University of Sydney Policy Reform Project

Research Paper for NSW Council of Social Service: Embedding "Experts by Experience" in Social Service Provision — Approaches and Barriers

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About the Sydney Policy Reform Project

The Sydney Policy Reform Project ('Project') facilitates University of Sydney students to write research papers for policy organisations, and submissions to government inquiries, under supervision from University of Sydney academics. The Project is a volunteer, extra-curricular activity. The Project is an initiative of the Student Affairs and Engagement Team within the Faculty of Arts and Social Sciences, and the Division of Alumni and Development, at the University of Sydney. The Project is funded by a donor to the University of Sydney. Any inquiries about the Project or about this paper should be directed to the Coordinator, Ms Nina Dillon Britton, at the following email address: <fass.studentaffairsandengagement@sydney.edu.au>.

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1. Executive Summary

In Australia, social service providers are increasingly working with people with lived experience of disadvantage. This stems from growing recognition that people with lived experience of disadvantage have the expertise to understand the needs of service users.

Scholarly literature examining lived experience roles in social service provision is emerging as the workforce expands. The aim of this report is to summarise the literature on the approaches and challenges of embedding lived experience in service provision, in order to answer the question: What are the methods social service providers employ when working with people with lived experience of disadvantage in Australia?

To this end, the authors conducted a systematic literature review of peer-reviewed literature published after 2000 from the Australian context. 54 papers met the inclusion criteria. Terminology and definitions related to practices of social service providers working with lived experience expertise were inconsistent across the literature. The included papers mostly discussed people with lived experience of mental health issues and Aboriginal and Torres Strait Islander individuals and communities. Several models of embedding lived experience in social services were described in the literature, including community-controlled organisations; co-production and co-design; lived experience advocacy, consulting, and informing; and peer support.

Barriers documented in literature concerning the practices of social service providers working with people with lived experience of disadvantage include:

- power dynamics,
- tokenism, and
- stigma.

The reviewed literature included limited discussion of the practical challenges faced by lived experience workers (LEWs). Underexplored topics include the influence of financial constraints, the practices of recruiting and training LEWs, and their work roles and arrangements. Additionally, understanding of the details that contribute to LEWs' effectiveness is limited. In light of this, we have formulated a list of recommendations.

2. Introduction

This report has been formulated at the request of New South Wales Council of Social Service (NCOSS) to increase understanding around working with people with lived experience (PWLE) of disadvantage in Australia. The term is commonly defined as a person with lived experience of a health issue or other circumstance that requires service support. A lived experience worker (LEW) is, therefore, a PWLE working in service provision. We decided to refrain from making the association between lived experience and disadvantage in this report. We believe that a focus on "identities of disadvantage" potentially risks dismissing the multifaceted social identities of PWLE and negates the increasing focus on strengths-based approaches.

Based on a systematic literature review, this report charts the different approaches and barriers to embedding "experts by experience" in social service delivery in

Australia. Correspondingly, this report illuminates future avenues for understanding and supporting PWLE in social service provision.

3. Context

3.1. Importance of lived experience

The importance of working with PWLE is increasingly recognised. Social service providers acknowledge the important perspectives they bring to addressing the needs of service users (Commonwealth of Australia 2017; Health Service Executive 2017; Happell et al. 2019; McCann et al. 2008). Including PWLE alongside non-lived experience colleagues is likely to improve outcomes across all organisational processes (Rock & Grant 2016), with evidence suggesting that services improve with lived experience expertise (Crawford et al. 2002; Simpson & House 2002 cited by McCann et al. 2008). Additionally, service delivery by PWLE can be as, or even more, effective than conventional service delivery (Davidson et al. 1999; Deegan 2003; Clarke et al. 2000; Klien, Cnaan & Whitecraft 1998; Felton et al. 1995; Kaufman, Schulberg & Schooler 1994; Lyons, Cook, Ruth, Karver & Slag 1996; Paulson et al. 1999; Solomon & Draine 1995; Chinman, Rosenheck, Lam & Davidson et al. 2000 cited by Gates & Akabas 2007, p. 294). However, more research is needed to understand the full capabilities of the lived experience workforce (Happell et al. 2019).

The mutually advantageous relationship between organisation (or employer) and LEW—particularly in service-user facing roles—has been emphasised in a range of studies (Welford, Milner & Moreton 2021). Namely, service users and LEWs experience reciprocal benefits, including greater confidence, social skills, and a sense of purpose (Dorstyn et al. 2020), empowerment (Tambuyzer & Van Audenhove 2015).

cited by Happell et al. 2019) and mutual recovery (Reid et al. 2018 cited by Happell et al. 2019). Conventional workers and LEWs, as experts by experience, also benefit from mutual knowledge sharing to improve their respective practices (Munns & Walker 2015). Further, when meaningfully integrated and accepted into social service organisations, LEWs typically experience greater work satisfaction (Scanlan et al. 2020).

3.2. History of Lived Experience Inclusion

Lived experience work has primarily emerged from the disability and consumer/survivor/ex-patient movements of the 1970s and 1980s (Davies et al. 2014; Smith 2014). Its underlying intention is better care for service users, who benefit from community involvement, procedural justice, and empowerment (Davies et al. 2014; Smith 2014). Catalysed by the women's movement and the Chelmsford Hospital incident, and backed by numerous reports of mistreatment, PWLE lobbied for systemic reform and more supportive legislative frameworks (Smith 2014). This prompted legislative change, paving the way for the formal participation of PWLE in social service provision, especially in the mental health sector (Smith 2014).

The integration of LEWs in social service provision for Indigenous communities has not only promoted more culturally sensitive and culturally secure practices by service providers (Freeman et al. 2014), but also facilitated wider community outreach and impact (Yu 2019). Notwithstanding, it is important to note that certain branches of social services that work with PWLE in Australia still operate within complex, exclusionary frameworks of "Whiteness" that have adversely affected Indigenous peoples, migrants, refugees, and asylum seekers (Walter, Taylor & Habibis 2011).

While the mental health sector has received significant attention in the literature on the embedding of lived experience in social service provision, the body of research examining other sectors continues to grow as interest in the value of a lived experience workforce increases (Every & Richardson 2018).

But there will always be people experiencing a first serious episode of mental ill health who do not have the personal resources that I have built over the years. In the area of mental health there will always be a need for strong advocates and vigilance about the current treatments and services that are offered to people experiencing mental ill health. Legislating for human rights is only part of the solution. Empowering people through education, advocacy, and support will always be an essential part of ensuring that the human rights of people living with mental ill health are protected.

- Smith 2013

4. Aims

This paper aims to provide a rapid, exploratory, and objective synthesis of scholarly literature on the actual and theoretical practices of social service providers working with PWLE.

In particular, the focus of this report is:

 To describe the different models of social service providers working with PWLE; and To describe the challenges that result from the actual practices of social service providers working with PWLE.

5. Methodology

Our approach was iterative, reflexive, and exploratory. To familiarise ourselves with the topic, we read the reports suggested in the project brief and reports on peer support suggested by one of the authors of this paper, who is a Peer Support Worker (PSW). Initial drafts of this paper were based on a synthesis of a small number of articles deemed relevant to the topic from a brief exploratory search of Google and Google Scholar. Through discussions with our supervisor Professor Judith Cashmore AO, we further refined our understanding of the scope of, and key concepts in, this line of inquiry.

Accordingly, we conducted a systematic literature review to select, map, and summarise key knowledge underpinning relevant literature. Systematic literature reviews are used to synthesise the prevailing nature of a topic and can serve to frame investigations and decisions (Patten & Newhart 2018).

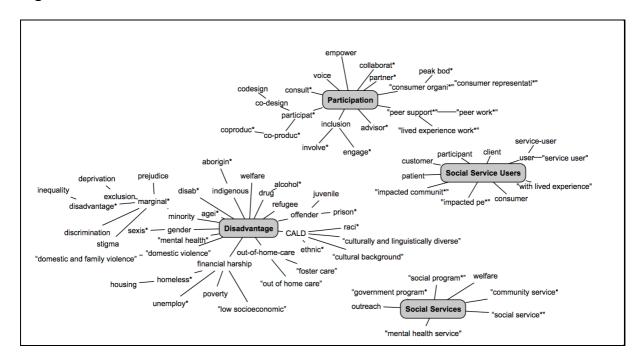
5.1. Search Strategy

In consultation with a university librarian, we developed a systematic search strategy (see Appendix A). Using terms (see Figure 1) informed by the project brief, initial readings, and the search strategy from a review on client-centred commissioning by Davies et al. (2020), we searched four databases:

- 1. Social Services Abstracts via Proquest
- 2. Family and Society Studies Worldwide via Ebsco

- 3. Multicultural Australia and Immigration Studies via Informit
- 4. Scopus

Figure 1. Clusters of terms used to search the literature.



5.2. Eligibility Criteria

The authors screened papers from the search (890 records) for relevance. 108 records remained after initial screening of titles and abstracts. We assessed the full texts of the remaining papers against inclusion criteria that accord with the "Population-Concept-Context" (PCC) framework for reporting literature reviews (Tricco et al. 2018). In particular, we included peer-reviewed scholarly literature:

- in English from the Australian context (population)
- published from the year 2000 onwards (*context*)
- discussing actual or theoretical ways PWLE have been involved in social service provision (concept)

54 papers met the inclusion criteria (see Appendix B for a summary table of these papers). To support the findings of our review, we also included case studies from other literature, including grey literature, cited in these papers, as well as additional information from articles identified in our above-mentioned, initial exploratory search.

5.3. Limitations of Approach

Given time constraints, the systematic literature review was limited to four databases. Likewise, to accelerate the review, abstracts and titles of studies retrieved in database searches were screened only once. We acknowledge that we may have missed some relevant insights and that a more exhaustive literature sample is needed to fully achieve our aim and reduce potential bias. The inclusion of more grey literature may also offer more insights from sectors that are underexplored in the scholarly literature from this particular line of research (e.g., aged care sector).

Although one author works as a Mental Health Peer Support Worker, both the present research team (see Appendix C for more information about researcher positionality) and most authors in the reviewed literature represent a limited range of lived experience perspectives. Given the nature of this report, additional input from people with a range of lived experiences in this work would have been valuable in contextualising the literature. Nevertheless, our review is important because it provides the first synthesis of this literature that we are aware of.

6. Findings

The following findings synthesise key insights from the reviewed literature. The literature points to a broad range of approaches to embedding lived experience in

social service delivery, including: co-production and co-design; community-controlled organisations; and lived experience input via advocacy, consulting, informing, and peer support roles. The literature also highlights numerous barriers experienced by PWLE working with social service providers under these approaches. This review identified three key barriers: power dynamics, stigma, and tokenism. Given that 54 articles were included in this review, the following findings will refer to a representative subset of these articles (n = 19), as well as other relevant articles identified prior to the systematic literature review that support our findings.

6.1. Approaches to embedding lived experience in social service:

A. Co-production and co-design

Co-production and co-design refer to the co-creation and management of knowledge and innovation through collaborative partnerships between social service providers and community members (Berends, Ritter & Chalmers 2015).

The processes of co-production and co-design benefit from the shared knowledge and differing expertise of PWLE and providers in informing successful social service delivery (Berends, Ritter & Chalmers 2015). Accordingly, best practice recommendations based on research on various sectors, including the alcohol and other drugs sector (Berends, Ritter & Chalmers 2015) and homelessness sector (Every & Richardson 2017), emphasise the importance of embedding these processes in social service delivery.

Co-production necessitates the inclusion of input from PWLE across all program stages, including design and implementation. For example, people with psycho-social

disabilities commonly engage in co-production with their social workers to create individualised recovery-oriented services (Brophy et al. 2015). In contrast, co-design necessitates the inclusion of input from PWLE at the design stage only (Community Mental Health, Drug & Alcohol Research Network n.d.). Based on input from young PWLE of out-of-home care and mental health professionals and researchers, the Bounce Project is an example of a co-designed training program aimed at promoting mental health for vulnerable youth (Rafeld et al 2020).

A notable example of co-design in the criminal justice system is a project led by the Aboriginal community (the 'Koori Caucus') with support from the Australian Centre for Social Innovation (The Australian Centre for Social Innovation 2019). Commissioned by the Victorian Koori Justice Unit, this project is an interlinking system of initiatives addressing Aboriginal over-representation in the Victorian criminal justice system. The Koori Caucus developed criteria to review potential initiatives aimed at promoting self-determined justice. Five prevention-focused initiatives have been co-designed with Koori caucus members, government decision-makers, and frontline staff.

B. Community controlled organisations

Community-controlled organisations are initiated, based in, and governed by specific communities of PWLE. Given that Western frameworks of wellbeing do not holistically address Aboriginal peoples' needs (Walter, Taylor & Habibis 2011), numerous community-controlled organisations have emerged in Australia to provide more culturally-aware, -respectful, and -safe services for Aboriginal people (Freeman et al. 2014),. Run by community members with local knowledge, these organisations have been effective in not only offering holistic and culturally sensitive services, but also

empowering the local community by giving them greater autonomy over their own wellbeing (Freeman et al. 2014; Yu 2019).

In light of rural and regional Aboriginal communities' negative experiences with white police officers, Aboriginal-led night patrols were established as community development initiatives in the 1990s. These patrols acted to resolve community conflicts and prevent violence, "not as police or an emergency service, but as local people who knew the individuals involved and the context" (Scott et al. 2018, p. 1032). Although Aboriginal-led night patrols have contributed to conflict resolution and prevention, they have also been criticised for promoting a "romanticisation of community self-regulation" and concealing the social disorganisation and inequalities that permeate Aboriginal communities (Scott et al. 2018, p. 1047).

The National Empowerment Project (NEP) is a community-led program that aims to reduce distress and suicide among 11 Aboriginal communities across Australia (Dudgeon et al. 2017). The project employs community members as co-researchers. By leading the research process, community co-researchers are empowered to identify issues impacting community health and wellbeing and solutions to address these.

There have also been a number of community-led services for refugees and asylum seekers, such as the Asylum Seeker Project (ASP) at Hotham Mission. ASP workers support people seeking asylum by providing housing and essential living assistance. By acting as role models, ASP workers support people who have been in detention and whose cases are still in progress (Vichie 2003). The program also helps refugees

and asylum seekers gain economic independence through the provision of moral support, funds, and workforce training. Many ASP clients not only achieve a successful immigration outcome, but also report feeling empowered by the program (Vichie 2003, p. 148).

C. Other Roles for Lived Experience Input

i. Advocacy, consulting, and informing roles

In advocacy, consulting, and informing roles, PWLE use their knowledge to inform improvements in service delivery. These roles can be either informal or formal and include working as a consultant, taking part in advisory groups and committees, and being a lived experience representative or advocate (Davies, Gray & Butcher 2013). Some PWLE avoid working with social service providers in a formal capacity to retain their level of control (Davies, Gray & Butcher 2013).

In these roles, opportunities for participation, particularly in a formal capacity, are typically controlled by authorities (Davies, Gray & Butcher 2013). Correspondingly, these roles are commonly associated with formal and legislated mechanisms for the input of PWLE that view service user participation as a right (Davies, Gray & Butcher 2013). In this respect, child-centred policy in Australia requires child protection workers to consult with and give weight to the child's perspectives in decision-making around care (Woodman et al. 2018). The planning and development of government welfare programs also involves consultations with established community groups (Mendes 2017). However, given that these consultations often do not engage with a diverse range of community perspectives, Mendes (2017) recommends open and

accessible democratic meetings that enable more inclusive and representative community consultation and even collective action.

Various Australian inmate or justice advocacy organisations give a voice to people impacted by the justice system on radio programs (Doyle et al. 2021). For example, presenters on the radio program Jailbreak are inmates, and their family and friends (Community Restorative Centre n.d.). This connects inmates with the community through their art, whilst informing the public on criminal, prison, and health issues. West Kimberley Regional Prison's weekly radio program presented by inmates promotes inmates' confidence and media skills (Bamford 2018).

ii. Peer support Roles

Peer support has been conceptualised in a variety of ways in the literature. It broadly refers to PWLE mutually helping each other in the face of social and/or health challenges (Penney 2018; Walsh et al. 2018). It capitalises on people's propensity to respond compassionately to shared struggles (Penney 2018). In Australia, peer support roles are relatively new (Dorstyn et al. 2020 p. 9). The use of peer support workers (PSWs) in mental health settings has promoted recovery-oriented practice, which emphasises rebuilding and reclaiming a meaningful and valued life regardless of diagnosis (Walsh et al. 2018). PSWs engage in many practices, including advocating, sharing resources, sharing lived experience, mentoring, supervising and training, promoting de-stigmatisation, and influencing team culture (Jacobson, Trojanowski & Dewa 2012; Davies et al. 2014; Nannen 2015).

A goal of peer support workers is to facilitate recovery and healing, such as inspiring hope and empowering peers.

(Collins, Firth, and Shakespeare 2016; Crane, Lepicki & Knudsen 2016; Gidugu et al. 2015 cited by Walsh et al. 2018)

Peer support is most prevalent in the mental health sector (Franke et al 2010), where it has been implemented to address the increasing demand for self-determined, recovery-oriented care (Davies et al. 2014; Pomery et al. 2016), as brought to attention by the survivor movement (Gray et al. 2017). Formal peer support models are also present in other sectors. Based on interviews with food charity volunteers, Lindberg, Lawrence and Caraher (2017) propose peer-to-peer support as a key service model to help meet the underlying social needs and increasing the resilience of people experiencing food insecurity.

Another form of peer support work is facilitation. In peer facilitator roles, PWLE facilitate interactions between service providers and users. Every and Richardson's (2018) guiding principles for a disaster resilience education program emphasise the need for providers to build safe relationships with homeless communities by employing peers to deliver the program. Similarly, McKenna et al. (2015) studied the role of Aboriginal Mental Health Liaison Officers (AMHLO) employed to promote Aboriginal peoples' access to the Northern Area Mental Health Service in Victoria. This study found that AMHLOs were involved in initiating the entry of Aboriginal consumers to the service, translating understanding, and building trust among the consumers and

clinicians, coordinating discharge pathways for the consumers and maintaining links with previous consumers.

6.2. Barriers Experienced by Lived Experience Workers

A. Power Dynamics

PWLE working with social service providers are affected by their position within a "distributed field of power relations" (Davies, Gray & Butcher 2013). When working with social service providers, PWLE paradoxically work within the very system in which they may have had negative experiences (Davies et al. 2014). Accordingly, LEWs value compassion and flexibility within service structures (Davies et al. 2014; Nannen 2015).

Existing social service systems often do not facilitate the inclusion of lived experience roles. Organisations often do not recognise lived experience "as a professional capability" (Gray et al. 2017). Consequently, LEWs experience uncertainty regarding their value and face distrust from their non-lived experience colleagues due to a lack of professional identity (Cleary et al. 2018; Davies et al. 2014). For example, when Nannen (2015) explained her lived experience qualification for working as a PSW in the mental health sector, she was scrutinised by colleagues. She hopes that the nationally recognised Certificate IV Mental Health Peer Work qualification will reduce this scrutiny. Recent research on the Australian forensic mental health sector revealed that LEWs are still widely considered service users rather than providers (Lambert 2021).

Resultantly, LEWs have mixed perspectives on sharing their lived experience expertise as consumer advocates in public forums, such as conferences and meetings (Davies et al. 2014). Although many LEWs view sharing their stories as empowering, some LEWs fear that in sharing their stories they would lose power over them (Davies et al. 2014). Concerns around retaining power extend across the lived experience workforce. Furthermore, PWLE may avoid working with social services as they believe that they lack the skills necessary to contribute and that their status will not be respected (Davies et al. 2014). Consequently, although LEWs should be considered qualified because of their lived experience, some LEWs may feel the need to pursue legitimacy by undertaking higher education (Davies et al. 2014).

Social service providers express concerns about the skills of LEWs and the value and suitability of their involvement in higher-level decision-making (Bryant et al. 2008). As a result, many LEWs are insufficiently involved in decision-making (Cleary et al. 2018); although, some organisations successfully involve LEWs at all levels (Munns & Walker 2015). In research by Bryant et al. (2008), drug rehabilitation services reported that limited practical mechanisms support higher-level involvement of service users in staff decision-making.

Additionally, many lived experience positions are poorly remunerated (Cleary et al. 2018), negatively impacting the willingness of PWLE to participate in service delivery. Interviews suggest that, generally, paid PSWs feel their expertise is more highly valued, while unpaid and/or under-resourced PSWs feel their contributions are unseen (Davies et al. 2014).

Relationship dynamics between LEWs and their non-lived experience colleagues are also an important consideration. PSWs have identified managers and supervisors who value lived experience expertise as important for embedding peer support work in existing service structures (Nannen 2015). Still, an analysis of PSWs' activity logs by Jacobson, Trojanowski and Dewa (2012) suggests that PSWs are minimally supported by non-lived experience colleagues. Relatedly, allyship between LEWs and sector professionals has been identified as important for the integration of lived experience in service delivery (Lambert et al. 2021; Scholz et al. 2020). In a two-day workshop aimed at producing recommendations to promote allyship in the forensic mental health sector, attendees emphasised the need for increased communications between different staffing groups about shared aims (Lambert et al. 2021).

B. Tokenism

PWLE, and their knowledge, can be subject to tokenism in social service settings (Davies, Gray & Butcher 2013; Lambert et al. 2021). Research on the social work and lived experience workforce in the Australian forensic mental health sector reveals concerns around lived experience expertise being undervalued and underappreciated in service delivery (Lambert et al. 2021).

Interviews with homelessness and mental health sector workers indicate that LEWs faced tokenism when they had been "asked to give input but felt their contribution had not influenced decision making"; "given positions on committees but not been asked their opinion"; "employed as an advocate but not treated as a professional"; and "told their input was valuable but had not been paid" (Davies, Gray & Butcher 2013). The systemic marginalisation of lived experience expertise and related undervaluing and

discrediting of LEWs has been referred to as epistemic injustice (LeBlanc & Kinsella 2016).

C. Stigma

The stigma against PWLE propagated by conventional professionals can limit the full integration and success of LEWs (Happell et al. 2019). Happell et al. (2019) found that nurses who reported stigmatised views of mental health service users valued the input of PWLE least. Similarly, Bryant et al. (2008) found that drug rehabilitation service users faced barriers to meaningful involvement with social service providers as they were considered 'lacking' due to their illness.

Despite this, research by Davies, Gray and Butcher (2013) and Stott (2017 p. 1187) shows that service users are motivated to engage in community representation, advocacy, and peer support activities to challenge stigma. In doing so, some reported facing pressure to conform to simplified identities (e.g., "homeless"), whilst others reported avoiding group or representative modes of participation, which were viewed as simplifying and misrecognising their identities (Davies, Gray & Butcher 2013).

7. Discussion

There is significant support for expanding the lived experience workforce in the available literature (Kent & Read 1998 as cited by Happell & Roper 2003). This literature review highlights the multifarious complexities of social service providers working with PWLE. Some of these barriers to inclusion are pay arrangements, participant selection limits, and timeframes (Community Mental Health, Drug & Alcohol Research Network n.d.; Daya, Hamilton & Roper 2019).

Our literature review also revealed limited scholarly, peer-reviewed research on several important topics associated with social service providers' practices of embedding lived experience in service delivery. These topics include:

- Poorly defined roles, which hinder the integration of LEWs into existing care models (Jacobson, Trojanowski & Dewa 2012). PSWs believe their effectiveness improves with clear, long-term roles (Davies et al. 2014).
- Working within highly structured and professionalised spaces overburdens
 LEWs. Davies et al.'s (2014) study reported that mental health PSWs are
 stretched to do substantial research to rapidly learn new knowledge and skills
 to engage with 'professionals'.
- PSWs value and require relevant training (Dorstyn et al. 2020; Davies et al. 2014). Research on effective training, including topics, skills, and deliverance methods, are absent from the literature.
- Research detailing selection trends and their impacts are also absent from the literature. The selection of workers likely impacts the work produced. Research by Lobo et al. (2020) indicates the presence of bias among LEWs, due to shared homogenous ethnic backgrounds, in a study on sex workers employed as peer researchers.
- Research proving the effectiveness of LEWs in improving services (Davies et al. 2014 p. 110) and revealing how to best deliver peer support (Dorstyn et al. 2020) is still relatively limited.
- There are concerns about PSWs becoming 'too friendly' with clients, blurring professional boundaries (Gray, Davies & Butcher 2017). It is important to

examine how to best set boundaries while maintaining mutually beneficial relationships with clients.

8. Recommendations

In response to the findings of this paper, we provide the following recommendations for consideration:

- Embed lived experience throughout organisations, at all levels, so that PWLE
 have meaningful control/influence in organisational decisions. Relatedly, more
 opportunities for career progression should be available to LEWs. This will
 contribute to LEW retention and, in turn, help to improve service delivery.
- Increase ratios of LEWs to service users so that service users have more access to support.
- 3. Pay LEWs similarly to conventional workers within the social service to adequately value, remunerate and retain workers, and bring fairness across teams. Consider developing a unique remunerative Award for LEWs such as PSWs that recognises their distinct expertise and contribution.
- 4. Diversify lived experience roles so that more PWLE can contribute to social service provision. Consider creating consumer reference groups, co-chairs, more PSW roles and hire lived experience specialists into team leader and management roles.
- Embed supervision and debriefing processes in lived experience work to ensure LEWs feel supported and use, retain, and strengthen their unique expertise.

- 6. Allow LEWs to have workplace flexibility to support the specific needs associated with their lived experience (e.g., cultural responsibilities or health appointments).
- 7. Educate conventional and non-lived experience workers on how to interact with LEWs and value their perspectives and expertise.
- 8. Conduct research to identify strategies around remedying and ending the effects of stigma and discrimination on LEWs. Moreover, run Quality Improvement Projects to improve team dynamics between conventional workers and LEWs.
- 9. Fund and hire PWLE to conduct research within their community.

9. Conclusion

This paper summarises recent academic literature exploring the practices of social service providers working with PWLE in Australia. Various models of delivering social services with LEWs were identified, including peer support; community-controlled organisations; advocacy, consultation, and informing; and co-production and co-design. Currently, the literature largely focuses on peer support and advocacy, consultation, and informing. Common themes in the literature describing these practices included power dynamics, tokenism, and stigma. There is limited literature exploring certain important areas, particularly those related to the practicalities of embedding lived experience in social services.

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Appendices

Appendix A: Detailed overview of search strategy

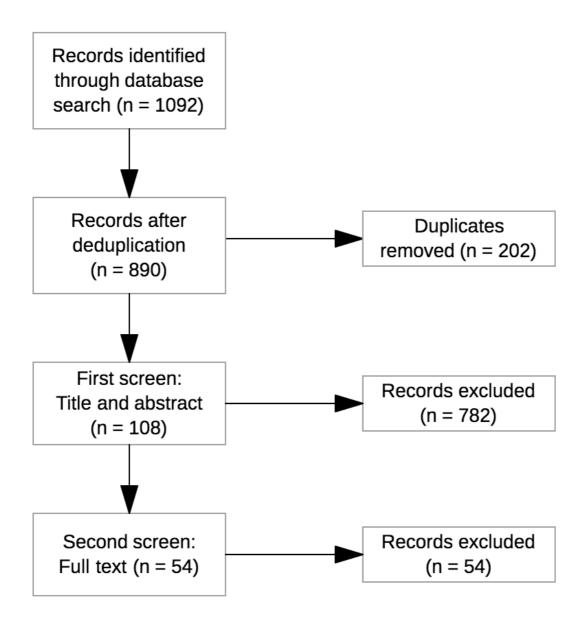
On 1 October 2021, we searched four databases using the following terms:

Key term	Search terms
Social Service Users	"with lived experience" OR "impacted pe*" OR "impacted communit*" OR consumer OR client OR customer OR participant OR user OR patient OR service-user OR "service user"
Participation	"consumer representati*" OR "consumer organi*" OR "peer work*" OR "peer support*" OR "peak bod*" OR participat* OR engage* OR inclusion OR voice OR advisor* OR consult* OR partner* OR involve* OR collaborat* OR empower* OR codesign OR co-design OR co-produc* OR coproduc* OR "lived experience work*"
Disadvantage	prison* OR out-of-home-care OR "out of home care" OR "foster care" OR alcohol* OR drug OR juvenile OR indigenous OR aborigin* OR "culturally and linguistically diverse" OR CALD OR refugee OR minority OR offender OR "financial hardship" OR "mental health" OR "domestic violence" OR "domestic and family violence" OR agei* OR disab* OR raci* OR ethnic* OR gender OR sexis* OR marginali* OR poverty OR exclusion OR deprivation OR discrimination OR prejudice OR stigma OR homeless* OR welfare OR disadvantage* OR inequality OR "low socioeconomic" OR unemploy* OR "cultural background" OR housing
Social Services	"community service*" OR outreach OR "social program*" OR welfare OR "social service*" OR "foster care" OR "mental health service*" OR "government program*"
Australia	australia*

The four databases were searched using the following strategies:

Database Database	Search scope	Additional search filters/limits	Number of search results
MAIS: Multicultural Australia and Immigration Studies via Informit Online	All fields (except full text)	Peer ReviewedPublished from 2000 onwards	5
Social Services Abstracts via Proquest	 All Subjects & Indexing Abstract Document Title Location = australia* 	 Peer Reviewed Published from 2000 onwards Location = australia* 	266
Family and Society Studies Worldwide via Ebsco	 Title Subject Terms Abstract Keywords 	 Peer Reviewed Published from 2000 onwards Geographic Terms = australia* 	414
Scopus	Article TitleAbstractKeywords	 Published from 2000 onwards Publication Stage = Final Subject Area = Social Sciences 	407

The article selection process is illustrated in the following flow chart:



Appendix B: Table of included studies (in alphabetical order)

Author year*	Title	Li	ved Experience	R	elevance
Berends, Ritter & Chalmers 2015	Collaborative governance in the reform of Western Australia's alcohol and other drug sector	•	Alcohol & other drugs	•	Co-production, co-design
Bridge 2012	Citizen centric service in the Australian Department of Human Services: The Department's experience in engaging the community in co-design of government service delivery and developments in egovernment services	•	Social, health and welfare programs	•	Co-design
Brophy et al. 2015	How social work can contribute in the shift to personalised, recovery-oriented psycho-social disability support services	•	Disability	•	Co-production
Bryant et al. 2008	Consumers' and providers' perspectives about consumer participation in drug treatment services: Is there support to do more? What are the obstacles?	•	Alcohol & other drugs	•	Power dynamics Stigma
Bryant et al. 2008	Consumer participation in the planning and delivery of drug treatment services: The current arrangements	•	Alcohol & other drugs	•	Advocacy, consulting, informing
Byrne, Happell & Reid-Searl 2016	Lived experience practitioners and the medical model: world's colliding?	•	Mental health	•	Peer support
Byrne, Happell & Reid-Searl 2017	Acknowledging rural disadvantage in mental health: Views of peer workers	•	Mental health	•	Peer support (rural & regional areas)

T.					
Carter et al. 2004	Alukura for my daughters and their daughters and their daughters'. A review of Congress Alukura	•	Aboriginal & Torres Strait Islander	•	Community- controlled organisations
Coates & Howe 2014	The importance and benefits of youth participation in mental health settings from the perspective of the headspace Gosford Youth Alliance in Australia.	•	Mental health	•	Consulting Co-design
Cortis 2007	What do service users think of evaluation? Evidence from family support	•	Child and family welfare	•	Service evaluation Advocacy, consulting, informing
Cowling et al. 2006	Mental health consumer and carer participation in professional education: 'Getting there together' for children of parents with mental illness and their families	•	Mental health Carers	•	Co-design Advocacy, consulting, informing
Davies et al. 2014	Putting the parity into service- user participation: An integrated model of social justice	•	Homelessness Mental health	•	Advocacy Consulting Tokenism Stigma Power dynamics
Davies, Gray & Butcher 2013	Lean on me: The potential for peer support in a non government Australian mental health service		Mental health	•	Peer support Power dynamics Tokenism Stigma
Ehrlich et al. 2020	What happens when peer support workers are introduced as members of community-based clinical mental health service delivery teams: a qualitative study	•	Mental health	•	Peer support Power dynamics Tokenism Stigma

Every & Richardson 2018	A framework for disaster resilience education with homeless communities	•	Homelessness	•	Peer support (peer facilitation) Co-design
Freeman et al. 2014	Cultural respect strategies in Australian Aboriginal primary health care services: beyond education and training of practitioners	•	Aboriginal & Torres Strait Islander	•	Community- controlled organisation
Gray, Davies & Butcher 2017	Finding the right connections: Peer support within a community-based mental health service	•	Mental health	•	Power dynamics Peer support
Happell & Roper 2003	The role of a mental health consumer in the education of postgraduate psychiatric nursing students: the students' evaluation	•	Mental health	•	Advocacy Consulting
Happell et al. 2019	Nursing student attitudes to people labelled with 'mental illness' and consumer participation: A survey-based analysis of findings and psychometric properties	•	Mental health	•	Stigma Advocacy, consulting, informing
Healy & Darlington 2009	Service user participation in diverse child protection contexts: principles for practice	•	Child protection	•	Advocacy, consulting, informing Power dynamics
Homel, Lamb & Freiberg 2006	Working with the indigenous community in the pathways to prevention project	•	Aboriginal & Torres Strait Islander	•	Peer support (facilitators)
Hungerford 2014	Consumer's perceptions of recovery-oriented mental health services: An Australian case-study analysis.	•	Mental health	•	Advocacy, consulting, informing
Jones et al. 2018	Perspectives of rural health and human service practitioners following suicide prevention training	•	Mental health	•	Co-production

	programme in Australia: A thematic analysis				
Kiraly & Humphreys 2013	Perspectives from young people about family contact in kinship care: "Don't push uslisten more"	•	Out-of-home care	•	Consulting Co-design
Lawn, Smith & Hunter 2009	Mental health peer support for hospital avoidance and early discharge: An Australian example of consumer driven and operated service	•	Mental health	•	Peer support Power dynamics Stigma, discrimination
Lindberg, Lawrence & Caraher 2017	Kitchens and pantries— helping or hindering? The perspectives of emergency food users in Victoria, Australia	•	Financial hardship Food insecurity	•	Peer support
LoGiudice et al. 2012	Lungurra Ngoora - a pilot model of care for aged and disabled in a remote Aboriginal community - can it work?	•	Aboriginal & Torres Strait Islander Older people Disability	•	Advocacy, consulting, informing
McCann et al. 2008	Mental health professionals' attitudes towards consumer participation in inpatient units	•	Mental health	•	Power dynamics
McKenna et al. 2015	"Cultural brokerage" and beyond: piloting the role of an urban Aboriginal Mental Health Liaison Officer.	•	Aboriginal & Torres Strait Islander Mental health	•	Peer support (peer facilitation)
Mendes 2018	Community as a 'spray-on solution': A case study of community engagement within the income management programme in Australia	•	Financial hardship	•	Consulting Power dynamics
Mesuraco 2002	Primary preventative intervention in a modern and diverse society	•	Culturally and linguistically diverse Child protection	•	Power dynamics
Michail & Kellet 2015	Child-led research in the context of Australian social	•	Child and family welfare	•	Researchers

	welfare practice			•	Power dynamics
Murrup- Stewart et al. 2018	Aboriginal perceptions of social and emotional wellbeing programs: a systematic review of literature assessing social and emotional wellbeing programs for Aboriginal and Torres Strait Islander Australians perspectives	•	Aboriginal & Torres Strait Islander	•	Co-design Co-production
Nannen 2015	Back this time with keys: the perspective of a peer support worker embedding peer support in a hospital setting	•	Mental health	•	Peer support Power dynamics
Oates 2020	Barriers and solutions: Australian Indigenous practitioners on addressing disproportionate representation of Indigenous Australian children known to statutory child protection	•	Aboriginal & Torres Strait Islander	•	Researchers Power dynamics
Petheram et al. 2010	Strange changes': Indigenous perspectives of climate change and adaptation in NE Arnhem Land (Australia)	•	Aboriginal & Torres Strait Islander	•	Co-design
Price- Robertson et al. 2019	Online peer support programs for young people with a parent who has a mental illness: service providers' perspectives.	•	Mental health	•	Peer support
Rafeld et al. 2020	Getting our voices out there: Acceptability of a mental health participation programme for young people with out of home care experience in Australia	•	Out-of-home care	•	Co-design
Robinson, Fisher & Strike 2014	Participatory and inclusive approaches to disability program evaluation	•	Disability	•	Co-evaluators

Sawrikar & Katz 2014	Normalizing the novel: How is culture addressed in child protection work with ethnic-minority families in Australia?	•	Child protection Culturally and linguistically diverse	•	Power dynamics
Scholz et al. 2020	Not in the room, but the doctors were': An Australian story-completion study about consumer representation	•	Mental health	•	Co-production
Schweizer, Marks & Ramjan 2018	One door mental health lived experience framework	•	Mental health	•	Peer support
Serr 2004	Voices from the bottom	•	Poverty	•	Advocacy, consulting, informing Co-design
Sheldon 2001	Psychiatric assessment in remote Aboriginal communities. Psychiatric assessment in remote Aboriginal communities	•	Aboriginal & Torres Strait Islander Mental health	•	Aboriginal Mental Health Workers
Smith et al. 2021	Good spirit, good life: a quality of life tool and framework for older Aboriginal peoples	•	Aboriginal & Torres Strait Islander	•	Co-design (participatory action research)
Stafford et al. 2021	Why having a voice is important to children who are involved in family support services	•	Children in family support services	•	Consulting Co-design
Tregeagle & Mason 2008	Service user experience of participation in child welfare case management.	•	Out-of-home care	•	Advocacy, consulting, informing Power dynamics
Vichie 2003	Seeking protection in a world of conflict	•	Refugees, asylum seekers	•	Community- controlled organisations
Visa & Harvey 2019	Mental health carers' experiences of an Australian Carer Peer Support program:	•	Mental health	•	Peer support (carers)

	Tailoring supports to carers' needs				
Walsh et al. 2018	Understanding paid peer support in mental health	•	Mental health	•	Power dynamics Peer support
Walter et al. 2011	How white is social work in Australia?	•	Aboriginal & Torres Strait Islander	•	Community- controlled organisations Power dynamics
Wearne, Chesters & Whyte 2006	Funding sources and consequences: the subverting of an Indigenous community outreach program.	•	Alcohol & other drugs Aboriginal & Torres Strait Islander	•	Community- controlled organisations Funding
Williams et al. 2006	Providing opioid substitution treatment to Indigenous heroin users within a community health service setting in Adelaide	•	Aboriginal & Torres Strait Islander Alcohol & other drugs (Heroin)	•	Community- controlled organisation
Woodman et al. 2018	Child protection practitioners: Including children in decision making	•	Child protection	•	Consulting

^{*}bold = cited in report

Appendix C: Author positionality statements

Brief personal intro with our backgrounds in the interest of disclosing bias/interest best as possible

Timothy Dutton:

Disciplinary Background	I am studying a Bachelor of Science/Bachelor of Advanced Studies, double majoring in Psychology and Data Science, and a Diploma of Language Studies, majoring in Chinese Studies (Advanced).
Relevant Experience	I have been a member of the Sydney University Psychology of Intergroup Relations Lab for almost two years. This lab is dedicated to the psychological study of diversity, stigma, and intergroup relations. As a volunteer research assistant at the lab, I have had the opportunity to engage with research that aligns with my interest in the areas of mental health and culture. Additionally, I am a Lifeline Telephone Crisis Supporter. In this role, I have had experience connecting with, attending to the needs of, sensitively reaffirming, and collaboratively empowering PWLE. Through this experience, I have also realised the limitations of the Lifeline service in addressing the complex, longstanding, and
	layered issues that many PWLE endure.
Contribution	My primary disciplinary background (Data Science & Psychology) is based on the epistemology and methodology of science. Correspondingly, my key contribution to the research was to conceptualise our literature review as a systematic, data-driven process. I led the design of our search strategy, conducted the database searches, and managed the 'data extraction' process.

Alina Haque:

Disciplinary Background	I am studying a Bachelor of Arts/Bachelor of Advanced Studies in the Politics & International Relations stream with an additional major in English.
Relevant Experience	I have completed a Policy and Advocacy internship at Youth Action, the Peak Body for youth services across NSW. During my time there I worked with a partner to submit a report that deconstructed structural issues enmeshing youth interaction in political issues and on the development of storytelling as a digital medium to transform policy for underrepresented groups. I have also worked as a Research Assistant for a PhD. candidate at the Department of Government & IR investigating the Syrian-Turkish border conflict. Most of the work involved categorising non-traditional forms of data to try and piece together the motivations of Freedom Fighters into a coherent narrative for Western audiences, allowing me to familiarise myself with the experiences of peripheral communities. I have also taken part in the year long Communities of Support (CoS) mentoring program for marginalised students and briefly worked as an Engagement Facilitator at USyd. I have additional experience building spaces for People of Colour (POC) to create unfiltered content on campus for the revue and society scene.
Contribution	My most important contributions revolved around contextualising and communicating the 'racialised' or 'othered' aspects that can affect lived experience worker identities, often in an intangible/unrecognised manner. As a person of colour from a culturally and linguistically diverse background, 'The history of lived experience inclusion' offers a contextual explanation of this approach. My contributions can also be seen in the 'included approaches to embedding lived experience in social services' section; in particular, the research on the effectiveness of community owned and/or controlled organisations for Indigenous communities.

Yujin Son:

Disciplinary Background	I am studying a Bachelor of Arts, majoring in International Relations and minoring in Spanish and Latin American studies.
Relevant Experience	I provided language services for children of low-income language minority families at the Multicultural Support Center in Korea. They included children from refugees and asylum seekers. I helped them learn Korean and English and offered translation for necessary documents such as housing and immigration. I realised significant differences in parenting and family cultures across different ethnic groups from the dominant culture of Korea. I learned about unfamiliar cultures and attempted to adjust teaching practices to include children from different cultures.
Contribution	I undertook comprehensive research of available literature of community-controlled organisations for people with lived experience, often focusing on culturally and linguistically diverse communities, given my previous experiences as a language service provider for multicultural families. I focused on the unique capacity of Peer Support Workers and barriers they face in terms of organisational recognition and skepticism from non-peer workers. Furthermore, I raised a point of discussion regarding the professional boundaries with PSWs - where to draw the line between professional and personal relationships.

Katie Thorburn:

Disciplinary Background	I am studying a Bachelor of Arts/Bachelor of Advanced Studies (Dalyell Scholar), double majoring in Sociology and Gender Studies. I also hold a Certificate IV in Mental Health Peer Work from the Mental Health Coordinating Council.
Relevant Experience	I am a mental health Peer Support Worker with Sydney Local Health District (NSW Health) and have a decade experience of mental health service use. I am also a Lived Experience researcher in mental health with particular passion and interest in Trauma Informed Care and supporting the LGBTQIA+ community. I have co-designed the 'Rainbow Embassy' - a community project and research concept for and by the LGBTQIA+ community - using initial funding from the 'Raising the Bar' initiative whilst employed as a Research Assistant with the Faculty of Medicine and Health (University of Sydney). I presented my findings on actualising Trauma Informed Care through Peer Support and relevant policy recommendations at the 2021 Sydney Local Health District Mental Health Research Symposium. At the time of submitting this report I had recently submitted an Ethics Application for a research project I designed on Peer Support Worker interactions through a Trauma Informed lens.
Contribution	My main contributions were threefold. Firstly, I used my expertise from the Lived Experience workforce to inform the initial trajectory of the research project and focused on the mental health context literature. Secondly, my passion for my workforce, and my personal access to understandings about it, meant I appreciated and thus contributed to the 'Barriers Experiences by Lived Experience Workers' section. Thirdly, I also developed the 'Recommendations' which were informed by the literature as well as my experiences in the workforce.

Michelle Woodgate:

I am studying a Bachelor of Arts, double majoring in Philosophy and Cultural Studies.
I have previously completed a report, 'Ripples in Redfern', alongside a team of students supervised by several academics. We worked alongside a local Aboriginal organisation to help reveal the academic links behind their 'Clean Slate Without Prejudice' program, and develop means of evaluation that bridged the divide between Western frameworks and Aboriginal Peoples ways of knowing.
Additionally, I have previously been involved in the Sydney Policy Reform Project; and subsequently co-authored a report on instances of Aboriginal involvement in policing practices for Just Reinvest NSW. I have also worked as a support worker for people with disabilities and volunteered as a youth mentor to other local youth in my area.
My background (academic and otherwise) is heavily focused upon people and ethics, for example, ways to produce better outcomes for more people, in a moral manner. Resultantly, I contributed significantly to the co-production section of the paper, and emphasised working 'with' not 'on' PWLE throughout.
Additionally, given my previous experiences and creative thinking style I sporadically contributed to most parts of the report. Notably, my contribution often focused upon inclusive, strength-based and plain English language or an 'outsiders' perspective. My position as a 'white Australian' from a lower-middle class background heightened this, as I consequently provided a different perspective. For instance, many references to upper class or non-Western cultures caught my attention due to unfamiliarity. Whilst my constant awareness of my privilege encouraged the aforementioned contributions.