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I have not come here because I have nothing better to do: The lived experience of presenting to the emergency department for people with a psychosocial disability and an NDIS plan—A qualitative study

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Abstract

Almost 60 000 people have a psychosocial disability (PSD) and a National Disability Insurance Scheme (NDIS) plan. As PSD can be a fluctuating condition, people with a PSD and an NDIS plan, at times, may require crisis care and present to the emergency department (ED). This national study explored the experiences of people with a PSD and an NDIS plan when presenting to the ED. To understand the unique lived experience of people with a PSD and an NDIS plan, semi-structured interviews were conducted with 24 people between March and November 2022 and were analysed thematically. A lived experience advisory group was engaged as part of the research team. Participants were asked about their experiences in the ED including barriers to therapeutic care and what worked well. Participants reported emotional distress caused by receiving a biomedical rather than a person-centred mental health response. A previous mental health history overshadowed diagnostic decisions and most participants interviewed stated they would not choose to return to the ED. Half of the participants spoke of one presentation only where needs were met. Four main themes emerged from the data: (a) *Diagnostic overshadowing*; (b) *Judgement and stigma*; (c) *Waiting without hope*; and (d) *If things went well*. This study provides evidence of the unique lived experience of people with a PSD and an NDIS plan when presenting to the ED. The results highlight the need for clinicians in the ED to understand the complexity and nuances of supporting people with a PSD. Recommendations for a person-centred care approach are provided. Alternative support options for this group of people need to be explored.

KEYWORDS

emergency department, lived experience, National Disability Insurance Scheme, psychosocial disability, qualitative, thematic analysis

BACKGROUND

In 2021–22 there were 8.8 million presentations to public hospital emergency departments (EDs) in Australia (339 presentation per 1000 people) (24 000 daily presentations) (AIHW, 2022a, 2022b). Approximately 3 per cent of all presentations to the ED related to mental health concerns (AIHW, 2023). It is not known how many of these people presenting to the ED have a psychosocial disability (PSD) and a National Disability Insurance Scheme (NDIS) plan.

Currently 60 000 people in Australia with a psychosocial disability (PSD) have an NDIS plan (NDIS, 2023). It is estimated that there are another 230 000 people in Australia who live with significant PSD who are currently not receiving, or able to access NDIS support (Smith-Merry et al., 2018). With the episodic nature of PSD, people with a PSD and an NDIS plan may experience a physical and/or mental health crisis requiring support from the ED.

Psychosocial disability is

> …a term used to describe a disability that may arise from a mental health issue. Not everyone who has a mental health condition will have a psychosocial disability, but for people who do, it can be severe, longstanding and impact on their recovery
>
> (NDIS, 2022).

In response to the needs of people with disabilities (including PSD) the NDIS was created and began to function in a pilot capacity in 2013 to provide individualised supports for those in the community with disabilities (Buckmaster & Clark, 2018; NDIS, 2021a; Productivity Commission, 2011).

The NDIS is Australia's first national scheme for people with disability, a hybrid service model with a neoliberal ideological framework, facilitated by a competitive private sector market-driven economic system (Esposito & Perez, 2014; Kotz, 2015; Langmead, 2018) aimed to provide services for those with an NDIS plan. As such the NDIS is a fee for service model (Stampoulis-Lyttle, 2019) with the aspirational motive of enabling empowerment and autonomy through ‘Choice and Control’ while respecting Human Rights (NDIS, 2013). This important principle is not always achieved in practice (Hamilton et al., 2023). For example, care providers can be limited in delivering services required (Langmead, 2018; Stampoulis-Lyttle, 2019) due to the cost of service delivery or staffing issues. As psychosocial and disability support (through the NDIS) has moved from a service-focussed funding model to a market-driven model, tensions have arisen that were not evident prior to the NDIS being created (Mellifont et al., 2023).

People with PSD may at times become unwell, due to a medical condition, a medicine adjustment, a relationship breakdown, financial stresses, homelessness or the fluctuating nature of PSD (ACEM, 2018). NDIS plans, to date, by their design are static lacking the flexibility to enable providers to increase supports as required to prevent a crisis (Hamilton et al., 2020; Langmead, 2018; Tune, 2019). Therefore, usual supports provided by NDIS service providers may be insufficient, at times, to meet changing needs and crisis care may be required.

When a person presents to the ED in crisis, requiring complex physical and/or mental health care they enter an environment operating within a biomedical model of care (ACEM, 2018; Roennfeldt et al., 2021) which does not necessarily consider the social models of health care (Berghs et al., 2016). Therefore, a presentation to the ED can be a complex encounter that does not always align with the person's immediate needs (ACEM, 2018; McIntyre et al., 2021; Roennfeldt et al., 2021).

This study was conducted in response to emerging reports from academics, clinicians, peer workers, support workers and others, that people with NDIS plans are being discharged from EDs without gaining the support and intervention they need. Once an NDIS plan has been declared all ED support ceases and people are discharged back into the situation that caused them to present to the ED, nor the limited follow-up those without an NDIS plan receive from community mental health supports. ED clinicians assume that if someone has an NDIS plan they do not require anything further (McIntyre et al., 2023). Results of this study aim to influence policy in order to change clinical practice, improve communication pathways so that person-centred continuity of care can be enhanced in this setting. Further outcomes will be reported elsewhere.

Significantly individual needs of people with PSD were not considered in the design of the NDIS and this is problematic (for critiques of the scheme see Furst et al., 2018; Smith-Merry et al., 2018; Tune, 2019). To respond to tensions between the NDIS and the fluctuating nature of PSD the NDIA Recovery Framework was introduced in 2021 (NDIS, 2021b). However, the effects of the framework have yet to be investigated (Hamilton et al., 2023; Mellifont et al., 2023). There is a need for research understanding patterns of crisis support for people with PSD on NDIS plans, including consumer and carer experiences of emergency care and interactions between EDs and NDIS providers.

METHODS

Study design

Thematic analysis, as a method within qualitative descriptive analysis, provides a reliable qualitative approach to identify themes within the data (Vaismoradi et al., 2013). As such, a qualitative descriptive study design was adopted with a generalist approach, using reflexive thematic analysis (Braun & Clarke, 2019). This enables the data analysis to report issues, experiences and perspectives, rather than deeper social structures or phenomenological constructs. As this study aimed to understand the lived experience of people with a PSD and an NDIS plan when presenting to the ED, a qualitative descriptive study enables researchers to stay ‘data-near’ (Sandelowski, 2000, 2010), while aligning with the lived experience perspective to provide relevant outcomes for policy change and clinical practice.

Formulation of study questions

An initial consultation was facilitated by the first author involving academic researchers, clinicians, peer workers and those with lived experience with the NDIS, national and community mental health and ED sectors around the engagement between the NDIS and the ED. The process helped establish the study aims. A lived experience advisory group was engaged to co-create the interview schedules, participant recruitment strategy, reviewed interview themes and wrote a response to the themes generated. This article, as part of a larger PhD study, reports specifically on how people with a psychosocial disability and an NDIS plan (with the complexity of mental health and physical health needs) experience seeking help from ED services. The overarching research questions are:

1. How do people with lived experience, carers and families experience service integration and coordination across emergency care and their NDIS providers?
2. What are the barriers to accessing therapeutic treatment within the ED through the health/disability/mental health interface?
3. How can barriers be transcended for improved person-centred care and recovery?

This paper will address questions 2 and 3; subsequent research papers will report on service integration and coordination across ED and NDIS providers.

Ethics approval was granted from the University of South Australia Human Research and Ethics Committee in April 2021 (Protocol 203626). The research team included a lived experience researcher and a lived experience carer researcher. The lived experience advisory group were paid for their time and expertise and are named authors on the publications for this project (Banfield et al., 2021; Happell & Roper, 2007).

Recruitment

A purposive and snowball recruitment was chosen in line with the guidelines of the approved national recruitment strategy. Researchers provided information forms to potential participants which contained information about the study and the lived experience of the researchers and gave opportunity for questions to be asked. Participants were advised that pseudonyms would be used and all data would be deidentified, including any information that could identify the participant. Participation was voluntary and potential participants were advised that they could withdraw from the interview at any point. All participants signed consent forms and interviews were conducted at offices in the university, at the participant's home or via zoom. Participants were notified that they could have a break at any time and have a support person present. There were no withdrawals from the project after the interviews were conducted.

Interviews and thematic analysis

Interviews were conducted by the first author, audio recorded and transcribed verbatim. The 24 interviews ranged from 20 to 81 (average 45) min, resulting in a total of 18.08 h of recorded information. Field notes (including reflexive journaling) were taken during the interviews to augment the audio-recorded-data. Saturation is difficult to gauge in reflexive thematic analysis. In an exploratory study, researchers agreed that anything over 20 participants would be considered enough (Creswell, 2013). All participants that applied over the nine-month period to be part of the research and that met the criteria were interviewed. After 24 interviews no new patterns or information were emerging. Data were sequentially and concurrently analysed while the interviews were being conducted so that researchers could gain familiarity and grow in understanding of the experiences of the participants, broadening their knowledge which in turn enhanced the subsequent interviews.

To organise the data, transcripts were uploaded to the NVivo software platform and were analysed thematically. Authors 1 and 2 then conducted a reflexive thematic analysis independently using the guidance of Braun and Clarke (2019). Qualitative data analysis is, as Braun and Clarke state (2019), about interpreting the collective story of a shared experience. By rereading and reflecting on the data, making connections and identifying exceptions, codes were created, using the language of participants to capture the nuances, variety and colour of their experiences. From these codes themes and subthemes were generated. Analysis and interpretation of the data enabled the inductive process of recording, discovering, analysing and interpreting what an experience means to a collective group of people in a certain setting, time and place (Reid et al., 2005).

Authors 1 and 2 compared coding results and proceeded to discuss differences regarding how their frames of reference and analysis were guiding the interpretation of themes and/or subthemes reflective of the data. Formulation of themes and subthemes occurred until the researchers felt key meanings that were prevalent in the data were expressed by the themes.

The multidisciplinary research team included the following disciplines: mental health nursing, psychology, sociology and applied science. The principles of research trustworthiness were employed (Lincoln & Guba, 1985). *Credibility* was ensured by checking the transcripts against the recordings, sending transcripts to participants for member checking and comparing themes across interviews. *Transferability* was enhanced by providing clearly outlined processes to enable the repeatability of the methods in other contexts and settings. *Dependability* was demonstrated through reflexive journaling to reflect on the intersubjectivity of the researcher (self-awareness, situational awareness, motivation, experience). *Confirmability* of the research is evident with the use of a qualitative, descriptive, inquiry approach, suitable for lived experience research (Prosek & Gibson, 2021), using reflexive thematic analysis and with findings coming from the data (inductive) (Braun & Clarke, 2019). The COREQ standards for reporting were adopted as a framework for reporting (Tong et al., 2007).

Participant demographics

Twenty-four people participated in audio-recorded interviews between March and November 2022; inclusion criteria and demographics are listed in Table 1. Twenty participants were people with lived experience of PSD (two with a dual role as a carer of an NDIS recipient) and four carers, from six states of Australia. Ages ranged from 25 to 65 with the majority being in the 25–34 age range. Nineteen participants identified as female, four as male and one self-identified as a trans man. Two participants identified as Aboriginal and four identified as culturally and linguistically diverse. Four participants reported living in a rural or remote area and 12 reported having experienced homelessness. Twenty participants reported chronic health conditions and their reasons for presenting to the ED are listed in Table 2 varying from anaphylaxis to suicidal ideation. Two participants had a peer worker attend the interview with them. Participants reported on multiple presentations to the ED; 19 stated they were discharged into the community, 11 were admitted to hospital, one left without being treated and one was arrested by police and taken into custody. In response to the question ‘Did ED staff ask you if you had an NDIS plan?’ six replied ‘yes’, 17 replied ‘no’ and one participant said their carer had disclosed that they had an NDIS plan. Two participants reported that they had been approached by a peer worker in the ED.

RESULTS

This paper reports on the subset of questions around experiences and barriers to therapeutic care and what worked well. Four main themes were constructed from the data: (a) *Diagnostic overshadowing*; (b) *Judgement and stigma*; (c) *Waiting without hope*; and (d) *If things went well*.

Theme 1: Diagnostic overshadowing

All participants expressed this overarching theme. If a person was known to have a mental health history, physical symptoms were attributed to mental health.

They literally tried to send me home because I was classed as a psych patient

Participants who presented to the ED with a physical emergency but also had a mental health history, reported that clinicians would overshadow medical symptoms, assuming a physical condition was secondary to a mental health presentation. This had the effect of casting a narrow focus on mental health as a primary concern and delaying or withholding medical intervention.

> She read my brief history of…psych related issues, and made a judgement, that I was presenting with a psych related issue. I was genuinely unwell…They literally tried to send me home because I was classed as a psych patient. (Participant presenting with unstable blood pressure and blood sugars.)
>
> (P16)

One participant presenting with chronic asthma stated,

> …one time I went it was [for an] asthma attack…and the consultant wouldn't let me get treated…he said not to help me for a panic attack, I just need to get over it. And it was a full-on asthma attack…because I'm psychosocial…they never treat me and they turn me away even when I'm having a chronic asthma attack.
>
> (P18)

If you are going to blame it on mental health, you really should engage the mental health team

Participants not only reported that physical conditions were overshadowed but that medical clinicians made mental health decisions without consulting the mental health team.

TABLE 1 Demographics.

Inclusion criteria	*Exclusion criteria*
Aged >18 years; have lived experience, psychosocial disability and an NDIS plan; not in acute care at the time of the interview; presented to the ED while in receipt of an NDIS plan within the last 2 years; or a carer who has presented to the ED with a person who has a psychosocial disability and is in receipt of an NDIS plan, within the last 2 years	Anyone that is not >18 years; unable to give informed consent; anyone that does not have a psychosocial disability or NDIS plan; anyone that has not presented to the ED; or a carer who has not presented to the ED with a person who has a psychosocial disability and is in receipt of an NDIS plan within the last 2 years
Participant	
Consumer	18
Carer	4
Consumer and carer	2
Age	
25–34	9
35–44	6
45–54	3
55–64	5
65+	1
Age of the person you care for	11, 13 and 15, 20, 40, 57
How do you identify	
Aboriginal	2
Caucasian	22
CALD	4
LGBTIQ+	3
Female	19
Male	4
Trans man	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
Asked by ED staff if you had an NDIS plan	
Yes	6
No	17
Disclosed by carer	1
Engaged with a peer worker in the ED	2

[a] Participants reported on more than one presentation to the ED.

TABLE 2 Reasons for attending the emergency department.

- Anaphylaxis
- Angina attack
- Anorexia
- Appendicitis
- Aspiration pneumonia
- Chronic asthma attack
- Dissociation from the complex PTSD, as well as a hypermanic episode
- Emotional distress
- Escalating psychosis, disorientated thinking
- GP asked her to go for pain relief for back injury as it was after hours
- Hallucinations
- Infected arm
- Medication change for bipolar
- NDIS removed all supports
- Paediatrician requested ADHD medicines to be prescribed
- Pilonidal disease
- Self-harming
- Suicidal ideation
- Suicide attempt
- Violent behaviour

> So that's the other thing. If you're going to blame it on mental health, you really should engage the mental health team.
>
> (P18)

Most participants reported a lack of access to staff from the mental health team. One participant with a chronic pain condition due to a physical disability stated,

> So when I expressed that it was impacting on my mental health, being referred to a mental health doctor or nurse even or team would have for me been at least some sort of outcome….
>
> (P5)

Theme 2: Judgement and stigma

All participants reported that their mental health history led to experiencing judgement and stigma when presenting to the ED and physical and mental health concerns were met with less urgency than warranted.

> And then if you do have mental health, I find it's stigmatised. It's stigmatised immediately. It's categorisation.
>
> (P12)

I felt like a criminal, treated like filth?

All participants reported feeling discriminated because of their mental health history. One female participant reported that when presenting to the ED while mentally unwell, the presence of security guards triggered feelings of vulnerability, increased anxiety and contributed to the prison like atmosphere of the ED.

> I often say to people, when you turn up to ED in a mental health episode, you just feel like a criminal…There's security guards placed around, watching you. Sitting outside the room or directly in the same cubicle as you.
>
> (P19)

The stigma of having a history of mental health impacts on how people are perceived when they present to the ED.

> …it's not just that you're treated like you're filth that you're talked about behind your back, you're almost assumed to be a druggie and everything, that you're low socio economic, all those stereotypes instead of just going, no, I'm a functioning adult, that just has some genetic things, some really sucky other things and that.
>
> (P16)

They just did not want me there – I just felt so neglected and unsafe

Most participants felt that they are seen as a burden and not taken seriously. One person with substance dependence who presented several times over a week due to feeling very unsafe reported:

> And they just would not listen to me… they just didn't want me there…'Oh, look him again'. It felt like they were just trying to turn me back the whole time, I just felt so neglected. I was like, 'Wow, these people really don't care about me, why am I here?'…I felt fucking hopeless…Yeah, I am a person just like them and not just, oh, yeah, you're worthless because you're an addict and you have no job and you've got nothing, and you're just coming in here for somewhere to stay. It's like well I've got a fucking house to stay at, I just need somewhere to go because I don't actually [feel] safe in my house by myself with my choices. I tried to explain it to them, but they just would not get it, and that's why I got locked up because I screamed at them man, and they called the cops on me.
>
> (P1)

All participants reported not feeling safe in the ED environment, due to not being heard or understood.

> Yeah, I didn't like being there, I didn't feel safe, I didn't feel heard, it was just, yeah, being misunderstood.
>
> (P11)

> It just doesn't feel a very safe environment.
>
> (P21)

Theme 3: Waiting without hope

All participants reported feeling powerless and hopeless, as physical symptoms and/or mental distress was minimised.

Waiting would really fuck you around

The ED is an over stimulating, uncomfortable and tense environment which is not beneficial nor therapeutic for someone who is in physical pain and/or emotional distress.

> …13 hours for the psych team to come around and ask those same five questions to tick a box and go, 'Oh, yes, you can go home now, there's no concern from us.'
>
> (P16)

> And just the waiting times were really, so I'm going to swear, would really fuck you around. Like, you'd be getting worse because you'd be waiting. That's eventually why sometimes I walked out.
>
> (P21)

Walking out of the ED to relieve anxiety from the environment, would be seen as non-compliant behaviour.

Not mentally ill enough – how much is enough?

Participants reported that they were told to go to the ED by a GP or NDIS support worker, as they were considered very unwell, and unsafe, only to have these concerns dismissed by ED staff.

> And then to have a psychiatrist kind of stand there who I've never met before going, you're not mentally ill enough to be admitted to a psychiatric ward for your own safety, but we believe you'll be fine if you go out in the world again. It's…really hard to explain how that makes you feel.
>
> (P13)

The minimisation of distress from ED clinicians can result in desperation for consumers. One participant recounted a conversation with ED staff that they felt were minimising their emotional distress,

> And I just said that I'd be back the next morning, the next afternoon with like a third-degree burn if they sent me home.
>
> (P20)

Even if you have cancer and you are going to die, I do not think you would leave feeling that unsupported

Most participants reported unfavourable outcomes at discharge without follow up or alternative services being organised. They often left the ED in a worse state than they were on arrival as expectations were not met. One mother brought her teenage daughter into the ED for a medication adjustment on the request of the paediatrician because they were not able to get an appointment with the paediatric psychiatrist for 12 months.

> Yeah, we left there, if I hadn't had [child's name] with me I would have just sobbed. Because leaving there I felt like there was no hope, there was nothing for her, what am I going to do with this child…I actually thought this is how we're going to live. How the hell [are] we going to get through this. And I don't think anyone should leave a medical space feeling like that. Even if you have cancer and you're going to die, I don't think you'd leave feeling that unsupported… But it took another six months before we could see a psychiatrist. So that's six months literally of hiding knives, hiding meds, monitoring her. Like, it's shameful and it shouldn't have happened…And it's not even that, what bothers me is that it's at such a crucial time of that child's life, socially, academically, everything…she's lost a year of her life…
>
> (P2)

I should not have gone

Most participants reported that they would not willingly return to the ED if they found themselves in need of physical or mental health support.

> It would probably take me being detained to present back at the hospital.
>
> (P5)

For one participant presenting to the ED in need of serious mental health care resulted in him being taken into custody.

> I just kept coming back. I was so lost, but, and then I just gave up in the end, after I went to jail. I was like, I'm not going back there, it's pathetic.
>
> (P1)

Negative experiences of ED presentations may lead to avoidance of the health care system and future complications. One participant who has a chronic cardiac history stated:

> So the emergency department…I would rather not go. I shouldn't have gone. I would not go again. I would not call an ambulance again in the same situation. I just wouldn't.
>
> (P14)

Theme 4: If things went well

Among the many traumatic reports during multiple ED presentations from interview participants, half of the participants described one positive interaction with staff. When asked the question 'What worked well for you in the ED?', one man who lived with chronic pain, and at times experienced serious emotional distress, talked about the long-lasting impact of engaging with a mental health trained nurse who demonstrated a therapeutic connection.

> I was on holiday I was unwell, so I went to one of the inner-city hospitals, and they had a different approach. I went and saw a guy there that was a mental health nurse, and he was brilliant…the very opposite to what I've experienced at the other hospital, or approaches. The guy was spot on…you could tell by the way he was talking to me, and the way he was interreacting with me, and some of the advice he gave. And I keep some of that advice with me now…For some reason I didn't wait very long. He had insight into what I was going through…That was incredible…He was just very personable. I felt calm with him. I know he wasn't scared of me. He just, he seemed like he was on my level…and genuine in trying to care for me…I know some of the things he said I didn't want to hear. But he knew his stuff; he was trained in that area. I trusted him.
>
> (P21)

This example of a mental health nurse who demonstrated a therapeutic connection, built trust through listening, displaying insight and providing care and comfort resulted in a life changing moment for this man. The following example shows incredible bravery by another participant and an example of ED staff really listening and facilitating an admission which changed the whole trajectory of her life:

> It all comes back to the fact that I was listened to…if I had not been going into [mental health ward] I'd probably be dead. I said that to the hospital… "If you let me out of those doors, I will die and I won't be found." And that's I think what cemented it. And if I didn't do the hard yards, and get admitted and work on myself, I would not be like this now. I would not be able to do University, I wouldn't be able to do TAFE. I wouldn't be able to be a carer, I wouldn't have a relationship…it all comes back to the emergency department and how they treat those people to get them on the right path.
>
> (P13)

A mental health nurse intervened in this example and was able to suggest a medication adjustment which has proved to be life changing for this young woman.

> That was my most positive one…the mental health nurse questioned why I wasn't on medication during the day and only on at night… which then sparked me to question my psychiatrist once I was able to go home… that admission was really the changing point for me being properly treated, because my psychiatrist wasn't convinced that it was bipolar at that point, despite having presentations of manic episodes…to have that admission into ED in a depressive cycle…that changed my life.
>
> (P19)

DISCUSSION

This study explored the experiences of people with a PSD and an NDIS plan presenting to the ED when needing crisis care. People with PSD have the knowledge of what is needed to effect change and influence person-centred care in this context (Daya et al., 2019; NHMRC, 2016; Pirkis et al., 2023). This discussion not only refers to academic literature but also includes reflective discussion commentary on findings from the lived experience advisory group who analysed the themes generated. These are provided at the end of the discussion.

Results of this study demonstrate that the expectations of people presenting to the ED and the clinicians attending to them are misaligned. Participants reported significant examples of discrimination, stigma and hopelessness. Their experiences included difficulties being listened to, having their physical conditions overshadowed and their mental distress and social stressors minimised, long waiting times and being discharged without receiving the help they require. This speaks to research that contends people with a PSD (and in this study an NDIS plan) report diagnostic overshadowing, minimisation of distress, stigmatisation and not being listened to (Duggan et al., 2020; Geiss et al., 2018; Hallyburton, 2022; Roennfeldt et al., 2021). Alternatively, this study demonstrates, when a person feels listened to, connected with, comforted and provided with adequate health/mental health care the outcome for them can be powerfully therapeutic and life changing (Wand et al., 2022).

Of concern is that people with a mental health history are still experiencing less than adequate crisis health and/or mental health care when their needs are acute and they present to the ED. Diagnostic overshadowing in EDs has been reported for decades (Carstensen et al., 2017; Clarke et al., 2007; Geiss et al., 2018; Happell et al., 2016; Roennfeldt et al., 2021; Shefer et al., 2014; Van Nieuwenhuizen et al., 2013). As we can see by the results of this study, stigma from a previous mental health history is still leading to overshadowing and delayed medical treatment leaving the person presenting with an overall sense that their personal circumstances are not understood.

While similar outcomes have been reported elsewhere (Carstensen et al., 2017; Johnston et al., 2019; Pascoe et al., 2022; Roennfeldt et al., 2021), people with PSD and NDIS plans experience of EDs draws our attention to the static nature of NDIS plans and their inability to deal with fluctuating condition (Hamilton et al., 2020, 2023). Indeed, although their presentation to the ED has occurred in a desperate attempt to gain assistance, the seriousness of their need is unseen and unacknowledged (Pascoe et al., 2022). Moreover, the sense of discrimination and vulnerability is magnified by the presence of security guards creating a prison like environment.

Most participants stated very strongly that they did not present to the ED unless it was critical, and they would not return voluntarily due to their previous experiences in the ED of feeling a burden or not good enough to be treated (Roennfeldt et al., 2021). As alternative services to the ED, for those in mental distress, are emerging and there is nowhere else to go (especially after hours) except the ED, this leads to the conclusion that many will be left in a state that defies comprehension (Sacre et al., 2022).

Although there were many reports of ED presentations being negative, half of the participants reported one incident when things went well. These included commonalities were being treated by a clinician with mental health training who could therapeutically engage through listening, insight, care and empathy. A recovery-focussed therapeutic engagement requires a person-centred approach (Picker, 2013) which can be a challenge within the ED setting (Happell et al., 2019) with its biomedical model focus. A systematic review by Sacre et al. (2022) supports the findings of this study that negative experiences in the ED occur when people's expectations are not met due to negative staff attitudes, minimisation of distress, long wait times and denial of treatment. Conversely, positive experiences occur when people receive care from mental health trained staff (Sacre et al., 2022). The results of this study centre on people with a PSD and an NDIS plan yet concur with previous studies reporting on the broader mental health population (Carstensen et al., 2017; Johnston et al., 2019; Roennfeldt et al., 2021; Sacre et al., 2022).

A lived experience perspective by members of the advisory group: Caroline Allen, Dean Barton-Smith, Brooke Bickley, Jewels Smith, Louis Vega and Ursula Wharton.

People with a PSD and an NDIS plan with the complexity of physical and mental health concerns will, at times, require crisis care. The ED environment can be incredibly confronting especially when you are in pain and/or distress. We make the following comments and recommendations about the findings:

EDs are not fit for purpose. In responding to people with psychosocial disability, what makes these services stay the same and not change? Who in the leadership of health services is accountable to the poor practices that consumers experience in EDs? Those in power are making decisions for society without including the people they are providing services for, nor being accountable to society for not meeting these needs. There needs to be a big picture view from all perspectives.

As GP access is becoming more limited (appointment availability and the cost of Medicare gaps) ED presentations are changing. Fighting NDIA cuts in the Administrative Appeals Tribunal is costing society more than the NDIS plans being cut. The invisible sideways cost personally and to society when a person requires further support and seeks that from a state provider, for example, the ED, need to be considered.

The face and culture of ED needs to change as the environment is confronting and staff can come across as intimidating. This is hard to navigate for people when in pain and/or distress. EDs are ableist and hearing centric and not designed for people with mental health issues and/or disabilities and do not cater for diverse needs. When someone has a complex health, mental health and/or a disability, mental health overshadows a physical health presentation. Telling your story three or four times before seeing a mental health nurse is very hard for people presenting to the ED. Often assumptions are made, and clinicians are not asking the right questions or listening to what has or has not been said.

Work from a place of respect and understanding, careful communication, awareness of enabling space and time for the person to communicate, and include communication supports if needed. Provide for diverse needs, for example, hearing impaired, neurodiverse, psychosocial disability, as needed and employ staff with diverse backgrounds. Create private, safe, low sensory environments with a focus on comforts and care. This will deescalate emotions, provide reassurance and a soothing environment. By softening the atmosphere it will change how the ED is perceived which will result in de-escalation of anxiety. This will enable the person seeking care to gather their thoughts, express their needs, to be listened to; this will assist clinicians with providing person-centred care. It is vital to provide shorter waiting times, mental health training for all staff and alternatives to the ED.

Improving safety can also occur by reducing the presence of security guards at EDs and changing how they look (from 'dress to scare' to clothing that is less confrontational); this will reduce anxiety for people coming into the ED. Security guards can be provided with extensive training specific to supporting people to manage their distress (rather than being heavy-handed); this would change the atmosphere and provide support rather than punitive measures.

Strengths and limitations

The strengths of this national study are the inclusion of a lived experience researcher, a lived experience carer and the invaluable input from a lived experience advisory group that codesigned the interview schedules, recruitment strategy and provided feedback on the themes generated. Limitations include a lack of diversity in the participants' backgrounds. Future research with diverse populations would increase knowledge of more nuanced lived experience.

CONCLUSION

Findings from this study deepen understanding and provide unique insights into the experiences of people (and carers) who have a PSD and an NDIS plan, when presenting to the ED requiring physical and/or mental health crisis care. Currently the ED environment does not lend itself to person-centred care or to recovery approaches. Participants report that they would not willingly return to the ED when in need of physical or mental health care. This study provides distressing evidence of system-wide delay, obfuscation, failure and an inability to respond to needs presented, along with induced trauma at the hands of crisis care services.

Although clinicians care about the people they are attending to in the ED, they are under resourced, time poor and in need of specific training in mental health. Alternatives to EDs need to be found for those in need of mental health crisis care and EDs need to change practice to serve people with PSD who need crisis medical care. Future research could investigate if flexibility within NDIS plans to provide added supports, when needed, could prevent presentations to the ED.

RELEVANCE FOR CLINICAL PRACTICE

For people presenting to the ED, hearing clinicians explicitly state that they understand, accept and value what is said, rather than having a previous mental health history overshadow diagnostic decisions, will facilitate comfort and promote a trauma-informed person-centred approach. Providing a psychologically safe environment, being inclusive and aware of the complex elements of PSD will provide a foundation for immediate and ongoing practical assistance and emotional support. Being understood, listened to, and believed, having hope, and being supported in meaningful ways can mitigate ever present experiences of waiting without hope, fears of a misdiagnosis, and ever-present preoccupation with not being believed.

AUTHOR CONTRIBUTIONS

NP, LH, ML and HM led the design of the study. NP, LH, ML and HM, CA, BB, LV, JS, UW, DBS cocreated the interview guides and the recruitment strategy and reflected on findings. HM conducted the interviews and HM and ML conducted the thematic analysis and led refining of the themes with NP, LH, CA, BB, LV, JS, UW and DBS. NP wrote the 'Relevance for Clinical' Practice section. 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 there is no conflict of interest.

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).

PARTICIPANT CONSENT FOR PUBLICATION STATEMENT

All interview participants signed a consent form which included the following statement: I understand that while information gained during the project may be published, I will not be identified and my personal information will remain confidential, unless required by law.

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