause with partners: creating a positive vision of the future built around the needs of our local population and what we really want to achieve.
2. A shared narrative to explain why collaboration matters.
3. A persuasive vision to describe what collaboration will achieve.
4. Behaving altruistically towards each other: asking 'how can I help'.
5. Sharing information about users (supported by appropriate information governance but not hindered by overly zealous interpretation of the rules).
6. Willingness to work beyond the boundaries of job descriptions to achieve the best results.

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7. Commitment to working together for the longer term – holding all of the above even when though the service delivery landscape changes and staff turnover.
8. Time and space to develop understanding and new ways of working.
9. Identifying services and user groups where the potential benefits from integrated care are greatest.
10. Making use of data to target expertise effectively.
11. Recognising the interdependencies of services and integrating all aspects of care.
12. Pooling resources to integrated teams to use resources flexibly and innovate in the use of funding.
13. Involvement of people who use the services in co-designing the models of integrated care that work, and the information about these services for other people.
14. Specific objectives, measures and evaluation that encompass a variety of dimensions of care including user experience, service utilisation, staff experience and the costs of delivering care.
15. Appropriate timescales (at least five years and often longer) and a coherent strategy that acknowledges the importance of all the lessons outlined here.

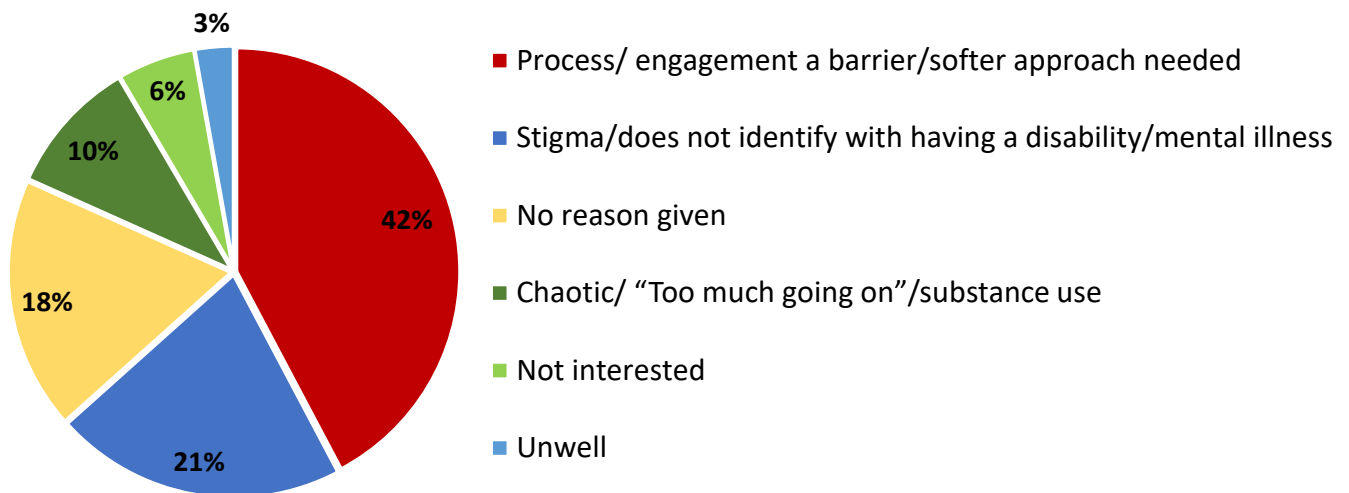
What are some of the significant challenges faced by NDIS participants in the access process?

The same functional impairments that make consumers NDIS eligible are the reasons they struggle with the Access process (and each point of the NDIS pathway) e.g.

- a. Impaired concentration, decision-making and organisational skills, motivation and judgement
- b. Difficulty coping with situations involving stress, pressure or performance demands
- c. Impulsivity
- d. Slowed thoughts
- e. Understanding information clearly from others
- f. Engaging with or understanding written material
- g. Managing correspondence
- h. Holding reciprocal conversations
- i. Articulating needs and seeking help
- j. Being understood by others
- k. Regulating emotions and managing interpersonal conflict
- l. Navigating service systems
- m. Establishing trust with others
- n. paranoid ideation and/or difficulties engaging with others and misinterpreting events

Our data indicates that St Vincent's mental health clinicians are able to reliably assess likely NDIS eligibility, and that half of consumers at our clinical mental health services need support but are not seeking NDIS access.

Figure 1. Reasons consumers decline to seek NDIS access



For the majority of consumers with significant mental illness and functional impairment the process asked too much of them – was too difficult, drawn out, demanding, unclear and intrusive.

- The language was a barrier for many, particularly for those who did not identify as having a mental illness or disability. Many were suspicious of “insurance” and “scheme”
- Many consumers have had traumatic experiences of engaging with bureaucracy and are distrusting of the new system of support and its requirements and feel vulnerable and judged by the process
- The experience of “interrogation rather than collaboration” creates anxiety and distrust and contributes to disengagement.
- Consumers feel suspicious of the application process and why so much personal information needs to be gathered and provided.
- Difficulties establishing rapport and trust, and ongoing situational crises and life events were barriers for many.
- “chaotic” and “too much going on” described consumers whose lives were characterised by complex, abusive relationships, unstable housing/homelessness, substance use, and were identified as requiring intensive support but unlikely to engage unless the response could be immediate, when the window of opportunity was there.
- Clinicians often used phrases like “We’re barely hanging in there/getting a foot in the door/It’s taken years to build this trust and relationship” and struggled to imagine how NDIS could engage with consumers with these multiple and complex needs.

St Vincent’s clinicians supporting consumers to test their eligibility have had a relatively high success rate with 60% of Access Requests meeting eligibility, and close to 100% once a new Access Request, Internal Review or AAT Review were undertaken. This compares favourably with the national average of 50% for people with a primary psychosocial disability (*People with psychosocial disability in the NDIS report*, 30 June

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2019 p.10). For consumers found ineligible on initial Access Request, approximately one third choose not to pursue NDIS at all.

The NDIS Act currently requires the NDIA to make a decision on an access request within 21 days from when the required evidence has been provided. How long do you think it should take for the NDIA to make an access decision?

21 days is reasonable for non-urgent decisions – when completed within that timeframe. When the timeframe is exceeded it has usually been due to administrative errors and no clear guidance to clinicians supporting consumers on how to pursue this. Acknowledgment of receipt of ARF and advice on when decision should be made and actions (including contact details) for when date has been exceeded would help address this.

What do you think the NDIA could do to make it quicker or easier to access the NDIS?

Consider a “subset” of NDIS to address the needs of the group and the barriers identified above

e.g. a non-stigmatising name (similar to, for example, Commonwealth funded programs Partners in recovery or Personal Helpers and Mentors, and Day to Day living) rather than disability

Given St Vs clinicians’ relatively high correlation between consumers considered eligible and those NDIA finds eligible, consider credentialed clinicians (e.g. similar to the AT credentialing) being able to work in partnership with NDIA to make process easier for consumers whose impairment is the barrier to them accessing NDIS.

A system like non-liability DVA cards which allow patients timely/ immediate to access a select number of services (ramps, meals on wheels etc.) which they have to have in place before they can be discharged home/ to community. The remaining supports services are worked out over time. The use of the card has to be authorised by two independent psychiatrists and it allows services to be provided for up to 3 months while access is sorted more permanently.

Is the NDIA being transparent and clear when they make decisions about people’s access to the NDIS? What could the NDIA do to be more open and clear in their decisions?

Documentation informing consumer of eligibility decisions refer to the relevant section of the Act and not the specific information that is missing, misleading or has led to a “Eligibility not met” decision.

What are some of the significant challenges faced by NDIS participants in the planning process?

In addition to the symptoms and functional impact of mental illness outlined earlier, the impact of trauma, poverty and stigma on consumers’ experience and confidence in making choices.

Are there stages of the planning process that don’t work well? If so, how could they be better?

- Supported decision making to support move to greater choice.
- Appreciation of “consumer goals” needs to be broader.
- Minutes of meetings need to recorder and circulated to attendees.

Is the NDIA giving people enough, and the right type of information, to help them prepare for their planning meetings? If not, what else could they provide?

No, information is not fit for purpose.

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Is the NDIA being responsive and transparent when making decisions in participants' plans? If not, how could this be improved?

No. Decision making regarding plans feels “secretive”. Content of plans does not often reflect meeting discussion. Collaboration and information seeking with clear guidance on what is needed to help NDIA make decisions would be useful. Planners/LACs often say “no you can't get A, B or C” rather than explaining what kind of evidence would be needed to justify that request.

What are some of the significant challenges faced by NDIS participants in using the supports in their plan?

- Lack of information sharing and collaboration
- Thin service provider market
- Not enough support coordination or no support coordination in plans
- Poor quality/unskilled support providers
- Support Coordinators will not commence service until participant has signed Service Agreement.
- Although Support Coordination is included in plans, planner/LAC is not initiating Request For Service – participant unable to do so.
- Administrative errors, lack of communication

What are some of the significant challenges faced by NDIS participants in having their plan reviewed (by planned or unplanned review)?

- Timeline around plan reviews.
- Lack of planning and collaboration, and information seeking.

Reviews of this significant level should have an integrated approach and the support people important to the person need to be invited to contribute, if not attend. When planning or plan review meetings are held, there is very little notice. Good practice when organising meetings with clinical workforce is 6 weeks' notice to allow shift and roster coverage to facilitate attendance.

What are some of the significant challenges faced by NDIS participants when they seek a review of an NDIA decision?

The review and appeals process is not clear. 30% of consumers choose not to seek a review and disengage from process.

What are the significant challenges faced by NDIS participants in changing their plan?

If a change is required due to a change in circumstance, usually a significant event has occurred and participants are even less resourced to manage the assertive communication and complicated administrative process required. In our experience this is admission to hospital, loss of accommodation, death of main caregiver and associated decline in function. Extremely assertive communication and advanced understanding of NDIS Act and operational guidelines are required, and even then, it's unclear what recourse we have when NDIS does not respond or declines to attend meetings.