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## Research Article

# Let Us Keep the Emergency Department Safe: National Disability Insurance Scheme Supports Workers' Experiences When Supporting People with Psychosocial Disability in the Emergency Department

Heather McIntyre, Mark Loughhead, Laura Hayes, Caroline Allen, Dean Barton-Smith, Brooke Bickley, Louis Vega, Jewels Smith, Ursula Wharton, and Nicholas Procter

Correspondence should be addressed to Heather McIntyre; heather.mcintyre@unisa.edu.au

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Internationally, community healthcare is provided by personal health budgets or personalised schemes as part of a consumer-directed care emphasis. Although the introduction of a personalised scheme in Australia has improved the lives of many, people with psychosocial disability (PSD) and their families have experienced many challenges with service integration. Six focus groups with 17 National Disability Insurance Scheme (NDIS) support workers were conducted between June and November 2022. Participants were asked semistructured questions about their engagement with emergency department (ED) clinicians when presenting with a person with PSD and NDIS plan. They were also asked how they contribute to service integration to improve communication practices between the two services. A qualitative, descriptive thematic analysis approach was used. Results indicate there is a need for improved service integration pathways between the ED and NDIS services. The thematic analyses identified five main themes: the ED is harmful and not safe, but nowhere else to go; make the ED safe; further training for ED staff; improving communication across services; and alternatives to the ED. This study reports NDIS support worker's experience when supporting a person they are caring for in the ED. NDIS support workers have an understanding of the needs of the people they care for; their wisdom can contribute greatly to ED clinical responses in crisis care. Recommendations are offered to assist with service integration between the two systems.

#### 1. Introduction

Empowering people to be in control of their in-home healthcare can improve the care they receive, as well as improve their wellbeing [1]. Internationally, community healthcare is provided by personal health budgets or personalised schemes as part of a consumer-directed care approach [2, 3]. Under these schemes, personal assistants, support workers, and care workers provide care for people in their own homes [3–5].

In 2013, the government in Australia introduced the National Disability Insurance Scheme (NDIS) with the goal to revolutionise disability care [6]. Over the last ten years, the NDIS has improved the lives of many people [7], yet, as a hybrid quasi-market-driven polycentric system [8, 9], the NDIS has some challenges [10]. Psychosocial disability (PSD) was added to the scheme without taking into consideration the unique needs of people with PSD [11–13]. A person with PSD, has multiple needs and requires care from

<sup>&</sup>lt;sup>1</sup>Mental Health and Suicide Prevention Research and Education Group, University of South Australia, Adelaide, Australia <sup>2</sup>MIND Australia, Eastwood, Australia

<sup>&</sup>lt;sup>3</sup>Mental Health and Suicide Prevention Research and Education Group, Adelaide, Australia <sup>4</sup>South Australia Lived Experience Leadership & Advocacy Network, Adelaide, Australia

various providers and systems, is living in the intersectionality of layers of complexity [14], while accessing services via a scheme that blends concepts that are incongruent [15]. These include the disability/permanency disconnect [16], static plans for a fluctuating condition [15], biomedical approach to assessment for people with disability/psychosocial disability [17, 18], and the "antagonistic forces" of "commercial confidentiality" and market competition created by a quasi-market private sector provision of disability/psychosocial disability care which has created silos and impedes service integration [19].

Support workers providing care for people under the scheme require minimal qualifications (short courses). In addition, mental health training is not a requirement for NDIS support workers (nor personal assistants/care workers internationally) and psychological therapies for people with PSD are not usually provided by the NDIS [20]. This results in complex needs (PSD) attempting to be serviced by carers who are not required to have the skills that are needed, which creates many challenges and gaps [21], leading to layers of disadvantage for people requiring care [22].

There are over 16,000 registered NDIS providers plus 154,000 unregistered providers [23]. Regulations for NDIS providers are minimal, the workforce is casualised, and mobile leaving support workers experiencing precarious employment [24, 25]. Although 62 percent of NDIS participants are male, 68 percent of support workers are female, many of whom are sole traders or casual [26]. Thin markets in both urban and rural areas occur due to location and/or availability of NDIS support workers, limiting choice and control for people receiving services [27–29].

People with PSD and a NDIS plan may experience a mental health crisis and require assistance from an ED which is well known to have access and quality care issues for people with mental health and/or psychosocial disability [30, 31]. They will present to the ED when community support has become insufficient [29], quite often out of hours [32].

Previous research has demonstrated that people with mental health and/or psychosocial disability when presenting to the ED have found the experience distressing and have not received the care that they have sought [29-31, 33, 34]. They enter the biomedical environment of the ED and wait longer for care [35], in an unsuitable and overstimulating environment [36, 37], often experiencing diagnostic overshadowing [38, 39], while being cared for by the staff who are not trained in mental healthcare [39]. Previous research has also reported that due to misconceptions about what the NDIS provides, people presenting to the ED in medical or mental health crisis experience service pullback and the person receives less care and follow-up from the ED than somebody without a NDIS plan [29]. Consequently, these people are discharged back into the situation that caused them to present to the ED without receiving the care they require [29, 34].

This paper is part of a larger project researching service integration between the NDIS and the ED [40]. Service integration can be a complex concept as there are many

definitions which can be from an organisational, clinical, or user perspective [41]. Ultimately, service integration aspires to provide healthcare while navigating across organisational divides to access services and can be defined as succinctly as

The process of building connections between services in order to work together as one to deliver services that are more comprehensive and cohesive as well as more accessible and more responsive to the needs [42].

Previous research papers have reported findings from the point of view of people with PSD and a NDIS plan [17, 43–45]. This study aimed to gather evidence of that experience from the point of view of NDIS support workers when engaging with the ED and their observations around service integration. How to make the ED safe, alternatives to the ED, training needs for ED staff, and communication practices to improve service integration between services are discussed. This participant group consists of people employed or self-employed as NDIS support coordinators, recovery coaches, and/or support workers [24, 46–48]. For the purpose of brevity, all participants of this study will be referred to as NDIS support workers.

#### 2. Materials and Methods

2.1. Study Design. This qualitative descriptive study with a generalist approach [40] explored the experience of NDIS support workers who assist people with a PSD and a NDIS plan when presenting to the ED. As this study is part of a much larger study and 24 individual interviews had already been conducted (with people with lived experience), the research team agreed that focus groups would be an appropriate method of data collection with NDIS support workers (conducting a further 20 interviews would have been unfeasible). The research team chose thematic analysis as a suitable and reliable approach within the qualitative descriptive analysis to identify themes [49], enabling researchers to stay "data near" [50, 51]. Analysis, therefore, occurs on the level of issues reported by those with lived experience as support workers and peers. Therefore, thematic analysis is an appropriate methodology, in alignment with a descriptive, exploratory approach. This project sought to have industry impacts (policy change affecting clinical practice) and included discussions of results with the lived experience advisory group. Ethics approval for the project was granted by the Human Research Ethics Committee of the University of South Australia in April 2021 (ID: 203626). All participants signed a consent form agreeing to participate in the project and maintaining the confidentiality of focus group discussions and the identity of other participants.

#### 2.2. Aims. The larger study aims are as follows:

(1) How do NDIS providers experience service integration and communication with ED care when supporting people with lived experience, carers, and families?

3

Health & Social Care in the Community

- fee for service). Some participants who expressed interest could not be accommodated.
- (2) What are the barriers to accessing therapeutic treatment within the ED through the health/disability/mental health systems interface?
- (3) How can barriers be transcended for improved person-centred care and recovery?
- 2.3. National Lived Experience Advisory Group. A national lived experience advisory group was formed (via expression of interest), including advisors residing in both regional and urban settings. As coresearchers, members of the advisory group gave direction and valuable input into the research instrument, specifically, in this case, the focus group schedule and the recruitment strategy. The advisory group reviewed interview themes and contributed to discussions of recommendations indicated by findings. Advisory group members were remunerated for their time and expertise.

2.4. Recruitment. The purposive and snowballing recruitment strategy employed by the researchers of this project was approved by the Human Research Ethics Committee of the University of South Australia. The lived experience advisory group assisted in compiling lists of contacts and organisations. These were approached via e-mail asking for support to advertise the project via their industry newsletters, internal networks, and posting on their social media and websites. The research team retained these e-mails of support. Recruitment material included project information, inclusion criteria (Table 1), approximate length of time of the focus group, contact information, remuneration details, statement of consent to be audio recorded, and deidentified excerpts of transcripts to be published and data storage. Potential participants contacted the research team via e-mail who then responded via e-mail and follow-up phone calls, where questions were answered and availability was ascertained. The research team then scheduled focus groups, providing all participants with a video conferencing link keeping in mind the time differences across states of Australia. Once each focus group was completed, the audio recording was sent to an online transcription service (with a confidentiality agreement already in place) and transcriptions were provided back to the research team within a few days. Participants were remunerated for their time.

During the focus groups, the researchers gave participants the opportunity for questions about the project, confirmed that all data would be deidentified, and gained agreement that conversations would remain confidential. Researchers asked additional clarifying questions of the participants to obtain a clearer understanding of the circumstances and situations that were being reported. Focus group discussions did provide a rich source of information as participants' conversations prompted further discussions as the focus groups progressed. Participants expressed how much they were learning from each other during the focus group discussions.

Conducting focus groups via a video platform was necessary to gain input nationally and was an advantage. Coordinating schedules to suit participants' availability was a challenge due to the nature of their work (casualised and

2.5. Sample. Seventeen NDIS support workers participated in six focus groups between June and November 2022. Focus groups were conducted over a video conferencing platform and participants came from five different states within Australia. Most participants were female (n = 16). Participants ranged in age from 25 to 70 and n = 5 were working in a designated peer role. Participants held a range of roles in support of people with PSD and a NDIS plan (some with more than one role due to the nature of casual employment). They are as follows: support worker, support coordinator, and lived experience as a veteran n = 1; support coordinator and a recovery coach n=3; support coordinator n=3; support worker n = 3; support worker and recovery coach n = 1; and support coordinator, support worker, and recovery coach n = 1. Participants had been employed in these roles from 10 months to >10 years (mean 4.7 years; median 3 years). The participants of this study had a high level of education and experience, much greater than what is required of NDIS support workers. Qualifications ranged from professional certificates to masters' degrees and can be seen in Table 1. Ten participants held at least one bachelor's degree (fields were education, psychology, social work, health sciences, nursing, and counselling); two participants held two degrees and one participant held three degrees.

2.6. Focus Groups and Thematic Analysis. The six focus groups ranged from 55 minutes to one hour and 20 minutes, resulting in 416 minutes (almost 7 hours) of recorded information with an average focus group time of 69 minutes. All focus groups were conducted by HM and were audio recorded and transcribed verbatim. Once the transcriptions were provided by the transcription service they were checked by HM against the recording and sent back to the participants for crosschecking to give an opportunity to add or change any of their responses. Transcripts were then uploaded to the NVivo software platform and a thematic analysis was conducted using the guidance of Braun and Clarke [52]

HM and ML independently conducted a reflexive thematic analysis and then compared the coding results. The researchers reread and relistened to the recordings repeatedly to gain data familiarisation. Initial codes were generated; these were added to and adjusted as further data were analysed. The themes that emerged were reviewed and compared with the initial themes to ensure accurate representation. Discussion around nuances and differences occurred until an agreement was reached on themes or subthemes. The process enabled reflexive conversations around the perspective and interpretation of the data. Discussions continued until both researchers were in agreement that the final themes accurately represented the data. It was agreed that data saturation was reached during the inductive thematic analysis when new codes or themes were no longer being generated [53]. The COREQ standards were used for reporting [54].

TABLE 1: Demographics.

| Inclusion criteria: 18+, working supporting people with |
|---|
| a NDIS psychosocial disability plan who have presented  |
| to the emergency department                             |

| a NDIS psychosocial disability plan who have presented                               |         |  |
|--|---------|--|
| to the emergency department  |         |  |
| Gender<br>Female/male  | 16/1    |  |
|  | 16/1    |  |
| Lived experience   | 9       |  |
| Lived experience-yes Lived experience as a veteran                                   | 1       |  |
|  |         |  |
| Designated peer role  Designated peer role   | 4       |  |
| Position   |         |  |
| Support coordinator  | $8^1$   |  |
| Support worker   | 5       |  |
| Recovery coach   | 5       |  |
| Disability advocate  | 1       |  |
| Mental health worker   | 2       |  |
| State residing   |         |  |
| QLD  | 2       |  |
| SA   | 11      |  |
| Vic  | 2       |  |
| NSW  | 1       |  |
| WA   | 1       |  |
| Length of service in mental healthcare   |         |  |
| <1 year  | 3       |  |
| 1-2 years  | 4       |  |
| 2–5 years  | 4<br>4  |  |
| 5–10 years >10 years   | 2       |  |
|  |         |  |
| Qualifications: undergraduate and professional<br>Aboriginal mental health first aid | 1       |  |
| Advance certificate in offender rehabilitation                                       | 1       |  |
| ASIST  | 2       |  |
| Certificate 3: aged care   | 1       |  |
| Certificate 4: child youth and family intervention                                   | 1       |  |
| Certificate 4: MH  | 3       |  |
| Certificate 4: community health  | 1       |  |
| Certificate 4: family support  | 1       |  |
| Certificate 4: leisure and lifestyle   | 1       |  |
| Connecting with people   | 3       |  |
| Diploma of community services  | 1       |  |
| Emotional CPR  | 1       |  |
| Hearing voices approach  | 1       |  |
| Intentional peer support   | 1       |  |
| Lifeline crisis support  Mental health first aid                                     | 1       |  |
| Power threat meaning framework   | 10<br>1 |  |
| Recognise and respond  | 1       |  |
| Suicide prevention   | 2       |  |
| Trauma course  | 2       |  |
| Qualifications: graduate and above   |         |  |
| Bachelor's degree (adult education, psychology, nursing,                             |         |  |
| health science, and social work)   | 10      |  |
| Honours degree (psychology and social work)  | 2       |  |
| Graduate and masters (social work and counselling)                                   | 5       |  |
| One degree   | 6       |  |
| Two degrees  | 3       |  |
| Three degrees  | 1       |  |
| <sup>1</sup> Some participants had more than one role with different organisations   |         |  |

<sup>&</sup>lt;sup>1</sup>Some participants had more than one role with different organisations.

#### 3. Results

This paper reports identified themes from the thematic analysis as follows: the ED is harmful and not safe, but nowhere else to go; make the ED safe; further training for ED staff; improving communication across services; and alternatives to the ED.

- 3.1. The ED Is Harmful and Not Safe, But Nowhere Else to Go. All participants expressed the view that the ED is not a suitable place to support someone in a mental health crisis due to the highly stimulating environment, lack of mental health-trained staff, and the long waiting times to access support.
- 3.2. ED Trauma, I Call It: Not a Safe Place to Go. Most participants spoke about the dichotomy of having one option to seek help for a mental health crisis but knowing that help would bring trauma.

They already know they're going to be retraumatised. ED trauma, I call it, and they know they've got to go because there's nowhere else to go. (FG4/10)

3.3. Elitism Creates a Barrier with Psychosocial Care. Just as people presenting to the ED experience stigma, NDIS support workers presenting with a person in distress also experienced their concerns being disregarded by the ED staff. The collateral information they offered through background knowledge and experience with the person presenting was not highly valued.

There's a slight form of elitism where you have clinical nurses that tend to look down on carers or support workers, as just being chauffeurs, that there's not an understanding of what really goes on. (FG2/4)

All participants spoke of their knowledge being dismissed by the hospital staff "because what do they know." (FG6/15)

There is a hierarchy, they won't really respect the opinions or the knowledge of NGOs and NDIS providers, and they won't take what you're trying to tell them on board because you're not a clinician and that can be really detrimental to the getting the whole picture. (FG1/1)

3.4. Up the Meds and Discharge. Participants reported that rather than incorporating a mental health or disability approach to care, the default response of ED staff was biomedical and initially included prescribing medication.

That's what I find a lot of the time happens, just medicate people more to fix it, and then send them out. It makes the situation worse once the medication wears off. (FG1/1)

This was accompanied by an observation of an attitude of futility from ED staff.

They just don't have any time and there's such brief intervention it doesn't feel like they expect anything out of it, to tell you the truth. (FG2/5)

- 3.5. Make the ED Safe. Participants gave many examples of strategies and suggestions used to keep the people they support safe in the ED and provide dignity, support, and comfort.
- 3.5.1. Support Worker/Peer Support/Active Advocates. One peer worker described her advocacy and the lengths she was prepared to go at one presentation, to keep the person she was supporting emotionally safe.

I would not have gone to the public bar, so to speak. I insisted that we go into this (private) room as a support worker in that situation, I had to try and provide as much safety as I could. (FG4/10)

All participants reported the actions and interventions they use in the ED when supporting someone. The skill level required to care for someone with a PSD is much greater than what is the minimum criteria for a disability worker with the NDIS.

Reframing, paraphrasing, so there's a whole lot of microskills that are used to get the information and to build that trust and rapport. If you're actively listening and displaying empathy that empathy from lived experience. I mean, it's like gold, because they feel heard, they feel really deeply heard. (FG4/11)

People known to the person presenting and other support can bring comfort and reduce a person's anxiety that is often caused by the ED environment and waiting. Support workers are going to extreme lengths to deescalate anxiety.

If that person is able to be with them (friend, family, or carer) it's amazing how things will calm down. For one client having her dog... come to visit her de-escalates her whole situation. The hoops I had to jump through to allow the dog to be brought in to see the client, oh my goodness. (FG5/12)

3.5.2. How Much Training Is Required in a NDIS Support Worker Role? Although caring for someone with a NDIS plan requires minimal qualifications, most participants of this study had some mental health training with over half having graduate and/or postgraduate qualifications in mental health that far exceeds that of ED clinicians they are presenting to.

So all of my trauma-informed education, and much of what I draw on in my psychosocial support role is at a master

level. Yeah, my Master of Counselling has informed much of what I do. (FG4/10)

3.5.3. What Lengths Will I Go to? All participants reported going above and beyond to assist their clients in the ED. One sole trading NDIS support worker (who identified as a peer), without the support of an organisation, would stay on the phone with a client to keep them and others safe for several hours while they walked to the ED.

As long as I'm on the phone they are safe. But if I can't be on the phone to support them then it's not safe that means (client) walking a 10 kilometre trip because you can't put him in a taxi, you can't put him in public transport, or try to get him into an ambulance or police car or anything like that. But we go to pretty big extremes I think sometimes to keep our clients safe. (FG5/13)

3.5.4. Designated Mental Health Positions in the ED. All participants suggested a designated mental health clinician be available at the presentation to provide trauma-informed care.

In (Capital city name) hospital when I was working there years ago, they actually did have a mental health nurse and they would at least start to talk to the person for a few minutes in the waiting room so they don't feel completely abandoned and alone; a designated mental health person in the ED. (FG6/16)

- 3.6. Further training for ED Staff. Participants highlighted areas of further training that could improve outcomes.
- 3.6.1. ED Clinicians do not Understand What NDIS Provides. All participants suggested training be provided for ED clinicians about the disability support provided by the NDIS (sometimes for only a few hours a week), which sits alongside all other healthcare systems.

[They] don't have any idea what the NDIS provide. All they see is this client has somebody else in place so we can toss them off our list they have very, very little idea of what the NDIS actually does. (FG5/13)

As soon as they hear they've got NDIS there's an assumption that they are connected to the community mental health team and there is no community mental health team involved (or available). (FG5/12)

The NDIS does not provide crisis care and NDIS support workers reported engaging in active advocacy to gain healthcare from the ED.

I find that we're constantly having to explain the fact that we (NGO) are not a crisis care service, we are not an acute care service and I often provide the COAG agreement,

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which is quite clear that acute care is still the responsibility of the Health Department. (FG5/13)

The assumption that the NDIS can provide all required care leads to service pullback, the person being left to wait and being discharged with less continuity of care and follow-up than someone without an NDIS plan, as ED clinicians assume the cost can be passed onto another part of the health service.

"Well, you shouldn't be here, you should be utilising your NDIS supports." And they're in and out as quick as they can get them out the door, basically, with no follow-up that people without NDIS would get if they presented to ED. (FG3/6)

They've got an NDIS plan, therefore we use their NDIS money. It's constant fighting about who's paying (FG5/12)

3.6.2. ED Clinicians Need Mental Health Training. All participants reported that ED clinicians lack mental health training, including trauma awareness, which contributes to the unsafe environment in the ED.

And a lot of ED staff are not mental health trained all they see is risk and that fear, it's almost like the client will feed off that. (FG5/12)

I think, for me, that the biggest thing I see with all the medical is there's just no trauma awareness. The only ones I'm seeing that are more trauma-aware is where the training has been done in England or America. (FG4/11)

Presenting to the ED and being cared for by clinicians without the skills required, lead to people with high suicidal ideation being discharged.

"Too bad, we're going to release you because we don't believe you, or we just think you're chasing medication." Then we're scrambling to make sure that they are safe and are not going to actually move forward with that plan. So it's very challenging.. (FG1/2)

- 3.7. Improving communication across Services. All participants expressed frustration at not being included in communication pathways or only being included if they continuously instigated communication with the ED.
- 3.7.1. Connect the Silos-Often in My Own Time. Participants spoke about the lack of communication between all health services and the NDIS.

That's right, they're all living in silos. (FG3/7)

All participants reported creating pathways of communication with ED clinicians and other services, in their own time, as service integration is not a funded item for the NDIS.

I'm not paid to provide that information, I'm only paid for my face-to-face time with the client. I believe support workers, good quality trauma-informed support workers, have an enormous amount to offer in terms of helping get pertinent information to the right people, with the client's consent, but I don't think they're really seen in that manner. (FG4/10)

3.7.2. NDIS Needs a Seat at the Table from Presentation to Discharge. Most participants reported that they would only be contacted by the ED when they were arranging discharge.

They usually only contact (NDIS) when they want to discharge. (FG5/12)

I think there needs to be a constant dialogue going on with what is occurring in the ED. (FG2/5)

The usual practice would be that the people they are supporting would be discharged without NDIS support workers being notified.

And NDIS support are not advised at this, so they're just literally throwing them out in the street. (FG2/4)

Suggestions to enable shared communication ranged from being included in care team meetings to a designated contact person in the hospital who communicates with NDIS service providers.

And having potentially maybe even care team meetings between the client and their supporting network. (FG3/8)

So a Community Coordinator that focuses on any presentations from within the NDIS space, and they are the point of contact. (FG2/4)

*3.7.3. Building Relationships.* Some participants spoke about the efforts required to build relationships with mainstream health service providers and through this, they can avoid the ED completely.

But it's just a really big slog with mainstream providers a long-time of relationship building. Once the clinics know us then they will arrange for admission without ED and we can just walk straight to the mental health unit and take a bed. So it's not just one hospital. It's trying to maintain those relationships with each one of those units. (FG5/13)

3.7.4. Working Together for Crisis Prevention. One NDIS support worker who identified as a peer and works for an NGO described one situation where communication with ED clinicians worked well and created a positive outcome.

We had quite a good situation recently where a client went to hospital by ambulance. It was a very collaborative process with the client. They knew that they needed to be

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there and wanted to be there. We made that call to say who we were and what we were doing. And then the consultant psychiatrists called me directly to get some background information and understand what had happened leading up to the deterioration, and really took that into account. They then went and assessed the client and then called me afterwards to run through what had come through in the assessment to determine what was baseline and therefore what needed to be focused on and they facilitated an admission and had communication with us throughout, so that we could remain involved and support the client in that admission. (FG1/2)

3.7.5. Less Casualisation of NDIS Workforce. As many NDIS support workers can be in casual positions within NGOs or as sole traders, this also contributes to communication gaps as people move employment.

In NDIS, there's just such a big turnover of staff, and that really does impair communication. (FG6/14)

3.7.6. Effective Tools and Plans. All participants talked about the various tools they used to promote choices and information sharing with mainstream health services.

I generally have a one-pager, which is like a sheet that shows everybody who's involved with a person and I overshare the hell out of that, and it's like a forcing people to cooperate tool, basically. (FG2/5)

Participants spent time with consumers to prepare tools (crisis plan, mental health advance care plan, emergency hospital admission plan, hospital management plan, and a folder of documents), which could be used in a crisis. When a person with PSD and an NDIS plan presents to the ED with a crisis plan signed off by the GP, psychologist, and psychiatrist, the care required is expedited.

We get it (crisis plan) signed off by their GP, their psychologist, their psychiatrist prior to admission. When we get that signed off by professionals it tends to have a bit more weight. (FG5/13)

#### 3.8. Alternatives to the ED

3.8.1. Alternative Services. All participants expressed optimism that alternative services could make a difference.

We're a little bit lucky that we can now redirect to the (alternative mental health service) have comfy chair, and a sandwich and a choccy milk, and there's peer workers that are staff there, so that's a very different experience I think, and they willingly go there. (FG6/15)

Alternative options to EDs which offer a recovery approach to care were endorsed by most participants.

I've read a lot of projects overseas which are almost like an ED for people with mental health, and they get sort of

brought in with warmth and understanding and friend-liness. (FG6/14)

3.8.2. Other Support Options to Sooth Distress. Participants spoke of de-escalation and soothing strategies used when clients were distressed to avoid going to the ED.

I'll remind her of how bad the hospital is and, "You're going to get cold, they're not going to listen to you." "Hey, you can stop now," and I can calm her, "You've got your warm bed at home," and it'll be nine times out of 10 now, I can deescalate and avoid the hospital. I'd almost be better taking her to the beach, quite honestly. (FG4/10)

#### 4. Discussion

This qualitative descriptive study heard from NDIS support workers about their experiences caring for people with a PSD and a NDIS plan when presenting to the ED. Findings concur with other studies that reveal a disconnect between the NDIS and other services [17, 19, 48]. NDIS support workers find that the ED can be an unsafe environment for the people they are caring for [30, 31] and actively intervene and advocate to promote safer interactions and shared understanding. Several intersecting elements may potentially contribute to the ED environment being unsafe. These include stigma being expressed by some ED clinicians towards NDIS support workers, ED clinicians not understanding what the NDIS provides, and their limited education in mental health. The lack of communication between services reduces service integration and affects the continuity of care. The interventions (including tools) that NDIS support workers facilitate to address this are discussed. Recommendations from the project's lived experience advisory group are provided.

4.1. How to Make the ED Safe. The participants of this study stated that the ED environment is unsafe for people in mental health crisis [55], yet there is nowhere else to go [32]. People presenting to the ED have the right to access healthcare and to feel safe when doing so [34] and participants of this study, as NDIS support workers, report actively advocating for the people they care for in the ED environment to make it safe.

EDs operate under the biomedical model and due to time and resource pressures triage with a medical crisis focus [35]. People presenting with a mental health emergency require a trauma-informed approach and a safe space for suicidal distress [56, 57]. Added to this, people with a PSD who present to an ED with a medical emergency, have their symptoms overshadowed due to a mental health history [39]. Education and support for ED staff in trauma-informed care and disability communication skills are important for supporting people to explain their difficulties while at the same time, they may also be navigating the uncertainty of an overstimulating environment. People in distress explain their actions and experiences through their stories [34]. Working side by side and coconstructing care are widely considered

essential for safety in mental healthcare to build rapport and decrease distress [31, 58]. Then, the person is better placed to ask questions, seek clarification, and leave the ED with coordinated planned actions, which will reduce healthcare avoidance in future [32, 35, 59].

4.2. Emergency Department Clinicians Need Mental Health Training. Internationally, there is a call for ED clinicians to upskill with mental health training [60]. Some hospitals have consultant liaison psychiatry teams who have higher levels of specialist knowledge for engagement and understanding of a person's complex needs, when they present to the ED with a mental health concern [61]. Calling these teams earlier to engage with a person presenting with a PSD will provide more appropriate care than what is offered by clinicians who are not mental health trained. It was evident from participant responses in this study that care was offered by medically trained clinicians and not mental health specialists. Conversely, when care was offered by clinicians with mental health qualifications, outcomes were predominantly positive. One study calls for mental health to be considered a core business for the ED, rather than being seen as a distraction [61].

4.3. Connecting the Communication Silos-Service Integration. Many studies report on gaps in system communication between the ED and primary care support post an ED presentation [30, 59, 62, 63]. Parallel to this, communication with health services and the NDIS has been highlighted as an issue systemwide [17, 19, 48, 64]. Although a lack of service integration was one of the four themes highlighted in the Productivity Commission Report [65] as a driver for introducing the NDIS, service integration was not a funded item under this scheme. Consequently, a lack of service integration between the NDIS and other healthcare services has been reported as a cause of service fragmentation [48, 66]. This study reports that NDIS support workers, often in their own time, are attempting to facilitate communication across health and mental health services including the ED [64], yet unless health/mental health/ community services/NDIS collectively take responsibility for service integration it will continue to be "ad hoc" [48]. This has implications for staff burnout which in turn will affect service provision for the people they are caring for. The introduction of the Psychosocial Disability Recovery-Oriented Framework attempts to address the specific PSD concerns with the NDIS [11].

Although the National Disability Insurance Agency (NDIA) claimed that communication pathways were established prior to the commencement of the scheme, the 2018 NDIS Evaluation highlighted communication between the NDIS and all other health services as being "perceived by the mainstream sector to be largely unresponsive and difficult to communicate with" [67] (pp. xx-xxi). As service integration is not a funded item with the NDIS, a call for support coordination has arisen to meet this need [48, 68].

4.4. Tools to Help Communication. Participants spoke of the tools they use to facilitate communication and to express needs and wishes with clinical staff. Advance care directives

are commonly used for palliative care. To assist service integration between various health services, similar tools are being implemented [69], providing documentation of diagnosis, plus user preferences and support when engaging with medical or mental health services [31]. All participants of this study reported using variations of these tools to provide ED clinicians with information to enable communication across services and assist with the continuity of person-centred care. It is unfortunate that these plans are at times overridden, yet it is hoped that barriers to implementation such as legal ramifications [70], lack of training and access [71], and language used [70] among others, are addressed to promote consumer autonomy and a recovery focus [72].

4.5. NDIS Support Workers. As part of the disability workforce, NDIS support workers enable social justice activation for those in need within the community [73, 74] by removing societal barriers and providing practical care and mental health support which leads to a more equitable experience of everyday living. To work as a NDIS support worker, the qualification requirements are minimal [4], yet many of the participants of this study have considerable qualifications (Table 1), which enables them to provide more appropriate care for people with PSD. The mental health qualifications of many of the participants of this study would, at times, exceed those of ED clinicians, yet this is not commonly recognised nor is their point of view considered by ED clinicians.

NDIS support workers are often in casual positions (or sole traders), more likely to be women [75] and may have a level of lived experience themselves [76]. They are providing vital one-to-one care for their clients, under precarious workplace conditions, working in less controlled and isolated environments (people's homes) [77] and at higher risk of burnout [73]. We are asking a vulnerable group of people to provide services to a more vulnerable group of people through a system with minimal regulation, potentially leading to risk for NDIS support workers and their clients [73]. It is recognised that the "workforce lacks skills and churns staff" [11]. Therefore, it would be just as vital to include reforms in addressing workplace inequities caused by the implementation of a privatised scheme [24]. Private sector NGOs reducing their workforce or closing a business contribute to the NDIS casual workforce being mobile. People who are receiving care from a personalised scheme also contribute to the workplace instability of support workers as they may choose to use another provider or change support workers as is their right [78]. The provision of care for the people requiring services is lost as they move around the NDIS system of providers. This affects communication pathways across services and continuity of care suffers as gaps in service integration appear [29]. This becomes a burden to the people they are caring for who require consistency and stability [48].

It should be noted that some NDIS providers specialise in PSD care and the recovery coach role is PSD-specific. Five participants were recovery coaches. As can be seen in Table 1, nine participants have lived experience of mental health and most participants hold high levels of qualifications. As this group of participants supports people with PSD, they acknowledge themselves that the learning and experience they bring to their role exceed what is required for disability support workers (Certificate IV in Disability). This reflects that the level of support needed for caring for people with PSD.

Lived experience perspective and recommendations by members of the advisory group are as follows: Caroline Allen, Dean Barton-Smith, Brooke Bickley, Jewels Smith, Louis Vega, and Ursula Wharton.

Themes from these focus groups sadly show that the system has not changed. The drivers of why a change of practice have not been implemented are complex and include a lack of accountability of health system leaders on the failure of standards in EDs, as well as inadequate flexibility in NDIS plans to provide extra support when needed. Other reasons include the lack of support after hours, including easy-to-access general practice and ED alternatives which can offer more risk-tolerant and effective care without having to refer consumers to EDs. Alternatives to the ED should be safe and comfortable spaces where care is provided primarily rather than crisis management. There should be improved overlap between NDIS support providers and ED teams, including enabling NDIS support worker's presence for longer periods in ED when critical decisions are made. It is important that health system leaders see the gaps in services between EDs, NDIS, general practice, and peer-based safe spaces and the harms that occur from a user' perspective. We encourage leaders to take a big-picture approach to improving these services as well as demonstrating accountability back to consumers and families.

Poor attitudes cannot be fixed by money, but can be by education. Workforces in both EDs and NDIS-funded providers need high-quality, specialist training, knowledge, and skills in mental health so that they can provide kind, consistent, and committed care for people with PSD. The knowledge we recommend includes trauma-informed care, specialist communication for people with disability, and better knowledge of NDIS and PSD support service roles. The skills we recommend include using easy-tounderstand language, listening skills, asking the right questions, checking assumptions, building trust, meeting reasonable adjustments/accommodations, setting up comfortable and private environments, effective communication with carers, and communicating/collaborating across different systems. These skills are essential. Sometimes, it is the smallest things, such as kindness and genuine care, which make the world of difference.

4.6. Strengths and Limitations. The strengths of this nationwide study include the variety and wide range of expertise gathered from NDIS support workers. The collective wisdom of the advisory group contributed immensely to the study. It could be seen as a limitation that the majority of participants in this study, who self-selected to take part,

indicated strong commitment and interests in mental health and their skills and qualifications reflect this, therefore they were highly motivated to participate in this project. In other reports, the NDIS workforce generally is considered to have an undersupply of skilled mental health workers. A broader participant group would increase knowledge in this area and would be vital as the NDIS continues to function to document any changes in current processes.

#### 5. Conclusion

This study demonstrates that incorporating the knowledge and expertise of NDIS support workers enhances engagement with ED clinicians for the people presenting. Providing ED clinicians with mental health training and clear guidance around the support NDIS offers is imperative to guide clinicians toward suitable care options for people with PSD and NDIS plans. Strengthening connections between the NDIS and ED services by sharing responsibility for service integration would improve communication and continuity of care.

## **Data Availability**

Any request to access the data for this project will be directed to the research team and the Human Research Ethics Committee.

### **Ethical Approval**

This project has been approved by the Human Research and Ethics Committee of the University of South Australia (Protocol ID: 203626). This project was conducted in accordance with the Declaration of Helsinki (1964).

#### **Conflicts of Interest**

The authors declare that they have no conflicts of interest.

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