



THE UNIVERSITY OF
SYDNEY

Engage-In Research Project

**Access to the NDIS for people with
psychosocial disability living in institutional
settings: Exploring the details of effective
advocacy**

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Executive summary

The Engage-In project, funded by an Information, Linkages and Capacity Building (ILC) grant, was delivered by People with Disability Australia (PWDA) between December 2020–June 2022. The project developed and delivered a pilot innovative service model that aimed to connect people living with psychosocial disability in institutional settings (including psychiatric wards, prisons, and boarding houses) to the National Disability Insurance Scheme (NDIS), while developing and documenting knowledge about the details of effective advocacy practices within such contexts. PWDA and the Engage-In team commissioned the University of Sydney to undertake a research study, as a key component of the Engage-In project.

The research study involved a co-designed, action research process that sought to walk alongside and document the progress, implementation, and learning achieved throughout the Engage-In project, through an iterative process of planning, action, observation, and reflection. The Engage-In research project sought to develop a comprehensive understanding of how disability advocates could effectively support people with psychosocial disability (PwPSD) who were living in or recently released from institutions, to gain access to relevant supports and resources, with a focus on accessing the NDIS. In summary, the aims of the Engage-In research project were:

1. to investigate the complexities of advocacy and disability rights when working with people with psychosocial disability in institutional settings, and
2. to document the practices and processes that best facilitated access to mainstream supports, such as the NDIS.

To achieve these aims, the study involved a series of action research meetings with two groups of participants, a Project Advisory Group (PAG) comprised of PWDA staff, peer support workers, and lived experience representatives, and a Communities of Practice group (COP) comprised of practitioners in the disability sector. Seven in-depth interviews with clients of the Engage-In project complemented the data generated through the action

research groups by providing detailed, first-person narratives of encounters with service providers, the impacts of living within institutional settings, and experiences of advocacy.

The project was informed by the social model of disability (Oliver, 2009), thus emphasising structural and systemic barriers within ‘hard to reach’ institutional settings and rejecting the oppressive notion of ‘hard to reach’ people. In this vein, the research was centred on the need for a disability rights lens (Oliver & Barnes, 2012) to be utilised considering the experience of when living within institutional settings such as prisons, long-term psychiatric facilities, and boarding houses, and to recognise the multiple and intersecting oppressions experienced by PwPSD, as well as their resistance and survivorship. Consistent with the values of PWDA, the social model of disability values experiential expertise and the importance of elevating first-person survivor knowledges.

The research found that significant challenges continue to exist, which prevent and limit the extent to which PwPSD experience “equal participation with others in the community” (NDIS, 2020). For example, the literature reviewed in this report demonstrates the substantial barriers to access, rights, and participation for PwPSD living in the community (Gendara et al., 2020; Hui et al., 2018). The findings in this study add to this literature by demonstrating that being in, or transitioning from, an institutional setting contributes an additional layer of complexity and injustice for PwPSD when trying to access supports.

The research also found that the inherent power imbalances between PwPSD, disability advocates, and institutions, created significant barriers to accessing rights and resources. Added complexities emerged due to harmful institutional norms, paternalistic assumptions about PwPSD, the de-valuing of lived experience perspectives, the need to navigate competing medical and recovery-oriented discourses of disability, and gatekeeping practices, posed additional challenges to effective advocacy, severely impinging upon the rights of PwPSD to exercise choice and to experience full inclusion and participation in the community (United Nations, 2006). Nevertheless, the research revealed that effective advocacy practices are underpinned by:

- critical thinking in response to deficit-based assumptions about disability

- building genuine partnerships and leadership opportunities for people with experiential expertise, in order to elevate the voices of PwPSD
- developing communities of practice around PwPSD that focus on a ‘doing with’ (rather than a ‘doing for’) approach, and
- putting the context back into medicalised accounts of PwPSD.

Such approaches assist advocates to work more effectively with people with psychosocial disability, within complex institutional environments. A set of *Practice Guidelines*, which captures the core components of effective advocacy practices that were explored within the research project, was also developed as part of this research study.

1 Overview

People with Disability Australia (PWDA) is a national disability rights, advocacy and representative organisation that is made up of, led and governed, by people with disabilities. Founded in 1981, PWDA seeks to empower people with disabilities to take control of their own lives and to work towards achieving social justice for all. Advocating for the rights of people with disabilities, as recognised within the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD), is integral to the work of PWDA.

A recent project conducted by PWDA was the Enable In research project, from 2018–2020 (Gendera et al., 2020). The Enable In project aimed to facilitate access to the National Disability Insurance Scheme (NDIS) and other related services, with a particular focus on increasing the awareness and capacity of people with disability living in ‘hard to reach’ settings, and those who support them. The project was centred on the experiences of people with disability who were homeless or at risk of homelessness, living in large residential institutions, and people with psychosocial disability. Two key lessons emerged from the Enable In project:

- There was a pressing need to support people who do not know about NDIS and who may find it difficult to trust services (especially people in hard-to-reach settings).
- To achieve this goal, substantial resources, time, and investment were needed, to build and sustain quality relationships, networks, and expertise (Gendera, et. al., 2020, p. 1).

This present report discusses the research component of a subsequent project undertaken by PWDA – Engage-In – which was built upon the findings of the Enable In Project. The Engage-In project was delivered by People with Disability Australia between December 2021 to June 2022, funded by an Information Linkages and Capacity Building (ILC) grant. The Engage-In project is a pilot innovative service model that aims to connect people with psychosocial disability living in institutional settings (psychiatric hospitals, prisons, boarding houses) with the NDIS. The focus of the Engage-In project on the experiences of people with psychosocial disability (PwPSD) is significant because PwPSD typically experience significant barriers to accessing the NDIS, resulting in cumulative disadvantage and social exclusion (Cortese, et al., 2020). The term, psychosocial disability, is used by PWDA and in this report, as it is a term that extends beyond the narrow and medicalised definitions offered by psychiatric diagnoses that focus upon individual deficits, instead referring more broadly to social consequences of disability (Mental Health Australia, 2020).

The research component of the Engage-In project consisted of a collaboration between PWDA and the University of Sydney, involving a co-designed, action research process that sought to walk alongside the Engage-In team in order to document the progress, implementation, and learning achieved throughout the Engage-In project, through an iterative process of planning, action, observation, and reflection.

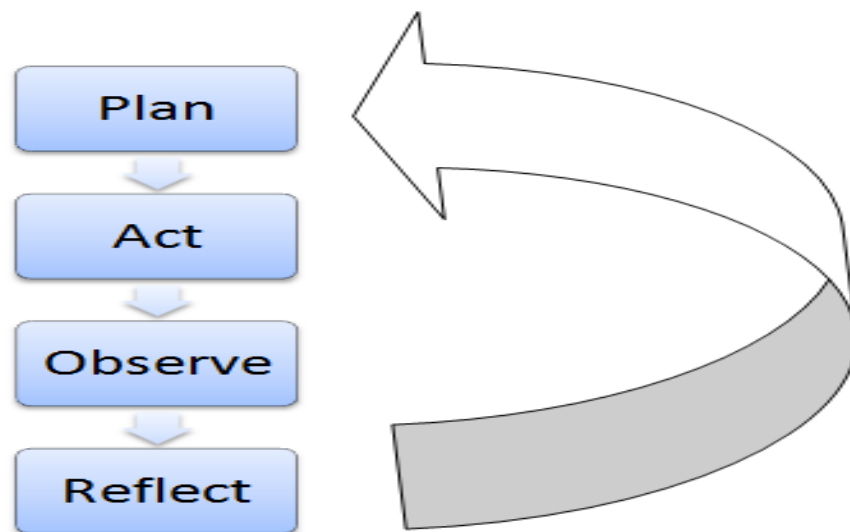


Figure 1. Kemmis and McTaggart (2000)

The project was informed by the social model of disability, premised on the notion of structural inequalities and ‘hard to reach’ institutions, rather than ‘hard to reach’ people. Moreover, both the social model of disability and PWDA value experiential expertise and the importance of elevating lived experience within disability advocacy, including, through building the capacity of the peer workforce. This approach allowed the research to focus on the systemic issues facing PwPSD, highlighting the need for a disability rights lens, in contrast to a simplistic, medicalised approach to disability that unjustly views the challenges that are faced by PwPSD as due to individual traits, such as a lack of skills or motivation (Oliver, 2009; Pacheco & McConnell, 2017). From a social and anti-oppressive perspective (Baines 2017), it is a hostile and discriminatory environment that prevents PwPSD from accessing services and resources that could enable fuller participation in the community. Institutional settings including prisons, long-term psychiatric facilities, and boarding houses, are often difficult to access and navigate, due to ableism, gatekeeping practices, and paternalistic assumptions that significantly diminish the rights of PwPSD living within such settings.

Drawing on the principles of action research, the Engage-In project sought to develop a comprehensive understanding of how disability advocates can effectively support PwPSD who are living in or recently released from institutions (or living in the community while at

risk of re-entering custody or an institution), to gain access to mainstream supports, with a focus on the NDIS. Therefore, the aims of the Engage-In project were:

- to investigate the complexities of advocacy and disability rights when working with people with psychosocial disability in institutional settings, and
- to document the practices and processes that best facilitated access to mainstream supports, such as the NDIS.

Through centering the voices of PwPSD, this qualitative research project sought to develop a deeper understanding of effective advocacy strategies to address the substantial barriers and challenges that PwPSD and disability advocates experience when attempting to access the NDIS. Participants in the research included clients of Engage-In, members of the Project Advisory Group (including PWDA staff, peer support workers, and lived experience representatives), and members of the Community of Practice group (practitioners working in the disability sector). A commitment to highly collaborative and reflective practices was demonstrated by all participants in the research project, enabling rich learning regarding the details of advocacy work and revealing the components of effective, anti-oppressive, and ethical practices that make a difference when working with PwPSD within a rights-based framework.

The findings of the research project have been formalised through the development of *Practice Guidelines* at the conclusion of the research project. It is hoped that the findings of the Engage-In project might serve as a practical guide for other organisations interested in utilising rights-based advocacy practices that are centred on and led by the voices of PwPSD. People with Disability Australia will be involved in further dissemination of the learning achieved through the project, via the development of an organisational capacity-building training package.

1.1 Background and rationale for the research

Disability service provision started in Australia with the government providing block-funding to disability services. It has since shifted to individualised funding for self-directed care, mirroring shifts in Western Europe, North America, and other OECD countries (Warr et al.,

2017). In Australia, the current scheme is known as the National Disability Insurance Scheme (NDIS), established by the *National Disability Insurance Scheme Act 2013* (Australian Government, 2013) – the first legislative reform in disability service provision in Australia in almost three decades since the *Disability Services Act 1986* (Australian Government, 1986). The stated aim of the NDIS was to deliver a person-centred, rights-based approach to disability support. Through a scheme based on insurance principles, people with disability, their families and carers were promised a new funding approach that focused upon supporting independence and participation of people with disabilities in social, economic and community life, underpinned by the principles of choice and control (Australian Government 2013; NDIS, 2020; Wapling, 2021). The scheme was celebrated when first introduced, and it was hoped that people with “permanent” and “significant” disabilities could now exercise choice and control over the design and delivery of their care (NDIS, 2020; Wapling, 2021).

However, it is important to note that it was only after some debate that the Productivity Commission recommended that people with psychosocial disability be included in the NDIS, and the scheme “has been fundamentally shaped by, and largely reflects the world view of, the specialist disability sector and does not fully ‘resonate’ with the mental health sector” (Williams & Smith, 2014). There remain ongoing tensions regarding the inclusion of psychosocial disability in the NDIS, and it has been noted that NDIS staff have limited understanding of psychosocial disability (Rosenberg et al, 2019). The focus of the NDIS on choice and control through personalisation approaches does not benefit everyone; indeed, people with psychosocial and neurological impairments are the least likely to find such processes beneficial (Stewart, Visser & Slattery, 2020). In addition, the NDIS assessment process utilises a biomedical approach, and the requirement for NDIS recipients to prove the ‘permanent and lifelong’ nature of their disability often poses challenges for PwPSD. Notably, such demands run contrary to the ‘recovery’ paradigm in mental health (Rosenberg et al, 2019; Wapling, 2021).

The first stated objective of the National Disability Insurance Scheme Act 2013 was to give effect to Australia’s obligations under the *Convention on the Rights of Persons with Disabilities* (Australian Government 2013, p. 4; United Nations 2006). Parties to *The Convention* recognise the right of people with disabilities to “live in the community with

choices equal to others” and undertake to “take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community” (United Nations 2006). Despite these promises, in the Australian context there is an urgent need for research exploring the inconsistencies and systemic challenges that are experienced by PwPSD who are attempting to access the NDIS, while also investigating, in detail, the advocacy practices that can counter such barriers (Smith-Merry et al., 2018). For example, there is substantial evidence that people who are from so-called ‘hard to reach’ groups, such as people from low socio-economic backgrounds, people who are homeless, people from cultural and linguistically diverse (CALD) backgrounds, and PwPSD, (O’Connor, 2014; Clift, 2014; Soldatic et al., 2014), are less likely to have their needs met under either the NDIS or other mainstream supports (Ennals, Waring, Storen, & Burns, 2017; Hui, et. al., 2018; Smith-Merry, et. al., 2018; Taylor & McLeod, 2018). It is also well-known that PwPSD face heightened barriers and challenges in accessing the NDIS (Ennals et al., 2017; Hui, et. al., 2018; Smith-Merry, et. al., 2018).

People with psychosocial disability face many forms of stigma and discrimination, as well as barriers to exercising their civil, economic, social, and cultural rights. These barriers are often heightened by additional challenges, which can include communication needs that are not being adequately met, social exclusion, and poverty, among other barriers (Fisher, Gendera and Kayess, 2022; Wapling, 2021; Hammond, 2022). In addition, as psychosocial disability is often episodic and invisible, it is often not well-identified in the first place. It may be hidden by individuals or their families out of shame, denial, or the fear of being locked up and stripped of their most basic human rights (Wapling, 2021). Further, people with psychosocial disability are often labelled as inherently ‘hard to reach’ people, for example, due to their perceived reluctance to seek help, or their lack of knowledge around the NDIS (Gendera et al., 2020). Smith-Merry et al. (2018) found some PwPSD did not apply for the NDIS because of anxiety or fear about the NDIS. Sometimes this was due to a lack of access to information and fear of losing their existing supports. Indeed, the stress experienced when applying for the NDIS sometimes exacerbated mental distress. However, there is still very little research regarding access to the NDIS by PwPSD who are currently living in institutional settings, such as hospital psychiatric wards, prisons, and

boarding houses (or people living in the community who are at risk of entering or re-entering such institutions). The focus of the Engage-In research project thus aimed to address this important gap in the literature, through generating new knowledge about effective advocacy work, in partnership with PwPSD living in institutional settings. Understanding the lived experiences and priorities of people living in ‘hard to reach’ settings is important in developing meaningful practice guidelines that can support PwPSD to access the NDIS and other supports, enabling PwPSD to live in the community and experience choice, participation, and citizenship. Further, understanding the difficulties in navigating supports due to gatekeeping practices, ableism, and paternalistic assumptions is essential in contributing towards the development of practical solutions to the issues that have been highlighted in the existing literature.

The NDIA characterises PwPSD as experiencing significant social disadvantages including unemployment, poor health, poor relationships, poor housing, and homelessness (Hui et al., 2018). It is, however, important to note the many social determinants that can lead to such disadvantages, including discrimination, social isolation, and trauma. As the Engage-In project was informed by the social model of disability, it was focused on the urgent need to counter the impacts of ableism, paternalism, and gatekeeping in diminishing the lives and rights of PwPSD.

1.2 What the evidence tells us

Many studies have identified that there are differing barriers to accessing the NDIS, depending on intersecting social locations and resources (Bigby, 2014; Gendara et al., 2020). Despite this evidence, the NDIS is predicated on the notion that people with a disability who require NDIS support will be able to access and navigate the system in order to exercise ‘choice’ and ‘control’ (Bigby, 2014). However, Cortese et al’s (2020) research found that participants who were experiencing social marginalisation, often with a range of psychosocial disabilities, frequently did not have the resources and support mechanisms to access appropriate services. They also found that for PwPSD the notion of ‘choice’ and ‘control’ in managing disability supports was simply outside of their participants’ day-to-day considerations, given the more pressing concerns of everyday survival and meeting basic needs including adequate food, accommodation, safety, electricity bills, and so on

(Cortese et al., 2020). An evaluation of the NDIS by Mavromas, Moskos, and Mahuteau (2016) demonstrated that people with psychosocial disability experience particularly poor outcomes under the NDIS, and that advocacy was therefore urgently needed to improve the experiences of PwPSD. For instance, Hancock (in St Clair, 2020) argues that “there is a lack of advocacy or support for people to assist them to clearly articulate what their needs are. People have not been permitted or encouraged to have family or service providers who know them well to attend meetings with NDIA”. Further, the NDIS requires participants to self-advocate to have their needs met. People with psychosocial disability may find this difficult, for example, due to services that do not acknowledge the additional supports that might be required to enable PwPSD to develop trust and to communicate with new people. Consequently, a lack of knowledge and/or unwillingness to respond to the nuances of psychosocial disability can negatively impact upon the participation and engagement of PwPSD in the NDIS process, and within advocacy services (Wapling, 2021).

Other studies have demonstrated a lack of knowledge and understanding of the NDIS among people with disability and their carers. It is important to locate such experiences within the context of systemic barriers, for example, the disadvantages associated with not having a mobile phone, inadequate internet access, or unstable accommodation (Genera et al., 2020). Bigby (2014) also pointed to the impairment-specific barriers faced by people with an intellectual disability, such as difficulty around articulating their particular needs. This is also well-recognised as an inherent challenge in the NDIS for people with psychosocial disability because of the impacts of living with paternalistic policies, as well as the limited availability of formal or informal advocates to “prosecute their interests” (Bigby, 2014 pg. 94). Researchers have raised further concerns about the capacity of the NDIS to recognise the needs of marginalised people experiencing intersecting disadvantages, especially those who are from the low socio-economic backgrounds, are homeless or involved in the criminal justice system, are from cultural and linguistically diverse (CALD) backgrounds, or who enter and re-enter the criminal justice system (O’Connor, 2014; Clift, 2014; Soldatic et al., 2014). In addition, the existing literature has found there are many people with disability in ‘hard-to-reach’ settings, including people at risk of homelessness, PwPSD, or people living in institutions, who have limited trusted

support to overcome the multitude of barriers they face (Ennals et al., 2017; Hui et al., 2018; Smith-Merry et al., 2018).

One of the keys to accessing the NDIS is to understand the kind of language a treating professional must use when providing evidence of a psychosocial disability. Research has noted the tensions between medicalised terminology dominant in the disability space and the capacity building terminology in the NDIS space. Gendara, et. al. (2020) provide the example of 'rehabilitation' as a medical term and 'capacity building' as a NDIS term. They argue these terms are used to describe the same circumstances and support needs, however, will lead to different outcomes in a NDIS application, thus highlighting how language can be used as a way to deny access to the NDIS. At the same time, the NDIS continues to be underpinned by medicalised assumptions, wherein people may feel that they need to 'perform deficits' (Wapling, 2021) in order to receive continued funding, in contrast to a recovery-oriented approach. Thus, there are often contradictory and disempowering discourses at play within NDIS applications, which must be complied with and navigated, in order to receive funding.

The NDIS promises to support a better life for hundreds of thousands of Australians with a significant and permanent disability (NDIA, 2020). As such, it aims to enhance independence, choice, and control by giving people with disabilities more choice about the type of help they receive, when they receive it, and who provides it. However, a shift away from a service model to a market-based consumer model represents a shift of responsibility from the State to individuals, raising questions about how the scheme ensures human rights, fairness, equitable access and safeguards for PwPSD (Pyysiainen, Halpin, & Guilfoyle 2017). This shift has come about within the context of an intensification of neoliberalism (Brown, 2021; Pratt, 2006). In short, neoliberalism emphasises free-market, individualism, reduced public expenditure, deregulation, and privatisation (Briggs, 2020; Harvey, 2010). As a result of neoliberalism, less regulated models of capitalism have emerged, alongside the paring back of welfare states, changes to the structure and accountability of organisations in the public and private sectors, and an increased emphasis on risk (Pratt, 2006). This shift positions the individual as responsible, rather than the State, for social risks such as illness, disability, unemployment, and poverty with a focus on the individual's ability to be self-managed, regardless of social contexts and

barriers to self-sufficiency (Brown, 2021; Liebenberg et al., 2013; Morrow & Weisser, 2012; Pyysiainen et al., 2017; Shamir, 2008).

In this market-based model, PwPSD are now seen as consumers who must negotiate the services they need. What is noticeable in the literature is there has been little investment in ensuring people with disabilities are 'informed consumers', particularly those with psychosocial disability (Briggs, 2020). Moreover, if PwPSD have lived in institutions where they have experienced abuse and neglect, they may not have a previous experience of being given the opportunity to exert choice as 'informed consumers' (Bigby, 2014; Briggs, 2020). Further, the deinstitutionalisation of mental health care and increasing reliance on private disability service providers reflects the continuation of neoliberal government policies designed to reduce State responsibility for the daily support needs of people labelled as 'mentally ill' (McDermott, 2017).

Another troubling aspect of neoliberalism and the NDIS is the shift toward the medicalisation of disability rather than the initial ideal of a social model of disability (Aitken et al., 2019; Fisher et al., 2019). The NDIS process now requires individuals to provide comprehensive medical assessments – that are often financially out of reach for PwPSD – which means access to the NDIS may be difficult or impossible for those who cannot afford these medical assessments. Despite the ideals of social inclusion under the NDIS, the medicalisation of disability, combined with everyday social impediments such as higher rates of poverty, may impact negatively upon a person's identity, sense of self and how they participate and engage with professionals and the community (Wayland et al., 2020).

As previously mentioned, the move towards individualised funding packages through the NDIS has represented a paradigm shift aimed at building capacity and authentic participation for PwPSD (Howard, 2019; Laragy, et. al., 2015). Indeed, the positioning and embedded ideals of individual decision making and meaningful choice and control as the central tenets of the NDIS reflect dominant discourses about disability that focus on the individual. This precludes taking an intersectional and human rights approach to practice that acknowledges the multiple intersecting oppressions experienced by PwPSD (Gooding, 2016; Horsell, 2020).

The existing literature has exposed several concerns relating to systemic and structural oppressions experienced by PwPSD, with material consequences relating to reduced access to the NDIS. This means that learning about and accessing the NDIS continues to be difficult for the very people it is intended to support. Therefore, access to the NDIS relies heavily on an individual's supports, resources, and social and financial capital. Being literate, including digitally literate; knowing about and understanding the language around the NDIS; having the skills and confidence to self-advocate, identify support needs and goals, and to exercise choice and control; and having a strong support network, are all pre-requisites to accessing the NDIS (Cortese et. al., 2020; Wapling, 2021). For PwPSD, structural disadvantages often result in poor access to such resources, and advocacy can be hindered by deficit-laden assumptions that it is the fault of PwPSD for failing to access supports. The existing evidence thus highlights the systemic barriers existing for PwPSD regarding access to supports, advocacy, knowledge, resources and rights. There is a need for further research regarding access to the NDIS for PwPSD living in institutional settings. In addition, there is an urgent need for research that provides a comprehensive exploration of effective, ethical, and anti-oppressive approaches to advocacy and navigating systemic barriers, deficit-focused discourses, and neoliberal policy contexts.

2 Conceptual framework

This research project was informed by a human rights framework, and the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006) has been used to shape the research process and analysis. In the Australian context, human rights have been operationalised in government legislation through the Disability Discrimination Act 1992 (Commonwealth), and the Anti-Discrimination Act 1997 (NSW). Historically, research around disability, including psychosocial disability, has been underpinned by individualising and paternalistic ideas of disability that often ignore the human rights of people with disabilities. For instance, people with psychosocial disability have been marginalized, shunned, and demonised throughout history, and psychosocial disability has frequently been associated with criminality, deviance and detention. Having a psychosocial disability is still used as grounds for excluding people from their basic rights afforded under

the *Convention on the Rights of Persons with Disabilities* (Oliver, 2009; Wapling, 2021). To address this oppression, the Enable In research project aimed to privilege and centre the voices of PwPSD.

Because of neoliberal ideals that construct PwPSD in medicalised ways while ignoring rights, the social model of disability has also been utilised to inform the research. The social model of disability conceptualises disability as a social process that requires governments and societies to respond to the inequalities and inequities imposed upon PwPSD, in contrast to approaches that situate the ‘problem’ within the individual (Spivakovsky, 2014). Within this perspective, PwPSD are not seen as ‘objects’ of charity who need social protection, but as ‘subjects’ with rights, who are able to make decisions for their own lives based on free and informed consent, and to be active members of society (Oliver & Barnes, 2012). In this context, a distinction is made between impairment and disability. Impairment is a medical condition that leads to disability; while disability is the result of the interaction between people living with impairments and barriers in the physical, attitudinal, communication and social environment (Oliver, 2009; Oliver & Barnes, 2012).

The contributions of critical mental health theory and Mad studies also informed the research project, including the importance of lived experience expertise as an important alternative to clinical understandings of psychosocial disability (Cohen, 2017). This theoretical framework emphasises the importance of attending to power relations, thus making it an appropriate framework as it closely links human rights, social justice, and the elevation of lived experiences.

Finally, the project’s concern with the details of advocacy practice meant that anti-oppressive practice (Baines, 2017, Chapter 1) was highly relevant to the research. In a similar vein, the project was also informed by Brown’s (2021) work on critical clinical mental health practice, which moves beyond the importance of identifying systemic barriers, in order to examine critical practices in the context of dominant ableist paradigms, and the importance of finding opportunities for critical practices even within the context of neoliberal and medicalised discourses.

2.1 Methodology

The project was designed using an action research framework, which was relevant due to its focus on undertaking research in communities, where the emphasis is on ‘participation’ and ‘action’. This is an approach commonly used for improving conditions and practices in a range of environments where the research aims have a social justice orientation (Lingard et al., 2008; Whitehead et al., 2003). Action research involves practitioners conducting systematic enquiries to help them improve their own practices, which in turn can enhance their working environment and, in turn, produce better outcomes for clients. As the purpose of undertaking action research is to bring about change in specific contexts (Parkin, 2009), a key strength of action research lies in its focus on generating solutions to practical problems and its ability to empower all involved, through participatory processes and a strong focus on collaboration (Meyer, 2000). Action research therefore views people with lived experience, including practitioners and service providers, but especially clients, as experts of their own lives; it is acknowledged that the research should be centred on the perspectives of people who have a stake in the issue. This enables voices that are often not valued within research processes to be privileged as sources of knowledge that can facilitate change.

Within action research, the reflective and continuous process of taking action and conducting research are linked through ‘critical reflection’; as such, a cyclical nature of learning, reflection and action is at the core of action research. Furthermore, the principle of co-production in Action Research dissipates traditional hierarchal relationships and power dynamics between the researcher and participant groups as it engages participants as co-researchers in a participatory process (Flanagan, 2020; Krueger-Henney & Ruglis, 2020; Laing, Irwin, & Toivonen, 2012; Tseris, 2020).

2.2 Ethical considerations

Ethical issues are important in all research but are especially pertinent in projects involving people with disabilities, who have historically experienced significant exploitation within research contexts (Bracken, Bell, MacDonald & Racine, 2017). Researchers have a responsibility to consider the effects of their actions upon participants and to always

preserve the rights and well-being of participants. Ethical considerations relating to confidentiality, informed consent and duty of care were key ethical considerations in this study. To ensure the wellbeing of research participants, the project focused on processes that ensured respect for participants, including an emphasis on the strengths and survivorship of participants, and de-identifying participant contributions.

It was acknowledged that reflecting on and discussing personal experiences of institutional harm could raise difficult emotions or elicit distress. Therefore, it was important that care was provided to all participants, in particular, those who had a lived experience of psychosocial disability and institutional living (Jacob & Furgerson, 2012), while also not adopting a paternalistic stance that assumed that participants would experience distress or require assistance. A supportive environment was facilitated to explore personal reflections, whereby the researcher and participants discussed preferences and strategies for managing distress. If concerns were raised by participants, they were supported to access their preferred supports. These options included contacting a nominated trusted support person or a peer support worker within PWDA who was not involved with the Engage-In project, and/or accessing external supports. For participants who were practitioners and who provided reflections on their practice, support and debriefing processes were also offered.

Reflexivity was an additional essential component of the project's ethical considerations. For the first author, this involved constant reflection on her positioning as both an academic researcher and as a person with lived experience of impairment and disability, to ensure that the voices and perspectives of participants remained central in the analysis.

Ethics approval for the project was granted through the University of Sydney Human Research Ethics Office. All participants reviewed a detailed Participant Information Statement and signed a consent form prior to participation, and participants were informed that they could withdraw from the study at any time.

3 Research process

Initial discussions between PWDA and the University of Sydney led to the facilitation of action research groups. The groups included the Project Advisory Group (PAG), a Community of Practice (COP) group, and an Inter-Pag group. The PAG was held bi-monthly for two hours and the COP was held one week after each PAG for one hour (see below for the details of participants in each group). The Inter-pag group was held approximately every month so the academic researcher, project manager and project officers could 'check in' and ascertain that the project was on track and to raise concerns if there were any. The second phase of the project involved seven individual interviews who were clients of Engage-In.

3.1 Recruitment

A research flyer was co-designed by Engage-In members and the research team. This was distributed to potential participants by a PWDA senior research officer, independent of the Engage-In project. PWDA advocates or peer support workers with experience of individual and systemic advocacy with psychosocial disability (PSD), peer consultants/advisors, and consumer representatives, were identified as the potential participant population. Prospective participants were encouraged to contact the University of Sydney research team to express their interest in participating.

3.2 Participants

The PAG consisted of nine participants, all of whom had lived experience of psychosocial disability; six were Engage-In team members and three were lived experience representatives. Of those, seven identified as being female and two as male. The COP consisted of eight sector practitioners who worked within the disability, welfare, advocacy and criminal justice space, who had both professional and lived experience expertise of psychosocial disability – of those, eight identified as female and two as male. This reflects the gendered nature of the health care and social welfare sector, in which an estimated 78% are female (Australian Bureau of Statistics, 2020). Seven individual interviews were

facilitated with people who were clients of Engage-In. The interview participants had lived experience of psychosocial disability and had recently been discharged from hospital psychiatric wards or prisons or were living in the community and at risk of returning to an institutional setting.

3.3 Data collection

Discussions within the PAG, COP and Inter-Pag meetings were audio-recorded, which assisted in the accurate reporting of the process and content of discussions and ensured that the researcher could facilitate the discussions without being distracted or required to take detailed notes. Discussions were semi-structured and were each based around two – three open ended questions that explored the complexity of practice and to evaluate the effects of the Engage-In project. For instance, in the initial PAG discussion the questions posed to the participants were:

(For Engage-In team) Could you describe your professional experiences of advocating for people living with a psychosocial disability and living in an institutional setting and connecting them to support services such as the NDIS? (For lived experience representatives) What makes a difference in terms of effective advocacy and connecting to services such as the NDIS?

What are your understandings of the different kinds of barriers that exist in relation to accessing the NDIS in these settings?

(For Engage-In team) What has been working well, or how have you managed to 'gain traction' in your advocacy work? (For lived experience representatives) What are your reflections on these perspectives about advocacy?

As the project was underpinned by an action research methodology, through the reflective group processes, further topics were identified and then discussed at future PAG and COP group discussions.

Individual, in-depth interviews took place between January and February 2022. The primary aim of the individual interviews was to explore participants' lived experiences of accessing supports including the NDIS and other mainstream supports. Participants who participated in individual interviews were interviewed once and interviews lasted approximately 90 -120 minutes, allowing ample time for a detailed sharing of experiences beyond what could be shared in a group format. The interviews were semi-structured; therefore, as well as pre-planned questions, questions were asked based on what the participants revealed. If a particular issue kept coming up, questions were asked in the following interviews to extrapolate further on that particular issue.

From March 2020 onwards, the COVID-19 pandemic led to some changes to the scope of the planned research activities. The majority of meetings and interviews in this project occurred online, via zoom technology, meaning that the research continued without delay, despite COVID-19 lockdowns and restrictions. To some extent this may have impacted rapport building with the participants, however, at the same time this change also had some positive effects due to the increased accessibility that an online platform offered to some participants.

3.4 Data analysis

Both face-to-face interviews and Zoom meetings were recorded and then transcribed by the first author, and de-identified prior to analysis to protect participants' confidentiality. Transcription enabled ongoing immersion in the data and iterative in-depth analysis in order to support the participants' ongoing reflective processes and learning, and to inform the directions of subsequent action research meetings. The qualitative data was analysed using Braun and Clarke's (2006) six stages to thematic analysis. Braun and Clarke's (2006) six stages regarding thematic analysis include:

1. familiarising yourself with your data
2. generating initial codes
3. searching for themes

4. reviewing themes
5. defining and naming themes; and lastly
6. producing the report (Braun & Clarke, 2006, p. 35).

Emerging themes were discussed among the research team and with participants in the PAG and COP meetings, to ensure that they adequately reflected the perceptions of the participants. The guiding conceptual frameworks of this project encouraged inductive coding, as it gave voice to experiences and meanings as reported directly by the participants, rather than pre-determined categories (Braun & Clarke, 2006). Verbatim quotes are used in this research paper to illustrate certain themes, alongside vignettes that were discussed within the PAG and COP meetings, as well as direct quotes from individual interviews. The quotes and vignettes assist in illustrating the details and impacts of effective, and less effective, practices in advocacy with PwPSD in institutional settings. They illustrate diverse approaches to practice and are useful in concretising the components of effective, anti-oppressive and ethical approaches in advocacy, thus informing the practice guidelines that have been developed as part of the research study.

4 Summary

This section of the report has presented a background and rationale for the study, a literature review, the conceptual framework underpinning the research, and the methodology including ethical considerations. The following section reports on the findings of the action research project, followed by a discussion and implications.

5 Findings of the Engage-In Project

This section presents the findings of the Engage-In project and outlines the main themes that emerged from within the analytical processes. It commences with participants' accounts of their experiences of disempowerment and exclusion. Each of the themes are discussed and illustrated with quotations from the participants. In presenting the findings,

“the majority” is used to refer to more than three quarters of participants; “several” or “a number of” is used to refer to at least half the participants; “a few” or “a small number” is used to refer to three or fewer participants (Rawsthorne, 2009).

6 Theme 1: Disempowerment and exclusion

When participants discussed their experiences in the institutions they were living in and/or transitioning from, whether that was psychiatric wards, boarding houses, or prisons, it was evident that they experienced disempowerment and were excluded in many ways. This was often the result of the social construction of PwPSD, in ways that pathologised PwPSD and positioned them as ‘non-citizens’, non-deserving, and having limited rights. These oppressive understandings highlight the power imbalances in these settings. For example, several PAG participants, drawing on their lived experience, stated:

“There is a culture of lack of deserved-ness of support for people with disability or people with mental distress.”

“We are permanently demeaned, our voices are apparently de-valued within society and by society.”

“They will have the nurses behind a glass barrier to protect them from us, so it is that feeling of us and them.”

Such experiences highlight the barriers to rights that exist at an institutional level, due to pervasive othering practices. A lived experience representative in the PAG also spoke about how they were negatively viewed by senior staff. This participant spoke about a response from a mental health practitioner when trying to report abusive behaviours in an institutional setting, which resulted in further disempowerment and mental distress, as the allegation was not believed due to the stigma of a psychiatric diagnosis.

“[I was made to feel that] the people around here are ‘nuts’ and they don’t know what they are talking about – meaning me – so I didn’t go and complain anymore, I just kept out of the way of that woman. It’s an awful feeling to say, “Oh, this didn’t happen because you are crazy, you are imagining it”, it’s even worse to hear [it], so I just deteriorated.”

Another PAG member reflected on how they had internalised negative disability stereotypes that emanate from medicalised notions of disability (Oliver, 2009), which then impacted on their ability to access supports.

“I thought that by having those kinds of supports was some kind of weakness ... admitting that I needed help, I kind of had a problem with that.”

Other COP and PAG participants spoke about disempowering experiences whilst institutionalised. Their accounts highlighted how ‘expert’ medical professionals did not listen or acknowledge their lived experience. A participant from the COP spoke about the paternalistic and ableist assumptions that occurred when interacting with a mental health professional. This highlights how paternalistic practice, and the lack of an intersectional lens, subjugates lived experience and impinges upon human rights. As such, this participant’s experience led to the invisibility of both their voice and their rights, and their ability as at PwPSD to make decisions was obstructed.

“I am going to talk about an interaction I had with a male psychiatrist, who was very kind of demeaning and dismissing. I was in hospital when I was 17, it was quite a long admission it was like 6 or 7 weeks, and I was hoping by the end of that to have a place to move out to so I didn’t have to live with my parents which was not a safe environment and when I told my psychiatrist that, he said, “No, you are just a little girl – so, mis-gendering me but also dismissing me.”

Disempowerment and exclusion came in many different forms. Several participants spoke about their inability to access appropriate care and services while residing in psychiatric

institutions and prisons. A PAG participant spoke about the lack of access to knowledge and advocacy in relation to the NDIS while in a psychiatric institution:

“So, my experience with that is that every now and then you would come across someone that is often like one person that is kind of an advocate in that psychiatric institution and like you may or may not see them within a stay. So, NDIS advocacy – it’s definitely not systematic – you can flick a coin as to whether you get to talk to someone or not. So, if you don’t come across somebody like that ... no-one will mention [the NDIS]. There is definitely no information on the ward about NDIS or anything like that – it’s just hit and miss about whether you get to come across someone [who provides information].”

Although existing literature highlights that a significant barrier to accessing the NDIS is the lack of appropriate supports (Ennals et al., 2017; Hui et al., 2018), this study found that when PwPSD are institutionalised, access to appropriate support becomes much more complicated. A client of PWDA spoke about the lack of care and supports whilst incarcerated and trying to access supports such as the NDIS:

“Everything [is] hard in jail, even if you want to send [an] email to my lawyer, okay the, the worst thing in jail is ... just to send paperwork to my lawyer, for example, it's very hard to do that ... Okay, they say you can post it to your lawyer, but sometimes ... for NDIS the Services and Program Officers (SAPO) don't want to help anyone”.

A COP participant also spoke about the complex barriers that can exist for PwPSD transitioning from custody to community, the lack of a trauma-informed approach and practice that was not attuned to social contexts led to unhelpful approaches to support. While this study found similar issues to those in the existing literature relating to barriers experienced by people from diverse cultural backgrounds (O'Connor 2014; Clift 2014; Solatic et al., 2014), this study also found other significant concerns related to both literacy and identity, that are yet to be adequately addressed for PwPSD.

“A lot of inmates from non-English speaking backgrounds have low literacy levels ... and they are coming out of that environment where they are controlled – they feel like they are going into another controlled environment [through the NDIS] and even no way to express what they actually need or want and then the NDIS people don’t understand either [about the] context of trauma from custody to the community.”

In addition to oppressive practices within institutional settings, participants from both the PAG and COP spoke about the barriers that can exist for PwPSD when seeking the support of advocacy organisations. For example, a lived experience participant spoke about a disempowering and disheartening experience when trying to access advocacy services, highlighting the need to engage more deeply with the experiences of PwPSD in navigating the NDIS and for advocacy services to reflect on practices that may be oppressive or exclusionary

“In my own personal experience of being knocked back for the NDIS ... I contacted so many different advocacy groups/organisations and they just kept palming off to the next and the next ... PWDA [said], ... ‘you need to get the internal review date before we can do anything for you, so contact us back after you talk to NDIS’ – and yeah that left me so disheartened because that is a whole other contact [that] I have to go through with NDIS.”

Advocates spoke about the need to recognise, critically reflect upon, and address the power imbalances that PwPSD may experience when seeking support from advocacy organisations:

“We need to look at how we can support people – so as advocates we can work with that power imbalance whilst still ensuring that people with psychosocial disability are validated – because ... participants feel invalidated by [both] us and the system.”

Participants from the PAG and COP also spoke about the need for advocacy organisations to address barriers to good practice, including whether services are reaching PwPSD across diverse social locations and from diverse backgrounds.

“So, one of the things that came out in a recent audit of PWDA services was that there were some barriers to service access – there was a lot around the sort of engagement with clients – particularly those who aren’t white men. We are not trying to engage with CALD, ATSI and/or LGBTQI people who have psychosocial disability.”

Another key issue raised within the action research groups was the need to challenge an expectation that PwPSD should know about and actively seek disability advocacy services, leading to a problematic expectation that clients actively approach PWDA.

“Some prisoners have access to iPads with certain sites that they can use, so Medicare etc ... [PWDA] were trying to get access so that if prisoners needed advocacy support, they could come to us, they could find us through their limited access iPads setups. But ... as an advocacy organisation, we really need to be looking at how we can better [approach] our reach.”

“So our organisation needs to reach out to people in need rather than the other way around, in terms of us [merely] responding to those who contact us. And I think that we as staff need to be better at understanding what PwPSD want, they don’t want to feel excluded. I have seen [advocacy workers who] ... just don’t understand what’s going on for PwPSD and the issues they are experiencing – but also, the strengths they have.”

PwPSD therefore experience multiple disempowering and exclusionary processes when trying to access the NDIS in the context of institutions, including pathologising assumptions about psychosocial disability, a lack of access to information and advocacy, paternalistic practices, literacy barriers, complex identity issues, and barriers to good practice within advocacy organisations. These experiences highlight how exclusion and disempowering processes reinforce institutional power, while also constraining the agency

and resources of PwPSD, leading to significant human rights concerns. While the existing literature has highlighted these barriers (Ennals et al., 2017, Hui et al., 2018), this study has revealed the multiple additional layers of complexity that arise as a result of the adverse impacts of living within institutional settings.

7 Theme 2: The challenges of competing discourses

Highlighted in the literature review were the negative implications caused by a shift toward a more medicalised approach within the NDIS (Briggs, 2020; Aitken et al., 2019). Participants' accounts in this study concur with the existing literature as they also spoke about the dominance of the medical model within diverse institutional settings. Peer workers in the COP stated:

“The way hospitals work is all about compliance. There is nothing about drawing on your own strengths or even working from a harm minimisation approach to first create safety, whatever form that safety may take. In one case mentioned previously, it was [thought that the person could] move into their own place, but that was not what was done in that current medical power dynamic that we have – that was not considered – it is only compliance that was considered.”

“I also think because of all the compliance measures and things like that that are put into place by psychiatrists and things like the Mental Health Act – it sort of enables those power differentials between survivors and professionals.”

“You go in there ... into this little bubble, it's really dehumanizing ... and even among the psych nurses there is not an understanding of the impacts of mental health, it's very pathologising”.

Competing paradigms of psychosocial disability are evident when navigating the NDIS, as it draws upon medicalised ideals but also espouses a recovery-orientated approach. Engage-In advocates spoke about navigating and working within contradictory paradigms and competing discourses, wherein both recovery-orientated and medically orientated approaches are evident.

“Concepts like validation, communication, choice and dignity – all ideals within the NDIS – but those are the things that when you're talking from a biomedical model of treatment of mental health – they are not acknowledged.”

“Institutions function using the medical model, others function on the punishment model predicated on political prejudices and stigmatisation of people with mental [distress], and we as advocates work within a human rights frame – complete opposites.”

Participants in the COP group also spoke about the constraints of a recovery-oriented paradigm for PwPSD who are institutionalised, due to the dehumanised way that PwPSD have historically been treated and because PwPSD have had very low expectations placed upon them by professionals.

“[Understanding recovery is] something they don't know themselves, it's something they have to learn themselves, because they have spent all this time in custody and have just been called a 'prisoner' and 'worthless' and so, for them to find their gifts and their skills and who they are – because when you ask them 'who are you?' and they [say] 'I don't know' – they have been called so many things and so they don't know who they are or what their dreams are or what they really want in society. They don't even see that they can be in society lots of the time because they have always been shifted away from it – so ... it's almost a foreign country to them – it's not something that they think that they could ever go to.”

Several lived experience representatives across the groups acknowledged that there were complexities caused between the competing recovery-oriented and medically orientated

approaches, as the NDIS necessitates that PwPSD identify as having an ‘enduring disability.’

“I was rejected the first time, the first and only time I applied for the NDIS, because they deemed me ‘non-permanent’, which they do with almost all psychosocial disabilities ... I’m not ‘disabled enough’ because I applied with psychosocial disability, including my other chronic conditions, ... and so dismissed my application”

It is well-recognised that psychosocial disability can be episodic and fluctuating. On a good day, symptoms could be easily masked; on other days, intensive support from known and trusted specialists is vital (Wapling, 2021). This highlights a specific consequence of a lack of fit between the realities of psychosocial disability and a highly medicalised approach in the NDIS, which leads to PwPSD being othered and denied access to the NDIS (Wapling, 2021). As a result of these barriers, PwPSD are not afforded their rights in line with the CRPD. Because of competing discourses, lived experience representatives spoke about having to ‘perform’ and ‘be at their worst’ to attain access to the NDIS. Moreover, this adds another layer of complexity for advocates when navigating access to the NDIS.

“So, they’ll (NDIS) arbitrarily decide that someone isn’t disabled enough when things are not ‘cut and dry’, particularly like episodic disability. I’m not episodically disabled I’m disabled all of the time, but I will have flare ups in my conditions so you know, there might be a time when I am like more able to manage my symptoms, and because my capacity at those times is different from when I am incredibly unwell, and need to go into hospital for example, they’ll then determine what my needs are at when I’m well, so, they kind of take you at your best. So, PwPSD catch on and try to do their assessments when they are unwell.”

Within the context of the competing medical and recovery-oriented discourses, lived experienced representatives discussed the importance of exercising choice regarding diverse forms of supports, and the difference made possible by supports that emphasise recovery.

“I have a recovery coach now instead of a support coordinator. It is really good because it frames things in a trauma-informed way and an actual recovery process rather than – I think if there is no recovery frame ... I want to progress and recover. I think the support coordinator fits the physical disability-based model so where you do need supports for everyday tasks, but it just doesn't work for the psychosocial disability stream because ... it doesn't allow you to move forward ... it provides an ... incentive for not recovering.”

8 Theme 3: The de-valuing of lived experience knowledges

The literature review explored the significant challenges to accessing supports that stem from the dominance of neoliberal practices now incorporated into the NDIS (Bigby, 2014; McDermott, 2017; Briggs, 2020). The dominance of neoliberalism within institutional settings was also highlighted in this research, in particular, notions of ‘responsible individuals’ that discounted the role of social contexts and the voices of PwPSD. Participants spoke about the priority given to professional knowledge over lived experience expertise. A critique was made by a PAG participant:

“This marks a distinct hierarchy within the scheme that puts workers as the experts above people with psychosocial disability. There is a lot of talk between the workers but there is bugger all with the clients.”

Participants from both the PAG and COP groups spoke about how medical professionals resisted listening to their lived experiences. This often resulted in PwPSD feeling dismissed and not having any kind of ‘choice and control’ over their decision-making. A few participants highlighted how difficult it was to get the mental health professional to listen to their lived experience.

“I wanted to talk about my situation but all I got was ‘Would you like to take something for that?’ I just want them to validate what I am talking about and listen to what I am actually saying, rather than assuming stuff.”

“I told him that I have significant trauma associated with men and when I first met him during my first appointment I [said] ‘by the way I can struggle with this, this can be a trigger’ and he said ‘we can do exposure therapy’ – so he was actually, being traumatic and abusive toward me. So yeah, a really clear example of medical professionals believing they know better than the patient and using dismissiveness to invalidate those kinds of things.”

“As much as they talk about person-centred care it is very paternalistic – it’s very much we (professionals) know better than you, we will establish rapport with you but only to the degree to which it helps us tick the box.”

Participants across all groups spoke about the lack of opportunities for meaningful dialogue between people with lived experience and professional ‘experts.’ This highlights how professional power dominates the dialogue within services and institutions, as people with professional identities resist listening, validating, or connecting with PwPSD. This finding highlights the importance of looking for spaces for more meaningful dialogue that incorporates, embodies, respects and emphasises human rights.

Participants spoke about how decontextualising the experiences of PwPSD results in practices that are ‘doing for’ and ‘fixing’ individuals. Several participants across both the PAG and COP groups reiterated the importance of working ‘with’ PwPSD rather than ‘for’ PwPSD. They highlighted that a medicalised paradigm facilitates paternalistic ways of ‘doing for’ PwPSD.

“Our work really needs to be framed around people’s humanity and the complexities of our identities and everything else which you know needs to be taken into consideration when working with people. Because we are walking with them we need to support them to actually ... know their

humanity again because that way we are able to walk with them; we don't walk in front of them.”

Participants from both the PAG and COP spoke about how mainstream services try to ‘fix’ people and the unhelpfulness of this pathologising approach.

“They jump in to try and fix things – I think the idea of fixing things just invalidates people and suggests to them that they haven't tried to fix things themselves so invalidates their genuine struggles. Obviously people genuinely try their hardest to deal with what's in front of them and sometimes those issues are very tricky, and we have to start by acknowledging the real stamina and real determination that PwPSD have shown and not just kind of treat them as ‘we can solve your problems **for** you’ – if it were that easy, [the problems] wouldn't exist in the first place.”

An Engage-In advocate provided a vignette that highlights deficits-based practice and a ‘doing for’ approach for client ‘T’, whereby a justice health organisation submitted a pathway out of custody, summarised below, which was strongly opposed by both ‘T’ and his advocate. ‘T’ had complex needs but started to show behavioural improvement, so the prison decided to ‘reward’ ‘T’ with job opportunities and extra audio-visual links to a psychiatrist.

The services of [a specialist unit] developed a management plan to be implemented at the Correctional Centre, in preparation for T's release from custody. The plan included:

- *An aim to reduce the incidence of T's ‘maladaptive behaviours’*
- *The need for individual therapy*
- *A move from a segregated unit to a general/mainstream unit*
- *Extra audio-visual links access*
- *Modified programs or work routines*

A direct transfer to community from the segregated unit was not seen as an option.

The lack of context in this vignette demonstrates that when practitioners decontextualize lived experience, harmful practice can occur, as there is little consideration of the complexities of lived experience, human rights, the social model of disability, or a willingness to collaborate alongside 'T'. The 'doing for' approach in this case does not consider the existing NDIS supports and telehealth appointments that have already been scheduled on a regular basis for 'T', instead imposing new strategies in a 'top-down' approach. The plan also does not acknowledge 'T's' diagnosis of PTSD, as a consequence of child sexual assault. Should 'T' return to the mainstream prison population, there is a strong chance that he will experience threatening situations and respond aggressively, potentially setting 'T' up to fail just as he is nearing release from prison. 'T' knows how he responds within different environments, and he does not want to return to the mainstream prison population and has said repeatedly that he has to live by himself. The above plan does not consider options for supported accommodation when 'T' is released into the community, nor does it provide a timeframe for when 'T' will be released from custody, even though the sentence has already been completed.

The existing literature highlights the barriers and poor outcomes for PwPSD accessing the NDIS who are not living in institutional situations (Gendara et al 2020; Mavromas et al, 2016; Cortese et al 2020). The findings of this study concur with this literature, however, also found that for PwPSD living in institutional situations there were added layers of complexity that resulted in poor outcomes. In summary, these added complexities arose within a context of paternalistic and ableist constructions of PwPSD and competing paradigms (medical – and recovery-oriented), that advocates found themselves working in when navigating the NDIS process. In addition, dominant medicalised discourses that de-contextualised experiences often resulted in oppressive practices that are underpinned with a 'doing for' approach.

The above accounts also highlight how both institutional settings and the NDIS utilise neoliberal practices that conceal the complexities around PSD, which then exclude PwPSD from accessing the supports and services that they have a right to access. Moreover, all groups discussed how the dominance of neoliberalism and the profit-driven nature of service providers accessed by people with psychosocial disability resulted in inequitable outcomes. A key finding was how the NDIS capitalises on the vulnerability of

people with psychosocial disability for profits, through the prioritisation of professional perspectives over lived experiences.

9 Theme 4: Navigating gatekeeping practices and institutional harms

Despite the ideals of social inclusion under the NDIS, the medicalisation of disability, combined with social inequalities such as poverty, frequently impact on how PwPSD are able to participate in the community (Wayland et al., 2020). Financial literacy has also been highlighted as a necessity to accessing the NDIS (Fisher et al., 2019). This study concurs with these findings, however, found more extensive barriers experienced by PwPSD living within institutional settings. For example, advocates who were trying to access the reports needed for the NDIS process reported that they were confronted with micro-aggressions within institutions. An Engage-In advocate spoke about micro-aggressions as ‘active-subversion’ and felt these subtle power plays demonstrated unjust gatekeeping practices.

“Holding things back and it’s very, very easy for an institution to use a mindset that will slow things down but it’s also very easy in many different little ways [for the institution] to subvert processes legally – you know is it a form of gatekeeping, keeping things from clients – people [should] have access to their own information, their own medical records to enable systems to work faster and to the benefit of the person and not to the benefit of the institutions.”

It has been noted that access to the NDIS relies heavily on an individual being literate, including digitally literate, and knowing about and understanding the NDIS (Wapling, 2021). This study concurs with this literature, as lived experience representatives identified having to know what the right terminology was in order to navigate and gain access to NDIS funding. In addition, this study found that the lack of transparency around what is required in order for an application to be successful is also a subtle but very effective

gatekeeping mechanism embedded within the NDIS process itself. A lived experience representative stated:

“It becomes really complicated and you have to know the NDIS back to front and how the funding categories work, the language in which to pitch it and all the rest of it. So, it’s hard because to access the NDIS is sometimes around the terminology and matching what you want to do or finding a way to get around the terminology – so ... you have got to play “jargon bingo” basically, use ... the buzz words they tick off ... and you don’t even know what the buzz words are – most people wouldn’t know what the buzz words are.”

Highlighted in the literature review were the financial implications associated with trying to gain access to the NDIS, for all people with disabilities (Aitken, et al., 2019). The NDIS process now requires people to provide many types of reports, including comprehensive medical assessments. Such reports are often financially out of reach for PwPSD – which means access to the NDIS may be difficult or impossible. The findings in this research are consistent with the existing research, however, demonstrated that the barriers become much more complex for PwPSD exiting institutions, due to the need to navigate institutional gatekeeping practices. A COP participant provided an example about an Engage-In client who was about to be released from prison. The work by advocates in trying to obtain access to the NDIS for the client prior to release was significantly impeded by the institution.

“Pete (not his real name) is going to be released in two weeks’ time, he has a history of recidivism and mental health [difficulties]. Because he has been in the prison system for most of his adult life, he hasn’t had much access to the public health system or community mental health, so his diagnostics have all been done through forensic psychologists/psychiatrist ... there are also court reports, GP reports within the prison system which contain [the] diagnosis – now Pete has the DSP but he doesn’t have the NDIS. I asked his SAPO for people in the system – ‘Okay, Pete’s been in prison for at least 10 years of his 27 years, what records have you got?’

and they [said], 'Oh well, you have got to ask for medico-legal.' Medico-legal operates as a quasi-private company within the system, catering for private and public prison establishments – so I contact medico-legal and they [said] 'What document do you want?' and I [said] 'Look, I don't know, what have you got?' ... and he [said] 'Firstly, if you want a record, you have to tell me what it is, and then you have to pay \$30 for each record'."

Navigating complexity also involves challenging institutional practices that abuse the rights of PwPSD. Practice underpinned by notions that the 'expert' knows better within the medical model silences the voices of PwPSD, and as such the 'expert' controls the narrative. As the literature review highlighted, the NDIS promises to "support a better life for PwPSD" (NDIS, 2020). Gendara et al., (2020) found that access to support relies on people having fair and just supports. However, the shift to a market-based consumer model represents a shift of responsibility from the State to individuals, raising questions about how systems are able to ensure human rights, fair and equitable access, and safeguards for PwPSD. Many participants in this study spoke about the ways in which their wellbeing was compromised by inappropriate supports that re-traumatised them when in institutional settings.

"Oh no, no, no – no trauma informed care [was provided], quite the opposite, I was told, and this was a senior nurse, that if I didn't get up and make my bed (which is basically flattening a sheet) that I would never be able to look after myself, and I'd end up in a nursing home she was really rough about it, you know, she was very nasty about it – they forced people to have showers, they would rip their clothes off and that is allowed, and I had that experience a few years back ... and I thought 'No, I can't complain about her because if I come back here again she will really get stuck into me.'"

"The last time I was hospitalised it was the least trauma informed experience that I have ever had – I have had some pretty profound un-trauma informed or re-traumatizing, let's be honest – re-traumatizing experiences – I had to tell my story about 8 times that day. I had to tell it to

3 or 4 separate people on the phone, at the triage centre, 2 separate [crisis] team workers, [the] admission nurse, someone else when I first came in and then I had a real emotional breakdown that just pushed me over my limit. I was already in the midst of a breakdown – and I had my breakdown in the middle of the hospital, and then instead of responding to that, they took me into a room with 7 clinicians – yeah so I was in the middle of [a breakdown] and they were surrounding me like it was an interrogation session – it was like something from the inquisition. So that was three months ago, so I am not sure that much has changed.”

These accounts highlight the abuses of power that are used as powerful forms of coercion and control within institutional settings. Institutional harms such as micro-aggressions, gatekeeping, PwPSD’s well-being compromised, medical professionals controlling the narratives and situations, all impede upon the rights of PwPSD accessing the NDIS and other resources. A key finding from this study was that PwPSD were systemically excluded from having a say about the systems, processes and programs that directly impacted upon their lives. The study found that people with psychosocial disability in institutions experience heightened harms, as they are located within contexts that are dominated by disempowering and dehumanising practices. These settings reinforce and reproduce the and barriers that exist for PwPSD in accessing and navigating the NDIS.

10 Theme 5: Addressing complexity

The challenge for advocates is finding ways to work within institutions that are so complex, challenging, hostile, and disempowering, when they are working with PwPSD. Advocates were asked about how they work within these systems and lived experience representatives were asked about the components of effective advocacy practices. Advocates and lived experience representatives stated that effective and positive practice and approaches involved:

“Making human connections – using language that is strength based and compassionate based, rather than a ‘compliance model’ that is coercive.

Also, a ‘compassionate model’ that is healing orientated, and trauma informed.”

Several PAG participants stated that they experienced positive practice when interacting with workers with lived experience of psychosocial disability.

“Peer workers were helpful and nice ... this is when I got the comfort and reassurances. I felt validated by the peer worker ... they don’t assume how I feel.”

Other advocates spoke about building teams around PwPSD that can support the client in a much more beneficial way.

“Something that comes to mind straight away is to build Communities of Practice around your clients, and so ... making sure that we are getting the consent right from the get-go so that information can be shared so that – look it just speeds things up – sharing information so that people don’t get the stories two weeks later or that they don’t have to tell the stories again and again. If the consent is given so the person has given permission, and the stories are shared and everyone on their team is on their side and knows what to do and tasks get delegated among the team members. In fact, some of the email headings around our Engage-In clients are you know are Team Maxwell (not real name).”

Lived experience representatives and advocates from the PAG also spoke about the importance of validation, deep listening, and respect with clients as a way to be ‘with’ the client and to ameliorate some of the power differentials.

“Really supporting the person that is telling their lived experience story and holding the space for them and making sure that they have a seat at the table.”

Lived experience representatives also discussed the crucial role of workers with relevant lived experiences of psychosocial disability in advocacy work:

“Has to come from the ground up ... we are standing next to the person, we are not standing above them telling them what to do. If they are in a hole, we are going to get down in the hole with them, and we are going to say, ‘Yeah I have been in this hole, before it’s really shitty isn’t it? You know, I have learnt a few things about being in that hole and getting out of that, it’s worked for me, but hey, we don’t need to get out of the hole either straight away, let’s just sit here and acknowledge this is a difficult place to be in and there are no necessarily easy answers’, but just sitting there with somebody I think is really important and also just validates them ... If you haven’t been in that hole yourself, how can you relate to the person in the hole?”

Participants across all groups spoke about a ‘doing with’ (rather than ‘doing for’) approach, as this way of working highlights and elevates the client’s narrative. A vignette was provided to highlight how ‘working with’ client ‘C’ resulted in positive outcomes that benefited all involved. The following vignette shows how workers built a team around client ‘C’, which enabled mutual respect because workers listened to and elevated ‘C’s’ voice.

The trauma-informed approach began in the pre-release stage by identifying: 1. C was more motivated than ever before to stay outside and have a life; 2. C had employable energy and skills; 3. Getting a job was C’s primary goal, in addition to re-establishing positive relationships. Recognition of C’s assets and expertise in identifying and realising his goals directed the plan. External experts argued that the priority ought to be 3 months rehabilitation to avoid reoffending. But 3 months of not working in rehab, when it had already been 1 year since C had used substances, was not C’s plan.

Working with C as a cohesive interagency, we supported each step of C’s plan. Within 1 week of release, C secured full time employment. C’s team assisted to stabilise C in his work, accommodation, and access to services. The interagency ensured complete ‘buy in’ by C around all decisions and supports. All stakeholders maintained daily communication and supported each other’s efforts to support C to feel safe, overcome setbacks and get his needs met. Doing things differently, acting in partnership and being led by the client, acted as a circuit breaker to two decades of recidivism.

The most critical, stressful time was the first 72 hours, where C was nearly lost again to the corrections system. Small details counted to support C in a time of distress due to trauma. Details such as engaging with a mobile phone service, meeting Centrelink requirements, re-establishing a bank account with minimal ID, were the difference between avoiding prison, and supporting C to battle on to find a place in the world. The intensity of hands-on support faded within a week to zero, as C gained the resources and skills required to get on with his life.

This vignette highlights the importance of always being trauma-informed in order to develop close and trustworthy partnerships with both clients and stakeholders. This requires an understanding of an individual's history and the historical context of institutional practices that often retraumatise people through the disempowerment of a 'doing for' approach, combined with blaming the client when they experience barriers and limitations to supports.

11 Summary of findings

The findings of this study reveal the inherent power imbalances between PwPSD, their advocates, and institutional settings, which are characterised by ableist and paternalistic paradigms, dehumanising approaches, and gatekeeping practices. These assertions of power by institutions added layers of complexity for PwPSD within these intuitions when trying to access supports. These complexities often resulted in PwPSD being denied their human rights, as their opportunities for decision making, access, and inclusion were impeded.

Participants' accounts highlighted that to address these power imbalances, trauma-informed approaches are required, including workers who had a deep understanding and mutual respect for the people they were working with, workers who took into account clients' life histories and experiences of injustice, workers who were really listening, passionate and caring, workers who had lived experience of psychosocial disability, and workers who built teams around their clients.

12 Discussion

The underlying premise of the NDIS is to deliver a person-centred, rights-based approach to disability supports, focused on supporting independence and the participation of people with disabilities in social, economic and community life, and underpinned by the principles of choice and control (Australian Government 2013; NDIS, 2020; Wapling, 2021).

Moreover, the NDIS is premised on the notion that PwPSD can now exercise choice and control over the design and delivery of their care, and those supports are intended to be entitlements, consistent with a human rights framework.

This research found there is still some way to go before PwPSD have their rights met in terms of equal participation with others in the community and full social inclusion. The literature reviewed for this project highlighted the many significant barriers to access and participation for PwPSD living in the community (Gendara et al., 2020; Hui et al., 2018). The findings in this study concur with this literature, while also demonstrating that being in, or transitioning from, an institutional setting added further layers of complexity for PwPSD when trying to access supports.

In a similar vein to the existing literature (Liebenberg, Ungar, and Ikeda, 2013), this study found that deficit-laden discourses and practice, underpinned by medicalisation and neoliberalism, decontextualised PwPSD from their lived experiences. This de-contextualisation de-sensitised professionals to the needs of PwPSD and often placed responsibility on PwPSD to access the NDIS without adequate support. By responsibilising PwPSD, the structural barriers and power imbalances that PwPSD experienced when seeking to access the NDIS were concealed. By not elevating the lived experiences of PwPSD, participation was hampered particularly for PwPSD experiencing intersectional disadvantages, who were contending with multiple additional barriers (Mavromas, Moskos & Mahuteau 2016; Wapling, 2021). As shown in the second vignette in this report, the intersection of institutionalisation combined with the trauma of child abuse, may impede access to supports for PwPSD, if advocacy is not provided that is sensitive to a person's social context and needs.

Concurring with existing literature (Cortese et al., 2020; Gendera et al., 2020; Hui et al., 2018), this study also found that the complexity of navigating the NDIS is exacerbated by the ongoing impacts of competing discourses (co-existing medical and recovery-oriented paradigms of disability). In addition, this study found that the competing discourses led PwPSD to engage in taxing emotional labour through pressure to 'perform' and 'be at their most unwell' to gain access to the NDIS; this has the potential to complicate the relationships between PwPSD and their advocates, as it impeded advocates from working from a comprehensively recovery-oriented perspective. Furthermore, this study found abuses of power against PwPSD within institutional settings because professional practice was often underpinned by 'the expert knows best' narrative. When professionals resist listening to participants' lived experience and employ gatekeeping strategies, these powerful mechanisms exclude PwPSD from the very supports they are entitled to. This clearly demonstrates that the barriers to access for PwPSD are due to the norms and practices of 'hard-to-reach' settings, rather than the individual characteristics of PwPSD.

Institutional power impeded the human rights of PwPSD by trivialising their needs whilst diminishing their dignity. These disempowering practices and experiences resulted in PwPSD being further excluded from participating in the community through having flow-on effects to their capacity to access the NDIS. This study found that PwPSD in institutional settings were routinely excluded and alienated from accessing the supports that they have a right to access and are entitled to. Hence, the quality of life experienced by PwPSD was hindered by structural barriers within NDIS policy, which assume that choice and control are possible, and institutional contexts, which deny choice and control.

Nevertheless, this study found that there were effective ways to ameliorate the existing power inequities within advocacy practice. Advocates and lived experience representatives spoke about the importance of elevating lived experience, embedding peer workers across all levels of practice, building the capacity of the peer workforce, and providing leadership opportunities to people with relevant lived experiences of psychosocial disability. Skills in 'going down the rabbit hole' with clients, including sitting with distress and deep listening with PwPSD are crucial. Anti-oppressive practice was also made possible through a commitment to working *with* PwPSD, rather than paternalistic approaches that *do for* PwPSD, and with consent, building Communities of Practice around clients.

As Brown (2021) argues, practitioners need to think and work critically within systems that are disempowering, re-traumatising, and underpinned by deficit-based discourses. Advocates can, when supported by senior management, challenge language, highlight structural barriers, provide alternative knowledges, and work within an anti-oppressive framework underpinned by human rights. Overwhelmingly, this research found that acknowledgement of lived experience needs to be elevated within all levels of practice. Furthermore, this study has highlighted the need to shift the dominant narrative from a pathologising discourse of ‘fixing’ PwPSD, as though they are the ‘problem’, to instead understanding the impediments to supports are embedded in the structures and systems within which PwPSD are located. A clear and conscious consideration of the disempowering and harmful systemic practices that deny the rights of PwPSD, alongside the elevation of lived experience, will assist those working in these advocacy roles to avoid the reproduction of ‘power over’ relationships with clients.

13 Strengths of the study

Investigations into the NDIS and its barriers have consistently explored the experiences of PwPSD in the community (Ennals et al., 2017; Cortese et al., 2020). A key strength of this present study is its focus on the experiences (and perspectives) of people with psychosocial disability who are living in, or transitioning from, institutions. This study has therefore focused on a group of PwPSD who have been under-represented in the literature, and who also remain under-represented in NDIS packages. Therefore, the findings are useful in documenting ethical, anti-oppressive, and effective advocacy practices and add to the current literature base.

In addition, as the majority of participants in the study were people with lived experiences of psychosocial disability, the research is imbued with experiential expertise, adding depth to the findings. What also sets this research apart from other investigations into the NDIS and its barriers is that it explored the construct of complexity, thus engaging with multiple and intersecting social contexts.

14 Limitations and future directions for research

As is the case with qualitative research based upon a purposive sample, a cautionary note regarding the transferability of the findings is needed. PwPSD who participated in this research are not representative of all PwPSD, for example, there was limited cultural diversity among the participants. The small sample size and location of the research within one agency places limitations on the generalisability of the findings.

15 Closing comments

This study has shown there are structural and systemic barriers for PwPSD in institutional settings that frequently exclude them from the supports they have a right to access. Through action research, this study has explored the lived experiences of PwPSD in institutions, as well as the perspectives of advocates working within institutional contexts. The findings have revealed the difficulties in navigating supports, due to ableism, gatekeeping practices, and paternalistic assumptions, while also demonstrating the details of advocacy practice that makes a difference.

While this study cannot ameliorate all the barriers that exist for PwPSD, nor the negative and deficit-oriented ways of understanding PwPSD that currently dominate social norms, it can contribute to transformative change in demonstrating the importance of privileging the under-represented voices of PwPSD in institutional settings in order to create a more inclusive dialogue of what it means to live with psychosocial disability, and to what it means to embody effective and inclusive practice.

References

Aitken, Z., Baker, E., Badland, H., Mason, K., Bentley, R., Beer, A., & Kavanagh, A. M. (2019). Precariously placed: Housing affordability, quality and satisfaction of Australians with disabilities. *Disability & Society*, 34(1), 121–142.

Australian Bureau of Statistics. (2020). *Gender indicators, Australia*. Retrieved from: <https://www.abs.gov.au/statistics/people/people-and-communities/gender-indicators-australia/2020>

Australian Government (2018). *Disability Services Act 1986*. Retrieved from: <https://www.legislation.gov.au/Details/C2018C00146>

Australian Government (2013). *National Disability Insurance Scheme Act 2013*. Retrieved from: <https://www.legislation.gov.au/Details/C2013A00020>

Baines, D. (2017). *Doing anti-oppressive practice: Social justice social work*. (3rd Ed.). Fernwood Publishing.

Bigby, C. (2014). Is the National Disability Insurance Scheme Taking account of People with Intellectual Disabilities? *Research and Practice in Intellectual and Developmental Disabilities* 1(2), 93–97.

Bracken-Roche, D., Bell, E., Macdonald, M, & Racine, E. (2017). The concept of “vulnerability” in research ethics: an in-depth analysis of policies and guidelines. *Health Research Policy and Systems*, 15(8), 1–18.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.

Briggs, D. (2020). The NDIS Should be About Choice and Control by People with Disability – Not About Commodities for Profit. *The Australian Journal of Community and Disability Practitioners*, 1.

Brown, C. (2021). Critical Clinical Social Work and the Neoliberal Constraints on Social Justice in Mental Health. *Research on Social Work Practice*, 31(6), 644–652.

Clift, K. (2014). Access to the National Disability Insurance Scheme for People with Intellectual Disabilities Who Are Involved in the Criminal Justice System. *Research and Practice in Intellectual and Developmental Disabilities*, 1(1), 24–33.

Cortese, C., Truscott, F., Nikidehaghani, M. & Chapple, S. (2021). Hard-to-reach: the NDIS, disability, and socio-economic disadvantage, *Disability & Society*, 36(6), 883-903.

Ennals, P., Waring, J., Storen, E., & Burns, A. (2017). Addressing homelessness for people with psychosocial disability: Will NDIS access issues get in the way? *Parity*, 30(4).

Fisher, K. R., Gendera, S., & Kayess, R. (2022). Reaching people who are marginalized in major disability policy reform. *Global Social Policy*, online first: <https://doi.org/10.1177/14680181221075558>

Fisher, K., Purcal, C., Jones, A., Lutz, D., Robinson, S., Kayess, R. (2019). What place is there for shared housing with individualized disability support? *Disability and Rehabilitation*, 19(1), 1–9.

Flanagan, N. (2020). Considering a participatory approach to social work – Service user research. *Qualitative Social Work*. 19(5–6), 1078–1094.

Gendera, S., Pearson-Gotting, M., Fisher, K. R., Kayess, R., Stensel, A., Rahman, T., & Wiseham, L. (2020). *Enable In Action Research: Final Report*. Sydney: UNSW Social Policy Research Centre.

Gooding, P. (2016). From deinstitutionalisation to consumer empowerment: Mental health policy, neoliberal restructuring and the closure of the “Big bins” in Victoria. *Health Sociology Review*, 25(1), 33–47.

Gorman, R. & LeFrancois, B.A. (2017). Mad studies. In B.M.Z. Cohen (Ed.), *Routledge international handbook of critical mental health* (pp. 107–114). Routledge.

Hammond, H. (2022). *What is Psychosocial Disability and How Can the NDIS Help?*
Retrieved from: <https://chessconnect.org.au/what-is-psychosocial-disability-and-how-can-the-ndis-help/>

Harvey, D. (2010). *A Brief History of Neoliberalism*. Oxford University Press.

Horsell, C. (2020). Problematizing disability: A critical policy analysis of the Australian national disability insurance scheme. *Australian Social Work*, 50(1), 1–13.

Howard, A. (2019). Who can argue with blue sky? The questionable alliance between difference and the market in disability policy. In D. Baines, B. Bennett, S. Goodwin, & M. Rawsthorne (Eds.). *Working across difference: Social work, social policy and social justice*. Red Globe Press.

Hui, F., Cortese, C., Nikidehaghani, M., Chapple, S., & McCombie, K. (2018). *Hard to Reach: Examining the National Disability Insurance Scheme Experience – A Case Study in Wollongong*. University of Wollongong. Retrieved from:
<https://ro.uow.edu.au/buspapers/1523/>

Jacob, S., & Furgerson, S. (2012). Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *Qualitative Report*, 17(42), 1–10.

Kemmis, S., & McTaggart, R. (2000). *The action research planner*. Deakin University Press.

Krueger-Henney, P., & Ruglis, J. (2020). PAR is a way of life: Participatory action research as core re-training for fugitive research praxis. *Educational Philosophy and Theory*, 52(9), 961–972.

Laing, L., Irwin, J., & Toivonen, C. (2012). Across the divide: Using research to enhance collaboration between mental health and domestic violence services. *Australian Social Work*, 65(1), 120–135.

Laragy, C., Fisher, K. R., Purcal, C. & Jenkinson, S. (2015). Australia's individualised disability funding packages: When do they provide greater choice and opportunity? *Asian Social Work and Policy Review*, 9(1), 282–292.

Liebenberg, L., Ungar, M., & Ikeda, J. (2013). Neo-liberalism and responsabilisation in the discourse of social service workers. *British Journal of Social Work*, 45(3), 1006–1021.

Lingard, L., Albert, M. & Levinson, W. (2008). *Qualitative Research: British Medical Journal*, 337, 459–461.

Mavromas, K., M. Moskos, & Mahuteau, S. (2016). *Evaluation of the NDIS – Intermediate Report*. National Institute of Labour Studies. Flinders University. Retrieved from: https://www.dss.gov.au/sites/default/files/documents/11_2016/final_intermediate_report_w_cag_compliant_24_nov_2016.docx

McDermott, S. (2017). Housing for Australians with serious mental illness. In J. Sylvestre, G. Nelson, & T. Aubrey (Eds.). *Housing, citizenship, and communities for people with serious mental illness: Theory, research, practice, and policy perspectives* (pp. 300–329). Oxford University Press.

Mental Health Australia. (2020). *Getting the NDIS Right for People with Psychosocial Disability*. Retrieved from: <https://mhaustralia.org/general/getting-ndis-rightpeople-psychosocial-disability>

Morrow, M., & Weisser, J. (2012). Towards a social justice framework for mental health recovery. *Studies in Social Justice*, 6(1), 27–43.

Meyer, J. (2000). Using qualitative methods in health-related action research. *British Medical Journal*, 320, 178–181.

National Disability Insurance Scheme (NDIS). (2020). *How the Planning Process Works*. Retrieved from: <https://www.ndis.gov.au/participants/how-planning-process-works>

National Disability Insurance Agency (NDIA). (2020). *NDIA annual report 2019–2020*. Canberra, ACT, Australia: National Disability Insurance Agency. Retrieved from: <https://www.ndis.gov.au/about-us/publications/annual-report/annual-report-2019-20>

NSW Government (2020). *Anti-Discrimination Act 1977*. Retrieved from: http://www7.austlii.edu.au/cgi-bin/viewdb/au/legis/nsw/consol_act/aa1977204/

O'Connor, M. (2014). The National Disability Insurance Scheme and People with Mild Intellectual Disability: Potential Pitfalls for Consideration. *Research and Practice in Intellectual and Developmental Disabilities* 1(1), 17–23.

Oliver, M. (2009). *Understanding Disability: From Theory to Practice 2nd Edition*. Palgrave Macmillan.

Oliver, M. & Barnes, C. (2012). *The New Politics of Disablement*. Palgrave Macmillan.

Pacheco, L., & McConnell, D. (2017). Love and resistance of mothers with intellectual disability from ethnocultural communities in Canada. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 501–510.

Parkin, P. (2009). *Managing change in healthcare: Using action research*. Sage Publications.

Pratt, A. (2006). Neoliberalism and Social Policy. In M. Lavalette and A. Pratt (Eds.). *Social Policy, Theories, Concepts and Issues* (3rd ed.). Sage Publications.

Pyysiainen, J., Halpin, D., & Guilfoyle, A. (2017). Neoliberal governance and 'responsibilization' of agents: Reassessing the mechanisms of responsibility-shift in neoliberal discursive environments. *Journal of Social Theory*, 18(2), 215–235.

Rawsthorne, M. (2009). Just like other families? Supporting lesbian-parented families. *Australian Social Work*, 62(1), 45–60.

Rosenberg, S., Redmond, C., Boyer, P., Gleeson, P., & Russell, P. (2019). Culture clash? Recovery in mental health under Australia's National Disability Insurance Scheme—a case study. *Public Health Research & Practice*, 29(4), e:29011902.

Shamir, R. (2008). The age of responsibilization: On market embedded morality. *Economy and Society*, 37(1), 1–19.

Smith-Merry, J., Hancock, N., Gilroy, J., Llewellyn, G., & Yen, I. (2018). *Mind the Gap: The National Disability Insurance Scheme and psychosocial disability*. Final report: The University of Sydney. Sydney Policy Lab.

Soldatic, K., G. van Toorn, L. Dowse, and K. Muir, (2014). Intellectual Disability and Complex Intersections: Marginalisation under the National Disability Insurance Scheme. *Research and Practice in Intellectual and Developmental Disabilities* 1(1), 6–16.

Spivakovsky, C. (2014). From punishment to protection: Containing and controlling the lives of people with disabilities in human rights. *Punishment & Society*, 16(5).

St Clair, R. (2020). *People with Severe Mental Illness Face Difficulties Accessing NDIS*. Retrieved from: <https://www.disabilitysupportguide.com.au/talking-disability/people-with-severe-mental-illness-face-difficulties-accessing-ndis>

Stewart, V., Visser, K., & Slattery, M. (2020). Supporting choice, recovery, and participation: Clear and easy to understand information is the key to NDIS access for those with psychosocial disability. *Journal of Social Inclusion*, 11(2), 33–46.

Taylor, L., & McLeod, D. (2018). Systems' reform: Better meeting the needs of people with psychosocial disability and reducing the risk of homelessness. *Parity*, 31(8), 14–16.

Tseris, E. (2020). The expansion of the peer adviser workforce: Opportunities and challenges for social work. *Australian Social Work*, 73(2), 162–174.

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved from: <https://www.un.org/development/desa/disabilities/conventionon-the-rights-of-persons-with-disabilities.html>

Wapling, R. (2021). *NDIS Access, Eligibility and independent assessments*. Victoria Council of Social Services – Issue Paper. Retrieved from: <https://www.vcross.org.au>

Warr, D, Dickinson, H, Olney, S, et. al. (2017). *Choice, Control and the NDIS*. University of Melbourne. Retrieved from: https://socialequity.unimelb.edu.au/__data/assets/pdf_file/0008/2598497/Choice-Control-and-the-NDIS.pdf

Wayland, S., Smith-Merry, J., Rakidzic, S., O'Shea, A., Schweizer, R., Gill, K., Hutton, V., & Sisko, S. (2020). Ableism. In V. Hutton and S. Sisko (Eds.). *Multicultural responsiveness in counselling and psychology* (pp. 217–240). Springer International Publishing.

Whitehead, D., Taket, A., & Smith, P. (2003). Action research in health promotion. *Health Education Journal*, 62(1), 5–22.

Williams, T. M., & Smith, G. P. (2014). Can the National Disability Insurance Scheme work for mental health? *Australian & New Zealand Journal of Psychiatry*, 48(5), 391–394.