

**ORIGINAL ARTICLE**

‘Everything would have gone a lot better if someone had listened to me’: A nationwide study of emergency department contact by people with a psychosocial disability and a National Disability Insurance Scheme plan

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Abstract

Australians with a psychosocial disability (PSD) and a National Disability Insurance Scheme (NDIS) plan may at times require emergency care due to the fluctuating nature of their physical and mental health conditions or when their supports have become insufficient. This nationwide study investigated the experiences of people presenting to an emergency department (ED) who have a PSD and an NDIS plan. The objective was to understand current care and communication practices and to provide recommendations for service integration. Twenty-four interviews were conducted with people who had a PSD and an NDIS plan. Participants were asked semi-structured questions about their experiences when engaging with NDIS processes and when engaging with the ED as an NDIS recipient and how communication practices could be improved between the two services. A qualitative, descriptive thematic analysis approach was used. A lived experience advisory group participated in the research and provided commentary. The findings of this study indicate that the NDIS, as a personalised budget scheme, presents challenges for people with complex PSD and physical needs. ED clinicians appear to be unclear about what the NDIS provides and communication between the two systems is fragmented and inconsistent. The themes identified from the analysed transcripts are: (a) People with PSD experience distress when dealing with the NDIS; (b) There's a blame game between the ED and the NDIS; and (c) Inadequate service integration between the ED and NDIS. Recommendations to assist with service integration include building service capacity, providing overlapping care and bridging the diverse biomedical, psychosocial and disability care services.

KEY WORDS

emergency department, lived experience, National Disability Insurance Scheme, psychosocial disability, service integration

Recommendations to be included in further training for ED clinicians from the lived experience advisory group can be found in the Supporting Information section at the end of this article.

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BACKGROUND

In Australia, it is estimated that over 290 000 people have a significant psychosocial disability (PSD) with various degrees of intersectional needs (Productivity Commission, 2020). Currently, 63 000 people with a PSD are in receipt of a National Disability Insurance Scheme (NDIS) plan (NDIS, 2023a). People with disabilities are almost twice as likely to present to an emergency department (ED) as the general population (AIHW, 2022).

The NDIS is a personalised disability support scheme that funds and facilitates disability support services for over 500 000 people in Australia. Introduced in 2013 in response to the Productivity Commission report (Australian Government, 2011) to reform disability care, the NDIS is administered by the National Disability Insurance Agency (NDIA). The NDIS provides core supports that assist with daily living, capital supports that provides assistive technology and equipment and capacity building supports to enable skills acquisition and independence (NDIS, 2021a). At times a person with an NDIS plan will require medical or mental health, emergency care (which is not provided by the NDIS but by state and territory governments) in an ED setting. As the NDIS was implemented without including service integration as a funded item, communication pathways between services have not been established. Therefore, the NDIS does not interface well with the health, mental health system or other mainstream services (Commonwealth of Australia, 2023). This study focuses on the collective experience of people with a PSD and an NDIS plan engaging with NDIS services and when presenting to the ED.

As with other personalised budget schemes, the NDIS requires the person receiving care (or their carer) to engage the services they require, thereby enabling them to choose what services they receive (Tune, 2019). This relies on the individual being able to navigate across different disability and healthcare systems. Previous reports have raised concerns about the NDIS and service integration (Duggan et al., 2020; Tune, 2019). As Australia has moved from a predominantly state-run disability support sector to a market-driven fee-for-service disability care system, a disconnect between services has become evident (Edwards, 2019). Emerging research reports communication disconnects between healthcare services and the NDIS leading to fragmented healthcare (Foster et al., 2022; Hamilton et al., 2023; McKenzie & Smith-Merry, 2023). Moreover, it has also been reported that people with PSD have more challenges accessing NDIS supports (Devine et al., 2022) due to intersectional needs, plus being required to navigate multiple disability care providers, while still navigating across the health and mental health systems. Without clear service integration pathways in place, this task has become onerous and unwieldy.

Personalised schemes first emerged in the UK and later in many countries in Europe in response to advocacy from disability groups (Williams & Dickinson, 2016). Although these schemes have had implementation challenges, they were introduced over a longer time period and had established communication and care pathways prior to being introduced, thereby, enabling improved service integration (Carey et al., 2018; Edwards, 2019). This was not the case in Australia, which has other unique challenges including the geographical spread of service provision, exacerbated by a smaller population and the diversity of needs (such as psychosocial disability) included in the scheme (Carey et al., 2018). The competition of a quasi-market within the disability support sector has resulted in the emergence of additional service providers, all with varied specialities offered to the public. Foster et al. (2022) reported that in a rapid and evolving climate of services moving into fee-for-service markets, where competition affected revenue, a business approach had to be adopted over a service approach. Foster et al. (2022) identified barriers to communication and service integration within a personalised scheme which holds 'antagonistic forces' such as 'commercial confidentiality and protecting the business niche, or in expecting providers to be able to work effectively across entrenched service boundaries' (p. 141).

People with complex needs require multiple supports from different providers and higher levels of service integration (Løken et al., 2022). Furthermore, the 'ongoing recovery and disability disconnect' in the design of the NDIS is incongruent for people with PSD (Hancock et al., 2022, p. 5) e.g. the NDIS states that it follows recovery principles but requires permanence of disability (Hamilton et al., 2020). This disconnect is apparent throughout the NDIS journey from the application process through to approval and annual/biannual or multiyear reviews i.e. if a disability is permanent, it would not be necessary to periodically reprove impairment (Hamilton et al., 2023). Recovery principles promote personal improvement and flourishing, yet static NDIS plans are not easily modified to grow with the person."

Applying for and managing personal support, plus contributing to service integration (as this is not a funded item with the NDIS) is undertaken by the person with PSD. National estimates state that 1.1 million people in Australia have a PSD with 38% being profoundly affected and 20% with severe impacts (ABS, 2018; Mellifont et al., 2023). People with PSD have underutilised accessing NDIS plans with only 63 000 people accessing supports. This cohort has the highest rate of applications rejected by the NDIS (Department of the Prime Minister and Cabinet, 2023) due to PSD being hard to define (NDIS, 2021b). A study by Devine et al. (2022) reports why this cohort has found accessing supports challenging (complex



interactions, lack of staff resourcing and disruption within the mental health system) and calls for policy and operational reform to enable greater utilisation of NDIS budgets.

McKenzie and Smith-Merry (2023) conducted a study in which they developed an inter-agency wraparound care model to assist with service integration between the NDIS and other providers. Participants in the study, who were staff within the sector, reported that communication pathways between services were 'ad hoc' and relied on their own individual networks. One participant stated, 'we are starting from scratch on each and every occasion' and participants had to go 'above and beyond' normal work practices to facilitate connection between organisations (McKenzie & Smith-Merry, 2023 p. 145). This aligns with some of the communication gaps that are reported in this study and reported in other literature (Fisher et al., 2023; Foster et al., 2022; Hamilton et al., 2023).

PSD can be a fluctuating condition and may be affected by medical comorbidity, social determinants and/or failure in support systems (Duggan et al., 2020; Gazey et al., 2018; Kaplan & McGrath, 2018), therefore, a person with PSD may, at times, require medical or mental health emergency care in an ED. When services fail to consider the intersectional service needs of people requiring physical and/or mental health care across services, service integration gaps can occur (Collings et al., 2016; McKenzie & Smith-Merry, 2023). This can be particularly evident in the ED setting (Australasian College for Emergency Medicine, 2018).

It is confronting for a person in emotional distress, navigating the complexity of their health and mental health, to enter the ED environment which has a strong biomedical orientation (Carstensen et al., 2017; Goering, 2015; Johnston et al., 2019). There are increasing reports that treating someone with mental health concerns with a purely pharmaceutical response is a reductionist approach (Tosam, 2022) without considering wider psychosocial and situational stresses. A holistic approach is more appropriate and includes awareness of context, social determinants, losses, psychological challenges and enduring physical needs (Baker & Procter, 2015).

This study focuses specifically on the experience of people with a PSD, the difficulty in interacting with the NDIS and the engagement between the ED and the NDIS. By preferencing the lived experience voice this study aims to provide greater understanding and assist in shifting the power dynamic for this group of people who find themselves navigating a biomedical system of health care with complex intersecting needs. Findings confirm that people with a PSD and an NDIS plan experience distress when dealing with the NDIS to gain support and when presenting to the ED requiring emergency care. Recommendations for improved communication practice between the ED and NDIS are provided.

METHODS

Study design and questions

This qualitative descriptive study is part of a larger mixed methods study (McIntyre et al., 2021) and reports on the outcomes of 24 semi-structured qualitative interviews (McIntyre et al., 2023). Qualitative description with thematic analysis is well suited to lived experience research (Creswell, 2013; Vaismoradi et al., 2013) with the aim being to inform policy, clinical practice and improve service integration (Braun & Clarke, 2019; Vaismoradi et al., 2013). The University of South Australia Human Research Ethics Committee approved this project in April 2021 (ID: 203626) and the interviews were conducted between March and November 2022.

Mental Health Plans nationally and internationally call for the inclusion of people with lived experience in the creation of policies, procedures and pathways to ensure an authentic user-led outcome (Department of Health, 2017; WHO, 2022). To incorporate lived experience the research team worked with a lived experience advisory group to co-design the interview schedules, recruitment strategy and analysis of themes. Co-design in research can vary greatly (Slattery et al., 2020). We aimed to keep the focus on the interview questions (established through prior consultations with people with lived experience and stakeholders) and view the outcomes through a lived experience lens and expertise to ensure a significant and purposeful focus on the recovery needs of the people this research is designed to benefit.

Over a series of four meetings and following the principles of the research group's *Lived Experience Engagement Framework* (Loughhead et al., 2020) researchers engaged with a lived experience advisory group. Researchers became students and those with lived experience led by imparting knowledge and highlighting areas of needed discovery from their lived experience of ED presentations (Roper et al., 2018). The conversations that occurred were characterised by divergent views; this led to some thought-provoking discussions and transformative reasoning as intersectional viewpoints were considered. Members of the advisory group pointed out when researchers needed to adjust their focus and not overshadow the lived experience point of view. The combined wisdom of the lived experience advisory group provided greater depth as can be seen by the data captured by the co-created interview schedule (Banfield et al., 2021). The research team included the following disciplines: mental health nursing, psychology, sociology and applied science. One of the researchers had lived experience of PSD and one researcher had carer lived experience.

A nationwide recruitment strategy (purposive and snowballing) was created and members of the advisory group assisted with identifying organisations to

approach. Recruitment occurred via social media by contacting organisations nationally who posted a call to participate on their platforms. People who wanted to participate contacted the research team who provided information about the project and the inclusion/exclusion criteria.

Interviews and thematic analysis

Participants expressed interest and had the opportunity to ask questions about the research and researchers prior to the interviews taking place. All interviews were conducted by HM; Four were conducted face-to-face at the participant's house or in an office at the university and 20 were conducted via a video platform. There were no withdrawals from the project. Two participants were accompanied by a carer; all participants reported having support in place if needed. Recorded interviews resulted in just over 8 h of audio recording with an average interview time of 45 min. Reflexive journal entries were recorded following each interview. The research team agreed that after 24 interviews new codes were not being identified. Data were analysed concurrently while interviews were in progress to encourage data familiarity; researchers could analyse and interpret participants' experiences thereby deepening knowledge to augment future interviews.

Lincoln and Guba's (1985) principles of research trustworthiness (the Four Dimensions Criteria) were employed. After transcription, author 1 checked all transcripts and participants were given the opportunity to crosscheck and ask for any changes or additions to be made before uploading the data to NVivo software for coding. A reflexive thematic analysis approach was considered appropriate to identify patterns within the data (Sandelowski, 2000, 2010). Authors 1 and 2 conducted coding individually with guidance from Braun and Clarke (2019) to discover, describe and interpret the collective shared experience of interview participants. Differences were discussed during the coding comparison phase of the research between author 1 and author 2 and themes were formulated through this collaborative process. By discovering, analysing and interpreting the common themes identified from the data a collective story emerged (Reid et al., 2005). The meaning and relevance of themes from a consumer and carer perspective were assisted by discussion and review with the Lived Experience Advisory Group. This discussion resulted in strategies for communicating findings to policymakers as well as specific recommendations about the training of ED staff. These later recommendations have guided the discussion of results (see Data S1). The formulation of research questions guiding this project has been reported elsewhere (McIntyre et al., 2023). As a framework, the COREQ standards were used for reporting (Tong et al., 2007).

Participants

Of the 24 people, from six states of Australia, who participated in the audio-recorded interviews, 18 reported having lived experience of PSD, four reported being carers and two people reported having a dual role of having lived experience of PSD and being a carer. The ages of participants ranged from 25 to 65+ with most participants in the 25–44 age range. In total, 19 participants were female, four were male and one self-identified as a trans man. $n=6$ participants were asked by ED staff if they had an NDIS plan and $n=3$ carers informed ED staff that the person they were supporting had an NDIS plan. Please see Table 1 for demographics.

TABLE 1 Demographics.

| Participant | |
|--|-----------------|
| Consumer | 18 |
| Carer | 4 |
| Consumer and carer | 2 |
| Age | |
| 25–34 | 9 |
| 35–44 | 6 |
| 45–54 | 3 |
| 55–64 | 5 |
| 65+ | 1 |
| How do you identify | |
| Aboriginal person | 2 |
| Caucasian background | 22 |
| CALD | 4 |
| LGBTIQ+ | 3 |
| Female | 19 |
| Male | 4 |
| Trans man (self-identified) | 1 |
| Rural and remote | 4 |
| Experienced homelessness | 12 |
| Coexisting chronic medical condition/s | 20 |
| State | |
| NSW | 5 |
| QLD | 3 |
| SA | 13 |
| TAS | 1 |
| Vic | 1 |
| WA | 1 |
| After leaving the ED | |
| Discharged to community | 19 ^a |
| Admitted to hospital | 11 |
| Put in jail | 1 |
| Left of own accord | 1 |
| Engaged with a peer worker in the ED | 2 |

^aParticipants reported on more than one presentation to the ED.



RESULTS

This paper reports themes identified around the issues of systemic interactions and possible improvements for people accessing the NDIS services and EDs: (a) People with PSD experience distress when dealing with the NDIS; (b) There's a blame game between the ED and the NDIS and (c) Inadequate service integration between the ED and NDIS.

People with PSD experience distress when dealing with the NDIS

All participants reported that the process of applying and negotiating with the National Disability Insurance Agency (NDIA) caused them unnecessary distress. The NDIS promises much. Rather than the provision of support for people with PSD being adequate it was described by participants as being inconsistent and subjective.

And they don't see that they're causing emotional distress...[they say] that there's this fancy Candyland [NDIS], you can go through and everything will be fixed.

(P16).

Most participants expressed frustration with the NDIS and that psychosocial disability doesn't quite fit within the structure and plans are not always matched to their needs i.e. not including psychology in an NDIS plan when the disability is psychosocial.

But the system wasn't designed for psychosocial disabilities and you can see it...it's like saying to someone, if you need a critical surgery, do you want to keep your right hand or your leg? Which one?

(P12).

Most participants spoke about their experiences advocating for themselves with NDIS services and the toll it takes on them.

I find a lot of time you have to fight...It's a battle...a bit of a full-time job...I keep on top of all the legislation, the wording, the changes...No-one has their facts straight, no-one knows what they're talking about. There's not clear information unless you're researching 24/7 yourself.

(P12).

Constant requests from the NDIA for further information and having to justify needs, weakens people's resilience and affects recovery:

...the amount of people that withdraw from NDIS, because they can't cope with the emotional load, the constant questioning having to justify everything. It's literally fighting for things, and then you might get something but you have to sacrifice something else.

(P16).

Participants expressed that progress would lead to less support funding, when in fact you may need other services to progress, impacting recovery.

You might start making progress, but then you can't continue because you don't have funds...I've got progress reports and everything it's used against you and then I can't access other recommended treatments, because they say that I'm too complex...and so it's Catch 22 that I can't make proper progress.

(P16).

Alternatively, one participant stated that not fighting was the only way she could keep well:

I chose to not fight about my funding, I chose to give up fighting to get the money...I cannot do this again...This is killing me...Because I chose to stop the fight to get more funding to be able to have the support I need, I've stayed well.

(P14).

There's a blame game between the ED and NDIS

All participants who were asked or declared an NDIS plans ($n=9$) to ED staff, during their presentation, reported that clinical staff were unclear about what the NDIS provides and made incorrect assumptions about the services people could access through the NDIS.

...I became homeless after leaving family violence...and the hospital discharged me believing NDIS would fix even getting me a house...and pretty much just tried to push everything to NDIS.

(P16).

Participants reported clinicians lacked understanding that the NDIS provides disability support not medical or mental health emergency care, resulting in a disconnect between the two services.



I find there's a blame game between the two systems...ED will often go, 'Oh, well, NDIS can deal with that. That's NDIS's problem,' and then NDIS will go, 'No, that's the health system's problem'.

(P12).

There were many examples of ED clinicians wrongly assuming that the NDIS provides medical and mental health emergency care. One participant with a major neurological condition who also experiences life-threatening respiratory distress asked ED clinicians to be referred to an outpatient clinic but was told to get support for aspiration from the NDIS.

...I really needed to become an outpatient because I've aspirated so many times...they said, oh, you've got an NDIS plan, right? And then basically they...just palmed me off – they said, oh, you need to see someone through the NDIS. They asked, [if I had an NDIS plan] but it's not they're concerned as to whether or not I have one. It's more just to kind of kick me out of the medical system.

(P15).

Participants who had declared NDIS plans spoke about clinical staff withdrawing services and pushing back onto the NDIS without checking if the NDIS provides the services required.

...once they have asked that question, all care seems to just fall back on the NDIS. Here's an NDIS package, see you later.

(P11).

But the moment I find they do go there [ask if you have an NDIS plan] is when it comes to something that may be at a cost to them...

(P12).

When an NDIS plan was known to exist ED staff assumed the NDIS would somehow provide all that was required. NDIS support workers are disability trained and are not required to have medical or mental health training. This does not seem to be clearly understood by ED clinicians.

Yeah, there's a pullback, like, ah, good. Okay. We don't have to organise anything. Just business as usual with your NDIS supports. And I'm thinking, well, his support workers are not mental health workers. They're disability workers. They don't understand about his long-term recovery.

(P22).

They're just so dismissive, and I'm sick of just being told link in with your supports when you get home...How is seeing an OT going to get my blood pressure up?

(P16).

This resulted in several participants advising not to declare an NDIS plan.

Inadequate service integration between the ED and NDIS

Most participants reported inconsistent and unclear communication practices with the NDIS, EDs and other health services.

There's a gap between NDIS and every service, not just hospital...

(P17).

Participants presented to the ED as their health or mental health needs had increased beyond what NDIS supports could cater for. It was suggested that repeat visits to the ED could be prevented if there were clear communication pathways between the ED and the NDIS. Knowing if someone has presented to the ED would signal to NDIS support workers that more supports are required.

I just feel that it would be good if there was open communication between the emergency department and the NDIS, or at least your support worker/coordinator because some people would re-present on numerous occasions and be turned away and having that, oh, you're actually not coping at the moment because you've presented this amount of times and what can we do to put support in place or just having feedback from the emergency department to them would be really helpful.

(P5).

All participants reported that there was very little engagement with NDIS support workers/coordinators instigated by the ED.

And I think that's one of the thing that's missing with the NDIS is this whole like case manager type thing, and I know, nobody can work 24/7.

(P11).

Most participants reported that they would inform their NDIS support workers that they were in the ED.



I normally let them [NDIS support workers] know...but that's the only way.

(P8).

To assist in communicating with ED clinicians most participants commented on the value of having a support worker or other person to advocate for them, communicating with clinicians when the person presenting was unable to, explaining to clinicians what NDIS supports the person can access, and to clarify communication around next steps of treatment while providing care, distraction and comfort.

Sometimes I've got a support worker to help explain because by that stage I'm not able to communicate properly...because I'm having an asthma attack. Emergency departments and doctors just blow me off...as soon as they [support worker] leaves, which can happen...[the ED] discharge me.

(P18).

Participants who reported having access to a support worker in the ED stated the benefits of that support in gaining more assistance from clinical staff in the ED.

It was a different experience because, bear in mind no-one takes you seriously, and at Christmas time I really needed the help to stay in hospital, and if it wasn't for [support worker] the doctor was just going to send me home with my injections to deal with the stresses...So lived experience, people that understand what you're going through, that would make it better

(P4).

All participants when asked if they were treated differently when they had a support person present in the ED reported.

It's like they believe that other person more than they believe the person that's been getting the help. That's what I found.

(P13).

They don't listen to me if I'm advocating about myself. But if I advocate for somebody else, they'll listen to me.

(P18).

Participants spoke about whom they would recommend ED staff communicate with:

I'm happy for them to disclose anything to my case manager [support coordinator].

(P11).

My main support worker...my support coordinator would've been a good one to notify.

(P14).

Support coordinator because I've got her down as a contact.

(P18).

Just ringing my support worker or support coordinator...would be a better way to go about things because then they can come and physically be present with me.

(P5).

And what ED staff should communicate:

What happened, when it happened, why it happened. What service did they offer, what service didn't they offer. What did I accept, what I didn't accept. How did I manage, how I didn't manage. Maybe what they've given me to take or take home with me, to actually improve practice.

(P20).

DISCUSSION

This qualitative descriptive study explored the experiences of people with PSD engaging with the ED for physical and/or mental health care. Findings are consistent with other studies that report engaging with the NDIS is confusing, inconsistent and a burden, and there is a disconnect between the NDIS and other health/mental health services (Foster et al., 2022; Hamilton et al., 2023; McKenzie & Smith-Merry, 2023). This discussion explores the relevance of findings regarding consumer access and engagement with NDIS and EDs, as well as issues about communication and continuity of care across the two service systems.

NDIS engagement

This study concurs with other studies and reports and has found that the NDIS requirements for access and engagement with the scheme are difficult for many people and cause distress (Bonyhady, 2023; Commonwealth of Australia, Department of the Prime Minister and Cabinet, 2023; Fisher et al., 2023; Foster et al., 2022; Hamilton et al., 2023; McKenzie & Smith-Merry, 2023). The market-driven transactional nature of the NDIS is criticised widely (David & West, 2017; McKenzie & Smith-Merry, 2023; Wilson et al., 2022) and has created different system gaps and a level of fragmentation which can be attributed to the many providers (over 180000 (National Disability Insurance Scheme, 2023a) with a semi-regulated provision of services (Hamilton et al., 2023)). Australia is a



large country with a small population which has led to thin markets, especially in remote areas (Reeders et al., 2019). Choice and control have been established as strategies for service reform rather than voice and listening (Thill, 2015), leading to NDIS recipients facing forced choices from limited services (Hamilton et al., 2023) due to market failure and/or thin markets (Reeders et al., 2019). People with complex needs are required to navigate multiple systems (multiple NDIS providers, plus the health care system, including the ED, the mental health system and primary care providers) to meet their physical and mental health needs (Fisher et al., 2023). Other personalised schemes have had better outcomes for service integration due to establishing communication and care pathways early in implementation (McKenzie & Smith-Merry, 2023). The recent NDIS review (Department of the Prime Minister and Cabinet, 2023) addresses many of these concerns including: recognising the complexity and unique needs of people with PSD, the recovery/permanency disconnect and recommends increases in psychosocial supports outside of the NDIS, the inclusion of foundational supports and the new role of the psychosocial navigator (National Disability Insurance Scheme, 2023b). It is hoped that this new role will enable improved access to mental health services and strengthen service integration between all sectors of the health, mental health system and the NDIS (Australian Government, 2023). How this reduces the need for ED services or improves care in the ED will be something to observe.

ED engagement

EDs have important roles to play in medical or mental health emergency response including treating the person with trauma-informed care (Greenwald et al., 2023), working side-by-side with the person and their loved ones (Acres et al., 2019) and connecting the person and their supports with follow-up services (Johnston et al., 2019). There are limited alternative service options (these are emerging) for people with PSD, especially out of hours, when NDIS and community support are less available (Duggan et al., 2020). As people with PSD often have a combination of medical and mental health needs, improving practices in the ED setting that incorporate wholistic, person focussed care (Procter et al., 2022; Sacre et al., 2022), including strengths-based recovery (Hayes et al., 2018; Lorien et al., 2020) and social theory approaches (Bunbury, 2019; Shakespeare & Watson, 2001) to augment a biomedical approach, will give a foundation to improve person-centred care and quality-of-care responses. Positive communication practices between services to enable follow-up with other support services will assist with continuity of care (McIntyre et al., 2022).

People with complex conditions and social support needs are seeking help from the ED despite this service not being adequate to provide care at the required level

(Roennfeldt et al., 2021; Sacre et al., 2022) and without established and budgeted service integration pathways (Mavromaras et al., 2018). These oppositional forces create an environment that may lead to health service avoidance (Foster et al., 2022; Smith-Merry et al., 2018).

This study reveals that ED clinicians aren't aware of the limits of NDIS services (disability support). This, in turn, causes emotional distress for the people presenting to the ED. It's concerning that the participants of this study reported that if ED staff did ask if they had an NDIS plan, rather than concluding that NDIS supports have become insufficient, it resulted in a pullback of intervention and a quick discharge to return to normal supports. This can be partly motivated by extreme workload pressures and/or passing costs on to other sections of the health system (Australian Institute of Health and Welfare, 2016). This information deficit leaves people being returned to a situation that had caused them to initially present to the ED, resulting in some participants of this study stating they are extremely hesitant to present to an ED in future, and if they do so will not declare their NDIS plans (McIntyre et al., 2023).

Uncertainty or an incorrect understanding of what the NDIS provides highlights deficiencies in formal communication pathways between the ED and the NDIS. Other studies concur that there are several factors at play that affect communication between NDIS services and the health service sector, impeding service integration (Foster et al., 2022; Hamilton et al., 2023; McKenzie & Smith-Merry, 2023). Service integration works best when all parties share responsibility between services (McKenzie & Smith-Merry, 2023). As the NDIS does not include service integration as a funded item (Mavromaras et al., 2018) how it is supposed to occur and who is to take charge of making it a priority is yet to be discovered.

The gaps in knowledge as well as consumers' experiences of 'service pullback' indicate the need for improved awareness and training for ED clinicians on the appropriate roles and supports offered by NDIS providers. This awareness includes the need to step up care (SA Health 2019), rather than rationing care, as a person in distress should indicate that extra care is required. ED clinicians understanding of how to support someone with a disability (Bunbury, 2019) is part of the required wider skills and capabilities in working effectively with people with psychosocial disability (Devine et al., 2022). These include effective skills for listening and trust building, skills for meeting diverse communication and information processing needs (e.g. neurodiversity, hearing impairments), practices for ensuring privacy and enabling low sensory environments (Loughhead et al., 2020).

Communication and service integration

This study reports a lack of communicating from the ED with support services, specifically the NDIS.



Post-discharge, if EDs do communicate with other services, it is usually limited to primary health care, outpatients or community mental health teams (McIntyre et al., 2022, 2023). Along with providing ED clinicians with clear guidance around what the NDIS provides, information sharing between both systems was something participants reported would be helpful. This would require some parallel procedures to what already occurs in the ED and could be overcome by the people presenting being asked, firstly if they had an NDIS plan and who they would like the ED to contact while they are in the ED and at discharge. The use of tools, such as mental health advance care plans, would enable people presenting to the ED to provide their wishes to clinicians and save time during the doctor/patient interview, including who to contact, information sharing permissions and privacy concerns (Lasalvia et al., 2023). Pre-consent and/or disclosure agreements could be added to current ED and NDIS provider systems and would greatly assist with the continuity of care between the two services (McIntyre et al., 2022).

NDIS worker engagement

Just as peer work in the mental health sector and the ED has proved to be beneficial in providing the people presenting with care and support including de-escalation of distress (Brasier et al., 2022; Stratford et al., 2019) NDIS support workers could provide an invaluable service in the ED environment for people with a PSD and an NDIS plan when presenting in a medical or mental health emergency. Communication with NDIS workers would provide ED clinicians with context and collateral information at presentation to the ED and assist with discharge, while also alerting NDIS workers that more supports at home are required.

Hearing the stories of engagement between these systems was incredibly distressing. People with PSD have been engaging with the mental health system for a long time. PSD is a known barrier to accessing the NDIS (Mellifont et al., 2023) due to the administrative requirements (Furst et al., 2018). Therefore, gaining access to the NDIS shows incredible resilience, as the system is extremely hard to navigate (Bonyhady, 2023; Hancock et al., 2022). The participants of this study who have accessed the NDIS know more about the NDIS and living with their condition than the clinicians they are presenting to. Yet the healthcare system doesn't recognise the learning and understanding that these people have accumulated about their own health/mental health needs.

It could be argued that the findings reflect interviews with people who were disappointed or disgruntled, rather than the many people who felt satisfied and supported by the interaction they had with the NDIS and ED staff. As mentioned above other studies and the NDIS Review (Australian Government, 2023) confirm the legitimacy of the findings of this study. A nationwide

survey of ED clinicians was conducted in 2023 and will be reported elsewhere.

Relevance for clinical practice

This article provides recommendations to assist ED clinicians and NDIS providers to facilitate greater person-centred care for people presenting with a PSD and an NDIS plan. Understanding the complexity and disability-related needs of a person's presentation, the opposing elements at play and what the NDIS offers, will assist in providing context and influence service provision. Consumers and families involved in this study report that including NDIS support in communication processes and shared planning will enhance continuity of care.

Strengths and limitations

The strengths of this nationwide study include the range of experiences captured, the inclusion of lived experience researchers in the team and the incorporation of the wisdom and expertise of a lived experience advisory group to cocreate the interview schedules, recruitment strategy and to review the themes generated. This project fulfilled some of the requirements of consumer collaboration including stakeholder consultations, lived experience advisory group, identification of research questions, co-design of interview schedules, participant recruitment strategy, data analysis, co-authorship of results and dissemination (Daya et al., 2019; Jones et al., 2021; Roper et al., 2018). Due to the nature of this being a PhD project with an industry scholarship, it was not possible to include the advisory group in the architecture of the project prior to it being created. $n=9$ participants had been asked if they had an NDIS plan or a carer informed ED staff; evidence presented in this article about the NDIS/ED interface is limited to this sub-section of the sample. Further research with a larger group would provide more depth of this experience. Future research with a more diverse population would increase knowledge of more nuanced lived experience. Research with NDIS support workers and ED clinicians will enhance this area of focus.

CONCLUSION

The results of this study reveal that people with a PSD and an NDIS plan are required to navigate a complex cycle of engaging with the NDIA and NDIS service providers (Mellifont et al., 2023). There is an urgent need to strengthen service integration pathways between the ED and the NDIS and improve standards and quality of shared care. This requires each sector to acquire further skills and service capacities to provide supportive, overlapping care for people with PSD and bridge the diverse



biomedical, psychosocial and disability service interests that are evident.

Valuing the voice of service users is being called for by mental health plans internationally (World Health Organization, 2022). People who have received ED services have the experience and knowledge to recommend changes. By hearing the voice of people with a PSD and an NDIS plan this study aimed to identify experiences, perspectives and valuable recommendations for change in practice (Thill, 2015) to decrease distress and to improve continuity of care. A wholistic approach would serve this group of people and enhance person-centred and continuity of care. For those with the power to enact change within the NDIA and state run EDs, the challenge will be, in listening, understanding and acting on what they hear.

AUTHOR CONTRIBUTIONS

NP, LH, ML and HM led the design of the study. NP, LH, ML and HM, CA, BB, LV, JS, UW, DBS created the interview guides and the recruitment strategy and reflected on the findings. HM conducted the interviews and HM and ML conducted the thematic analysis and led the refining of the themes with NP, LH, CA, BB, LV, JS, UW, DBS. HM wrote the initial draft of the manuscript and all authors contributed to the final manuscript. All authors read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare they have no financial interests to disclose regarding this research.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

This project has been approved by the University of South Australia Human Research and Ethics Committee (Protocol 203626).

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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