

# Optimising engagement in psychosocial care

A review of St Mary's House of Welcome's NDIS psychosocial program



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# Optimising engagement in psychosocial care: A review of St Mary's House of Welcome's NDIS psychosocial program

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#### **PROJECT ACKNOWLEDGMENTS**

This report is a product of a partnership between St Mary's House of Welcome (SMHOW) and Australian Catholic University (ACU). The Project Team extends its sincere and grateful thanks to all at St Mary's House of Welcome who contributed to this project. This project was activated through the Stakeholder Engaged Scholarship Unit (SESU), which was established to provide an avenue through which ACU can address issues of social, cultural and economic importance as identified by communities. Completing this project through the SESU enables ACU to live its mission to be deeply engaged in and produce better outcomes for communities experiencing disadvantage or marginalisation.

#### ACKNOWLEDGMENT OF COUNTRY

In recognising Aboriginal and Torres Strait Islander peoples' spiritual and cultural connection to Country and in continuing ACU's commitment to Reconciliation, the authors acknowledge the First Peoples and the Traditional Owners and custodians of the Country where ACU campuses are located.

We respectfully acknowledge Elders past and present and remember that they have passed on their wisdom to us in various ways. Let us hold this in trust as we work and serve our communities.

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### **Executive Summary**

For more than 60 years, St Mary's House of Welcome (SMHOW) in Fitzroy, Victoria has provided care and essential services to people with a psychosocial disability, an oftenunder-supported cohort, with the addition of a targeted NDIS program. SMHOW's open access walk-in approach to the provision of food, services and emergency assistance importantly establishes a low threshold for initial engagement.

In the project that is the subject of this report, we sought to understand ways in which to optimise engagement for adults with a psychosocial disability in SMHOW's National Disability Insurance Scheme-funded program of social and psychological wellness activities, and to apply that understanding in the development of recommendations for the service.

From a social justice standpoint, this study provided those who use SMHOW's services with an active voice, as well as overt recognition of their unique perspectives on the phenomenon of interest. Further, the project provided both the participant-consultants who provided data and the staff members who contributed their experiences and perspectives with agency to impact the future of the SMHOW psychosocial program.

Seven project objectives were set, and a mixed methods approach was used to achieve them. The initial projected timeline was 9 months (March–December 2021). However, that was extended in response to changes to SMHOW service provision that resulted from COVID19-related lockdowns and to public health restrictions in 2021 and the first half of 2022. These meant that participant recruitment and data collection could not be completed in accordance with the original timeline.

The project presented in this report was conducted to answer three questions, and to achieve seven aims. All questions were answered, and all aims were achieved; however the findings are limited by the minimal representation of intersectionality outside of having housing insecurity and mental illness in our consumer-consultant participant group. Our findings may not be illustrative of the experiences and opinions of the whole population that attends SMHOW.

Eleven participant-consultants from the SMHOW service user group agreed, at significant personal psychological risk, to share their views, insights and suggestions about NDIS activity provision and engagement at SMHOW for this project. To our knowledge this is the first time the voices of this population have been captured in relation to this subject. Further, at a time when the SMHOW staff were trying to maintain their support and care of those who depend on them during the height of the COVID19 pandemic of the early 2020s, six made time to speak with us. A total of 47 learning points emerged from the rich data these informants provided, and all have the potential to become actions.

We recognise, though, that some are outside the organisation's ability to address, and an engagement optimisation framework has been proposed that enables discretion to be applied at all levels in relation to which actions are taken forward, along with an evaluation approach that will enable continued quality improvement of those actions and interventions.



### L. Background

It is well established that people with a psychosocial disability are among those experiencing the most marginalisation in the Australian community and frequently have to navigate mental illness, homelessness, discrimination, physical illnesses and pronounced economic and social disadvantage (Australian Bureau of Statistics, 2020).

With complex needs and a circular relationship between these factors there are understandably considerable challenges when aiming to provide holistic care. However, it is clear that psychosocial support is an integral piece of this puzzle as the benefits can extend beyond the ability for individuals to directly improve their physical, social and psychological health by improving their ability to access and engage with broader support systems (Barber & Thornicroft, 2018; Parsell et al., 2020). Mental health advocates have welcomed the implementation of the National Disability Insurance Scheme (NDIS) as an opportunity to provide essential support for persons with a psychosocial disability, but emphasise that it is crucial to understand and address the complex barriers to engagement that they face (Taylor & McLeod, 2018). For more than 60 years, St Mary's House of Welcome (SMHOW) has provided care and essential services to this often-under-supported cohort, with the addition of a targeted NDIS psychosocial program. SMHOW's open access, walk-in approach to the provision of food, services and emergency assistance importantly establishes a low threshold for initial engagement. This has been identified as central in making contact with those who face the most substantial barriers to engagement, who are known to otherwise fall through the gaps in the available support services (Hancock, et al., 2018). SMHOW's NDIS psychosocial program provides immediate support to this cohort, but also provides an opportunity to elucidate the experiences and outcomes of participants to provide valuable insight and optimise service provision. From a social justice standpoint, this will also provide participants in the program with an active voice, overt recognition of their unique perspectives, close the communication loop and provide them with agency to impact the future of the psychosocial program. In addition, with the potential to advance the support, solutions and hope offered to this community experiencing disadvantage, this project is notably in unison with the missions of both SMHOW and ACU.



# **Project questions, objectives and scope**

#### **PROJECT QUESTIONS**

This project proposed to answer the following three questions:

- 1 What are the barriers and drivers impacting engagement with the SMHOW NDIS psychosocial program by adults aged 19-70 who are living with a psychosocial disability?
- 2 What framework can be developed to optimise the likelihood of engagement with the SMHOW NDIS psychosocial program by adults aged 19-70 who are living with a psychosocial disability?
- Begin and the second se

#### **PROJECT OBJECTIVES**

Seven objectives were set for the project, and these are listed below.

- 1 To identify the drivers of, barriers to, and value of, engaging with the SMHOW NDIS psychosocial program among adults aged 19–70 with a psychosocial disability (relates to project question 1)
- To explore the drivers of, barriers to, and value of, engaging with the SMHOW NDIS psychosocial program among adults with CALD and LGBTQI+ identities who are living with a psychosocial disability, and those who have an acquired brain injury, to ascertain whether there are any that are specific to these populations (relates to project question 1)

- To distinguish between service and participant driven barriers to engagement by adults aged 19–70 with the SMHOW NDIS psychosocial program (relates to project question 1)
- To construct a framework to optimise engagement by adults aged 19–70 with a psychosocial disability with the SMHOW NDIS psychosocial program (relates to project question 2)
- **5** To develop a process by which to evaluate the success of the framework developed in objective 4 (relates to project question 2)
- To provide an evidence base of the impact the program has in client's lives (relates to project question 3)



To explain the framework developed in objective 4 to SMHOW stakeholders to support future investment into the program (relates to project questions 1, 2 and 3)

#### **PROJECT SCOPE**

The project was conducted with paid and unpaid staff members and clients of St Mary's House of Welcome, which is situated in Fitzroy, Melbourne.





A mixed methods approach was used for this project, as detailed in Table 3.1.

The project team comprised the five members listed in Table 3.2. All members were engaged in the project throughout its duration.

Regarding the project schedule, the original and revised project milestones are detailed in Table 3.3, however these were adjusted for the reasons outlined in Table 3.5.

In relation to conduct deviation, uncertainties and mitigation strategies were identified prior to the project's start. These, and the challenges that actually eventuated, are listed in Tables 3.4 and 3.5.

Lastly, Table 3.6 lists the stakeholders or stakeholder groups who were impacted by the project and describes how they were engaged by ACU Stakeholder Engaged Scholarship Unit staff throughout the project.

#### TABLE 3.1

#### **PROJECT METHODS**

#### OBJECTIVE

To identify the drivers of, barriers to, and value of, engaging with the SMHOW NDIS psychosocial program among adults aged 19–70 with a psychosocial disability

To explore the drivers of, barriers to, and value of, engaging with the SMHOW NDIS psychosocial program among adults with CALD and LGBTQI+ identities who are living with a

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To distinguish between service and participant driven barriers
 to engagement by adults aged 19–70 with the SMHOW NDIS
 psychosocial program

**4** To construct a framework to optimise engagement by adults with a psychosocial disability aged 19-70 with the SMHOW NDIS psychosocial program

**5** To develop a process by which to evaluate the success of the framework developed for objective 4

To provide an evidence base of the impact the program has in client's lives

To explain the framework developed for objective 4 to SMHOW stakeholders to support future investment into the program

#### TABLE 3.2

PROJECT TEAM AND ROLES

PROJECT TEAM AND ROLES				
TITLE	NAME, POSITION, ORGANISATION			
PROJECT MANAGER	Vivien Cinque, Manager of the Stakeholder Engaged Scholarship Unit (SESU), ACU	Oversee and buo Provide		
PARTNER LEAD CONTACT	Robina Bradley, CEO, St Mary's House of Welcome	Work w program stakeho activitie		
ACADEMIC STAFF MEMBER	Sara Bayes, School of Nursing, Midwifery and Paramedicine (SoNMP), ACU	Design findings		
ACADEMIC STAFF MEMBER	Ben Coyte, SoNMP, ACU	Design findings		
SESU ADMINISTRATOR	Jillian Cox, SESU Administration and Research Officer, ACU	Provide Provide		

	METHOD
S	A systematic review of literature was completed Individual interviews were conducted with 11 participant- consultants and with one SMHOW staff member; one focus group was conducted with five SMHOW staff members, and one member of staff participated in an individual interview
n	Variation was pursued within the participant-consultant sample to include these cohorts
rs S	These were distinguished in the analysis of 'barrier' interview and focus group data
	A Participatory Action approach was employed in which service staff members discussed and approved this framework
	A Participatory Action approach was employed in which service staff members discussed and approved this framework
n	Specific questions relevant to this objective were asked of individual participant–consultants in their interviews and these data were analysed explicitly to achieve this objective
•	A Participatory Action approach was employed in which service staff members discussed and approved the framework and evaluation strategy developed in objectives 4 and 5

#### ROLE

ee signing of Partnership Project Agreement, track project schedule idget

le administrative and research support to academic/s and partner/s

with academic/s on Project Plan design, facilitate access to existing um/client data, introduce project team to other relevant partners/ olders, facilitate access to clients, participate in data collection ies, communicate updates that may impact on project progress

n Project Plan with partner/s, collect data, analyse data, write up gs, produce output, conduct and report project evaluation

n Project Plan with partner/s, collect data, analyse data, write up gs, produce output, conduct and report project evaluation

le support to project manager

le administrative and research support to academic/s and partner/s

#### TABLE 3.3

ANTICIPATED AND ACTUAL PROJECT MILESTONES				
MILESTONE	DUE DATE (ORIGINAL)	COMPLETION DATE (ACTUAL)	RESPONSIBILITY	
PROJECT PLANNING				
ACADEMIC WORKLOAD ALLOCATIONS APPROVED	End March 2021	End March 2021	ACU Executive Dean/s & SESU Advisory Group	
BUDGET APPROVED	End April 2021	End April 2021	PVC Engagement ACU	
PROJECT PLAN APPROVED BY PVC ENGAGEMENT AT ACU	End April 2021	End April 2021	Project manager & PVC Engagement	
PARTNERSHIP PROJECT AGREEMENT SIGNED	End May 2021	End May 2021	Partner lead/s & project manager	
ETHICS APPROVAL RECEIVED FROM ACU RESEARCH OFFICE (IF REQUIRED)	Mid-May 2021	Mid-May 2021	Project manager, SESU administrator & academic staff member/s	
PROJECT EXECUTION				
DATA COLLECTION COMPLETE	End July 2021	End August 2022	Academic staff member/s	
DATA ANALYSIS COMPLETE	Mid- September 2021	End September 2022	Academic staff member/s	
WRITE UP OF FINDINGS COMPLETE	End October 2021	Mid-October 2022	Academic staff member/s	
PROJECT OUTPUTS COMPLETED [PROJECT REPORT]	Mid-November 2021	End October 2022	Academic staff member/s	
DISSEMINATION OF FINDINGS	End November 2021	Mid-November 2022	Academic staff member/s, SESU administrator	
PROJECT CLOSE				
CONDUCT EVALUATION TO CAPTURE FEEDBACK AND LESSONS LEARNT	Mid-December 2021	February 2023	Project manager, SESU administrator	

#### TABLE 3.4

ANTICIPATED RISKS AND RESPONSES			
ANTICIPATED RISK	ANTICIPATED IMPACT	PLANNED MITIGATION RESPONSE	
VULNERABLE POPULATION, WITH HIGH RATES OF TRAUMA	Triggering or exacerbating	Trauma-informed approach, with individual interviews	
POWER DIFFERENTIAL	Ethical risk	Develop a Participatory Action approach	
ENGAGEMENT AND SAMPLING	Sampling bias to omit those experiencing barriers to engagement in the program	Explore options for varied recruitment and ensure variation within service user sample to include cohorts experiencing marginalisation	

#### TABLE 3.5

PROJECT CHALLENGE SUMMARY				
CHALLENGE ENCOUNTERED	IMPACT	PLANNED MITIGATION RESPONSE		
COVID 19-RELATED LOCKDOWNS NECESSITATING CLOSURE OF SMHOW TO SERVICE USERS AND STAFF	Unable to access participant-consultant or staff participants to collect data	Deferral of data collection and consequential deferral of remaining subsequent project steps		

#### TABLE 3.6

STAKEHOLDER MANAGEMENT AND ENGAGEMENT				
STAKEHOLDER GROUP	PURPOSE OF ENGAGEMENT	PRIMARY CHANNELS OF ENGAGEMENT		
PROJECT TEAM (PROJECT MANAGER, PARTNER LEAD/S, ACADEMIC STAFF MEMBER/S, SESU ADMINISTRATOR)	Managed Partnership Project Agreement, Project Plan and budget sign-off, supported data collection, coordinated project progress updates, coordinated post-project evaluation to capture feedback	Meetings, email and phone		
SMHOW	Advised of impacts to service during the project period Provided updates and outcomes pertaining to their involvement on project	Email and phone		
SESU ADVISORY GROUP	Announced project completion and project outcomes	Meetings and email		
INTERNAL ACU STAFF AND EXTERNAL MEDIA	Announced key project updates and project completion and outcomes	Meetings and email		





To understand what was already known about the phenomenon of interest prior to collection of data from SMHOW participant-consultants and staff members, a systematic scoping review of literature concerned with NDIS access for adults with psychosocial disabilities was completed by ACU project team members Benjamin Coyte and Sara Bayes. The review abstract is provided in Abstract 4.1, and the full report is included as Appendix 1.

The results of the project are presented against project objectives 1, 2, 3 and 6 in Table 4.1, and against project objectives 4, 5 and 7 in Table 4.2. Achievement of objectives 4, 5 and 7 occurred through a process of consultancy with members of staff from the executive team, the support coordinator group, support workers, and the SMHOW Homelessness Team Leader. Seven staff members in total were present for this session, which was held on 2 December 2022 at the St Mary's House of Welcome site.

Lastly, a three-step framework was proposed that includes continued consultation with key stakeholders – specifically, service users and staff members. This framework is designed to optimise engagement for those adults affected by a psychosocial disability with the SMHOW NDIS program. Essentially, we suggest that the leadership group considers all the learning points that emerged from this project (see Appendix 2), and then work with service users and staff members to take forward those that are actionable. The framework is presented in Figure 4.1.

#### 4.1. What barriers and drivers exist to engaging with the SMHOW NDIS psychosocial program among adults aged 19-70 with a psychosocial disability according to SMHOW participant-consultants?

Eleven users of the SMHOW service were consulted about what encourages engagement with the SMHOW NDIS psychosocial program, and what hinders it. These participantconsultants shared their views and experiences of barriers and drivers at both the personal and organisational levels. Data were also collected about the impact on participation that the COVID19 lockdowns conferred; however these are not detailed below as that particular disruption has now passed and its effects were not modifiable.

Where direct quotes have been used to illustrate the narrative summary, the participant has been identified using a number as their pseudonym.

The data for this section has been divided into three subsections: personal barriers, service-level barriers, engagement drivers.

#### **Personal barriers**

Seven different sorts of participant-driven barriers were identified by our participant-consultants.

#### I DON'T ALWAYS FEEL UP FOR IT

A number of respondents put forward that they were not naturally inclined to participating in the program's activities, and this was for various reasons. For #12, it was that they are "... a loner. I like to be by myself", and #20 had "knocked it (back) a few times, [because I didn't feel up for it] ... I was going through a lot of mental stages. I lost my Dad last year". Others, like #17, couldn't pinpoint why they didn't feel inclined to join in, it was just a case of how they felt on any given day: sometimes, she said, she just doesn't feel like it, and at other times she just "felt tired or slept in".

#### I'VE GOT A LOT GOING ON

Some participant-consultants shared that they were too busy dealing with other competing priorities to find time for the program, for example #20, who said he had had "a lot of stuff [going on], and a lot of homelessness, and then I was moving places ...", and that all made it "really hard" to get to activities sometimes. Another gave the example of how time consuming it was trying to reassimilate into society after a period in prison:

"[I'm] getting back out into the life at the moment, because I've been in jail. I haven't been out that long. I've only been out for about a week, so I'm trying to get used to it again." (22)

#### **APPOINTMENTS CLASH**

Two participant-consultants highlighted that living with a psychosocial and other disability, being homeless, seeking work, managing being a benefits claimant and/or having a criminal conviction can mean a lot of appointments, and that sometimes these are scheduled for the same time as (and take precedence over) NDIS psychosocial program activities. Participant-consultant #21 said "... you make one too many appointments and you're too injured and sick to go", #24 gave the following example: "If it sometimes clashed with a doctor's appointment, sometimes I couldn't go", and #10 disclosed that "sometimes with my corrections appointments or something like that, they could clash."

#### DRUGS/DRINK MADE ME NOT WANT TO DO IT

Substance use was what stopped one participant-consultant from engaging with the activities. He said:

"I will admit once upon a time I was smoking marijuana and yeah, I just didn't wanna do anything of course. Because when you stoned you just sit there. Yeah. So I went for a little phase of that for about a year." (11)



Conversely, one informant who had ceased using alcohol found it difficult to be at SMHOW because they associated it with that former habit:

"[I] used to go down [to SMHoW] and meet down there for drinking. And now I've gotten away from it... Now I'm not drinking."(12)

#### I'VE GOT A BAD MEMORY

Some participant-consultants struggled to engage with the program because they had difficulty remembering what they had committed to, as highlighted by the following informant:

"Yeah, and just like remembering. I've got a bad memory of remembering times..." (19)

#### IT FEELS DEGRADING

One participant-consultant provided clear insight into the fact that some people find the idea of accessing a service like SMHOW humiliating, and felt as if they would be seen by others as lazy by doing so:

"... sometimes I don't like coming here, a lot of those street bum... Well, we'll call them people without a job, or whatever, never wanted to work... I'm reluctant to come here, I just feel like I'm degrading myself." (21)

#### YOU CAN'T TRUST PEOPLE

Finally, wariness of being around other people when that had not always gone so well in the past was one reason put forward by participant-consultants for not readily engaging with the psychosocial program. Informant #12, for example, disclosed that he has "got to the state that I can't trust people", and described one of a number of ways that affected his ability to join in social activities: "If I get on a tram, I've got to have my back to the wall. I won't stand in the middle there."

#### **Service level barriers**

In addition to the seven personal barriers to program engagement discussed above, participant-consultants also identified five at the organisational level.

#### I'M NOT SURE WHAT'S AVAILABLE

One participant-consultant shared that she didn't think she had been made aware of all of the activities available, which she saw as a barrier to her engagement in them. Although this is only one contributor's perception, it is included as it may signal that others may also perceive this to be the case.

### THE ACTIVITIES ON OFFER AREN'T FOR ME OR THERE'S NOT ENOUGH PLACES

Several participant-consultants discussed the nature or the scheduling of activities as off-putting. For #17, for example, activities were largely timetabled when it was inconvenient for her to attend and she felt there was no flexibility in

the program, and for #12, the only activity he was drawn to – fishing – had been discontinued and that led him to conclude that that "really there's not much point going [now]." Participant-consultant #10 said he enjoyed art activities but felt that "Art's more for mental health patients", which he didn't identify as, and similarly, #19, a young person, couldn't enjoy art activities because "mainly the elderly ones want to do… You know, like, colouring and drawings and all of that. And I'm not into like colouring and drawing."

### STAFF CHANGES ARE DISRUPTIVE AND HARD TO COPE WITH

Several informants spoke about the impact of staff turnover on their engagement with the program. For one, it was simply that when staff left, sometimes activities stopped:

"it's just going to start back up again because the other two workers left. So it's starting it all again after time away." (22)

For another, it was about having to make a new relationship every time it happened:

"[Changing workers has] been a lot [to cope with]" (20)

And for #19, communication difficulties played a part:

"getting new workers like... The last worker they tried to give me didn't speak very good English, so..." (19)

### YOU'RE DEPENDENT ON THERE BEING ENOUGH WORKERS

Even when staffing was stable, some participant-consultants felt there weren't enough workers to effectively support the amount of people wanting to participate in the program:

"...there's so many people wanting one-on-one support, so there's a waiting list." (10)

"with [one of the workers] I used to have, I think, two hours, and ... he'd walk into the footy oval, and then he'd leave. So, I got a bit upset with that because he promised to stay around with me, and chill with until I started training, then leave. And, nah, he'd always just take me and drop me off and leave."(20)

#### IT DOESN'T FEEL SAFE OR SECURE

A key factor in several participant-consultants' hesitation in engaging with the program, or indeed their decision not to, was their perception that doing so would not be safe for them. For one informant (#17), the anxiety she felt at the thought of bumping into a former partner who also attended SMHOW led to her staying away, and others had different reasons: "You say something to someone [at SMHoW] and the next day the whole world knows. It's best to stay out of there. I'd do the [cooking] course... [at SMHoW] but ... there's trouble down there and I don't want to be involved in it. I just don't want to go near it." (12)

"the only problem we have here at one stage we ended up getting a security guard because there was a lot of people coming in intoxicated and fights starting outside. And when I seen the security guard, I thought, yeah, it's getting pretty full on." (11)

"when I was going down [to SMHoW], this bloke, he threatened a couple of us. That was enough... didn't want any more of that." (12)

"I quit hydra-pool, but I shouldn't have. That's over a man flicking me with water... Well, this old man. I felt embarrassed. He used to pick on me. And I didn't really need that." (21)

"I had a drunk attack me here one day. And I responded back self-defence and I got [sent] down for affray." (11)

#### **Engagement drivers**

#### **CURRENT FACILITATORS OF ENGAGEMENT**

A range of the current characteristics of SMHOW's psychosocial program were identified by participantconsultants as factors that supported their engagement with the program. Some participants were encouraged to engage with the program because the types of activities offered resonated with them. "The fishing trips, outing trips, and I love camping and just bush walking even... Just to get us out of the [neighbourhood]" (11). Several participant-consultants also reported that the existing timing of the available activities and ease of access to transport or activity locations suited their needs. The clarity of communication was also cited as a facilitator of engagement with the program, both at the planning stage, "they helped me as much as they can and if they can't [it's] fully explained so I understand why" (11), to the announcement of scheduled activities.

"they've got it written up on the window. They use a whiteboard marker on a window and it's got from Monday to Friday and then all what they've got running throughout the window... and everyone knows... so it's very good."(11)

Understandably, the in-house activity schedule may be less accessible for participants who less frequently attend SMHOW.

"Although changing a Support Worker was identified as a challenge for participants, characteristics of the Support Workers themselves were commonly identified



as facilitating engagement with the program. The valued support extended from planning stages, "she was wonderful... if you didn't understand what she was saying, she'd go over it with me", (12) to maintaining engagement, "Support workers ... help me keep motivated and keep focused on what my goals are" (15), to affecting participants' general perception of the program. "I've had [NDIS support worker] and they stuck by me. They're good. Yeah, they're really good." (11)

#### **INCLUSIVITY OF SMHOW AND THE NDIS PSYCHOSOCIAL PROGRAM ACTIVITIES**

The participant-consultants reported that there were some activities where they could potentially feel more included, due to the perceived limited diversity of the other participants, in respect to culture, gender or age. "In the art group, I'm the only bloke at the moment, so I feel a bit left out" (24). However, largely the participant-consultants reported that SMHOW and the NDIS psychosocial program provided an inclusive environment, with respect to sexuality, "I'm glad that St Mary's House of Welcome support the gay and lesbian community" (24), or disability.

"That's where St. Mary's have been really good 'cause I got an ABI [Acquired Brain Injury]... if I'm lost, rather than me [using] Google, I'll come over here and speak to [SMHOW staff], of any problem... and most of the time I don't walk off disappointed."(11)

#### SUGGESTIONS FOR ENHANCING ENGAGEMENT

Participant-consultants drew on their expertise of participating in the NDIS psychosocial program to make recommendations for enabling further engagement. A number of activities were suggested, including those which were interrupted by COVID-19 lockdowns. Recommendations included more "outdoor activities, like not just in this [SMHOW] building, going to other places... to the botanical park, or stuff like that" (19). Bushwalking, picnics, going out for coffee or fishing were other proposed group outings. There were a number of SMHOW-based activities put forward as well, such as movie-screenings, music-related activities or a men's group, and active options were suggested also, such as basketball, football, cricket, going for a run or a gym session. It was suggested that some of the more energetic activities could be tailored for an older or younger age bracket, so a particular scheduled activity could better appeal to either older or younger participants. In deciding between the many possible options, a collaborative approach to activity planning was supported by one participant-consultant, who recommended:

"I would... have a meeting with everyone, saying, 'What would youse [sic] like to do?'... so it gives them [participants] a sure purpose. I think that might be good for us. Or they [participants] might not like something, so [it would] give them the chance to have a say."(10)

Some participant-consultants recommended broadening the timing or location of activities to enhance accessibility. A preference was expressed for the provision of later, afterhours activities in the afternoon or evening, "yeah, like, just to wind down... but it's always closed [after work]" (19). Varying activity location was proposed as a way to engage those who feel apprehensive about attending the SMHOW building or are challenged by the required transit.

The provision of more frequent and flexible support from support workers was suggested as a means to enhance engagement and address individual challenges with socialisation. The capacity to accommodate drop-ins was considered desirable, "one day you might wanna [sic] come in and have a five-minute chat with someone and then leave" (19). However, participant-consultants also indicated that they would value the opportunity to provide support to others and actively contribute through SMHOW.

"[I would like to] give back to the community... Just because [participants are] impaired or they're disabled or something like that, there's always ways... they can be employed and it makes them feel good because they've given that opportunity to give back to the community ... what they've been offered. So that's what I'd like to see" (15).

Finally, given that (as noted earlier) some service users have memory problems, one participant-consultant suggested that ... "if you put your name down they should either give you a text or send you an email. Just so you remember, say like the day before" (19).

## 4.2. What barriers and drivers exist to engaging with the SMHOW NDIS psychosocial program among adults aged 19-70 with a psychosocial disability according to SMHOW staff members?

As well as asking service users about what stops or encourages NDIS psychosocial program engagement, we also invited four SMHOW staff members who work with those who attend the facility to share their own experiences and views on the topic. All of the data collected from these contributors endorsed, gave further context to, and included remedial suggestions about the program participation challenges put forward by the participant-consultants.

The staff gave clear confirmation that they all believe in the immeasurable value of the program and provided many examples of SMHOW service users whose lives had been improved significantly as a result of having individualised worker support to engage in the NDIS psychosocial program. For instance, an older Vietnamese woman began attending the service following a hospital admission during which she was assisted to apply for NDIS funding. After only four months of working with an SMHOW Culturally and Linguistically Diverse (CALD) support worker and participating in activities the woman, who was living with trauma, PTSD, depression and Parkinson's Disease, had:



"become much better now... she got clear of deadlock inside herself... She [is] really, really happy now. She said ... "I feel that my life is so easy now with all the help of NDIS."

Among the many other examples were those of two previously malnourished and isolated men whose first language is not English; both were also provided with guidance from a CALD support worker and were consequently socialising, eating well and were a healthy weight as a result of receiving NDISfunded help at home with cooking. Perhaps the most starkly compelling story of the impact the program has had is that hospitalisations were reduced and "[the] suicide rate would be definitely down", which the group squarely attributed to the ongoing connection those vulnerable to it now have with SMHOW and its workers who "check in with them every week" as a result of having NDIS funding.

Conversely, it was evident in the data from staff that when SMHOW attendees whose first language is not English met with an NDIS planner who was not bilingual, there was the potential for them to "just say yes, without really understanding the implications behind each of the funding options", and this was also highlighted as an issue for people with a mental health condition: "People with mental health problems, they don't say anything [in planning meetings]". There was also consensus among this group that just the concept of what the NDIS is was a barrier in itself for some people, and that it often came to light when service users didn't turn up for activities: "We'll contact them [and] it's like, "what is this?" So, "where are you? You're on the NDIS now". And they go, "Oh great. I don't know what that is."

This, the staff said, is an issue because if allocated funding isn't used, less is given next time:

"you get to planning time and it's like, well, why hasn't this participant used their funding? And then they threaten to take it off."

In relation to the planning meetings themselves, staff identified that the reason these are so succinct and why extensive discussion about the proposed plan with the service user is not facilitated in them is that they are not funded, and that this is a problem because, as previously identified, this can lead to people being on plans that they don't really understand or know how to implement, and that can include activities or items they are not invested in:

"[it's] basically, "Okay, we'll see you for an hour. We'll see you at the planning meeting. We'll come up with some ideas for you. What do you think of those?" "Yeah. They're great." Because if they've been in a compliant world for so long, it's part of that institutionalised process, isn't it [to just say Yes]?" Two potential remediation approaches to this issue were put forward; the first was that "we need pre-funding [to orientate people to the Scheme] before they get their funding", and the second, perhaps more practical suggestion, was to convene peer support groups to help people transition from not being an NDIS participant to being one. In order to try and provide individualised support as far as possible, the staff respondents shared that they are,

"constantly doing kind of quick surveys with the clients, always seek to understand their support needs, and try all different models, so that we can provide the best group activities for them."

but also recognised very clearly that there are limits to what is possible because of the funding model. For instance, one staff member would have liked to give people the opportunity to try an activity before the service implemented it, or before a client committed to adding it to their plan, but noted that there is no financial capacity for that. Overall though, the value of the program was perceived by the staff to be that instead of always responding to crisis, it enabled support workers to help people proactively minimise the risk of crises occurring:

"Someone asked me the other day, because I've been here 10 years.... something that's happened here that I've thought that was worthwhile for St. Mary's. And I said, NDIS. It's like the best thing really..."

#### STAFF IDENTIFIED BARRIERS TO ENGAGEMENT

Like the participant-consultants, staff recognised that some service users have memory difficulties and did, where they could, try and help with that. As one staff member said, "... you can call them if they struggle sometimes or a phone call just to remind them to come in." They also acknowledged that often service users had other priorities than joining in program activities ("people have a lot going on behind the scenes"), and what some service users said about there not being activities that resonated with them and that some of this was due to the SMHOW service, like many others, not being open 24/7:

"one of the restraints of working within this particular service is that we open 8:30 to 4:30 Monday to Friday, [so] as long as those goals fit in those business [hours], they're much more attainable and we've been able to achieve that, which is great. But [not] when those goals kind of fall outside of that, often of that social kind of nightlife kind of goals that people have..."

The other consideration that impacts service user engagement with the program that the staff agreed with service users on was the potential for and impact of workers changing as staff left and others started:

"Change is hard for a lot of clients; we're really aware of it".

The group offered insight into what underpins staff attrition in this workspace and attributed it largely to the "need to be billing for six hours a day" in a context where there is a lot of hidden work that cannot be billed for and no time within that to give and receive support between themselves:

"There's a lot of in between. Dealing with a traumatic call and then switching from [that to...], it's... I look at my day, like it's flat out, how I've been going nonstop and then I'll look at it. And it's actually only billable for two and a half hours, but I hadn't stopped. Or three hours or something. But I would've been at hospital [with someone], I would've been dealing with distressing calls..."

"We just started doing a [peer support] catch up once a week, just support coordinators and our manager... but that's even a pressure just doing that. We're counting the dollars."

Related to this, two other factors outlined by the staff that contribute to people leaving this work are 1. being asked to help others understand why they had spent time doing something unbillable, and 2. not having a clear understanding of what their role is. The following quote relates to the first of these:

"... exhaustion from constantly self-advocating. Having to constantly justify and explain ... what a crisis situation looks like... And it's really draining because it's almost retraumatising ... because you've got vicarious trauma of dealing with that situation, then you have to go through it again, to justify why ... you were needed..."

and the quote below, from a fairly new team member, relates to the second:

"What is support coordination? What does it look like? Because there doesn't seem to be a real uniform standard of it. Do you know what I mean? I don't know ... it seems like it's a case manage sort of thing?"

In summary, the staff group all agreed with their colleagues who said, "we all support each other", "[but] you can see why there would be such high burnout."

One issue this group identified that the participantconsultants didn't was that many of their service users' NDIS plan items reflect fundamental human rights but are framed as 'goals' for them, and this felt unjust and to some degree, futile, because not having these things in place already was not their fault. In relation to this, one staff respondent said,

"some people have told me, I guess they've been feeling they'd kind of feeling frustrated because some of the goals are like just basic needs... it wouldn't be considered a goal to anyone living without a disability, like to have stable, secure employment, to have housing and regular community



access, mental health service... so why is it kind of built in... that an individual should be striving to address barriers that have been placed against them because of their disability."

Another went on to explain further:

"the housing one really is striking because that just seems like a moot point. Redundant effectively, given housing shortages. They're never really going to be able to achieve that [by themselves]"

And another put forward that the SMHOW clients' plans tend to include "the basics" but they wondered whether they could also include quality of life activities as well:

"... should we be looking at more sort of, not things are out, out of reach ...but more sort of fun? Because so many of the clients are focused on, all their funding's used on going to medical appointments, getting shopping, [and] I often say to clients, like you can have a support worker to go and do something fun."

This contributor's colleagues reflected on this however, and suggested that this state of affairs may be because most clients are just "focused on survival so that's what we focus on as well"; they also said that while they agreed with providing non-essential support, they could also see how negatively that approach might be perceived by wider society, and put that forward as another barrier:

"Can you imagine how the general public would respond to that though? People in the NDIS are going to these activities and this is how NDIS funding is being used. ... I totally agree with the same thing [but] I'm just also thinking about Murdoch headlines."

Another challenge to participation that staff identified additional to those put forward by the participant-consultants was that there was still sometimes a monetary cost to the NDIS recipient to participate in some activities (i.e., having a support person to help a person get to and/or participate in an activity would be funded, but the cost of the activity itself was not), so that is a direct barrier to those on a tight budget. This is compounded by the time restrictions around how long a worker can spend with a client on an activity:

"[they might want to do] an activity that's six or eight hours. So for one that's really limiting because we only work 7.6 [hours], and you need a lunch break ... probably two hours is ... the most we can do."

As well, a longer serving staff member described how difficult it had been for some longer term service users to get used to things being different before and after the introduction of the NDIS: "having so much structure [has challenged some people]. I guess pre-NDIS St. Mary's was just like, walk in, grab a worker, have morning tea, lunch, whatever. And [now we've changed] that to, "All right, we'll see you at 10 o'clock on next Tuesday."

A similarly long-serving colleague added,

"Yes, and for some clients, it still doesn't work. I can speak to a client once a week, but it's ... about crisis stuff every week again. So you're not actually ever feeling like you're doing anything other than just managing crises. And they'll just pop in and try and grab you... [they want] that flexibility of when they need it, they want it now, not in a week's time."

Further, inherent inadequacy within NDIS provision for people living with psychosocial disability was identified by the staff group as a barrier to participation. The example was given that people who find it difficult to engage in society more generally need additional funding for support to cope with the stress, anxiety and confusion engendered by engaging in NDIS-funded activities as well as life events (like meeting with health care or housing professionals):

"it would be lovely if they said, "Look, this person obviously is going to use more of their funding because of this situation. Here's a top up." "it's no really reflective of the communities that they're seeking to advocate for or with effectively."

Other barriers identified by the staff group to service users' engagement with the NDIS psychosocial program at SMHOW included earlier negative encounters with other services ("One of my clients, he has got unpleasant experience with the previous providers. I think that's the reason why he is not very engaging"), "group dynamics" (by which it was meant that issues on the streets being brought into group activities was problematic), personality clashes between workers and service users ("there are some clients that just don't particularly like us"), and substance misuse that makes service users unpredictable ("[it] does really restrict the amount of support that we can provide them with").

Lastly, the fact that there are still some service providers that provide psychosocial programs that do not require participants to be NDIS-funded means there are alternative options for those who do not wish to apply for the Scheme (because, for example, the Functional Impact statement required as part of the application process is very difficult to obtain for people with a psychosocial disability or they don't have an identification evidence), or they are ineligible for NDIS funding, like those who are over 65 years old:

"[For instance] (another provider)... we've got all our guys that couldn't get on NDIS, but loved all the programs, over there." "... the NDIS has currently brought in a hundred points of ID in terms of getting plans up and running. Most of our clients with psychosocial disability don't have photo ID, don't have birth certificates."

"If you're over 65, you're not eligible... There's a service up the road for over 65s."

#### 4.3. What impact does engaging with the SMHOW NDIS psychosocial program have on adults aged 19-70 with a psychosocial disability?

Lastly for this data set, we sought to understand how exposure to and participation in the SMHOW NDIS psychosocial program impacted SMHOW participant-consultants' lives.

The reported impact of St Mary's House of Welcome and the NDIS psychosocial program on the participant-consultants' lives was multifaceted, but the expressed experiences were commonly positive. These reported outcomes included reliably meeting participants' essential daily needs, but also empowering them to manage adversity and their physical and psychological health, to gain life skills and employment, and provide a dependable platform where they can receive social support and gain confidence engaging with others through positive social interactions.

Meeting various essential daily needs was frequently cited by the participant-consultants as a key impact upon their life. Often this was providing access to immediate necessities that many in Australia are able to take for granted. But beyond the physiological need, this also alleviated stress and supported personal dignity.

"You get a meal, you get a shower, you can get cream treatment, a towel... Which is great, because walking around the city, I've been homeless... [with] no shower. It really is a good place to come to and I really love it. They gave me my own shower [and] when I have a shower here, the whole world and pressure's off me, and I'm free... when you have your own shower, it's different." (21)

Additionally, the NDIS psychosocial program helped participants to establish a stable foundation of their own, with housing, furniture and ongoing support from a cleaner. Again, this had reported benefits beyond the immediate, with one participant-consultant reflecting that having regular support from cleaners "made me more domesticated too" (15).

The program has also reportedly assisted participantconsultants to manage adverse life circumstances and empower them to address their physical and psychological health. Commonly this involved assistance with arranging and maintaining appointments with doctors, specialists, psychologists and dentists to meet needs of varying complexity. One participant-consultant reported: "I lost my dentures when I was last in hospital, so, yeah, I've got no teeth, so, I'm working on them, yeah, getting that fixed... they've been helping me with that" (11). Additional capacity building had been achieved by participants, through support for them to gain employment and attain practical skills. "It's helped me get a computer course and all that sort of stuff, and work out how to work the phone properly and all that sort of thing" (22). In addition to new practical skills, the psychosocial program has also helped participants to develop psychological skills that support self-esteem and goal attainment, such as by recognising their own achievements and successes when they occur.

"I set my... goals very high and I need the right people around me just to... look at it from a different way, like, 'Hey, you've achieved something. You have taken that one step'... [so] I can look at it and say, 'Yeah, okay. I guess I can look at it this way. I have achieved that." (15)

The interactions with NDIS workers were perceived as invaluable to participant-consultants who experienced a range of challenges socialising. Some participants reported having very limited avenues for social interaction in their life:

"I go out once a week with [NDIS worker] and now I've just started going out with another worker down there... I'm a loner, I like to be by myself. This is when I come out, that's the interaction I have." (12)

In addition to the direct provision of social support by NDIS workers, the interactions facilitated between participants was also seen to be important. "It's a good place to hang out and see my friends, and that, and do some courses and different things here. Yeah... [it} helps out a lot" (22). Through engagement with the psychosocial program, there was also evidence of perceived improvement and capacity building in participants' social skills.

"I didn't have the confidence to get around a lot of people, now I do. I go down there every day, I go socialise, I go do stuff. I'm getting myself out more, going to get help, going to see workers, going to see doctors." (20)



#### TABLE 4.1

OB	OBJECTIVES AND OUTCOMES 1, 2, 3 AND 6			
	OBJECTIVE	OUTCOME		
1	To identify the drivers of, barriers to, and value of, engaging with the SMHOW NDIS psychosocial program among adults aged 19–70 with a psychosocial disability	Achieved		
2	To explore the drivers of, barriers to, and value of, engaging with the SMHOW NDIS psychosocial program among adults with CALD and LGBTQI+ identities who are living with a psychosocial disability, and those who have an acquired brain injury, to ascertain whether there are any that are specific to these populations	Achieved to some extent <sup>1</sup>		
3	To distinguish between service and participant driven barriers to engagement by adults aged 19-70 with the SMHOW NDIS psychosocial program	Achieved		
6	To provide an evidence base of the impact the program has in client's lives	Achieved		

1. Only one participant-consultant declared themselves to have an intersectional identity additional to those of being a person living with homelessness and a person with a psychosocial disability - that of being a person with an acquired brain injury; none of the participant-consultants identified themselves as a member of any of the LGBTQI+ populations, or as a CALD community member

#### **TABLE 4.2**

OBJECTIVES AND OUTCOMES 4, 5 AND 7				
	OBJECTIVE	OUTCOME		
4	To construct a framework to optimise engagement by adults with a psychosocial disability aged 19–70 with the SMHOW NDIS psychosocial program	Achieved		
5	To develop a process by which to evaluate the success of the framework developed for objective 4	Achieved		
7	To explain the framework developed for objective 4 to SMHOW stakeholders to support future investment into the program	Achieved		

#### **FIGURE 4.1**

PROPOSED FRAMEWORK FOR OPTIMISING SMHOW-PR		
WHO?	WHO WILL DO WHA	T, AND HOW?
LEADERSHIP GROUP	1. Consider key learning points	1a. 'Town Ha Meetings' wi staff and ser- users to deci which Learn Points can become Actions
LEADERSHIP GROUP AND STAFF AND SERVICE USERS REPS	2. Design > Plan > Do > Study > Act (PDSA) strategy for each action	2a. Develop PDSA strategimplementat protocol (wh will do what, when?)

#### **ABSTRACT 4.1**

#### ABSTRACT: 'WHAT IS KNOWN ABOUT NDIS ACCESS FOR ADULTS WITH PSYCHOSOCIAL DISABILITY? A **SCOPING REVIEW**.'

Background: The National Disability Insurance Scheme (NDIS) is an opportunity to provide essential support for people with psychosocial disability, but it is crucial to understand and address the complex hurdles to engagement that this population may face in accessing NDIS funding and programs that may be helpful to them.

Objective: The objective of this review was to learn what is known about what hinders and what might help adults (people aged 18+ years) with psychosocial disability to engage with NDIS funding and psychosocial programs.

Eligibility criteria: The criteria for what sources of information should be included in the review were based on the population and concept of interest: 'adults with psychosocial disability' and 'NDIS access'. We chose to include both white and grey literature.

Sources of evidence: Six sources of evidence, three white and three grey, emerged from the search and appraisal process as suitable for inclusion in this review.

Charting methods: A six-item charting process was used to capture pertinent information about each evidence source. Data extracted from each source were allocated to either an 'engagement barriers' or an 'engagement helpers' grouping.

Data Analysis and Results: Data related to the NDIS access barriers faced by adults with psychosocial disability were found to fall into seven themes, and six themes were derived from the data about potentially helpful interventions to engagement. Almost all of the information available at the time of writing about access to and uptake of the NDIS among adults with psychosocial disability has been gathered from people working with the population of concern and very little has been gathered from the population itself.

Conclusions: Some information has been gathered from the population of interest about the barriers to adults with psychosocial disability accessing NDIS funding and about proposed solutions to those barriers. Further research is warranted wherein these key stakeholders' views and opinions are captured and their involvement in co-design of interventions to improve NDIS access and uptake is facilitated.

#### OVIDED NDIS ACTIVITY MANAGEMENT

[all vith rvice ide ning

gy tion

3. Implement each PDSA activity

3a. Evaluate (Study) effectiveness and quantitative and qualitative data



The findings of the project were presented by Professor Sara Bayes in summary form to seven members of the SMHOW staff group on 2 December 2022, and their comments and reflections were invited as follows.

#### Staff reflections on the findings

### PARTICIPANT-CONSULTANT DATA: BARRIERS TO ENGAGEMENT

Regarding the client comment that joining the program 'feels degrading': staff thought this was a very interesting finding, and it led to discussion of the stigma attached to identification as someone with a psycho-social disability or other 'problem' (e.g., drug and alcohol user) and how there is a need to accept this (as part of a recovery model) in order to receive the help from the programs they run.

#### PARTICIPANT-CONSULTANT DATA: FACILITATORS OF ENGAGEMENT (SUGGESTED)

Sara noted some client respondents felt they were about to 'graduate' from their current position and enter a more stable period/situation, and that some had suggested that they could contribute to SMHOW as consumer-advisers. Staff noted there could be scope for future participants to be peer workers in this respect, and Robina is interested in offering an invitation to those people to demonstrate SMHOW would value their input (we noted we'll follow this up and check if they're happy to be identified).

### STAFF PARTICIPANT DATA: STAFF ROLES AND EXPECTATIONS

Robina noted they need to do some work to revisit staff roles and expectations, though there has already been some movement with regards to this since data collection with staff took place. Their team have changed, with several staff leaving and being replaced with new staff.

### STAFF PARTICIPANT DATA BARRIERS TO ENGAGEMENT

In terms of the finding relating to a lack of established role description, Sara noted one staff member's point that they'd like to connect with a community of practice made up of other support coordinators to learn what others in the sector are doing, and whether they are doing the right thing or could be doing things better. Robina suggested she'd be supportive of staff potentially utilising their PD in this way. A staff member noted that the AOD sector works together a lot even though comprised of many different organisations, so there is scope for building on or joining in with existing collaboration in that space too. Another staff member suggested that quality control over staffing in the sector is loose, that one doesn't need qualifications and that anyone can be an NDIS support worker, which is problematic as it leads to a lack of quality.

### RELEVANCE OF FINDINGS ACROSS A RANGE OF SMHOW PROGRAMS

Staff commented that some of these findings will be relevant to other SMHOW programs (e.g. the safety and security issue noted from the client data, which we suggested was likely related to the temporary use of a security guard during the COVID lockdowns) is relevant to their homelessness service clients. Robina noted they have a legacy with their clients they are still trying to shake off (a hangover from COVID the last few years) and a disparity in client experience that during COVID some workers would take their clients who presented for a meal out to the courtyard and share some time with them, and then other clients (of other programs) saw this and wondered why they didn't have the same opportunity to do this.

### CHALLENGE OF DETERMINING WHICH ACTIVITIES WILL BEST MEET CLIENT'S NEEDS

Staff noted that it is a real challenge to identify the activities to include in their clients' NDIS plans (which often end up being social inclusion activities), and to identify how these will meet the overall remit of their funded plan. For example, it is difficult for them to demonstrate how the identified planned activities fulfil the purpose of the program for their homelessness service clients as they're funded to provide services on site rather than on an outreach basis (and thus need to get external professionals in to host activities).

#### Evaluating the efficacy of the framework for optimising engagement by adults with a psychosocial disability aged 19–70 with the SMHOW NDIS psychosocial program

The 'Plan, Do, Study, Act' approach was proposed as the most effective way to implement, evaluate and refine the framework described above to ensure it continues to achieve what it is intended to achieve – enabling and including as many service users as possible to participate in NDIS activities at St Mary's House of Welcome.

For each Action taken forward we suggested to collect data in the 'Study' phase of the PDSA cycle about:

- 1. Its cost effectiveness
- 2. Its effect on participation
- 3. Service users' views/experiences of it (with reward given for contribution)
- 4. Staff members' views experiences of it (with time provided for contribution)

as well as quarterly + half-yearly + annual comparison data about NDIS-funded activity uptake to gauge effect of actions on broader engagement.

# Explaining the framework and evaluation strategy to SMHOW stakeholders

Staff reflections on how SMHOW could adopt the proposed participation optimisation and evaluation frameworks:

- The PDSA cycle (Plan> Do> Study> Act) was the proposed method to adopt for the participation optimisation framework. The SMHOW CEO, Ms Robina Bradley, noted that she is familiar with this approach and explained it to staff present.
- Robina noted that a 'Town Hall' approach sounded like a good fit in terms of a model for them to adopt in taking the findings to their staff and clients and determining which key learnings to adopt.
- Robina also suggested that staff could do some of this work 'on the ground' as they are working every day with their clients, but that they could also bring this back and review client feedback and learnings in a higher-level review/discussion about their programs. She noted that they generally use a co-design approach with their clients already and that she sees this as an important part of their work, to act (put into practice agreed plan) with their clients, then to check with them what is working and what isn't.
- A staff member noted an example of them listening to their clients and adjusting their program in response was when clients said they wanted a choir, and they created one and it is now their most popular program.
- In terms of evaluating the key learning points they decide to activate, a staff member noted that they hear feedback from their clients on a daily basis and would be keen to see a way of embedding some kind of system for capturing/ using this.
- Robina considered that a key issue they need to address is how they work through the subtle tension she suggests exists between NDIS and homelessness clients and programs.
- In response to the finding from the staff data (barriers to engagement) that their ability to facilitate activities (amount and duration) is limited because 'hidden' (unbillable) work takes staff away from (billable) activity work: Robina noted that while the NDIS is all based on utilisation and time/billable hours, she wants to flip this model and start with identifying from the client what works for them, then use that as the basis of their NDIS plan and thereby prove the need for their NDIS funding thus a client-centred, needs-based approach.

#### Actions arising for SMHOW

Work with staff and clients to identify what key findings they want to implement and test and which elements of the framework to action.



The project presented in this report was conducted to answer three questions, and to achieve seven aims. All questions were answered, and all aims were achieved. However the findings are limited by the fact that there was minimal representation of intersectionality apart from those having housing insecurity and mental illness in our consumer-consultant participant group. This means that our findings may not be illustrative of the experiences and opinions of the whole population that attends SMHOW.

On a positive note, 11 members of a population known to be highly inaccessible for myriad reasons (who were then additionally impacted by COVID19-related health orders, including lockdowns) agreed, at significant personal psychological risk, to share their views, insights and suggestions about NDIS activity provision and engagement at SMHOW. To our knowledge this is the first time the voices of this population have been captured in relation to this subject.

Furthermore, in the period during which this project was conducted, the SMHOW staff were dealing with trying to maintain their support and care of those who depend on them, but nonetheless six staff made time to speak with us.

We wish to extend our deep gratitude to both participant groups for their generosity and grace in contributing their knowledge and insights to this project. A total of 47 Learning Points emerged from the data collected during this project (see Appendix 2), and all have the potential to become actions. We recognise, though, that some are outside the organisation's control to address. The optimisation framework put forward enables discretion to be applied at all levels in relation to which learning points are taken forward with a view to increasing the engagement of SMHOW attendees in the SMHOW NDIS psychosocial program. The evaluation approach will enable continued quality improvement of those actions and interventions.



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### Appendix 1. Literature review

#### What is known about NDIS access for adults with psychosocial disability? A scoping review

Sara Bayes and Benjamin Coyte

#### ABSTRACT

**Background:** The National Disability Insurance Scheme (NDIS) is an opportunity to provide essential support for people with psychosocial disability, but it is crucial to understand and address the complex hurdles to engagement that this population may face in accessing NDIS funding and programs that may be helpful to them.

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#### INTRODUCTION

It is well established that people with psychosocial disability are among those that experience the most marginalisation in the Australian community and frequently have to navigate mental illness, homelessness, discrimination, physical illnesses and pronounced economic and social disadvantage (Australian Bureau of Statistics, 2020, Psychosocial disability). With complex needs and a circular relationship between these factors there are understandably considerable challenges when aiming to provide holistic care.

However, it is evident that psychosocial support is an integral piece of this puzzle as the benefits can extend beyond the ability for individuals to directly improve their physical, social and psychological health, by improving their ability to access and engage with broader support systems (Barber, 2018; Parsell, 2020).

Mental health advocates have welcomed the implementation of the National Disability Insurance Scheme (NDIS) as an opportunity to provide essential support for persons with psychosocial disability but emphasise that it is crucial to understand and address the complex hurdles to engagement that they face (Taylor, 2018), and what might help. One strategy is to take an open access walk-in approach to the provision of food, services and emergency assistance, which importantly establishes a low threshold for initial engagement with those who face the most substantial barriers to engagement and who are known to otherwise fall through the gaps in the available support services (Hancock, 2018). The objective of this review was to learn what is known about what hinders and what else might help adults (people aged 18+ years) with psychosocial disability to engage with NDIS psychosocial funding and programs.

#### **METHODS**

This scoping review was conducted in accordance with the step-wise approach detailed in the Joanna Briggs Institute's 'Manual for Evidence Synthesis' (Aromateris et al. 2020).



Development of the review title – 'What is known about NDIS access for adults with a psychosocial disability?' – was established through identification of the population of interest and the concept of interest: 'adults with a psychosocial disability' and 'NDIS access'.



The criteria for what sources of information should be included in the review were also based on the population of interest and the concept of interest: 'adults with a psychosocial disability' and 'NDIS access'. We chose to include both white literature (reports of original research, published in peer-reviewed journals), and grey literature - defined as "multiple document types produced on all levels of government, academics, business, and organization in electronic and print formats not controlled by commercial publishing i.e. where publishing is not the primary activity of the producing body" (GreyNet International, n.d., Grey Literature Network Service 2021), in our review because we identified very few primary research studies published in peer-reviewed academic journals in an initial cursory search. Finally, we limited our search period to 'since 2014' to reflect the fact that the NDIS was trialled in 2013.

The three-stage search strategy recommended by Aromateris et al. (2020) was utilised for this review. In Stage 1 an initial cursory search conducted in late March 2021 of one electronic database (Google Scholar) for evidence sources published since 2014, sorted by relevance (no citations included), using the search string 'NDIS AND access AND adults AND psychosocial disability' yielded 650 results. White and grey sources of evidence about the following were included in these results. This initial search indicated there is literature available about:

- Inability to access the NDIS + reasons
- consumer perspectives
- care provider perspectives
- · Unwillingness to access the NDIS / engage with the NDIA + reasons (e.g., barriers to choice within the NDIS)
- · Interventions to assist NDIS access

These results informed, through an analysis of the text words contained in the title and abstract or information snippet of relevant retrieved sources of information, a set of search terms (see Box 1) that were used to develop set of search strings (see Box 2).

In Stage 3, focused searches were conducted using the search strings developed in Stage 1. The searches were undertaken across all relevant databases, which for this review included PubMed, CINAHL, PsycInfo (for white literature) and Google Scholar for white literature published in journals not indexed by PubMed, CINAHL and PsycInfo, and for grey literature (as defined in Step 2 above). All sources of evidence identified as potentially relevant to the review (as per the criteria stated in Step 4 below) were either retained or rejected on the basis of article title and abstract. The reference lists of information sources retained at this stage were searched for additional sources; however none were identified.

Evidence source selection occurred at both the second and third stages of Step 3. If the title of the evidence source included 'psychosocial disability' or an alternative term (see Table 1 and 'NDIS' or 'National Disability Insurance Scheme' or 'National Disability Insurance Agency', and the abstract or information snippet (in Google Scholar) indicated information may be contained therein about barriers and facilitators to access NDIS funded support or services at Stages 2 and 3 of Step 3 above, it was retained for full text review. When full text review had occurred to determine the usefulness of the evidence source for helping address the objective of the review, it was either retained or rejected. De-duplication was then performed. The process and outcomes of evidence search and retrieval are summarised in the flow chart in Figure 1, which is based on the PRISMA flow chart published by Page et al. (Page, 2021, The PRISMA 2020 statement: an updated guideline for reporting systematic reviews), and in Table 1 (white literature published in journals indexed by PubMed, CINAHL Complete and PsycInfo)

and Table 2 (white literature published in journals not indexed by PubMed, CINAHL and PsycInfo, and grey literature).

Extraction of relevant data from the evidence sources retained for review was conducted using a data charting process. The charting table items include author(s), year of publication, origin/country of origin (where the source was published or conducted), source/s of funding, key findings that relate to the scoping review question/s (see Table 3.1 - 3.6). Consistent with the JBI approach to scoping reviews, the evidence we include in our review was not assessed in any way for quality.

To analyse the evidence we include in our review, we simply extracted the relevant data from each source and mapped them descriptively in broad themes.

#### BOX1

6

SEARCH TERMS		
POPULATION (PEOPLE WITH)	CONCEPT	
PSYCHOSOCIAL DISABILITY	NDIS access	
SEVERE PERSISTENT MENTAL ILLNESS	NDIS uptake	
MENTAL HEALTH DISABILITY	NDIA engagement	

#### BOX 2

#### SEARCH STRINGS Psychosocial disability AND NDIS access 2 Psychosocial disability AND NDIS uptake 3 Psychosocial disability AND NDI engagement 4 Severe persistent mental illness AND NDIS access 5 Severe persistent mental illness AND NDIS uptake 6 Severe persistent mental illness AND NDIA engagement 7 Mental health disability AND NDIS access 8 Mental health disability AND NDIS uptake Mental health disability AND NDIA engagement 9

#### TABLE 1

#### WHITE LITERATURE PUBLISHED IN JOURNALS INDEXED

SEARCH STRING	PUBMED	CINAHL COMPLETE	PSYCINFO
Psychosocial AND disability AND NDIS AND access	Results: n = 1	Results: n = 4	Results n = 1
Psychosocial AND disability AND NDIS AND uptake	Results: n = 0	Results: $n = 0$	Results n = 0
Psychosocial AND disability AND NDIS AND engagement	Results: n = 1	Results: n = 1	Results n = 0
Severe persistent mental illness AND NDIS AND access	Results: n = 0	Results: n = 0	Results n = 0
Severe persistent mental illness AND NDIS AND uptake	Results: n = 0	Results n = 0	Results n = 0
Severe persistent mental illness AND NDIA AND engagement	Results: n = 0	Results n = 0	Results n = 0
Mental health disability AND NDIS access	Results: n = 2	Results n = 1	Results n = 6
Mental health disability AND NDIS AND uptake	Results: n = 1	Results n = 0	Results n = 2
Mental health disability AND NDIA AND engagement	Results: n = 0	Results n = 0	Results n = 0

#### TABLE 2

LITERATURE

#### SEARCH STRING

Psychosocial disability OR Severe persistent mental illness OR Me AND NDIS OR NDIA AND engagement OR uptake OR access

BY PUBMED.	CINAHL COMP	PLETE AND PSYCINFO	

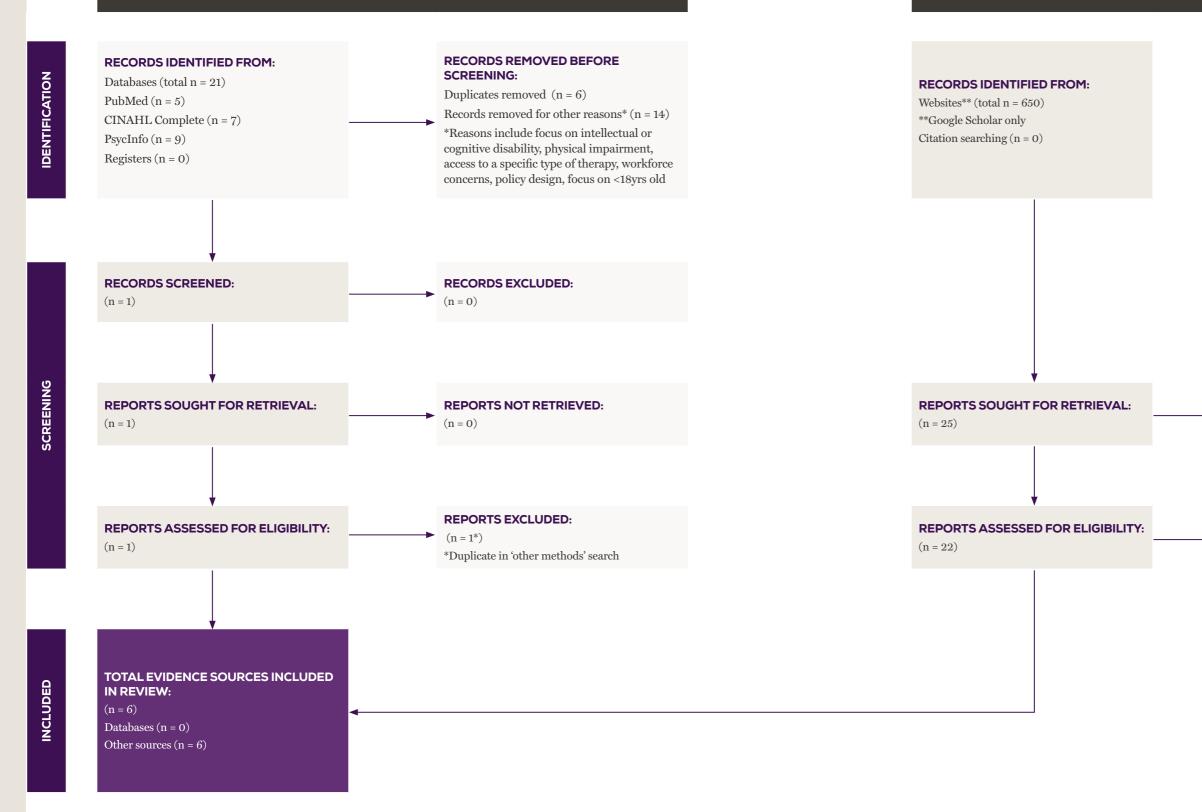
#### WHITE LITERATURE PUBLISHED IN JOURNALS NOT INDEXED BY PUBMED, CINAHL AND PSYCINFO, AND GREY

	GOOGLE SCHOLAR
ental health disability	Results n = 650

#### **FIGURE 1**

#### EVIDENCE SOURCE SEARCH AND RETRIEVAL PROCESS AND RESULTS

#### IDENTIFICATION OF STUDIES VIA DATABASES



#### IDENTIFICATION OF EVIDENCE SOURCES VIA OTHER METHODS

#### **REPORTS NOT RETRIEVED:**

(n = 3)

#### **REPORTS EXCLUDED (N = 16):**

Workforce experience focus (n = 2) NDIS design (n = 2)Interpreters' perspectives (n = 1)Policy/Strategy design suggestions (n = 2)Focus on housing (n = 1)Focus on referral patterns (n = 1)Data not specific to psychosocial disability (n=3) Policy analysis (n = 1)No information about NDIS engagement drivers/barriers (n = 1)Summary of publications (n = 1)About transitioning to NDIS (n=1)



#### FINDINGS

Presentation of the results of the review is in tabular form and a narrative summary. Six evidence sources emerged from the search and appraisal process as suitable for inclusion in this review (see Tables 3.1-3.6); three are reports of primary research published in peer-reviewed academic journals, and the remainder are grey literature items (see Table 4). Barriers to NDIS access for adults living with psychosocial disability were referred to in all six evidence sources, and access facilitation suggestions were noted in three.

Although some data about barriers were derived from adults living with psychosocial disability, most of them were not. None of the data about potential interventions to improving NDIS access and uptake in this population were drawn from its members; this is despite mention of participant-focused design and models owned by communities in two of the evidence sources.

#### TABLE 3.1

#### DATA CHARTING REPORT, EVIDENCE SOURCE 1

NDIS LAUNCH SITE

#### SOURCED FROM

Smith T. 'Further unravelling psychosocial disability: experiences from the NSW Hunter NDIS launch site'. newparadigm - The Australian Journal on Psychosocial Rehabilitation. 2014. Summer edition. Elsternwick, Victoria: Psychiatric Disability Services of Victoria (VICSERV). Pages 20-22

#### **FUNDING SOURCE**

Mental Health Commission of NSW and Mental Health Coordinating Council in NSW

#### **KEY RELEVANT FINDINGS - NDIS ACCESS BARRIERS**

Large volume of psychosocial assessment information required (1) Priority focus on acute and sub-acute mental health treatment (1) NDIA's practice to keep 'registered providers' ... at a distance, including not requesting client information from them or allowing them to participate in assessments (1)

#### **KEY RELEVANT FINDINGS - NDIS ACCESS FACILITATORS**

The project has met with consumers, carers and member agencies to better understand their experiences and needs in relation to ... the NDIS (1)

#### SMITH, 2014, FURTHER UNRAVELLING PSYCHOSOCIAL DISABILITY: EXPERIENCES FROM THE NSW HUNTER

#### **TABLE 3.2**

DATA CHARTING REPORT, EVIDENCE SOURCE 2

MASTERS, 2017, ACCESSING THE NDIS ASSISTING PEOPLE WITH PSYCHOSOCIAL DISABILITY TO ACCESS THE NDIS: A GUIDE FOR COMMONWEALTH-FUNDED COMMUNITY MENTAL HEALTH SERVICE PROVIDERS

#### SOURCED FROM

Masters SC. Shelby-James TM. 'Accessing the NDIS. Assisting people with psychosocial disability to access the NDIS: a guide for Commonwealth-funded community mental health service providers'. South Australia: Flinders University; 2017. Pages 12-17

#### **FUNDING SOURCE**

Australian Government Department of Social Services

#### **KEY RELEVANT FINDINGS - NDIS ACCESS BARRIERS**

Information collected under s55 includes the participant's contact details (2)

If the potential participant does not wish to be contacted directly, the provider should include the contact details of an alternative person(2)

People with psychosocial disability may not identify as having a disability, nor perceive that the NDIS can assist them in their recovery iournev(2)

People with psychosocial disability ... may be wary of engaging with a new system of supports which appears complex and bound by administrative rules and procedures (2)

It is very common to speak to other people who we trust and who have relevant experience or expertise, when making decisions. Social isolation can prevent people from making decisions (2)

Insecure housing, poor literacy and drug and alcohol dependence can increase the need for support, while some groups may face barriers in accessing the NDIS related to culture, language, sexual preference and gender identity (2)

#### **KEY RELEVANT FINDINGS - NDIS ACCESS FACILITATORS**

Support workers will need to consider carefully the language that they use to accurately represent the NDIS, but also to fit with a strengths-based, recovery framework (2)

Some people with psychosocial disability may ... require support with decision making regarding NDIS access, through a practice called supported decision making (2)

For people with severe and persistent mental health conditions, intensive support is a key factor in achieving access to the NDIS (2)

Skills in connecting with people 'where they are at', describing how the NDIS may assist them to achieve their personal goals, and assisting program participants to complete the access process may be critical (2)

Supported Decision Making (SDM) builds the person's expectation (and identity) to be a decision maker. Staff who are enthusiastic about the potential of the NDIS to change the relationship between program participants and providers, and who practice SDM, can make a difference (2)

Support workers with appropriate knowledge, experience, confidence and positivity, can help alleviate concerns (2)

Workforce diversity can help engage people from a range of cultural and linguistic backgrounds (2)

Peer workers can build trust and rapport through shared experience of mental health issues (2)

'Assertive outreach' strategies (are) successfully able to connect with excluded cohorts, including people experiencing homelessness and Aboriginal and Torres Strait Islander people. Assertive outreach involves devoting time and resources to actively seeking out people in the community (e.g. rough sleepers) and building trust and engagement with people prior to their entering formal service. Assertive outreach also involves having resources available for people with mental health conditions to connect with services in an unplanned way, for example through connecting to support workers via telephone, having face-to face-drop-in centres available, and after-hours supports (2)

'Respectful persistence' - how trust develops through a series of everyday interactions (2)

Cultural competency (2)

Local solutions (2)

Participant-focused design (2)

Culturally appropriate communication (2)

Collaborate with LACs and other services that host 'NDIS information sessions' and offer to translate the session (2)

#### **TABLE 3.2 CONTINUED**

#### **KEY RELEVANT FINDINGS - NDIS ACCESS FACILITATORS**

Schedule sessions for CALD program participants to step through the access process; this creates a network of information and support for participants (2)

Use bilingual staff where possible to improve access (2)

Create an open door policy to outreach; a homeless person with psychosocial disability will require intensive support to access the NDIS and may be too unwell to even start the process (2)

#### TABLE 3.3

#### DATA CHARTING REPORT. EVIDENCE SOURCE 3

SMITH-MERRY, 2018, MIND THE GAP: THE NATIONAL DISABILITY INSURANCE SCHEME AND PSYCHOSOCIAL DISABILITY

#### SOURCED FROM

Smith-Merry J. Hancock N. Gilroy J. Llewellyn G. Yan I. 'Mind the Gap: The National Disability Insurance Scheme and psychosocial disability final report: Stakeholder identified gaps and solutions'. New South Wales: Sydney University; 2018. Pages 12-22

#### FUNDING SOURCE

The University of Sydney Policy Lab

#### KEY RELEVANT FINDINGS - NDIS ACCESS BARRIERS

Lack of understanding or knowledge of the Scheme (3)

Overwhelming complexity of the process (3)

A lack of specific support (i.e. Aboriginal workers) for Aboriginal and Torres Strait Islander people (1) A lack of culturally appropriate support for people from culturally and linguistically diverse backgrounds (3) Costs of acquiring reports ... to provide evidence of functional impairment and permanence of disability (3) Anxiety, fear and illness-related barriers (3)

The language of permanent and lifelong disability is contrary to the mental health system's focus upon hope, recovery and living well (3)

The language of disability is a barrier for Aboriginal people (3)

Many Aboriginal and Torres Strait Islander people feared engaging in government services and asking for support, because of a distrust about government programs stemming from past poor treatment or compulsive programs (3) Social and geographical isolation (3)

Complexity for this cohort of collecting the evidence required by NDIA to prove that they had a permanent, functional disability and thus met the Scheme's eligibility criteria (3)

Evidence [is] particularly hard to obtain for people who are often disconnected from services and supports or don't have access to services and supports (such as people (who) are transient and/or homeless, or face difficulties in accessing services and information such as with people with language barriers (3)

#### **KEY RELEVANT FINDINGS - NDIS ACCESS FACILITATORS**

Advocates, including peer workers already working with people from culturally and linguistically diverse backgrounds, should be provided with ongoing NDIS training to assist people to engage with the Scheme (3) Acknowledgement that some people need significant help with the process (not one size fits all) and that this may need to be a slow, back and forth, face-to-face process and take between 30-100 hours (3)

Culturally-specific support (3)

An active "outreach model" owned by communities has been effective in engaging isolated communities (3) Develop capacity within the Aboriginal and Torres Strait Islander communities to work in NDIS-related roles and provide leadership

(3)

Information on the NDIS should be provided through information sessions provided by Aboriginal and Torres Strait Islander community controlled organisations (3)

#### **TABLE 3.4**

DATA CHARTING REPORT, EVIDENCE SOURCE 4

STEWART, 2020, SUPPORTING CHOICE, RECOVERY, AND PARTICIPATION: CLEAR AND EASY -TO-UNDERSTAND INFORMATION IS THE KEY TO NDIS ACCESS FOR THOSE WITH PSYCHOSOCIAL DISABILITY

#### SOURCED FROM

Stewart V. Visser K. Slattery M. 'Supporting choice, recovery, and participation: Clear and easy- to- understand information is the key to NDIS access for those with psychosocial disability'. Journal of Social Inclusion 11(2) [online]. 2020

#### **FUNDING SOURCE**

School of Human Services and Social Work at Griffith University

#### **KEY RELEVANT FINDINGS - NDIS ACCESS BARRIERS**

Confusion regarding more specific aspects of the scheme (4)

Confusion related to how much funding or financial supports would be received and how the funding was to be managed (4) Conflicting information about the NDIS (4)

Confusion for participants between the NDIS and Centrelink ... they believed the two different organisations to be one and the same (4)

Confusion regarding income support (e.g. Centrelink) and the NDIS funding (4) Frustration at the complex language used in the NDIS literature (4)

#### TABLE 3.5

#### DATA CHARTING REPORT, EVIDENCE SOURCE 5

VISSER, 2020, HELP OR HINDER? AN ASSESSMENT OF THE ACCESSIBILITY, USABILITY, RELIABILITY AND READABILITY OF DISABILITY FUNDING WEBSITE INFORMATION FOR AUSTRALIAN MENTAL HEALTH CONSUMERS

#### SOURCED FROM

Visser K. Slattery M. Stewart V. 'Help or hinder? An assessment of the accessibility, usability, reliability and readability of disability funding website information for Australian mental health consumers'. Health and Social Care in the Community 00:1–13 [online]. 2020

#### **FUNDING SOURCE**

Nil

#### **KEY RELEVANT FINDINGS - NDIS ACCESS BARRIERS**

Low accessibility, usability and reliability of [NDIS information on] mental health support websites (5)

No (NDIS information) website returned an acceptable readability score  $\dots$  based on the Australian Government's recommended educational grade level (5)

#### TABLE 3.6

#### DATA CHARTING REPORT, EVIDENCE SOURCE 6

WILSON, 2021, EXPLORING THE PERSONAL', PROGRAMMATIC AND MARKET BARRIERS TO CHOICE IN THE NDIS FOR PEOPLE WITH PSYCHOSOCIAL DISABILITY

#### SOURCED FROM

Wilson E. Campaign R. Pollock S. Brophy L. Stratford A. 'Exploring the personal, programmatic and market barriers to choice in the NDIS for people with psychosocial disability'. Australian Journal of Social Issues [early view – online]. 2021

#### **TABLE 3.6 CONTINUED**

#### FUNDING SOURCE

#### Mind Australia

#### **KEY RELEVANT FINDINGS - NDIS ACCESS BARRIERS**

Limited prior experience with choice making (6) Lost their ability to identify their own preferences (6) Disempowerment or loss of voice ... prevented them from exercising choice (6) The ability to think beyond the immediate is limited (6) Unaware of what supports and activities they could choose and were entitled to as part of establishing a participant plan (6) NDIA processes confronting and intimidating as well as being confusing (6) Funding was often not provided for supports deemed necessary (6) Lack of choice in not being able to spend funds on supports that were often urgently required (6) Restrictions on funding packages meant people may have the money but lacked the control in being able to spend it in ways they deemed appropriate, and that were considered by the participants to be central to their life and their disability (6)

#### TABLE 4

DATA SOURCE SUMMARY			
PARAMETER	RESULTS	RESULTS	
NUMBERS OF PUBLICATIONS	Total number of sources of evidence published between 2014 (Jan 1)-2021 (Apr 26)	6	
NUMBER OF SOURCES OF EVIDENCE PUBLISHED EACH YEAR	2014 2015 2016 2017 2018 2019 2020 2021	1 0 0 1 1 0 2 1	
TYPES OF PRIMARY RESEARCH STUDIES	QUALITATIVE STUDIES         Exploratory qualitative cross-sectional design         Content analysis         Qualitative interview design         QUANTITATIVE STUDIES	1 1 1 1	
TYPES OF GREY LITERATURE	Practice Guide Project Report	1 2	
POPULATION/S IDENTIFIED	Adults 18+		
QUALITY OF LIFE DOMAINS	Psychosocial wellbeing		
FORMAT/NUMBER OF ITEMS	Web-based document Peer-reviewed print journal article	3 3	

## Barriers to NDIS access for adults with psychosocial disability

The data related to NDIS access barriers faced by adults with psychosocial disability fall into seven themes.

#### A LOT OF INFORMATION IS REQUIRED, AND THE PROCESS IS OVERWHELMING

The NDIS criteria require a volume of information sufficient to establish that the applicant's impairment is likely to remain permanent and not be satisfactorily addressed by evidencebased medical treatment (1). Acquiring sufficient evidence is particularly challenging for persons who are homeless, lack access to services or can struggle with cognitive demands due to the nature of their condition (3, 6). The complexity of this process and the subsequent stress experienced by applicants has been associated with non-participation and withdrawal of partially completed applications (3). Although mental health services may assist people to access NDIS funded support, only a minority of persons actually have contact with these specialist services, as many live under-supported lives in the community and may actively avoid contact with mental health services due to past trauma (1).

#### MAY NOT IDENTIFY OR WANT TO IDENTIFY AS HAVING A (PERMANENT LIFELONG) DISABILITY

The language of permanent disability is in conflict with the recovery paradigm that informs contemporary mental health care and advocates for each person's unique journey to be underpinned by hope (2). People who are recognised to have a psychosocial disability may not identify as having a disability, so the reliance on labelling terminology that they perceive as stigmatised and unrepresentative can alienate them and make them reluctant to pursue support (3).

### MAY NOT PERCEIVE NDIS WILL HELP WITH RECOVERY

In addition to the misalignment of NDIS criteria with overarching concepts of recovery, issues were identified with the perception of the assistance offered in practical terms. Funding models have been perceived by consumers as restricting them from spending the money received in a manner that they think is appropriate to address their needs, essentially discounting the knowledge of their own disability (6). Funding was often not received for supports considered necessary and urgent by the person themselves, undermining the sense of agency in their own care (6).

#### WARINESS AND DISTRUST

People who have experienced trauma as a result of their mental health condition may actively avoid specialist services and be reluctant to divulge the personal information collected (1,2). The complexity and rigidity of procedures are likely to add to the distrust of a new system and people receiving support are concerned that they may be worse off than they already are in their current situation (2). Specific cultural groups, such as Aboriginal and Torres Strait Islander people may experience fear in engaging with government programs due to a prolonged history of poor treatment and disempowerment (3).

#### INTERSECTIONAL FACTORS CONSPIRE AGAINST NDIS ENGAGEMENT

The nature of a psychosocial disability itself provides a number of barriers, with co-occurring issues and compounding factors that in combination make participation and assistance challenging. Illness-related obstacles such as anxiety, fear, paranoia and the subsequent social isolation can all undermine the ability to engage and to make the necessary decisions (3). Common experiences such as housing insecurity, poor literacy as well as drug and alcohol dependence can all combine to increase the need for integrated and holistic support (2). People may also face additional barriers to access, due to geographical isolation, sexual preference and gender identity and require further specialised support that is not readily available (2).

#### **CONFUSION AND LACK OF UNDERSTANDING**

Participants expressed confusion regarding an array of specific elements of the scheme, particularly around the management of funding and the differentiation between Centrelink and the NDIS (4). The availability of information regarding the NDIS and the efficacy of the methods of communication have both been identified as having shortcomings. Adults with a psychosocial disability have branded the language used as confusingly complex and voiced issues with accessing the internet to receive such information (4, 6). For those that can access the internet, the NDIS website falls short of accessibility and readability goals, impairing the ability for consumers to understand the content and navigate through the NDIS website to find the information they require (5).

### ACCESS TO CULTURALLY APPROPRIATE SUPPORT IS AN ISSUE

Culturally diverse groups have not applied at the expected rate, with linguistic support and culturally specific support requiring attention from the application process onwards (3). For Aboriginal and Torres Strait Islander people the language of disability and rigid understanding of mental health utilised in the NDIS can undermine access, with a recognised formal diagnosis typically assisting the application process (3). The lack of a representative workforce is identified as a potential contributor to the underutilisation by this cohort also (3).

#### Suggested facilitators of NDIS access for people with psychosocial disability

Six themes represent the factors and interventions that are proposed in three of the evidence sources as potentially helpful for improving NDIS access for adults with psychosocial disability.

#### A COLLABORATIVE, PERSON-CENTRED FRAMEWORK

Utilising a collaborative approach is advised, to include consumers, carers and agencies to enable better understanding of the specific needs of persons who might access the NDIS (1). This significantly enhances the potential for an effective and participant-focused design and can help consumers see the NDIS as a pathway to their individual goals (2).

#### **BUILDING TRUST THROUGH SUPPORT WORKERS**

Skilled support workers with appropriate training, experience and positivity can help to ease consumers' concerns, address knowledge gaps and build confidence in the NDIS (2). In doing so, support workers should recognise the importance of language used when discussing the NDIS with consumers and implement a strengths-based and recovery-oriented approach (2). Additionally, peer workers can provide effective support and address issues from a place of shared experience, to further improve trust and understanding (2).

#### ENHANCING THE CAPACITY FOR SELF-DETERMINATION

As people with a psychosocial disability may find decisionmaking challenging for an array of intrinsic and extrinsic reasons, the utilisation of the supported decision-making model is recommended (2). This builds decision-making capacity and self-efficacy and as this skill is necessary to participate in many aspects of life including engaging with the NDIS, staff who practice this can positively affect participants' experience (2).

### PROVIDING INTENSIVE SUPPORT FOR THOSE WITH COMPLEX NEEDS

It is important to acknowledge that some people with a psychosocial disability may need significant assistance to navigate processes and may require a substantial investment of time and face-to-face interactions (3). Excluded cohorts who may not effectively engage with support services are at a distinct disadvantage in accessing the NDIS, so assertive outreach strategies are encouraged to extend services to these populations (2). This can involve dedicating resources to make contact with groups such as people who are experiencing homelessness, to build rapport prior to any formal application being considered (2). Rather than exerting an overt and overbearing focus on beginning an NDIS application, "respectful persistence" during interactions is recommended as a more effective alternative (2).

#### MAKING AVAILABILITY PERSON-CENTRED

In conjunction with assertive outreach services, it is important to provide a range of highly flexible pathways for consumers to maintain contact with services, so connections can be dictated by their own needs rather than by bookings or typical organisation-driven processes (2). Person-centred availability also advocates for the provision of local solutions that can help to connect communities that are disadvantaged by geographic, cultural or social isolation (2-3).

#### PROVIDING CULTURALLY COMPETENT SERVICES

Engagement with culturally diverse populations can be facilitated by the provision of culturally specific and culturally competent support, with linguistic assistance provided as needed (2). Scheduling specialised support sessions for culturally and linguistically diverse applicants can provide them with the additional information required, while enabling them to develop their own support networks (2).

Workforce diversity can also assist in the provision of a culturally safe environment and the building of capacity for Aboriginal and Torres Strait Islander people to occupy NDIS roles is similarly important. As well, access, understanding and awareness can be facilitated in this cohort through the utilisation of existing Aboriginal and Torres Strait Islander-controlled organisations to provide information that is trusted and culturally appropriate (3).

#### TABLE 5

PREFERRED REPORTING ITEMS FOR SYSTEMATIC REVIEWS AND META-ANALYSES EXTENSION FOR SCOPING REVIEWS (PRISMA-SCR) CHECKLIST			
SECTION TITLE	ITEM	PRISMA-SCR CHECKLIST ITEM	REPORTED
TITLE			
TITLE	1	Identify the report as a scoping review	Y
ABSTRACT			
STRUCTURED SUMMARY	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Y
INTRODUCTION			
RATIONALE	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach. Introduction	Y
OBJECTIVES	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Y
METHODS			
PROTOCOL AND REGISTRATION	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	No discrete protocol exists; the methods steps are described in the report of the review.
ELIGIBILITY CRITERIA	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Υ
INFORMATION SOURCES*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Y
SEARCH	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Υ
SELECTION OF SOURCES OF EVIDENCE†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Y
DATA CHARTING PROCESS‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Y
DATA ITEMS	11	List and define all variables for which data were sought and any assumptions and simplifications made.	N/A

CRITICAL APPRAISAL OF INDIVIDUAL SOURCES OF EVIDENCES	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A – no critical appraisal of evidence sources was conducted
SYNTHESIS OF RESULTS	13	Describe the methods of handling and summarising the data that were charted.	Y
RESULTS			
SELECTION OF SOURCES OF EVIDENCE	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	У
CHARACTERISTICS OF SOURCES OF EVIDENCE	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	У
CRITICAL APPRAISAL WITHIN SOURCES OF EVIDENCE	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A – no critical appraisal of evidence sources was conducted
RESULTS OF INDIVIDUAL SOURCES OF EVIDENCE	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Y
SYNTHESIS OF RESULTS	18	Summarise and/or present the charting results as they relate to the review questions and objectives.	Y – reported as themes
DISCUSSION			
SUMMARY OF EVIDENCE	19	Summarise the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Y
LIMITATIONS	20	Discuss the limitations of the scoping review process.	Υ
CONCLUSIONS	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Y
FUNDING			
FUNDING	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Y



#### SUMMARY AND CONCLUSIONS

The objective of this review, which was to learn what is known about what hinders and what may help adults (people aged 18+ years) with psychosocial disability to engage with NDIS psychosocial programs, was achieved through a process consistent with the approach detailed in the Joanna Briggs Institute's 'Manual for Evidence Synthesis' [6], which is captured in the 'Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist' [15] (see Table 5).

It is evident from the information currently available on the challenges and assistors to engagement with NDIS for adults with a psychosocial disability that myriad factors exist in the lives and minds of those in this population to hamper their access to this funding and by extension, to supportive programs and services. What is also clear is that some initial work has been done to date to propose solutions to these challenges; however, very few of these proposed solutions have been developed by the principal stakeholders – the affected population itself.

Further research with adults living with psychosocial disability wherein their views about how this population's NDIS access and uptake might be improved is warranted.

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### Appendix 2. Learning Points emerging from data

#### Literature review

- A lot of information is required (to apply for the NDIS); the process is overwhelming
- Some people don't want to identify as having a permanent, lifelong disability
- Some people are not convinced the NDIS will help them
- Wariness and distrust related to disclosing personal/ disability information
- Additional intersectional factors impact decision making and access to / engagement with scheme activities

#### Participant-consultant data: Barriers to engagement

#### **INTRINSIC BARRIERS**

- Just not feeling like it sometimes
- Competing life priorities
- Commitment clashes
- Alcohol and substance use
- Feels degrading
- Mistrustful of others

#### **EXTRINSIC BARRIERS**

- Lack of knowledge about what's available
- Activities lack appeal
- · Not enough places
- Staff changes
- Staff availability
- Safety and security

#### Participant-consultant data: Facilitators to engagement (current program/ approach)

- · Activity options that get people out and about
- Timing of activities
- Activity location easy to get to
- · Activity program written up in an accessible place
- Support workers keep people motivated and focused

#### Participant-consultant data: Facilitators of engagement (suggested)

- More outdoor activities including being in nature, coffee shop visits, picnics, sport
- Include movies, music groups, men's groups

- Broaden timing of activities
- Broaden location of activities (to facilitate inclusion of people who don't like coming to the building or for whom transport is a problem)
- Focus activities for age groups
- Collaborative approach with service users to activity planning
- After hours 'wind down' activities
- Flexibility around access to support provide drop-in chat option
- Provide opportunity for service users to be employed
- Send frequent text or email reminders to people who have nominated for an activity

# Staff participant data: Barriers to engagement

- Service users don't always know what they are agreeing to / have agreed to during planning (because of either English Language sub-Proficiency or psychosocial disability)
- No funding for 'preparation for planning' counselling
- No provision for 'how to be on the NDIS' guidance
- No 'try an activity before you commit' option
- Some service users have memory difficulties
  - Service is provided 8.30-4.30 M-F
  - Ability to facilitate activities (amount and duration) is

limited because 'hidden' (unbillable) work takes staff away from (billable) activity work – so activity work is underserved.

- High risk / incidence of staff burnout leading to attrition > disruptive to service users
- No established role description (for support coordinators)

   possibility of service users not getting all they could be getting
- Goals stated in plans aren't always within the power of the service user to attain
- Goals stated in Plans are predominantly about basic life needs and rarely about enjoyment/enrichment
- Activities often incur a cost to the service user that they may not be able to afford
- Activity participation can engender additional support needs for this population (and there is no 'top up' funding to provide that support)
- Client mistrust / the time it takes to engender client trust
- NDIS is extremely difficult to obtain for people with a psychosocial disability either because GPs find it hard to write a convincing Functional Impact Statement, they are 65+, or they don't readily have the required 100 points-worth of ID



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