Author/s:
Wilson, E;Campain, R;Pollock, S;Brophy, L;Stratford, A

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Exploring the personal, programmatic and market barriers to choice in the NDIS for people with psychosocial disability.

Authors:

Professor Erin Wilson, Uniting Kildonan Chair in Community Services Innovation, Centre for Social Impact, Swinburne University of Technology

Professor Erin Wilson is the Uniting Kildonan Chair in Community Services Innovation at the Centre for Social Impact, Swinburne University. She has worked extensively in the field of participatory social change and disability and inclusion, encompassing research in Australia, Papua New Guinea and Vanuatu. Her work has focused on the design of inclusive and participatory methods that enable diversity of participation, including children and adults with diverse disabilities. Her current interests include outcomes measurement and capacity building for social inclusion.

Dr Robert Campain, Research Fellow, Centre for Social Impact, Swinburne University of Technology

Dr Robert Campain is a Research Fellow at the Centre for Social Impact, Swinburne University. His research has focused on social inclusion for people with disability and mental health conditions, as well as evaluating outcomes for recipients of service provision. His research has involved working in partnership with people with disability through inclusive and participatory practices. These partnerships have included children and adults with diverse disabilities.

Dr Sarah Pollock, Executive Director of Research and Advocacy, Mind Australia

Dr Sarah Pollock has recently commenced the role of Chief Mental Health Advocate for Western Australia. Prior to this she was the Executive Director of Research and Advocacy with Mind Australia. She is an experienced senior executive who has worked in a range of research, development and policy roles in the health and social care NGO sector. She is committed to a strong and vibrant mental health service system.

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Professor Lisa Brophy, Professor and Discipline Lead in Social Work and Social Policy at La Trobe University

Lisa Brophy is Professor and Discipline lead in Social Work at LaTrobe University, and Adjunct Senior Research Fellow in the Centre for Mental Health, Melbourne School of Population and Global Health at the University of Melbourne. Lisa's research focus is on people experiencing mental ill health and psychosocial disability and their recovery, social inclusion and human rights. Her teams have included people with lived experience and partner organisations leading to research and evaluation activities that foster participation and codesign.

Mr. Anthony Stratford, Senior Advisor Lived Experience with Mind Australia.

Mr Anthony Stratford uses his lived experience of mental ill-health and recovery to inform his work with Mind and other related organisations both in Australia and internationally. His work involves advocating for the rights of people with mental health conditions as well as championing the benefits of mental health peer work. He is a Visiting Scholar at Yale University School of Medicine, an Honorary Fellow in the Department of Psychiatry, University of Melbourne, and Expert Advisor to the World Health Organisation.

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DR. ROBERT CAMPAIN (Orcid ID : 0000-0002-3999-5557)

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rccampain@swin.edu.au

Exploring the personal, programmatic and market barriers to choice in the NDIS for people with psychosocial disability.

Abstract

The aim of this paper is to inform the design of individualised funding schemes via an examination of discourses and experiences of choice related to people with psychosocial disability. Mind Australia, in partnership with Deakin University, interviewed 22 individuals with psychosocial disability who are recipients of individual funding packages in three National Disability Insurance Scheme (NDIS) trial sites across Australia. This research involved examining the policy and assumptions of choice under the NDIS, as well as the experience of undertaking choice through individualised funding arrangements which position people with psychosocial disability as consumers in a market-place of service provision. The findings demonstrate that choice is an ongoing activity and that at every stage personal, programmatic and market barriers impact individuals' capacity to maximise choice. The intent of Government policy to provide choice to individual funding recipients based on an optimally functioning market-place with empowered self-actualizing individuals, collides with a complex reality where barriers abound at every stage of the choice-making process. Enhancing choice-making of people with psychosocial disability within the NDIS requires governments and services to explicitly address the personal, programmatic and market-based barriers to choice.

Key words

NDIS   Psychosocial disability   Policy   Choice   Market

Introduction

Australia's National Disability Insurance Scheme (NDIS) commenced trials across Australia in July 2013 to provide support to people with a significant and permanent disability to take part in everyday activities. The Scheme represents a transition to a market model of service delivery that changes the essential characteristics of disability support service delivery. Prior to the NDIS, government funding of service provision was largely based on a 'commissioning model' where disability service providers competed to receive block funding to deliver services (Carey, Malbon, Olney & Reeders, 2018a:22). The NDIS represents a paradigm shift to a personalised approach with funding packages provided to individuals for direct purchase of services (Green & Mears, 2014). This shift away from collective welfare provision in favour of markets and self-directed care, via individualised funding, has occurred in many industrialised countries over the past thirty years. During this time, advancements such as the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD), have required policy to shift to a human rights and autonomy focus (Purcal, Fisher & Laragy, 2014). In this context, a key aim of the NDIS is to provide people with 'choice and control' in pursuing their goals, and in the planning and delivery of their supports (Australian Government, 2013). For many people with disability there is the possibility of enacting choice and flexibility, and promoting independence and self-determination, to an extent that they have not previously had the opportunity to do (David & West, 2017).

Choice however is an ambiguous concept, taking on different interpretations dependant on both the paradigmatic and practical context. This paper explores this notion of 'choice' by examining the discourses of choice that underpin and are articulated in the NDIS, then presenting the experiences of choice for NDIS participants with psychosocial disability and the barriers they encounter. Psychosocial disability is the term used to describe a disability arising from a mental health condition. A mental health condition can be caused by life events or genetic factors and include mood, anxiety, personality, psychotic, and compulsive disorders. Not everyone though who has a mental health condition will have a disability. When a person with a mental health condition experiences disablement and participation restrictions, then the term psychosocial disability is used to 'describe what is often the outcome for a person with a mental health condition attempting to interact with a social environment that presents barriers to their equality with others' (NDIA, 2018: 3). Throughout this paper, we use the term psychosocial disability as our primary focus is on people who have been deemed to be eligible for NDIS funding based on this classification. However, the terms 'mental health condition' or 'mental illness' have been retained where these have been used by individuals (peer researchers, research participants) or in cited literature, such as in the discussion of the concept of recovery.

While experiences of choice for NDIS participants have been examined in an emergent literature set (Warr et al., 2017; Mavromaras et al., 2018), this paper focuses on people with psychosocial disability as a group whose needs have not been well met in the initial design of the NDIS (Mavromaros et al., 2018; Productivity Commission, 2017; Tune, 2019), and who have often appeared as only a subset of research participants in other studies (Glendinning et al., 2008; Mavromaras et al., 2018; Productivity Commission, 2017; Tune, 2019; Warr et al., 2017). The focus of this paper is on the complexities of designing a Scheme based on 'choice' – read through neo-liberal market, human rights and recovery narratives– while attending to the interface of personal, programmatic and market contexts that construct this experience for Scheme participants.

The concept of choice – neoliberal markets, human rights and the recovery approach

Choice (and freedom of choice) is a concept that is frequently considered as central to wellbeing and leading a good life. Having choice and control is also aligned with the growth of neo-liberal ideology and practices throughout the last 30 years which have emphasised competition and consumerism (Purcal et al., 2014). Western nations are promoting greater choice and control through service systems where citizens can choose services that best meet their needs (Carey et al. 2018a; Christensen & Pilling, 2014). In the discourse of new public management, 'choice and control' within public sector services is understood as 'a way to gain economic efficiency, while enabling citizens to have a more empowered relationship with the state' (Carey et al. 2018b: 388). Policies based on new public management thinking position communities and service users 'as free to create their own defined visions, missions, and goals' (Dunn & Miller, 2007: 354). The discourse is not, however, without substantial critique around notions of 'choice', focusing on the dominance of consumerist thinking where 'people are likely to be viewed as nodes in a market, exercising choice as utility maximizers, not citizens' (Dunn & Miller, 2007: 356).

In Australia, consistent with new public management thinking, emphasis on the value of choice is evident in the Productivity Commission (2011) inquiry into disability care and support, the catalyst to the establishment of the NDIS. The Commission argued:

> The capacity to exercise choice can represent a valuable 'good' in its own right for many people, as revealed by the efforts people make to secure such freedoms. Many people would prefer to make their own decision on something, even if a benevolent outside party were to make exactly the same decision on their behalf. And, even if people end up asking someone else to choose for them, the option to make a choice remains valuable (p. 358).

This policy logic extends beyond Australia and has become increasingly evident in many European and North American countries which use individualised funding packages to support people in many areas of social care, particularly in aged and disability care (Laragy et al., 2015; Needham & Dickinson, 2018; Webber, et al., 2014).

This interest in 'freedom' of service users through enacting choice in markets has developed alongside a progressive human rights agenda and a focus on empowerment (Purcal et al., 2014). The establishment of the CRPD recognises the human rights of people with disability, encouraging law and policy that increase independence and social and economic participation for people with disability, and that provide opportunities for individuals to enact choice (Degener, 2016). The fundamental right to choice permeates the CRPD, with the Preamble outlining 'the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices' (United Nations, 2006: Preamble). As part of establishing equal recognition before the law, Article 12 of the CRPD underscores decision making rights and supports as essential to 'exercising autonomy and having the freedom to makes one's own choices' (Schulze, 2010: 83). Subsequently, in legislation, policy and practice, focus on the nature of supports to decision making has encompassed both formal and informal mechanisms (Kokanović et al., 2018). In the context of people with psychosocial disability in Australia, these have included advance statements, peer support, and legal recognition of supported decision making (Brophy, 2020; Brophy et al., n.d.).

Equally, for people with a mental health condition and those with psychosocial disability, the recovery approach (which is the basis of community-based service delivery) aligns with the CRPD and its recognition of individual autonomy. A recovery approach emphasises empowerment, with the focus on the promotion of a meaningful life with a positive sense of identity founded on hope and self-determination (Byrne et al., 2018; Rosenberg et. al., 2019). Tew et al. (2012) emphasise five inter-locking processes of recovery, commencing with 'empowerment and reclaiming control over one's life' (p. 445). As with the human rights approach, the recovery paradigm also aligns with a focus on supported decision-making practices (Brophy, 2020; Kokanović et al., 2018) to support choice and autonomy for people with a mental health condition.

Overall, the marketisation and privatisation of social services under neo-liberal reform, along with the paradigms of human rights and recovery, position choice as 'a central policy driver' (Purcal et al., 2014, p. 89). As Purcal et al. (2014) state, 'neoliberalism emphasises choice of providers in a free market, and human rights advocates emphasise choice of the person with disability over their lifestyle and support services' (p. 89). However, neoliberalism and human rights are underpinned by different values and drivers and, so despite common language, the meaning of choice is obscured rather than reinforced. In this context, as argued by Fyson & Cromby (2013), , the rights of people with disability have in practice become:

> largely synonymous with the promotion of the 'choice' agenda … Personalisation has moved away from being about the minutiae of social interactions between individuals and is now primarily associated with the delivery of welfare through 'self-directed services' whereby individuals are given money in lieu of services and are then 'free' to purchase the services on the open market … in practice, permissive rights gain primacy over protective rights (p. 1166).

This critique of the diminishment of features of the human rights agenda, including via personalisation of supports for life activities, is an important cue as it re-emphasises the broad role 'choice' can play in achieving the aspirations of people with disability. As Purcal et al. (2014) conclude, policy makers and service providers have a responsibility to understand and address service system constraints under a market based system, as well as to ensure the protection of the rights of people with disability, while 'maximising people's level of personal choice' (p. 99).

Understanding choice

Despite the increasing discourse of choice in social care services and policy in the Western world, the concept remains ambiguous and is rarely defined (Christensen & Pilling, 2014; Lakhani et al. 2018). To provide people with choice requires a recognition that choice is a multifaceted concept with degrees of complexity in how it is defined as a principle and how it is operationalised, including the conditions required to maximise people's choice-making capacity.

In everyday life, choice has many manifestations, is experienced to varying degrees, is greatly affected by context, and has both positive and negative implications. Choice can be identified at the personal level involving both everyday choices and lifestyle choices, as well as 'pervasive' choices of larger consequence such as work, education and personal relationships (Ramcharan, 2012 in Purcal et al., 2014). Other authors focus on the extent of choice - ranging from limited to extensive (Leadbeater, 2004 in Purcal et al., 2014). At the operational level, choice is constructed of practicalities – the who, where, what, when and how (Le Grand, 2005 in Purcal, et al., 2014). Fyson & Cromby (2013) argue that to make choice meaningful, the individual who is choosing must understand (i) the full range of options available; (ii) the personal consequences of making a particular choice, both immediately and in the longer term; and (iii) the likelihood that a choice can, in the future, be reversed without causing permanent harm. Choice is highly contextualised: context impacts choice and the social determinants of choice, including inequality and entrenched disadvantage, will limit and affect the choices people can make (Fisher et al., 2016; Marmot & Bell, 2011). Finally, choice is not an unequivocally positive experience: choice can create a fear of making wrong decisions, which leads to dissatisfaction and distress and potentially less, rather than more, happiness and satisfaction (Schwartz 2004, in Fyson & Cromby, 2013).

This complexity of defining and understanding choice highlights that to posit choice in policy requires further exploration of what choice is and how individuals undertake it. Choice cannot be considered a self-evident unambiguous concept. Choice is multifaceted and this intricacy needs to be recognised in understanding how the NDIS both enables and hinders choice in its complex guises, and how recipients understand choice across aspects of their lives and the experience of undertaking it in a market environment.

The NDIS

The shift to personalisation and choice

Given the notion of choice is open to various interpretations, it is necessary to consider how choice is outlined according to the government Act regulating the NDIS - the focal context of this paper. According to the *National Disability Insurance Scheme Act 2013*, a key object is to:

> enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports (Australian Government, 2013: Chap 1, Part 2, 3(1) e).

'Choice' is not explicitly defined in the Act but is evident as a key principle throughout. Overall, three components related to the above key objective with regard to choice can be identified in the Act:

First, people with disability have a right to exercise choice:

> People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity (Chap 1, Part 2, 4 (8)).

Second, people with disability's decision-making capacity is to be recognised:

> People with disability are assumed, so far as is reasonable in the circumstances, to have capacity to determine their own best interests and make decisions that affect their own lives (Chap 3, 17A (1)).

Further to this, people with disability should be involved in decision making processes that affect them, and where possible make decisions for themselves (Chap 1, Part 2, 5 (a)).

Thirdly, people should be supported to exercise their choice-making capacity:

> People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports (Chap 1, Part 2, 4 (4)).
>
> People with disability should be supported in all their dealings and communications with the Agency and the Commission so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs (Chap 1, Part 2, 4 (9)).

In the main, as these clauses attest, the Act echoes the intent of the CRPD; choice is related to self-determination and people with disability are able to determine their own best interests, with their decisions respected and appropriate support in decision making provided where required. However, while the Act affirms choice, it is not a 'free for all'. There are a number of caveats placed on individual choice. Choice is strongly focused on the pursuit of goals and supports, and the Act places the parameters of 'reasonable and necessary' around the funding of these supports (Foster et al., 2016). Such constraints on choice and on what can be funded as 'reasonable and necessary' are discussed by participants in the 'Choice' research described below. In addition, the Act also draws a link between choice and 'capacity' suggesting that people with disability are to 'engage as equal partners in decisions that will affect their lives, to the full extent of their capacity' (Australian Government, 2013: Chap 1, Part 2, 4, (8)). While this could be read as endorsing supports for decision making consistent with the CRPD, both the notion of capacity and of partnered, rather than autonomous, decision making, suggests limits to self-determined choice-making for all.

The operational elements of individualised funding in the NDIS

The principle of choice should apply throughout all aspects of an individual's engagement with the NDIS. While beyond the scope of this paper to outline in comprehensive detail, some basic insight into the core operational features of the NDIS that frame the opportunities for choice is necessary.

The participant 'journey' in the NDIS ideally follows a basic design: assessment for eligibility; identification of participant needs and necessary supports via a (short) planning process; approval of plan and funding allocation of a support package; selection and activation of service providers; expenditure of funds on approved activities; plan review; and funding renewal. At each of the journey stages, the individual with disability is meant to be central to decision making and choice. Key formal roles supporting this and having a significant effect on the enactment of choice, are the roles of planner (within the NDIA) and of support coordinator (if the participant is allocated funding to purchase this role from a service provider). Ideally, the NDIA planner works with the participant to ascertain each participant's goals and aspirations, their level of functional restriction and to then determine the appropriate supports. A statement of goals and aspirations is developed which includes information about the participant, including: their living arrangements, community supports, and social and economic participation. A support package is put together to help the participant progress towards their goals. The planner and the participant decide when or under what circumstances the plan will be reviewed, as well as how the plan will be managed through options such as self-management, management by the NDIA, or using a plan management provider. Many participants who have higher or complex needs or are at risk of not implementing their plan, will be funded to acquire the services of a support coordinator. This role assists participants to connect with informal, community and funded supports, and supports participants to increase their capacity to maintain relationships, manage service delivery, live more independently as well as being more included in the community (Productivity Commission, 2017; Tune, 2019).

Despite an expected participant cohort of 64,000 people with psychosocial disability (Productivity Commission, 2017), actual numbers are around 10% of the current 390,000 NDIS active participants (NDIA, 2020). With a substantial gap between actual and anticipated numbers, multiple reviews have identified problems related to eligibility for entry to the Scheme as well as enactment of choice throughout the process in relation to this cohort (Mavromaros et al., 2018; Productivity Commission, 2017; Tune, 2019).

The 'Choice' research

Since NDIS commencement, formal reviews of the Scheme have been conducted (Mavromaros et al., 2018; Productivity Commission, 2017; Tune, 2019) along with studies into people's experiences of personalisation and individualised funding (Foster et al., 2016; Mavromaras et al., 2018; Warr et al., 2017). However, prior to this current study, only limited attention had been paid to the experience of people with psychosocial disability in such systems and even less to understanding their experiences as choice-makers. To address this gap in knowledge, Mind Australia, in partnership with Deakin University, undertook the 'Understanding people with psychosocial disability as choice-makers in the context of the NDIS' project, here referred to as the 'Choice' research. Research was conducted in three NDIS trial sites across Australia, interviewing 22 recipients of individual funding packages from the NDIS - 4 from Victoria's Barwon Region (BR), 9 from the wider Perth region of Western Australia (WA) and 9 from the Hunter Valley (HV) in New South Wales. The main aim of the research was to explore how people with psychosocial disability understand and operationalise choice in the context of the NDIS.

The study benefited from initial input into the research design by an expert panel comprising academics and industry stakeholders, as well as a highly experienced consumer advocate with knowledge of the NDIS at whole-of-Scheme level. The feedback and advice from this diverse array of people was considered by the research team and was used to shape the project. Also on the panel was a peer-researcher (adult with a lived experience of a mental health condition and recovery) in recognition of the importance of peers as 'experts through their lived experience' (Stratford et al., 2016: 77). The peer researcher played a crucial role throughout research design, interviews and analysis, ensuring that interpretations and meaning-making at all stages was consistent with the world-view of participants.

A qualitative approach was used incorporating individual interviews as the sole method of data collection. The study was designed in accordance to similar studies that examined the lived experience of groups, using interviews to elicit information based on the understanding of people as experts of their own experience (Foster et al., 2016; Mavromaras et al., 2018; Rich et al., 2013; Warr et al., 2017 Jenkin et al., 2017). The peer researcher conducted a majority of the interviews alongside a fellow researcher and played a vital role in establishing empathy and trust with participants through being able to briefly acknowledge his own experience with a mental health condition.

Ethics approval was provided by Deakin University in July 2017, with interviews conducted between September 2017 and March 2018. Inclusion criteria involved being an NDIS participant with a psychosocial disability in one of the three trial sites. There were 9 male and 13 female participants, with ages ranging from 28 – 62 years of age with an average age of 49 years. Participants self -reported a wide-range of diagnoses included bipolar disorder, schizophrenia, post-traumatic stress disorder, schizoaffective disorder, borderline personality disorder, depression and anxiety. All participants had an individual funding package and a plan, were aged 18 and above, and provided informed consent.

A grounded textual analysis, which allows categories to emerge from the data, was used to analyze interviews. According to Hsieh & Shannon, the advantage of this approach to content analysis is 'gaining direct information from study participants without imposing preconceived categories or theoretical perspectives' (2005: 1279-1280). Interviews were transcribed and read repeatedly by the researchers to achieve immersion and obtain a sense of the key themes across the range of interviews. Data was organized according to the identified themes which were revisited by all the researchers to ensure data was represented logically with explanations and interpretations representing the respondents' viewpoints (Fossey et al., 2002).

The following themes were identified that aligned with the key research questions:

1. Participants' understanding of choice;
2. The personal context of choice-making;
3. The labour of choice;
4. Programmatic barriers to choice in the NDIS;
5. Market barriers to choice and the limits of service providers under the NDIS; and
6. Enablers to choice through the NDIS.

All themes, with the exception of themes 3 and 6, are presented below. Given the novelty and depth of the findings of theme 3 which engages with each step of the NDIS participant journey, this data is the subject of a separate publication (forthcoming), while theme 6 is incorporated in the Discussion section.

Participants' understanding of choice: alignment with NDIS policy principles

As discussed above, choice is a multi-faceted concept. As Williams & Porter note, if government policies are based on 'choice and control' then we need to learn from personal budget users 'their own experiences and lived understanding of those terms' (2017: 106). The 'Choice' research elicited views on what choice means to NDIS participants with psychosocial disability, the significance of it to them, as well as the issues relating to the exercising of choice. A variety of descriptions of choice were offered by participants with the following representative of key ideas:

> I think it's [choice] one of the most important things you can have because I think a lot of mental ill health and a lot of ill health, and just lack of emotional wellbeing, comes from people feeling they haven't got a choice (*WA3 –female*).

> It's [exercising choice] very empowering, obviously empowering. It makes me more independent to have choice, more confidence, more content and happy (*WA9 –female*).

> Having a choice is kind of like knowing what options are out there first, knowing which ones of those apply for you, and being able to weigh up the pros and cons of each thing, and then you make an informed choice. That's what being able to make a choice is to me. You can't really make a choice unless you know what there is out there to choose from (*HV8 –female*).

The value of choice as a major principle of the NDIS in supporting people to make decisions and determine their requirements to live a good life was recognised by participants. Participants clearly valued having choice and saw it as essential to their wellbeing and self-determination. Such understandings and applications of choice are in line with the NDIS' stated aim of supporting people with disability to determine their goals and choose their required supports, and are in line with the NDIS principle that people with disability have the right to 'realise their potential for physical, social, emotional and intellectual development' (Australian Government, 2013: Chap 1, Part 2, 4, 4, (1)).

The personal context of choice-making

To fully ensure people are able to exercise choice in a market-economy, the ability of individuals to exercise choice based on their life circumstances needs to be considered. As it stands, the largely unproblematic acceptance of choice, as it flows from policy principle to the programmatic level, assumes informed and autonomous individuals operating in a market-place and able to exercise their choice in meeting their personal needs. Such understandings obscure the lived experience of individuals who are undertaking the 'labour of choice' (Wilson et al., 2018) often under complex personal and social circumstances. The 'Choice' research identified key aspects of the personal context of choice-making, highlighting that people with psychosocial disability have a range of unique circumstances which impact their ability to exercise choice in their lives, as identified below.

The majority of participants had limited prior experience with choice-making or felt they had lost their ability to identify their own preferences. The ability to make choices or take control should not be assumed as the same for all. Each individual has a different pre-disposition around choice, affected by their life circumstances and mental health.

> A lot of my life I haven't had choice because of mental illness, because of just struggling from day to day. I was just surviving. There's no choice in that … When you've got mental illness and depression, and suicidal tendencies and anxiety, you have no choice … And so a lot of my

> life I haven't really had a choice … but when you're so far down or so depressed you really do need help. You're so disabled, or you're so unable to actually ask for help, that you can't (*HV7 -male*).

Each individual comes with a legacy of choice or denial of choice experienced in childhood and adulthood. Many of the participants had experienced trauma (including physical and psychological abuse) at some stages of their life, whether it was within their family and intimate relationships, or through their experiences of various services. Such trauma not only impacted their ability to make choices at the time but continued to have a profound impact. For many, this had resulted in disempowerment or loss of voice which prevented them from exercising choice.

> I couldn't choose anything at this stage. Because I was under welfare until I was 21, because I'd been in and out of institutions all my life. I didn't even know what the world was like out there. I had a lot of problems with getting bashed up and raped and stuff. So I've still got to go through the trauma with that …Then losing - I lost my dad in 2012, lost Mum 2013 - so I've got a lot of trauma (*WA5 -female*).

> My sister said 'But you used to be able to speak out for yourself'. I think I used to be able to at some stage. But when I got married I started getting beaten around a bit, and I lost my voice and I could never regain it ... But once you've been beaten around you just don't ever feel safe. You lose your voice and you can't assert yourself and your personality, and you can't be who you were - and that's gone forever (*WA4 -female*).

> My mental health went rapidly downhill from the age of 17 or 18. I moved out of home at 17. I moved in with my partner. The relationship ended and that partner went out of the way to completely destroy my life to the extent that this is still going on, you know, 23 years later … Within a couple of years I had moved to Adelaide and one of the women I was living with was so abusive to me, she was really awful, and I came back just devastated (*WA8 –male*).

Financial hardship and a lack of material and social resources throughout people's lives have a significant bearing on people's ability to make choices. For many, such deprivation has meant that choice-making is limited to daily needs, so that the ability to think beyond the immediate is limited.

> I just had no place to live. So it's kind of difficult with all of my shit and stuff in the boot, lying in the back seat to get to sleep … That was quite different, living in my car for a bit … I had a drink every now and again. I know that much. What kind of choices did I have? I don't know. I was just driving around. It was a tough time (*WA6 –male*).

> It was terrible … just literally was suicidal all the time. And any support I had, friends in the neighbourhood or whatever, just dropped off. Because it was chaos. It was horrible. And then I kept trying to get someone to listen to me … I got turned down by about 13 services (*HV3 - female*).

The personal context of an individual emerged as an important factor in framing the disposition of each person as a choice-maker. This personal context and individual disposition is brought into the NDIS environment, often with little or no support to identify and mitigate its effects.

Programmatic barriers to choice in the NDIS

The personal factors to choice-making identified in the previous section are compounded by barriers set up by specific NDIS procedures and processes throughout the planning process and the resultant plan that often did not reflect people's requirements. Three major areas emerged as discussed below.

1. Lack of NDIS information and communication that undermines choice.

Many people indicated that they were unaware of what supports and activities they could choose and were entitled to as part of establishing a participant plan. The lack of information meant many people were attending planning meetings and reviews in ignorance, and therefore were unable to exercise choice at this important stage of the process.

> I don't know if I'm entitled to this or I'm entitled to that … It's what makes the situation so frustrating … We don't know what we're entitled to; we don't know what's out there … I don't know what to ask for. I don't know what's available - I try to just ask for a general thing (*HV5 - female*).

> I was confused about what choices I could even make. They expected me to come up with, 'I need blah-blah-blah' - and I didn't even know that those things existed. So how can I say that I choose something if I don't know that it's there … I didn't know what choices to make because I didn't know what choices there were (*HV8 -female*).

2. Personnel and meeting processes do not foster choice.

The NDIS was often viewed as impersonal and more of a hindrance than a help. People were made to feel unimportant and often were not listened to, with the planner making decisions that did not reflect the life and needs of the individual. Rather than exercising choice and control, people spoke of being compliant and passive recipients of funds that were seen as a privilege rather than a right.

> It was like that woman that I spoke to for the first review – she told me the review had been done and they weren't giving me any more funding. She was quite rude about what my needs were and also condescending (*HV4 -female*).

> When you go in there for the planning I always feel just so thankful for what I get rather than the feeling that I have the right and entitlement. So, because I feel like that, I'm very reticent to ask for anything specific. I keep all my goals really general (*HV5 -female*).

Given the nature of people's disability, consideration needs to be given to how challenging the application process and meeting/planning may be for people. People found NDIA processes confronting and intimidating as well as being confusing. All this added to people's anxiety and uncertainty.

> But, well, the first time [of planning] it was like - it's a bit scary. This new NDIS place building is huge. They just said 'this, this and this is going to happen', and there was another lady before who was taking down different notes about something else. It was very difficult to understand I think. Obviously, that was a choice but I just - like I couldn't really understand or comprehend what they were talking about (*WA6 -male*).

Many noted that having an advocate such as a family member, friend or trusted support worker, was valuable and necessary given how confronting the planning process was.

> I would advise everyone to go with someone - an advocate - someone who will speak up when you're being railroaded … I'd make it compulsory that people have an advocate with them - that they don't get interviewed without that. And all interviews are face to face. The planning meeting is onerous. My point is that you just have to go in with someone who knows as much as possible, rather than go in there raw (*HV5 -female*).

> She [support worker] was with me for two hours asking all the right questions and pretty much wrote this amazing three-page thing out to say [to the NDIA planner] 'this is what she needs'. Those couple of pages was all it took (*HV1 –female*).

3. <u>Limitations and inadequacies of the plan that affect choice.</u>

The most common grievance of people was that funding was often not provided for supports deemed necessary, with participants frustrated with the lack of choice in not being able to spend funds on supports that were often urgently required. The restrictions on funding packages meant people may have the money but lacked the control in being able to spend it in ways they deemed appropriate, and that were considered by the participants to be central to their life and their disability.

> Well, my choices have sort of been prescribed for me in the sense that there was not only the plan but then there was the coordinator of supports working out what was best for me … So, what I'm trying to say is that I didn't have choice in who was provided to me. I didn't have choice in terms of what the actual structuring of the money was (*HV2 -male*).

People spoke of their dissatisfaction in not funding what they saw as essential to ensuring their wellbeing: this included things such as psychology provision, education and employment, as well as assistance/companion dogs, peer support, gym memberships and assistance for transition to work/volunteering. People spoke of having plans that did not address their needs and contained items that were not necessarily required by the person.

> I had asked them, 'I'd like to join a gym. Could that be factored in?' She said, 'No, we don't do that'. No health programs. You know who really needs health programs? People with mental health or anxiety or bipolar - their biggest outlet, their biggest way to overcome their anxiety and their depression, is to do physical stuff. Often they're sitting at home - they're passive, they're overweight, they're eating. They're eating to control their anxiety (*HV7 -male*).

Market barriers to choice and the limits of service providers under the NDIS

Once participants had their plan approved the next stage was to navigate a complex market-place to enable their supports to be put in place. Participants identified inadequate responses from service providers as a key barrier to exercising choice. This included things such as the providing of support coordination, the organising of supports and services, the replacing of support workers when there was a requirement for new workers, and the lack of replacement of support workers when a worker went on leave.

> In terms of the service providers – you had to pick from the ones that were provided to you. I did get a choice in the sense that I phoned up about four or five of them. A couple of them I wasn't in the area so that there was no choice in the sense that I wasn't in their target population. Of the others, of the three or four left, I left messages asking for people to ring me. And I think that was highly disconcerting for a lot of those support organisations. Because most of them didn't ring me back. I think they would have preferred to talk to the planner or the coordinator rather than me directly (*WA3 -female*).

Support co-ordinators were recognised as both a valuable enabler to choice yet could also be a barrier when co-ordinators were unsatisfactory. Participants noted that sometimes there was a lack of contact/response from co-ordinators, a lack of organising of supports, often they inappropriately took control of decision-making, or they lacked adequate knowledge of the NDIS and how the funding works. Some participants also spoke of uncertainty about the co-ordinator role and what was reasonable to expect of them.

> So there are no options, we don't know what choices we've got, nobody knows. I feel like the support coordinators and the support workers really don't know what to do (*HV1 -female*).

Participants often found that there was a lack of choice and flexibility with services. There was frustration and uncertainty expressed by participants as to what they were entitled to from services, recounting uncertainty as to what sort of supports could be provided and what their funding entitled them to ask of services. Some spoke of being 'boxed in' with others, for example, where only groups were available in which people had little choice in the activities to be undertaken and when. Often when they did wish to join a particular service there were no available places, leaving people without the supports they required and had chosen.

> I was put into that service which is on the High Street. And I went there and it was a whole group of us just walking around. That's not me. Or sitting down knitting … We've all got different issues but we're all boxed in the same thing (*BR2-female*).

It is also evident that support workers have a significant impact on people's daily lives. A quality worker could greatly enhance choice for people, while an inadequate support worker could diminish a person's autonomy and personal wellbeing. Issues with support workers included lack of knowledge related to psychosocial disability, inappropriate and unacceptable behaviour, as well as lack of attention to the participant's needs.

To enhance the quality of support workers for participants and to maximise the possibility of a good supportive relationship, participants considered the choice and consistency of support workers as vital. This was commented on by many participants, noting unfilled staff absences, ad hoc changes of staff with no notification, high staff turn-over and poor organisational systems for managing this.

Often it was difficult for participants to take control in their exchanges with support workers – to take a more active role in what they expected and to exercise choice in how they wished the support relationship to proceed. Participants often felt vulnerable and were unable to effectively liaise with support workers to reach satisfactory arrangements. Many attributed difficulties here as a common characteristic of people with psychosocial disability, as many found confrontation difficult or impossible. Enacting choice and control was spoken of as extremely difficult as it requires a degree of assertiveness not always consistent with people's experience of psychosocial disability.

> A lot of people on NDIS they'd be given somebody [support worker] - they'd know it's completely wrong for them and they wouldn't be able to say anything … And I say, 'Well, why don't you talk to your support person?' They said, 'Oh I can't'. That's one of the biggest things for people on the NDIS. They're very disempowered. They're unable to do it and they won't do it. People say, 'Well, why didn't you say something?' They can't. They can't. They're so disempowered they can't (*HV7 -male*).

Discussion

This research explores understandings of choice in order to make visible some of the multiple elements that affect and support choice-making within the NDIS for people with psychosocial disability. Consistent with previous reviews of the NDIS (for example Productivity Commission, 2017; Tune, 2019), participants in this research reported numerous problems and barriers to their enactment of choice within the Scheme. Discursive underpinnings related to choice, plus personal, programmatic and market factors, all interact to construct the experience of choice. Given this complex interplay of factors, enhancing choice within the NDIS for people with psychosocial disability is likely to require a multi-pronged set of strategies.

The values associated with choice in the CRPD and in the recovery approach, were those also affirmed by people with psychosocial disability in this research. At the level of choice as a principle, participants welcomed the NDIS focus on providing people with disability choice within the Scheme. Choice was deemed central to the person's sense of self, their autonomy and right to make decisions in their life, their physical and mental health, as well as being part of a community to which they could contribute - all notions reflected across the breadth of the CRPD. Consistent with these ideals, UK studies have confirmed that individualised funding has both allowed people with a mental health condition to experience greater levels of choice than previous arrangements (Glendinning et al., 2008; Stevens et. al., 2011) and that a wide range of outcomes result from this (Larsen et al., 2015; Manthorpe et al., 2008; Tew et al., 2015; Webber et al., 2014). Similarly, in Australia, an evaluation found that the NDIS leads to improved satisfaction with choice and control for the majority of participants, though those with psychosocial disability experienced lower levels of choice and control than other disability types (Mavromaras et al., 2018).

A strong finding of this study is the influence of personal factors on the enactment of choice for people with psychosocial disability. For many participants, their history of choice-making is fraught, and they are left with a legacy that shapes their ability to engage in processes of choice. Many discussed the variable impact of psychosocial disability on choice-making at different stages of the individualised funding life-cycle, highlighting how personal trauma, financial hardship and lack of sufficient resources left people disempowered. While this experience may be common to participants from other disability groups (particularly those experiencing cognitive disability and those with complex support needs [Collings, Dew & Dowse, 2016, 2017]), the context of clinical restraint, legal denial of decision making capacity, and mental health conditions, must be understood as imposing a unique legacy that disrupts and denies choice-making for people with psychosocial disability.

While both Tune (2019) and the Productivity Commission (2017) have identified the need for NDIA-related personnel to have a greater understanding of psychosocial disability as a mechanism to better respond to the needs of this group, any increased knowledge of psychosocial disability would need to encompass a recognition of the personal legacy of trauma and its effect on choice-making. A stronger articulation within the Scheme of the CRPD’s mandated rights to decision making supports, along with wider use of informal supported decision-making practices, could go some way to address the issues arising here. However, formal supported decision making may not address the pervasive effect of this disenfranchisement of choice-making in day-to-day decisions in daily life, especially for people who appear to be experiencing few or mild functional limitations resulting from their psychosocial disability. In this context, the NDIS has the opportunity to adopt a stronger capacity building approach (Productivity Commission, 2011) in supporting the development of new choice-making experiences and skills among participants with psychosocial disability as they engage with the NDIS.

The experiences of participants in this study evidence a Scheme whose program design assumes and requires agentic activation of choice throughout the NDIS journey. Program features related to the application process, the planning process, the amount of funding, the things which will and will not be funded, the skills, knowledge and personal characteristics of planners and NDIA personnel, and review processes, all impact people’s choice-making capacity. Similar concerns were identified by Collings et al. (2016, 2017); Mavromaras et al. (2018) and the Productivity Commission (2017), while Warr et al. (2017) found that some participants struggled to ‘mobilise capacity for choice and were not aware of their entitlements or what might be available to them’ (p.53). Lack of information sufficient to choice-making across the stages of the NDIS journey was repeatedly noted by participants in the current study. As identified earlier in this paper (Fyson & Cromby, 2013; Purcal, et al., 2014), choice is dependent on a range of practicalities such as information about options, an understanding of consequences, and of the who, what, when and how of choice relevant to each stage of the NDIS choice-making journey.

Participants in this study noted the importance of being clear in what they required from the NDIS via support from advocates who enabled them to not be passive and reactive in dealing with the NDIA. Advocates, peers and some service providers were commended as supporting information-sharing about the NDIS, assisting with pre-planning, and providing support during planning meetings. Through this lens, the programmatic features of the Scheme have been designed with insufficient understanding of the elements necessary for choice-making, including information provision and support.

Added to this fraught environment within which choice-making is required to occur, a range of authors note the additional difficulties of the episodic nature of psychosocial disability which leads to times when choice-making within the Scheme will need additional support, as well as programmatic features that enable ad hoc changes to planning processes, services, equipment and support (Glendinning et al., 2008; Griffiths, 2013; Larsen et al., 2015; Tew et al., 2015; Tune, 2019; Warr et al., 2017). In this context, Scheme design needs significant refocusing on the ongoing information necessary to enable choice, as well as the provision of supports to maintain choice-making across the NDIS journey, particularly for those with fluctuating health and wellbeing.

Finally, while new public management discourse emphasises the ‘freedom’ of individual choice and control via marketized social services, this study shows that many features of the market constrain choice. Participants are required to enact choice in a poorly functioning system where the quality of support services and staff, and the variety and availability of services, had a significant impact on how NDIS recipients exercise choice. A neoliberal marketized approach requires a robust market as a precondition of choice. By contrast, a number of studies have documented a lack of service providers, long waiting lists for services, limited information about provider options and inflexibility of service provision (Mavromaras et al., 2018; Tune, 2019). Several authors now note that this fraught context is likely to persist for some time beyond full Scheme ‘roll-out’ (Gilchrist et al., 2019; Productivity Commission, 2017), arguing that the ‘current state of the system is the new system’ (Gilchrist et al. 2019, p. 6 original emphasis) despite its shortcomings for some participant groups. In this context it is unsurprising that this study shows that choice at the point of selecting and contracting service providers needs substantial support.

Participants highly valued ‘good’ support coordinators as brokers and supporters in service selection, where these were knowledgeable and empathetic, and actively supported choice in planning, managing funds, acquisition of knowledge of the NDIS and services, and problem solving. In the absence of further market development, the role of support coordinators (where funded) has strong value in addressing market barriers to choice. In addition, they could also play an expanded role in supporting participants to manage support staff. Participants with psychosocial disability reported barriers to enacting their preferences and choice when these required directly supervising support staff, as many felt they could not voice their concerns, criticisms or suggestions for improved practice. This kind of choice enactment requires further funded support via support coordinators, advocates, or others.

Similarly, the role of support workers in terms of building choice-making capacity was noted by participants in this study. Skills particularly valued were vigilance in care for the person; experience in mental health including lived experience; listening skills; ability to support skill development in life planning and organisation; ability to suggest but not coerce; ability to support decision making through posing questions and options; and capacity to become a friend. In this context, it is imperative that support workers have the necessary skills to meet the requirements of NDIS participants (Dowse et al., 2016) and, if funded to do so, the market has the opportunity to offer support workers whose role encompasses building choice-making capacity.

This research posits that choice is an ambiguous concept whose experience is constructed by many paradigmatic and practical factors. Overall, addressing the complex interplay of personal, programmatic and market barriers to choice requires multiple elements of scheme re-design. NDIS policy, and the programmatic elements of its implementation, needs to be based on a recognition that choice is not equally available for all, and that people have a personal history and contemporary circumstances that impact their capacity to exercise choice. Scheme redesign is required, along with explicitly requiring and resourcing the market to deliver supports to choice-making as part of its practice models, just as supports for decision-making are mandated under various Mental Health Acts. To do so would be consistent with Australia's obligations under the CRPD. Given its infancy, the NDIS continues to undergo reform to address problems identified with the NDIS, including information provision to the Scheme, planning, thin markets, and the provision of services and staff with disability knowledge - including awareness of psychosocial disability (NDIA, 2019, 2020; Tune, 2019). Recently, NDIS accessibility reform has led to pathway enhancements for those with psychosocial disability. This includes a streamlined access process, greater flexibility in funding use, enhanced planning to respond to the episodic nature of psychosocial disability, and increased recognition of the role of supporters to accompany participants to planning and other choice-making events (NDIA, 2019, 2020; Tune, 2019). Further research is required to assess the impact of these changes on the choice-making of people with psychosocial disability.

Limitations

As with any study there are both strengths and limitations that need to be acknowledged. This is a modest study that encompasses a small sample of participants from trial sites that may not be representative of other regions – particularly rural and remote regions – nor of the diversity of people's gender or cultural identity, or the impact of their psychosocial disability. The lack of follow-up interviews prevented the opportunity of determining how people's capacity to enact choice changed over time and how subsequent planning and funding may have impacted choice-making capacity – though it should be noted that 55% of research participants had undergone more than one NDIS planning/package allocation. Nor did the study have the capacity to include people who have not managed to access the NDIS. As previously noted, there have been changes to the NDIS since the initial trials so that findings from this study do not encompass these changes. However, the findings evidence the complexity of choice both in its enactment due to personal circumstances and the interplay with the social environment. The strength of the research is in providing unique insight into people with psychosocial disability's involvement with the NDIS, with the semi-structured interviews privileging service-users' knowledge and their lived experience. Future research is required to build on the findings here and assess the impact of changes within the NDIS on people's choice-making capacity.

Conclusion

Choice is frequently promoted as a social good consistent with both neoliberal values and concepts underpinning the CRPD to which Australia has aligned its disability policy. Research undertaken in three regions across Australia shows that people with psychosocial disability likewise value it as a policy principle, envisaging that it is potentially empowering and agentic. Choice, however, is problematic in that it is not equally available to all, with personal circumstances and wider systemic conditions constraining choice. The broad endorsement at the level of policy principle belies the challenges of choice that need to be addressed at the operational level of program delivery. This problematic of choice needs to engage with how it is constrained by personal, programmatic and market factors. This confluence of factors requires purposeful response in the form of supports to choice-making across the ecosystem of the NDIS (individuals with disability, service providers and their staff, Scheme guidelines and processes) with a systemic assurance of supports for choice-making where required and requested by participants.

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