Understanding people with psychosocial disability as choice-makers in the context of the National Disability Insurance Scheme (NDIS)

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Glossary of terms

CBT	cognitive behaviour therapy
DP	direct payment/s
IB	individual budget
IRB	Individual Recovery Budget
LA/LAS	Local Authority/ies
LAC	Local Area Coordinator
MH	mental health
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NHS	National Health Service (UK)
OT	occupational therapist
PA	personal assistant
PB	personal budget
PCA	person-centred approaches
PTSD	post-traumatic stress disorder
SDS	self-directed support

Executive summary

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)

Background

Over the last 30 years, there has been a trend in many Western nations of giving citizens greater choice and control through providing a service system where people can choose the services that best meet their needs (Carey et al. 2018a). Australia's National Disability Insurance Scheme (NDIS) provides support to people with disability, as well as to their families and carers. The main component of the NDIS is the individualised funding package, which aims to give people choice and control in pursuing their goals and in the planning and delivery of their supports. Many people with psychosocial disability can enact choice to a greater extent than they have previously been able.

There is a gap in knowledge about people with psychosocial disability as choice-makers in individualised funding schemes. What evidence there is indicates that such schemes are yet to maximise people's choice-making capacities, and that there are a number of concerns to be addressed. Given this, there is a need to understand how choice operates in the context of the NDIS. There is also a need to understand how to support choice-making so that NDIS participants with psychosocial disability can draw from the Scheme the greatest benefit at the earliest opportunity, thus maximising its potential.

Mind Australia Limited, in partnership with Deakin University, undertook research in three regions across Australia (the wider Perth region of Western Australia, the Hunter Valley in New South Wales and Victoria's Barwon Region). The researchers interviewed 22 people who had received NDIS funding in the form of individual packages. The main aim of the research was to explore how people with psychosocial disability make choices in the context of the NDIS. The project was

designed to assist NDIS participants, planners and policy-makers through the provision of a research report and a series of practical resources.

The National Disability Insurance Scheme (NDIS)

In 2010, the Australian Government asked the Productivity Commission to carry out a public inquiry into long-term disability care and the establishment of a national disability support scheme. The resultant scheme, the NDIS, is based on the principle that 'participants should be able to exercise choice and control over the services and supports they receive' (Productivity Commission, 2017: 3).

While the NDIS was designed to support people with disability in general, the Commission explicitly recommended that it should support people with psychosocial disability; this would provide them with 'the wider benefits of the scheme, including individualised supports and more choice in what supports are provided, when and by whom' (Productivity Commission, 2017: 23). It is anticipated that, by the time the Scheme is expected to be rolled out in full (2019-20), around 13.5 percent (64,000) of participants will be those with a primary psychosocial disability (Productivity Commission, 2017).

Project design

The shift in disability support funding from pre-NDIS block funding direct to service providers to individual funding direct to the recipient of services raises the need to consider how people will exercise choice, and what the significant issues in doing so are. The key questions guiding the research focused on the experience of NDIS participants with psychosocial disability, and included:

- What is choice, and what does it mean to have choice?
- What choices do people with psychosocial disability have in the NDIS in terms of funding and planning?

- What gets in the way of people being able to make the choices they want (the barriers)?
- What enables people to make the choices they want, and what needs to change to assist them?

Interviews were conducted with NDIS participants with a psychosocial disability between September 2017 and March 2018. Interviewees were from a range of trial sites, including Barwon (four), Newcastle (nine) and Western Australia (nine). All participants had an individual funding package and a plan, were aged 18 and above and were capable of giving – and gave – informed consent. In total, 22 participants were interviewed. These comprised:

- 10 participants who had prepared one plan through the NDIA
- 12 participants who had prepared (or were about to prepare) their second or third plan.

There were nine male and 13 female participants. Their ages ranged from 28 to 62 years, with an average age of 49 years. The types of psychosocial disability with which they were living were wide-ranging and included bipolar disorder, schizophrenia, post-traumatic stress disorder, schizoaffective disorder, borderline personality disorder, depression and anxiety.

A grounded textual analysis, which allows categories to emerge from the data, was applied to the interviews. A range of major themes was identified, with data within these themes sorted into sub categories. This thematic analysis identified participants' views and their experience of choice, as well as the enablers and barriers to exercising choice. Analysis was also undertaken to identify the key choice activities (termed the 'labour of choice'), including experiences in each activity and advice for undertaking each stage.

Findings

Understanding 'choice'

The principles of choice and control are central to the NDIS. Choice is a complex concept that is

difficult to define. The following, a brief summary of some definitions expressed by participants, highlights a number of themes:

- having basic needs met first, then higher-level needs
- money defining and providing the choices one makes – having to be practical
- knowing the options one has, weighing them up and then being able to make an informed decision
- being able to make one's own decisions and doing what one wants to do – with support if required
- self-direction and being able to voice one's preferences as opposed to being told or having choices forced upon oneself
- always having options
- to have a voice and be able to express it
- being able to say yes or no
- to be empowered with freedom and independence.

Such understandings and applications of choice are in line with the NDIS's stated aim of supporting people with disability to determine their goals and choose the supports they require. Participants clearly valued having choice and saw it as essential to their wellbeing. The potential of the NDIS to support people to make decisions and determine their requirements for a good life was recognised through the way it addresses day-to-day needs, as well as long-term and 'higher-level' goals such as education and employment.

The personal context of choice-making

Individuals often have limited experience of choice-making or feel they have lost their 'voice' or the ability to identify their own preferences. The level of ability to make choices or take control should not be assumed to be the same for all. Each individual has a different predisposition around choice, and this is 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. You're just struggling to get through a day. You don't have a choice … 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 … When I'm depressed you can't decide anything … you're being pulled all different directions. Your mind – you're just confused all the time. You can't make a decision. When you're not depressed it becomes clear. (Hunter7 –male)

Each individual has a legacy of having experienced choice or denial of choice in childhood and adulthood. It is evident that many people have experienced trauma at some stages of their lives, perhaps within their family and intimate relationships or through their experiences of various services. Such trauma not only affected their ability to make choices at the time it was suffered but continues to have a profound impact. For many individuals, this has resulted in disempowerment or loss of voice, which prevents them from exercising choice.

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. I mean, that's why my marriage broke down ... 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 for ever. (WA 4 –female)

Financial hardship and a lack of material resources throughout people's lives also significantly affects their ability to make choices. For many, such deprivation has meant that choice-making is limited to daily needs, so their ability to think beyond the immediate is limited. People's access to a variety of resources, and to what may be deemed 'social capital', can have a huge impact on their choice-making capacity. People's personal contexts are important factors in framing their individual dispositions as choice-makers. Both personal context and individual disposition are

brought into people's engagement with the NDIS, often with little or no support to identify and mitigate their effects.

The labour of choice

One of the main focuses of this study was to investigate the act of choice-making for NDIS participants with psychosocial disability. All 22 participants in the study described extensive and challenging choice-making activities across the whole life cycle of NDIS individualised funding. They also described the strategies they had used – or would suggest others use – to assist with this labour.

Whereas a substantial focus of the discussion of choice-making in the information about the NDIS is on the planning 'moment', the labour of choice for participants was identified at each of the following stages:

* applying to the NDIA
* pre-planning
* planning
* immediately after NDIS package approval
* utilising the funding – purchasing and managing supports and services
* reviewing the plan
* appealing decisions (where relevant).

Participants recounted their experiences, gave their advice and discussed how their history of choice-making had influenced their ability to engage in these processes. Their responses suggested that the labour of choice in the context of the NDIS is complex and often extremely difficult.

Barriers relating to choice in the context of the NDIS

A number of significant barriers were identified in relation to both the NDIS and support services. These barriers affected people's experience of choice and form the context for the labour of choice that people are required to undertake as NDIS participants.

The key barriers that limit people's capacity as choice-makers as identified by research participants (can be categorised as those relating to the NDIS and those relating to services and supports. The number of participants who reported each barrier is indicated in brackets following the description of the barrier.

Barriers relating to the NDIS

Three major areas emerged:

1. Limitations and inadequacies of the plan that limit or deny choice:
   • lack of choice in structuring funding and what to spend it on; not funding what is required (16)
   • inappropriate plans that do not address a person's real needs and goals (11)
   • lack of psychology provision (7)
   • increased broader life participation choice required – especially education, employment (5).

2. Lack of information and communication that undermines choice:
   • lack of information about entitlements (13)
   • lack of communication from the NDIA, including delays in processing applications (11)
   • lack of information/clarity about what an individual's plan and funding mean (10).

3. Personnel and meeting processes do not foster choice:
   • dealing with different staff and the anonymity of the NDIA (14)
   • an impersonal system where people do not feel listened to or supported to make decisions – are made to feel unimportant (12)
   • arduous/intimidating meetings and a confusing/complex application process (12)
   • staff do not understand mental illness and psychosocial disability – are often rude, condescending, focus on physical aspects of health/life (11).

Two other themes emerged:

• uncertainty and worry over reviews and the possible reduction of funding (11)
• inconsistency with funding across recipients (4).

Barriers relating to services and supports

• delays in adequate response and/or service establishment (10)
• inefficiencies of support coordinators (10)
• lack of choice and flexibility of services (9)
• unsatisfactory support workers (8)
• lack of choice of support staff and consistency of regular workers (8)
• uncertainty of what they are entitled to from services (6)
• difficulties in taking control and liaising with support workers (5).

The NDIS – making life easier and better

Despite these barriers to choice-making, it is important to recognise that – although the point was not specifically investigated as part of the research – many people (13) explicitly stated that funding from the NDIS had made their life easier and/or better. For many, it was the first form of financial assistance they had received and it had given them more control over their lives and enhanced their capacity to make choices. Significantly, some people acknowledged that adequate financial support and greater control over their lives had the advantage of enhancing their health and reducing the need for hospitalisation; this is beneficial both to individuals and those closest to them. It also benefits the health system and the wider community.

Enablers and suggested improvements relating to choice in the context of the NDIS

A number of significant enablers (things that aided participants in choice) and suggested improvements that affected people's experience of choice were identified. These relate both to the NDIS/NDIA and to support services.

- The key enablers and suggested improvements identified by research participants are summarised below. In each case, the number of participants is indicated in the bracket at the end of the description, skills and qualities of personnel – support workers/coordinators (19)
- the importance of specific funding for a wider range of services, both as an enabler where currently provided and as an area for improvement (14)
- more flexibility and control required in spending the total package (13)
- the importance of having an advocate and supporting documentation from family/general practitioners/therapists (13)
- self-efficacy – individuals knowing what is good/best for them, identifying clear goals and the ability to change supports (12)
- resource information – list of clear options with cost attached and profiles of staff to choose from; getting information by direct face-to-face contact (6)
- more overall clarity required from the NDIA and improvements needed in being able to contact it (5)
- support of peers (5)
- pre-planning – aid in identifying goals; support of service in accessing the NDIS (5)
- competent NDIA planners (4)
- individual choice considered important, though often this is in collaboration with others, who may make choices for the person (4)
- review and appeal processes to be quicker and easier, with certainty regarding future funding (3)
- planning process – all interviews to be face-to-face, with questions relevant to person's life (3).

Discussion

Choice was considered to be essential by the participants in this research. They regarded it as central to providing their ability to voice what was important to them, their sense of self, their autonomy and their right to make decisions in their lives. They considered it to be vital to their physical and mental health. They also saw choice as being key to their being part of a community to which they could contribute. However, choice is also a central discourse and policy driver in free-market economies, and this is more problematic for people with disability. The experiences of participants in this study identify that the market is not necessarily conducive to them enacting choice, nor does it always meet their needs. Indeed, participants are required to enact choice in a poorly functioning system that, together with ongoing issues related to mental illness, acts to constrain and deny choice and negatively affect outcomes.

Choice is also not an automatically positive, or even neutral, experience and is affected by a variety of factors both personal and within the social and policy contexts. Many participants' history of choice-making is fraught, leaving a legacy that affects their ability to engage in choice-making of any kind. Significantly, many participants discussed individual circumstances that highlighted how personal trauma such as mental and physical abuse had a long-lasting and profound impact on their ability to make choices for themselves. This was often compounded by financial hardship and lack of sufficient resources – including inadequate support services – that left people disempowered. Our research reveals that a raft of elements – personal, interpersonal, organisational and systemic – can make choice-making difficult.

Consideration also needs to be given to the manner in which the NDIS can support recovery for people with psychosocial disability. It is critical that recovery is seen as being fundamentally allied to psychosocial disability. Many participants discussed the way in which individual funding was vital to their recovery journey, and the need for

planners and services to support them through the provision of services that assist them in recovery. Any consideration of enhancing choice under the NDIS must consider the importance of the recovery approach and the ways in which all aspects of NDIS processes and individual funding must be in line with this paradigm. This also means providing funding and support arrangements that allow for contingencies such as mental distress and other forms of crisis.

The research indicates that for people with psychosocial disability there are many barriers to choice to be overcome, and indeed that this set of barriers becomes the context in which they are required to undertake the labour of choice. Outlined here are a number of issues to be considered for the NDIS to enhance the choice-making capacity of people with psychosocial disability.

- An NDIS application process that is not arduous and that minimises delays at all of its stages is needed. This requires clear and ongoing communication between the NDIA and the applicant. The applicant should have access to a person that is allocated to them to provide a more personal and less bureaucratic process.
- All planning processes are to be undertaken face-to-face by staff who communicate clearly, listen to the applicant and work with them collaboratively to devise a plan that addresses their needs. Applicants are to be encouraged to have an advocate with them throughout the planning process (it must also be recognised that it is their right to engage with the NDIA alone).
- There should be very clear guidelines on what will be funded – they are currently opaque at best – and these guidelines must be available to applicants. Participants uniformly requested a clear set of guidelines about available options and where the limits are. There should also be more flexibility concerning what people spend their money on, and how they do so. This will enable more choice in meeting people's needs, which is critical to their wellbeing. What is most essential is that the NDIS addresses people's needs and goals as identified by them (with the possible assistance of their advocate) with

a whole-of-life approach rather than a limiting 'one-size-fits-all' arrangement.

- Planners/NDIA staff must be trained to understand psychosocial disability. Staff should have good communication skills that encompass listening, understanding and talking to people with clarity, respect and empathy. NDIA staff and planners need to understand the choice-making context of individuals, including their current or historical experience of trauma, financial hardship and other factors. This also requires recognition that people's level of distress and capability varies over time, and that the NDIA and supports need to be flexible in assisting people to manage during times of crisis, including in the use of their funding at those times.
- Finally, choice can only be enhanced when the services available and the support staff provided have the flexibility and the capacity to meet the needs of people with psychosocial disability. This requires ensuring that available services do not simply continue with a standardised approach (for which they have been criticised) but that consideration is given to ensuring that they meet a diversity of needs across a diversity of locations.

Choice and control are key – yet somewhat vaguely defined – principles of the NDIS. This research has sought to consider the issues that participants face in exercising choice, including how they define it and the value they place upon it. If choice is to be successfully exercised by participants in the NDIS, a range of issues needs to be addressed throughout all stages of the NDIS process – from application (including pre-planning) to accessing supports and ongoing engagement with the NDIA and support services. Importantly, processes must be clear and smooth, with staff available to support people throughout their NDIS application and beyond. Most vital is that the quality of people who support them – whether in the NDIA, support services or the wider community – is integral to exercising choice and ensuring that activities are undertaken successfully.

Understanding people with psychosocial disability as choice-makers in the context of the National Disability Insurance Scheme (NDIS)

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)

Well, I think that an extra-hard part of having a psychosocial disability is that your choices are taken away from you systematically. You're restrained, secluded, scheduled, your finances are handled by someone else – and you have to take your medication. Your freedom – you have it and then it's taken away. So, I think a psychosocial disability has a unique quality there and, I think, if I'm articulate, intelligent [and] I have trouble with the NDIS – what hope do other people have? (Hunter5 –female)

That's one of the biggest things for people on the NDIS. They're very disempowered … People say, 'Well, why didn't you say something?' They can't. They can't. They're so disempowered, they can't. (Hunter7 –male)

Introduction

Australia's National Disability Insurance Scheme (NDIS) provides support to people with disability, as well as to their families and carers. The main component of the NDIS is the individualised funding package, which aims to give people choice and control in pursuing their goals and in the planning and delivery of their supports. Many people with psychosocial disability can enact choice to a greater extent than they have previously been able.

There is a gap in knowledge about people with psychosocial disability as choice-makers in individualised funding schemes. What evidence there is indicates that such schemes are yet to maximise people's choice-making capacities, and that there are a number of concerns to be addressed. Given this, there is a need to understand how choice operates in the context of the NDIS. There is also a need to understand how to support choice-making so that NDIS participants with psychosocial disability can draw from the Scheme the greatest benefit at the earliest opportunity, thus maximising its potential.

Mind Australia Limited, in partnership with Deakin University, undertook research in three regions across Australia (the wider Perth region of Western Australia, the Hunter Valley in New South Wales and Victoria's Barwon Region). The researchers interviewed 22 people who had received NDIS funding in the form of individual packages. The main aim of the research was to explore how people with psychosocial disability make choices in the context of the NDIS. It is intended that the project will contribute to knowledge of how people with psychosocial disability understand themselves as choice-makers, as well as of the labour of choice-making in the context of the NDIS, thereby assisting NDIS participants, planners and policy-makers.

The project benefited from initial input into the research design by an expert panel that comprised academics and industry stakeholders. It was also informed by a number of conversations with NDIS participants about their experience of choice.

These conversations were significant in shaping the thinking of the researchers about the research topic and in constructing the interview topic guide and questions. Finally, a peer researcher (an adult with a lived experience of mental illness and recovery) was engaged to work with the academic researchers throughout the project. The peer researcher played an important part in the research: peers are 'recognised as experts through their lived experience and, as a result, their voice needs to be heard in relation to knowledge development' (Stratford et al., 2016: 77). The same authors (p86) argue that 'there is increasing evidence that consumer engagement in research is to everyone's benefit'. In this instance, the peer researcher assisted in interviews at each site as well as providing advice on the research questions. This advice included how the questions should be worded and put to the participants, as well as how most effectively to engage with them.

Background

Choice and the Australian economy

Choice and freedom of choice are concepts that are frequently considered to be central to a good life. In a modern consumer society, choice is fundamental to economic policy and nations' economic development. Over the last 30 years, there has been a trend in many Western nations of giving citizens greater choice and control through providing a public service system where people can choose the services that best meet their needs (Carey et al. 2018a). Providing 'choice and control' of 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). The Australian Government established the Competition Policy Review (Harper et al., 2015) to consider how well Australia's competition policy, laws and institutions had been functioning since the last major review of competition policy, which was conducted in 1993 (Hilmer Review). The Competition Policy Review was also to examine whether the policy, laws and institutions were continuing to direct the market economy and government services to better serve the long-term interests of Australian consumers. The underlying assumption was that the quality of life of Australians is improved by providing more freedom in everyday choices, whether they relate to goods or services – including social services. According to the Review, putting users in control of the human services they access through the provision of greater choice drives service providers to become more responsive to individuals' requirements:

> Choice is a powerful dynamic force for improving our lives. Enabling our individual requirements and preferences to be expressed through choice encourages governments to adapt their services to better serve our needs. On the other hand, choice is not about having unlimited options or facing a bewildering array of possibilities. It is about having our needs and preferences met easily and affordably, in a timely fashion, and at a place and time of our choosing … (Harper et al., 2015: 24).

The concepts of government ideology and the practice of choice were further evident in the recent Productivity Commission (2016) inquiry into Australia's human services. The inquiry sought to identify areas for reform and to improve outcomes through introducing principles of competition and informed user choice. The Commission claims:

> Informed user choice places users at the heart of human services delivery. With some exceptions, the user of the service is best-placed to make choices about the services that match their needs and preferences. Putting this power into their hands lets individuals exercise greater control over their own lives and can generate incentives for service providers to be more responsive to users' needs (Productivity Commission, 2016: 7).

The Commission's reports raise a number of questions about the issue of choice. A standard argument in their report argument is that increasing the power of the market and decreasing the role of government as a provider of public services will increase consumer choice and lead to greater service efficiency. More choice is deemed to increase personal wellbeing, dignity and freedom. However, this assumes a thriving and capable market, one that is responsive to demand and in which consumers can purchase services. Such a market does not yet exist in Australia (Carey et al., 2018b). In that assumed context, the risk and responsibility for dealing with inadequate services falls back onto the individual. Government provision of necessary services to its citizens as a right is undermined, with the individual consumer bearing the cost of choice – such as locating an appropriate and reliable provider of necessary supports – within a market that is 'thin' and/or of variable quality.

Further, the emphasis on choice risks undermining efforts to address inequality, with the consequent risk of advancing exclusion:

> Choice based models can create economic, social and racially stratified communities, because they depend on market-based approaches which, ultimately, produce winners and losers (Carey and Crammond, 2014, quoted in Carey et al., 2018: 402).

Confirming this, Carey et al. (2018a) note that evidence from the United Kingdom has shown that people with physical disabilities are better able to take advantage of individual funding than those with intellectual impairments, and hence there is the risk of widening inequities between people with different types of disabilities. Additionally, unless individualised funding schemes are 'embedded in broader social safety nets' (Carey et al., 2018b: 387), inequities are further exacerbated by individuals' financial inability to supplement scheme funding (in order to access necessary supports), as well as by their lack of personal support networks (that might support more empowered utilisation of the funding scheme) (Carey et al., 2018a). The implications for equity under the NDIS remain uncertain. However, 'inequities are likely to emerge' from a range of personal and market factors (Carey et al, 2018a: 27). This problematises choice by highlighting that the capacity to exercise it will vary widely across individuals.

The National Disability Insurance Scheme (NDIS)

In 2010, the Australian Government asked the Productivity Commission to carry out a public inquiry into long-term disability care and the establishment of a national disability support scheme. The Productivity Commission (2011) found that the disability support system (pre-NDIS) was underfunded, unfair, fragmented and inefficient, and gave people with a disability little choice and no certainty of access to appropriate supports. The Commission stated that a national disability insurance scheme was required to ensure individually tailored supports, with choice over how individual needs were met, including choice of service provider (Productivity Commission, 2011). The NDIS is based on the principle that 'participants should be able to exercise choice and control over the services and supports they receive' (Productivity Commission, 2017: 3), funding reasonable and necessary supports for Australians with disability; these supports should 'help participants live as ordinary a life as possible, including care and support to

build their skills and capabilities, so they can engage in education, employment and community activities' (Productivity Commission, 2017: 3).

The subsequent legislation, *The National Disability Insurance Scheme Act 2013*, established the NDIA, which has responsibility for delivering the NDIS. Two of the key objectives of the Act are to 'give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities (CRPD)' and '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, 2016: 4). There are eight guiding principles that underlie the Convention and each of its specific Articles. These include: 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons' (United Nations, 2006: 5). This has clear links to the intent of the NDIS. In effect, the establishment of the NDIS means that the activities of the NDIA can be considered from the perspective of whether they progress, or comply with, the rights of people with disabilities as detailed in the United Nations CRPD.

While the Commission supported people with disability in general, it explicitly recommended that people with psychosocial disability be supported through the NDIS, and stated that doing so would provide them 'with the wider benefits of the scheme, including individualised supports and more choice in what supports are provided, when and by whom' (Productivity Commission, 2017: 23).

At the end of 2017, around 6,000 active NDIS participants with psychosocial disability had approved plans, a figure that accounted for seven percent of the Scheme's participants (NDIA, 2017: 19 in Productivity Commission, 2017). Further, data (to December 2016) indicates that 81 percent of people with psychosocial disability who lodged an access to the NDIS request were eligible for the Scheme. However, this is a lower eligibility rate than that for applicants with most other conditions (NDIA, 2016: 56 in Productivity Commission, 2017). As of September 2018, a total of 15,747

people with a primary psychosocial disability had accessed the Scheme, comprising eight percent of the total number of NDIS participants (Council of Australian Governments, 2018). By 2019-20, when the Scheme is expected to be rolled out in full, it is anticipated that the total number of NDIS participants will be approximately 475,000. It is estimated that around 13.5 percent of those (64,000 participants) will be people with a primary psychosocial disability (Productivity Commission, 2017).

These are large numbers of participants accessing the Scheme in a short amount of time. The transition phase of the Scheme and its early roll-out stages are a unique period in the life of what is an ambitious and revolutionary social policy initiative. It was recognised that there would be significant challenges to be addressed during the Scheme's implementation, with a large number of participants entering it in a compressed period of time, service providers transitioning from block funding to a market-based approach and participants having to navigate a new scheme and a service environment where they have to exercise choice and control over their supports (Productivity Commission, 2017). The NDIS has moved quickly from being 'a broad set of aims and principles to being implemented in community settings … called upon to meet the needs of very diverse service users with very diverse needs and circumstances' (Warr et al., 2017: 34). Given this, it is only to be expected that the Scheme will have imperfections that must be addressed, and any studies of it should recognise the ongoing adjustments that are being made, and need to be made, as it develops.

An evaluation of the NDIS that assessed its impact in South Australia, Tasmania, New South Wales, Victoria and the Australian Capital Territory considered choice and control as one of its main themes. The intermediate evaluation report (Mavromaras et al., 2016) found that, overall, the NDIS had increased choice and control for almost all respondents, although people with mental illness and psychosocial disability are 'more likely to report less choice and control over supports

since becoming NDIS participants' (2016: 74). Exercising choice was also constrained for those living in non-metropolitan locations with fewer service providers in their area, while many people with disability continued to be disappointed to see that items and activities they had hoped to access were not funded under their NDIS plan (Mavromaras et al., 2016). The evaluation found that experiences of choice and control and unmet demand under the NDIS are connected to reported personal wellbeing. The more choice NDIS participants have concerning the decision on what support they get or where they get this support from, the higher their reported wellbeing. Correspondingly, those who had experienced unmet demand for support after joining the NDIS reported significantly lower levels of personal wellbeing (Mavromaras et al., 2016).

Forty-two interviews were conducted as part of a more recent study in the Barwon trial site. These interviews explored the experiences of NDIS participants (26 interviews), including some with psychosocial disability, and the experiences of their family members who provide care and support (16 interviews). One of the key issues to emerge related to choice and control. The study found that services and resources to help people exercise choice and control were not always available, and that there were 'implications around the capacity of service providers to be flexible and innovative in meeting the needs of service users' (Warr et al., 2017: 4). Significantly, service users, especially in regional areas or where people had specific needs that could not be locally met, had limited choice, with funds often being consumed in travel to access services. For people with psychosocial disability whose health and wellbeing often fluctuate, 'there was no scope for them to have a "contingency plan" to purchase services, equipment and support on an ad hoc basis' (Warr et al., 2017: 5).

Other issues affecting people's choice and control included: poor planning processes; inadequate communication about the Scheme and within its processes; the complexity of the system and its administrative requirements; challenges in

accessing and understanding the large amount of information relating to the Scheme; and NDIA staff shortages and high turnover of personnel. Notably, the study found that insufficient attention was being paid to promote equity of outcomes for service users: 'Factors that are well-recognised in driving inequality – household income, education, residential location and household structure – remain critical in filtering opportunities and capacities for service users and their carers to have choice and control in accessing services and resources under the NDIS' (Warr et al., 2017: 5).

Finally, a Productivity Commission report into NDIS costs found that 'the groups at risk of having a less positive experience include those with psychosocial disability' (Productivity Commission, 2017: 20). The report also found that NDIS planning is complex and confusing, and that planners often have a limited knowledge of psychosocial disability. There was a concern regarding availability of services as providers transition to a market-based approach, specifically that some people with disability may be left without them. Consequently, the Commission recommended the establishment of a 'Psychosocial Disability Gateway'. This would provide face-to-face 'iterative' planning by skilled 'specialist' planners, as well as outreach activities that would include linkage and referral to appropriate services as a mechanism to address barriers to NDIS participation and equal outcomes for people with psychosocial disability (Productivity Commission, 2017).

Choice and individual funding

While the studies discussed above provide a welcome insight into both the NDIS and its participants' experience of it, overall there is a limited amount of studies in mental health and individual funding[1] (as opposed to intellectual disability, disability in general and aged care). Most of the work in this area to date has been conducted in the United Kingdom. A key reference is Webber et al.'s (2014) systematic literature review of empirical data/research regarding individualised funding and outcomes for people with mental health problems. This review identified 15 studies conducted in the United Kingdom and the United States of America. Fourteen additional studies were identified in the research for this project (these are summarised in Appendix 1). The studies are not directly comparable as they encompass a range of methodologies, locations, different budget/individualised funding types, severity and complexity of mental illness, cohort types/respondents and other variables. However, taken together, they do provide some common themes and insights, although some caution needs to be applied in coming to definitive conclusions. The following is a brief discussion of the key identified issues or findings.

Arguably, one significant key finding was common to all the studies: that there is a range of positive outcomes for mental health service users who receive individual funding (there are a number of complex issues and barriers that are often systemic in nature and require addressing). These positive outcomes include greater choice and control (empowerment) in determining how funding is to be spent, and with which providers; improved quality of life; greater levels of social connectedness and personal relationships; and improvement in personal wellbeing and self-esteem. In particular, carers play a significant role in advocating for a person in applying for and accessing individual funding. They may also play a key role in helping to manage individual funding for some recipients.

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[1] Individual funding is often referred to in Western Europe and North America as 'personalisation', 'direct payments', 'individual budgets', 'self-managed care', 'consumer-directed care', 'cash for care' (Purcal, Fisher and Laragy, 2014) or 'personal budgets'. The term 'individual funding' will be used throughout this report.

While these positive benefits are important, a range of issues (or barriers) is identified in the studies, and these must be recognised in understanding individual funding and choice for people with psychosocial disability. They are wide-ranging across the studies and can be summarised – albeit not exhaustively – as follows:

<u>Issues</u>

- The nature of mental illness engenders concerns about funding recipients' management of payments and finances, especially during periods of worsening mental health and distress. It was recognised that there is a need for contingency plans and support during difficult times (carers were found to play a major role in these circumstances).
- Bureaucracy and paperwork, along with complex and stressful processes, were major barriers to obtaining and managing individual funding. Disappointment resulting from a rejected application left people feeling disempowered.
- There was often a lack of knowledge about individual funding and eligibility among both professional staff and eligible clients.
- People found the appeals process stressful.
- People found reviews stressful, often because they were anxious about the security of their funding. They expressed concern that reviews were used to reduce the amount given.
- There was a tendency for staff and clients to consider individual funding as a gift and not a right.
- Staff often had concerns about an individual's capacity to manage their personal finances, and limited awareness of different options for assistance (often based on worst-case scenarios or a generalisation about mental health problems rather than on a person-by-person basis).
- Staff often had concerns about the potential risk to an individual (this is a complex area as there are varying arguments in critiques on the decline of the welfare state and the subsequent transfer of risk and responsibility to the individual). Staff were uncertain about where funding-related responsibility lay.

- Local Authorities or fund allocators have the final say on funding – tight budgets meant that many people with a mental illness and their families felt that personal funding decisions were based on cost-saving and services available rather than individual needs.
- Carers played a significant role and often felt they were the key to success in obtaining funding, which highlights the role of advocacy. Many carers saw negotiating with administrators as combative rather than collaborative.
- There was a low uptake of individual funding for people with psychosocial disability compared with other disability types. This was due to the factors identified above.

Significantly in the context of this research project, none of the studies specifically explores what choice actually is. Nor do they explore how choice is experienced and exercised by people with mental illness, both in *planning* (that is, when working with a planner to determine both budgets and how funding will be spent) and in the acts of *choice-making* and *purchasing* in the market.

Project design

This research is an explorative undertaking to understand the 'how' and 'why' of choice in the context of the NDIS for people with psychosocial disability. The shift in disability support funding from pre-NDIS block funding direct to service providers to individual funding direct to the recipient of services raises the need to consider how people will exercise choice, and what the significant issues in doing so are. The key questions guiding the research focused on the experience of NDIS participants with psychosocial disability, and included:

• What is choice, and what does it mean to have choice?
• What choices do people with psychosocial disability have in the NDIS in terms of funding and planning?
• What gets in the way of people being able to make the choices they want (the barriers)?
• What enables people to make the choices they want, and what needs to change to assist them?

The project benefited from initial input into the research by an expert panel. The panel comprised academics and industry stakeholders who advised on the research design, including its key aims and methodology. Also, a number of conversations were conducted with nine NDIS participants and one mother of a participant (three in Geelong, three in Newcastle and four in Perth) to discuss the NDIS and their experience of choice. These discussions were significant in shaping the thinking of the researchers about the research topic and in constructing the interview topic guide and questions. The specific questions used to guide the research interviews are listed in Appendix 2.

Methodological approach

A qualitative approach was used, incorporating individual interviews as the sole method of data collection. A qualitative methodology was deemed the most appropriate, given that the research aims to explore people's understanding and experience of choice, and how this impacts their behaviour and life circumstances under the individual funding system of the NDIS. Also, people's perceptions of enablers and barriers and ways to enhance choice can be explored more thoroughly using a qualitative methodology, which helps to understand the 'story' of choice and the meanings people attach to their experience. This methodology is prominent in the identified research in this field (as above).

Participants

Ethics approval was provided by Deakin University in July 2017, and interviews were conducted between September 2017 and March 2018. Participants were from a range of NDIS trial sites, including Barwon (four), Newcastle (nine) and Western Australia (one). Inclusion criteria involved being an NDIS participant with a psychosocial disability in one of the three trial sites. All participants had an individual funding package and a plan, were aged 18 and above and were capable of giving – and gave – informed consent. This is in accordance with the legal rights and recognised capability of people with disability to all aspects of social inclusion outlined in the Convention on the Rights of Persons with Disabilities (United Nations, 2006).

In total, 22 participants were interviewed. These comprised:

• 10 participants who had prepared one plan through the NDIA
• 12 participants who had prepared (or were about to prepare) their second or third plan.

There were nine male and 13 female participants. Their ages ranged from 28 to 62 years, with an average age of 49 years. Their living arrangements varied, with some living alone, some with family and some with a partner. The size of participants' packages varied. Some told us they were getting $5,000 a year, another person received $21,000, two ranged from $56,000 to $61,000 and one person indicated that their package was $115,000. Many were unsure of the amount they were receiving or whether it was for one or two years. This uncertainty makes analysis based on funding

impossible. The types of psychosocial disability with which they were living were wide-ranging and included bipolar disorder, schizophrenia, post-traumatic stress disorder, schizoaffective disorder, borderline personality disorder, depression and anxiety.

Data collection

Face-to-face interviews were conducted at a venue of the participants' choosing, with thirteen interviews conducted by two researchers (including a peer researcher). Interviews were recorded for transcribing with the interviewees' consent. Interviews ranged from 30 to 60 minutes in duration. Participants were asked a range of open-ended questions related to choice under the NDIS (see Appendix 2). These questions were designed as a set of prompts to guide a discussion and were based on the review of literature and advice from the expert panel and peer researcher, as well as on prior conversations with NDIA participants with psychosocial disability.

Data analysis

A grounded textual analysis, which allows categories to emerge from the data, was used to analyse interviews. According to Hsieh and 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 their main themes. Key thoughts, ideas or concepts from the content were highlighted with a coding scheme. A range of major themes was identified, with data within these themes sorted into sub categories. This thematic analysis identified participants' views and their experience of choice, as well as the enablers and barriers to exercising choice. Analysis was also undertaken to identify the key choice activities (termed the 'labour of choice'), including experiences in each activity and advice for undertaking each stage. Quotes used throughout the report have been

slightly edited to ensure the confidentiality of the participants and improve clarity. Care has been taken to preserve the intended meaning of the quotes, particularly when reproduced at some length.

Dissemination

Two major approaches to knowledge and product development were agreed upon by the researchers. The first was the production of a research report (this document) to summarise key findings related to participants' understanding of choice, the labour of enacting choice under the NDIS and the barriers and enablers to doing so, with some discussion of potential improvements/ solutions. The second product is a series of 'advice' documents for planners and consumers to support the process of planning.

Limitations and strengths of the study

As with any study, there are both strengths and limitations that need to be acknowledged. It is a modest study that involves a small sample of participants from trial sites that may not be representative of other regions – particularly rural and remote regions. While participants often discussed their living situations and socio-economic circumstances, such data was not explicitly sought. Therefore caution must be applied in evaluating the data on the basis of the diversity of people's circumstances, including the impact of their psychosocial disability. Also, while quotes are attributed to people based on their gender and location, analysis has not been carried out specifically on this basis. Data was not obtained from people who do not speak English (although provision was made for their inclusion in the research method), nor from Aboriginal and Torres Strait Islander people. Consequently, their experiences and needs relating to the NDIS and choice are missing from this research.

The strength of the research is its provision of insight into people's involvement with the NDIS; the semi-structured interviews allowed people

to share their experience of, and insights into, choice under the Scheme. Generally, participants' cognitive capacity enabled clear understanding of the questions and provided thoughtful and sophisticated responses that were often rich in their complexity. Participants were self-selected, and this may have led to a bias towards a particular group of people (that is, those who are more open to research and willing to discuss their experiences). However, this cannot be definitively concluded.

Findings

Understanding 'choice'

The principles of choice and control are central to the NDIS (particularly choice, which is the subject of this research). Choice is a complex concept and is difficult to define. Purcal, Fisher and Laragy (2014), in their analysis of choice through their examination of Australian individual funding policies, outlined a range of frameworks from a range of authors. They noted that choice can be identified both at the personal level – everyday choices, lifestyle choices and pervasive choices such as those relating to work, education and personal relationships (Ramcharan, 2012) – and at the policy level (Clarke et al., 2007). Other authors focus on the extent of choice (ranging from limited to extensive (Leadbeater, 2004)) or its practical aspects (the who, where, what, when and how (Le Grand, 2005)). The Productivity Commission (2011) dealt with choice as relating to the source of disability support and who holds the funds.

Given the complexity of defining and understanding the concept of choice, how then is it defined by the NDIA and the Government Act that regulates the Scheme? How do NDIS participants with psychosocial disability understand choice and how it is exercised? An NDIA glossary of terms defines choice and control as: 'a participant has the right to make their own decisions about what is important to them and to decide how they would like to receive their supports and who from' (NDIA, 2017: 2). The emphasis here is on autonomous decision-making about what is important to the NDIS participant and determining the support required.

Notions of choice are also inherent in the principles of the *National Disability Insurance Scheme Act 2013* (Australian Government, 2016). A general principle guiding the Act states: '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' (Australian Government, 2016: 5). In relation to participants, the Act states that the Scheme will 'respect the interests of people with disability in exercising choice and control about matters that affect them' (Australian Government, 2016: 22), and that a key function of the NDIA 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 and ensure that the decisions and preferences of people with disability are respected and given appropriate priority' (Australian Government, 2016: 111-112). Here the intent of 'choice and control' refers to people's autonomy in determining their goals within a planning process as well as deciding on the supports required to achieve them. The decisions of people with disability are to be prioritised and treated with respect.

This research elicited views on what choice means to NDIS participants with psychosocial disability, its significance to them and the issues related to exercising it. The following is a summary of some of the definitions provided by participants. They highlight a number of themes.

- Having basic needs met first, then higher-level needs:

  Choice is having your basic needs met – I suppose as a priority – then having additional needs met if you can that are more higher level. Like, my basic needs are being met at the moment: exercise, cooking, house cleaning, that sort of thing. (Hunter2 –male)

- Money defining and providing the choices one makes – having to be practical:

  When you don't have a future – the choices you make are about money. You know, is this cheaper or that cheaper? Or which child needs this? It's all very practical in-front-of-your-face choice. (Hunter3 –female)

- Knowing the options one has, weighing them up and then being able to make an informed decision:

  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. (Hunter8 –female)

- Being able to make one's own decisions and doing what one wants to do – with support if required:

  It means a lot, because you don't have a choice. Going to a day program, you have not a lot of choice. But with choices – if they're individual support, you can actually go, 'All right'. You get up, go, 'Well, I want to go see a movie or go do the cleaning'. You can go do that. (Hunter9 –male)

  It just means that I can do what I want to do if I need to do it – like I've got the support there if I need it so that I can do it … Because if you didn't have a choice, you'd be stuck here all the time and you wouldn't be able to do anything. (WA1 –female)

- Self-direction and being able to voice one's preferences as opposed to being told or having choices forced upon oneself:

  Well, it's [choice] something that I really didn't have until I lost everything. Even in who I saw and what medication I took and everything else – I didn't have that choice because my partner made me or stopped me … So, actually finding out how many choices I did have, and could choose in different ways of treatments – and especially living by myself for the first time at 38, it was pretty daunting. I'm not saying that I've made the right choices, but with the NDIS I thought it was going to be more like I could choose things I wasn't getting – which hadn't really been my experience, or wasn't able to access because of funds. Even like the coping strategies that I've got now – I didn't have the choice to even develop them or use them because I was in an abusive relationship with three kids and running a business, or trying to. And it was either I worked and

I did everything good like a good mum – but if I was unwell I was in hospital for months and months until I could pretend I was all better again. [Choice gives me] self-direction, I suppose, and being able to feel and being able to voice what's working and what's not. Whereas before, I just got told. (WA2 –female)

- Always having options:

  In terms of value, it's [choice] incredibly valuable to me … Always having an option. Always having a back door, always having an alternative, always having a stage left. I think it's 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)

- To have a voice and be able to express it:

  It means to have a voice, express your voice … To me, mental health healing comes from this voice. That's the key element. People have lost their voice. And some of these things, like, they're not mental health issues or some disorder – borderline personality – they're people who aren't having their voice. And then they might be violent or be something else because there must be some resentment or some psychological thing going on because they're not having a voice. (WA4 –female)

- Being able to say yes or no:

  In my eyes, it [choice] is important. Gives you that opportunity to say yes or no. And it gives you time to think about it before you speak – because before I'd just go rattle along like nothing. But now I stop and think what I'm going to say … Because I've got the choices, I try and make the right decisions at the right time. But sometimes it doesn't go like that, you know? (Hunter6 –male)

- To be empowered with freedom and independence:

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

Such understandings and applications of choice are in line with the NDIS's stated aim of supporting people with disability to determine their goals and choose the supports they require. Participants clearly valued having choice and saw it as essential to their wellbeing. The potential of the NDIS to support people to make decisions and determine their requirements for a good life was recognised through the way it addresses day-to-day needs, as well as long-term and 'higher-level' goals such as education and employment.

The personal context of choice-making

Individuals often have limited experience of choice-making or feel they have lost their 'voice' or the ability to identify their own preferences. The level of ability to make choices or take control should not be assumed to be the same for all. Each individual has a different predisposition around choice, and this is affected by their life circumstances and mental health.

> I'm not a very outgoing person and I'm very fearful, anxiety kind of person. So, doing things and then someone asking me is, like, 'You're asking – I don't know'. It's like my husband will ask me, 'What do you want for tea? We're going out for tea. Where do you want to go?' Don't give me that question. I'll throw it back again … I can't make choices. I don't know what I want, really. (Barwon2 –female)

> 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. You're just struggling to get through a day. You don't have a choice … 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. You've got to pretty much be taken in by the police or something or just end up crying in the gutter or something, really – a total implode or something. It's like the more further we get down the hierarchy, the further we get down into mental health, the less choice you have. (Hunter7 –male)

> When I'm depressed, you can't decide anything … you're being pulled all different directions. Your mind – you're just confused all the time. You can't make a decision. When you're not depressed, it becomes clear. (Hunter7 –male)

Each individual has a legacy of having experienced choice or denial of choice in childhood and adulthood. It is evident that many people have experienced trauma at some stages of their lives (including physical and psychological abuse), perhaps within their family and intimate relationships or through their experiences of various services. Such trauma not only affected their ability to make choices at the time it was suffered but continues to have a profound impact. For many individuals, this has resulted in disempowerment or loss of voice, which prevents them from exercising choice.

> But even making choices as a kid was something that I didn't do. Looking back, I definitely felt like I was just a slave within the family that was there … if [I] couldn't do what [I] was meant to do, [I] wasn't wanted. So that sort of continued from the childhood sort of stuff. (WA2 –female)

> 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. (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. I mean, that's why my marriage broke down ... 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 for ever. (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 my 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)

I wasn't diagnosed until 35. But I come from a broken family and I sort of fell between the stools in terms of care. And so, even though I exhibited many, many disturbing symptoms, I wasn't actually diagnosed until 35 …. And consequently, I think my outcome in life has been a little bit poorer than it might have been had I been diagnosed earlier. (Hunter2 –male)

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)

Financial hardship and a lack of material resources throughout people's lives also significantly affects their ability to make choices. For many, such deprivation has meant that choice-making is limited to daily needs, so their ability to think beyond the immediate is limited. People's access to a variety of resources, and to what may be deemed 'social capital', can have a huge impact on their choice-making capacity.

But I also realised that I didn't understand how to make choices. Because … when you don't have a future … the choices you make are about money. You know, is this cheaper or that cheaper? Or which child needs this? Or, you know, like, it's all very practical in-front-of-your-face choices, so … [based on what is] critical and desperate – because that's how I kind of lived my life. (Hunter 3 –female)

Most of my life I haven't had stability … What turned things around for me was stability. Once I eventually did get housing a couple of years ago, that was a big one. That was a really, really big one. Secure housing … A lot of people in Housing Commission, they're in there because their lives have turned to shit. They do have mental illness. They're dysfunctional. The Government puts them in Housing Commission flats with all the other mental [health] people and it gets worse and worse and worse. That's not a good result …. Once everything's in place, some people with mental health can begin getting well. If things aren't in place they can't. That's how it works, mate. (Hunter 7 –male)

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 … So yeah, 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 the chaos. It was horrible. And then I kept trying to get someone to listen to me … I got turned down by about 13 services, like [mental health and disability support services] all turned me down. (Hunter3 –female)

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

The labour of choice

One of the main focuses of this study was to investigate the act of choice-making for NDIS participants with psychosocial disability. All 22 participants in the study described extensive and challenging choice-making activities across the whole life cycle of NDIS individualised funding. They also described the strategies they had used – or would suggest others use – to assist with this labour.

Whereas a substantial focus of the discussion of choice-making in the information about the NDIS is on the planning 'moment', the labour of choice for participants was identified at each of the following stages:

• applying to the NDIA
• pre-planning
• planning
• immediately after NDIS package approval
• utilising the funding – purchasing and managing supports and services
• reviewing the plan
• appealing decisions (where relevant).

Participants recounted their experiences, gave their advice and discussed how their history of choice-making had influenced their ability to engage in these processes. Their responses demonstrated that the labour of choice in the context of the NDIS is complex and often extremely difficult. This highlights that these stages need to be considered in enabling people with psychosocial disability to maximise their choice-making capacity with the minimum amount of stress and anxiety. Each of the stages is briefly summarised below. (Note: This data has been organised into a series entitled 'Peer Advice', which covers each stage in the NDIS life cycle. It has also been organised into 'Advice to Planners', which will be made separately available to stakeholders.)

Applying to the NDIS

Some participants expressed uncertainty about their NDIS eligibility, particularly given the perception that the Scheme focuses mainly on physical disability. There was also uncertainty about eligibility related to episodic mental illness. Many relied on others to link them to information about applying or to help them complete their application. Supports included family members, support workers, counsellors, friends, workmates, case workers and peers. Some participants were proactive and made their own contact via 1800 phone numbers or websites, while others relied on supporters to draft responses to application questions for them.

> It was me – I had a different case manager at the time. I think we went to the [NDIS] office, and we sat down with a lady and she just went over everything and said, 'This, this, that, blah-blah-blah. And, here's how you apply and this is what you need to do'. So, lots of filling out forms and stuff like that. And they gave me a bit of help with the filling out of forms, because sometimes I find forms difficult. (Hunter8 –female)

> Yeah, [I put in an NDIS application] with the help and guidance from the support worker … She was with me for two hours, asking all the right questions and pretty much wrote this amazing three-page

thing out to say 'this is what she needs'. So those couple of pages was all it took. (Hunter1 –female)

Some participants discussed the process of organising assessments and additional documentation, again both with and without support.

> [Organising the OT for house assessment] was done through a mental health planner and the Department of Housing. But that took a while too because I was in August and they were still doing January's. So, I just rang up the girls one day – 'How's this work, how long have I got to wait?' And I was on the phone with her about half an hour, she goes, 'What are you doing tomorrow?' … She came out, she did the assessment. (Hunter1 –female)

Four participants recounted their experiences of being rejected at the first point of applying to the NDIS. In each case, subsequent re-application, sometimes involving multiple attempts, eventually resulted in success.

> I was banging against a door that nobody wanted to open ... But a lot of it – it's hard to reach out and ask for help. And when nobody's offering it, you don't go. Like I pounded that NDIS door for two years – four applications. (Hunter1 –female)

> The first attempt to get NDIS support failed and that was because I think the system was very new and they didn't listen to me. And I had a lady who was assessing me … and she never met me in person, she only interviewed me over the phone. She decided there was no cause for me to have the NDIS, there was no need. And even though I explained to her the housekeeping was an issue, she said, 'Are you physically capable of house-cleaning?' I said, 'Yes'. And she said, 'Well, that's it. You don't need us'. So, I waited six months until the period when she would review it was over and then put in another application with a different … assessor – and it was successful. (Hunter2 –male)

Sometimes this labour of re-application was required because the NDIS had not provided a response to an initial application. In these cases, consumers had to be particularly vigilant and follow up when no communication

was forthcoming from the NDIA. Participants commented on how difficult this process was, requiring both resilience and determination, which may be difficult for some people to summon up.

> I got in – got knocked back first. Then they reviewed it and got passed. I've spoken to people, and it happens quite a bit. They'll get knocked back once. They won't go and reapply … They'll give up. People with mental health, people that are dysfunctional or people that can't initiate things themselves – they'll do things once. They won't do it again. (Hunter7 –male)

Pre-planning

Preparing for the planning process entails making a set of decisions and engaging in activity. One of the first decisions is where to hold the planning session, along with the preferred mode of planning (face-to-face or by phone). Most participants advocated for face-to-face planning, with some seeking to have the planning session in their own home. Others met with planners in the NDIA office, the library or at a local service provider. The level of assertiveness required by consumers in communicating their preferences was identified by one participant as a significant challenge:

> It's a pretty big thing, too, for a lot of people, to say, 'No, that's not what I want to do' [phone planning]. (Hunter5 –female)

Whether to take a supporter to the planning meeting (and who to take) were additional considerations. Some people took family members while others took peer workers, support workers or advocates.

> Yeah, I asked for an advocate … Because you do have choices, you can always make the right one or the wrong one, you know what I mean? I try not to make the wrong decisions, that's why I get my advocate in to give me something to think about. (Hunter6 –male)

In general, consumers endorsed the value of using peers for support and advised that 'people should not go in alone' (Hunter3 –female).

> It's a good thing [to have an advocate attend] because sometimes I forget about a few things, and they might bring something up and I say, 'Oh, that's right, I did that but I didn't know it at the time.' Stuff like that, you know? But it's good to have one, in my eyes anyway – especially with the way my mind is. (Hunter6 –male)

A major labour of the pre-planning phase is thinking about what one wants in terms of goals, supports and needs. This entails thinking about past needs, including those at times of illness, as well as thinking about what services and supports have been – or may be – useful.

> I went in with a fairly clear idea in my own head of my journey over the last ten years as to the sort of things that I'd put in place to help support me … So, I wanted that [current and ongoing] service funded because it was an incredibly vital service from my own perspective as one of the things keeping me well. (WA3 –female)

> I wrote down a few bits and pieces that I thought I might want … but the rest of it was like, 'I don't know.' … Even then, it's, 'Well, I don't know what I want, really' … You just go into a meeting and they just ask you and such, and they don't say 'be prepared' or 'get someone to help you.' Come in with your baggage, this is what I want, or I need, or whatever it is. You go there – 'Here I am'. (Barwon2 –female)

> I don't remember sitting down and doing a great deal of preparation. I would have spoken to my support coordinator about it … I think we did just sort of roughly go through history and goals and things like that. But otherwise, nothing intensive really. (WA8 –male)

> When I was going for my first interview with my local coordinator officer, I wrote my wish list down of what I would like, and I put them first – I put them ordered. So: cleaner fortnightly, episodic care when discharged from hospital – because when you get out of hospital, you're still not right; you're still crazy. (WA9 –male)

Some found that thinking about the services they required made them anxious, particularly when coupled with the fear of losing – or not getting funding to support – existing services.

I mean, I'm worried about the cleaner now. Until it's found out whether I'm going to get the cleaner, I worry about things. I worry about losing my cleaner. My life might get really, really bad. I don't know. (WA9 –male)

Participants drew on support for this phase of thinking and decision-making.

I helped a person with – it's like a social disability – get her NDIS plan … And the process was completely inaccessible to her. There was about 20 times she said, 'Oh my God, if you hadn't explained, I would have given up.' … But when I went through with her – and it literally took us three, four hours sitting down and doing some art so that she could actually think about goals and whatever. (Hunter3 –female)

For some, the level of preparation (or lack of it) was a critical factor in the kind of plan and package that they ended up with. For example, one participant regretted not having thought through the difference an NDIS package could make to her life, and as a result "got very dull … requests … goals." (Hunter5 –female).

Planning

The planning phase was reported to involve many decisions and labour of choice beyond participating in the session itself. These decisions included whether to request a one- or two-year time frame for the plan (and package), along with deciding who would manage the funds when allocated (that is, would funds be self-managed, managed by the NDIA or managed by a broker). Bringing and using evidence to support requests for services is also a task relating to the planning session and involves some preparation, including research.

The process that happened in terms of the service was they [the planner] wanted evidence to support why I thought this service was useful. I gave them a letter in terms of why it was important to me, and then I gave them a whole lot of research in terms of the types of services that supported people with bipolar or with PTSD. But they wanted specifically a report from my psychiatrist and my psychologist.

So, I got one of those from each of them supporting the service and what I was doing, but from different perspectives related to me. (WA3 –female)

The major labour of planning was being 'heard' by the planner and putting forward preferences, goals and needs in a context that was frequently felt to be disempowering.

The planning meeting is onerous. I spent two hours with that woman [the planner] that day. It's always been about one hour, so this time it was two hours, and the questions weren't relevant to my life … It is very much like Centrelink. And I have trouble dealing with Centrelink, because they're kind of authority figures, and I find myself getting very meek and mild, which is what happens here, when I'm not generally meek and mild. So, it's a measure of how onerous it is. (Hunter5 –female)

But I couldn't say no at the time, as often I can't. With people on the NDIS – and I've talked to a lot of people here that are pretty far down the spectrum – they're doing it tough. They're kind of borderline autistic Asperger and they've got schizophrenia and various other things going on as well. They're really, really struggling with the NDIS. They get it and then they take it, and then they get this program made and it's made for them. And they go and they're nodding their head and then they're not really – I don't think they're consulted enough. (Hunter7 –male)

This labour of exploring and explaining preferences occurs in an environment of lack of knowledge about the process.

I didn't know what to expect. Well, the first time it was like – it's a bit scary… They just said 'this, this and this is going to happen' and there was another lady [planner] before who was taking down different notes about something else. It was very difficult to understand. Obviously, that was a choice but I just – like, I couldn't really understand or comprehend what they were talking about. (WA6 –male)

The planning process is lengthy and involves significant participation, sometimes over several meetings or contacts.

We met – there was a preliminary – there was a couple of preliminary meetings. In the first preliminary meeting, which was one local coordinator, she went through the process and said what it involved, and whatever else, and gave me the empty boxes to think about in terms of the plan. By the time I came back for a second meeting, there was actually another local coordinator, so they'd shifted the people, or whatever. Then she went through the goals and all that sort of stuff with me in terms of that process. Then, the next meeting, she come back with a plan that basically had these hours and these services that I hadn't actually asked for but encapsulated some of what we'd discussed. (WA3 –female)

The complexities and inadequacies of the planning process inevitably also result in an emotional workload for participants. Some of this relates to the emotional toll of managing or dealing with planners with poor process, and some relates to the anxiety arising from the uncertainty of a high-stakes process.

My very first planner listened very well. But I found the interview incredibly traumatic. I just cried for hours after it. (Hunter5 –female)

The lady at the NDIS was a bit disrespectful in the way that, like, mental illness is not considered a proper disability … And [the planner] was being really rude to my sister [with mental illness] … [The planner said] 'Oh, you're all right, there's nothing wrong with you, you look fine'. But she's got a mental illness, and … she couldn't stand up for herself in the face of being told that she didn't really have a disability – because it was a mental illness and not a physical one. I think that is so wrong … It makes me angry. (Hunter8 –male)

It was really inappropriate that she spoke to me as though I was a five-year-old. (Hunter5 –female)

They've now got to 40 questions or so … So, she [the planner] sat behind a computer and typed them in. And it was, 'Can you take a bath? Do you have any friends with disabilities?'… 'Do you want to work?' And I said to her, 'Of course I want to work. If I could work, I would be working'. It was such a terrible question to ask me. (Hunter5 –female)

Participants reported a raft of strategies for supporting their choice-making in the planning moment. These included taking a supporter or advocate as well as being well prepared with questions and identified goals.

I would advise everyone to go with someone. An advocate, someone who will speak up when you're being railroaded … My point is that you just have to go in with someone who knows as much as possible, rather than go in there raw. It's the only way. (Hunter5 –female)

Immediately after NDIS package approval

One of the first tasks following planning is to get information about the application decision and the parameters of the package allocated. Although this sounds fundamental, many participants reported poor or no communication about it. Some remained confused about the communication that was provided. One participant commented that he had made numerous enquiries to the NDIA but had not been given any information about his package. He had no written information from the NDIA outlining his funding arrangements (Barwon 1).

Commencing action to investigate the allocation and how best to spend it is also daunting.

I got the letter to say you've been approved. And then that was it. That's when I went in to NDIS and said, 'Well, what am I supposed to do now I've been approved?' 'Oh, you've got to go and talk to that one, that one, that one'. I just went, 'Oh, okay'. So, I got in the car and went home. I'm not going to go and talk to all these different people. I find conversations difficult enough as it is with people that I don't understand or don't know … I wasn't going to go and instigate conversations not knowing what the hell my plan means. Nobody explained what the plan meant to me. (Hunter1 –female)

For some, correcting assumptions or appealing decisions written into the plan is an important task.

Even when they first knocked me back in terms of one of the support services I wanted, I wrote a letter to them ... It was like meeting this monolith that just didn't want to move. (WA3 –female)

However, for many, the major workload of this stage is getting information about services that might be available, determining the criteria for selecting services and making decisions about utilising them. Some people sought out information about possible services and others drew on the advice of support coordinators, a process that engendered varying levels of comfort.

> But having to find a company to deal with you – that just blew me out of the water. I just [said] … 'Can't you just allocate me someone?' [NDIA said] 'No, you've got to find them yourself.' (Hunter1 –female)

> I phoned up about four or five of them [services] … 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)

> It sounds simple to anyone: 'Oh, you've got some organisations, just choose one', but for me that was very hard. I don't want to reject an organisation based on a half-hour conversation and the look of their website. (WA8 –male)

> I find it hard to – sometimes I get things mixed up and find it a bit hard to understand what they're saying … [So] I just go and ask somebody what it means – 'Is it suitable for me and what can I do? How can I change to make it suitable for me?' (WA1 –female)

> [My] support coordinator… said, 'There's this organisation, I think they're great. Why don't we meet with them?' I was happy. The explanation that I was given about how that organisation worked, their philosophy, I thought, 'that's really good', so I didn't look any further. And I was happy enough with that. I guess you're not really making a totally informed choice if you decide to do things that way, but that comes back to 'well, I'm not that comfortable making the choice anyway.' If it seems to work out well with the first person that I meet, the first organisation that I speak to, I will pursue that because that's perhaps just easier. (WA8 –female)

Some participants described expending considerable time and energy on meeting with and reviewing services as part of the selection process.

> I would meet with her [support coordinator) and the representative from one of the organisations and then the representative would leave, and the support coordinator and I would sit and have quite a long conversation about what we'd seen. We were in contact back and forward via text message and phone calls several times. It took a lot for me, but eventually I said to her things like, 'I don't want to go with this organisation because I felt they were trying to sell me something', and that took a lot from me. But that had to come from me – I had to get the courage. (WA8 –female)

Finally, not all results from this workload were positive, and participants were also required to deal with the workload of rejection by services.

> I got turned down by about 13 services … all of the mental health ones and also disability ones turned me down… And this man said, 'Oh yeah … she was too complex so we didn't take her.' (Hunter3 –female)

Utilising the funding: purchasing and managing supports and services

Purchasing services and supports, even when supported by others, involves an ongoing workload that encompasses multiple elements. Participants described the ongoing activity of reviewing their funds and deciding which services to purchase, even when the administrative burden of funds management is handled by someone else. Many rely heavily on support coordinators for support with this work, and some report strong partnerships where there is an emphasis on building financial, service and NDIS literacy through active skills development via the support coordinator. This ongoing management process poses many challenges for participants.

> But I still look at that core amount on a daily basis and go, 'Well, other than the three services, what else can I do with that money?' I don't know what to do. Everybody's situation is different, everybody's

entitled to different things and I'm not being told what my choices are. I'm not being told what's out there. So, I've done a lot of finding out things myself to the point where I just throw my hands in the air and go, 'Yeah, it's just helping with the usual, there's nothing more I can do'. I'm not going to ask any more questions because nobody really understands how to answer them anyway. So, the majority of the time they don't even know what the options are for us. (Hunter1 –female)

They want me to have [support person] twice a week but I'm sort of putting off until I can think in my own head 'What's going on here?' (Hunter6 –male)

For some, this process of constant review also presents opportunities to reframe elements of the plan to make them more relevant.

I had quite a bit of funding that wasn't being used in my first and second plan, because this was money to put away for when I become unwell. Because in the first month or two months after that, I need a lot of support. But I've started spending that money, basically … and I'm better for it. (Hunter5 –female)

Even when participants are using the services of a broker (or support coordinator) to manage the funds, financial management is still a substantial activity for many. In some cases, interaction with the support coordinator about finances and service expenditure takes considerable time.

[My support coordinator and I] have a meeting every so often … we go over it and she says, 'You'd like to have two hours with this person, but only an hour would be really available at the moment' … so she's kind of keeping me on track that I don't go over… if I do go under, she'll let me know at the end of the year. The second year, I'll be able to possibly use a bit more, use the funding that I haven't been using or something like that. (Hunter7 –male)

[My support coordinator] comes around to Mum's house, and I go to Mum's house and then we sit down and have a planning meeting and she tells me what I got and I don't have … I'm happy that it's managed by somebody else because it's too much information for my brain to handle and I get confused. (Hunter9 –male)

I sometimes worry it [the budget] may come up a bit short but they [support coordinator] assure me that everything is all – there will be enough. (Barwon4 –male)

Some participants engage (or have attempted to engage) directly with the NDIS portal to manage services and funds.

[My support coordinator] sits me down at her table and says, 'Now, you access the portal on my computer and I'll work with it on this computer and together we'll put in both sides of the account. We'll put in the consumer's and the worker's simultaneously.' So, we worked it that way. So, we'll do both sides simultaneously. (Hunter2 –male)

Because we can now go into NDIS online and we've got portals, we can go into there and I can just have a look, but I've got no idea what's what. (Barwon2 –female)

Directing and managing paid staff to undertake tasks is a workload that many people find difficult. It entails deciding what tasks paid staff should do, selecting the staff and managing their performance.

When I chose her [support worker] … she came with her boss for an interview, for me to check her out. (Hunter5 –female)

We had sheets of different people I could choose from … I went back to NDIS to actually ask them whether I could [choose or change support workers], because I wasn't quite sure whether I could or not. I thought maybe I got someone and that's where you stayed for that plan but, no, they said I could choose. (Barwon2 –female)

I always have a list for them [support workers] of things I can't do or things I need them to help me with. Once I've got those sorted, I can get on with my week and do more things. (Hunter7 –male)

Participants reported that they found managing support workers' performance particularly difficult.

I'd feel very uncomfortable [changing support workers if they were no good] … I'd really struggle with that – rejecting somebody. Having mental

illness your whole life's about rejection and not fitting in, so for me to reject somebody else – to say, 'That's not working for me', I'd really struggle with that ... A lot of people on NDIS, they'd be given somebody, they'd know it's completely wrong for them and they wouldn't be able to say anything … They're very disempowered. They're unable to do it and they won't do it. (Hunter7 –male)

It's full-on inconsistency, and it's only that I stomp my feet up and down with the support coordinator that he emailed them [support workers] and said, 'Come on, guys … this needs to stay consistent'... Because I'm too embarrassed to ask them – I don't want to feel like a burden ... But it's still very hard to tell them what you need them to do. (Hunter1 –female)

I did come down really heavy – I was going to sack her [the support worker] because she wasn't doing what I wanted to do ... [My support coordinator] said, 'You don't have to put up with that. Just tell her straight out, you know, smarten her ideas up'. (WA5 –female)

Similarly, participants also discussed the difficult workload of making complaints about services.

I have [made a complaint about the worker claiming travel time]. I called them at NDIS. She said she'll check on it. She wants me to write down the hours what they [the support workers] do. So I have been doing that. (WA5 –female)

I've actually put a complaint in. I made a choice on my own, against one of the support workers in that organisation … I spoke with my support coordinator first and then she said, 'Well you know, you can either ignore it, or you can talk to – not the NDIA but – the organisation.' So after sitting on the fence for a while, I mentioned to my support coordinator that I would like to disclose to the support worker's supervisor what I thought was going on, and I did that. (WA8 –male)

I was writing full-on emails saying, 'Look, this is what we agreed. This is what you said you'd do. Nothing's happened.' And [the service provider] wouldn't investigate. They would just send me letters saying, 'Oh, we investigated the matter and everything's fine', without speaking to me … And in the end, I went to the Ombudsman and … I went to some Mental Health Conference and actually handed

Eddie Bartnick a 17-page letter, him and Frank Quinlan … Eddie got me in touch with a manager who spoke to me for an hour and said, 'Well, everything you're saying makes perfect sense and let me see what I can do'. (Hunter3 –female)

While the support coordinator is frequently referenced by participants as a valuable support, dealing with them is a workload, which includes managing problems.

Now, this is a biggie. You get a person [support coordinator]. You get comfortable. You get secure. You get feeling this will work out, and that person leaves and they give you another person. Then you have to kind of retry and get it all going with a new person. Then that person leaves. This happens a lot. (Hunter7 –male)

I've just recently changed coordinator of supports … I wasn't satisfied with her because she was talking about my NDIS packaging with somebody else who shouldn't have known anything about my NDIS package … And I thought, 'Well, that's not right'. My coordinator of supports should not be talking to other people about my package. So, someone gave me the name of the new guy that I'm with ... He's a really, really good caseworker … He asks me questions, he says, 'How can I help you better?' (Hunter8 –female)

Reviewing the plan

Seeking a review can be understood as a proactive strategy to get a more appropriate plan and funding package. If the review does not occur at the previously agreed time, the process involves both making an application for a review and dealing with the consequences if it is denied.

And we put in a review and they said, 'No, sorry. You've got adequate services.' And then we put in a subsequent review about five months ago and haven't heard anything. Not even documentation to say they received it. (Hunter4 –female)

Other participants are vigilant about when a review is due (for example, at the end of 12 months) and take action to prepare for it, including seeking someone to attend the review as a supporter.

I've got 50 days before my plan runs out, and I still haven't been told when my next appointment is. So, I rang up, left messages … because I hadn't heard anything about it, no letters or anything. (Barwon2 –female)

Part of the preparation for a review entails justifying the services needed and the results they achieve. This can also involve a support coordinator or others in assisting with the re-thinking of goals and support needs.

I think that I could justify two hours in the house and the walk, and the sort of management of my total caseload as it stands at present – which would be probably about $15,000 a year. I don't know. I'm hoping that it goes up a little bit next time but I don't know. (Hunter2 –male)

[I've spoken with my support coordinator about the review and options] and I have with hubby as well … [and I've spoken to] the Salvo lady [support worker] as well. I've spoken to her – what I would like. So, she's told me to write some things down – and she's written some things down, too. (Barwon2 –female)

Yeah, [I have a sense of choices this time around] because I spoke to a few people – what I can and can't have and what I have. But I know what I want … so I can sit there and say, 'Can I have…?' or 'I'd like this' or whatever. (Barwon2 –female)

Yeah [before the review] … my support coordinator usually catches up with me and finds out where things are at, what else needs to happen or change. (Barwon4 –male)

However, as with most stages of arranging NDIS funding, the workload at this step also involves dealing with negative outcomes – or the fear of them.

People have had their funding cut smaller because they're not using it or something, and then someone else I heard of had their funding cut completely because they'd ploughed through the whole lot. That's a real concern – what if my funding runs out? What do I do then?... It makes you feel uncertain about what are you going to do with yourself if the funding disappears because you become very reliant on it. (Hunter8 –female)

[I was worried because] we were thinking because I broke my ankle … for three months I didn't use that funding towards the support worker for most of that time. There was a bit of concern around whether I would get that money again for a support worker to come and visit me – which is very important. But then if you don't spend the money that's on the NDIS package, you might lose that. Which means I don't have a bloody support worker. (WA6 –male)

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. (Hunter4 –female)

Appealing decisions

Participants reported appealing at different points in the process.

I did [appeal about the funding being reduced] but then I was told the sort of success rate of it is pretty limited as in not everybody – most people usually don't get it. Sort of have to jump through a lot of hoops to get there, apparently. (Barwon4 –male)

Although outcomes may be negative, one participant identified making an appeal as being important to a sense of identity.

So, it [the system of NDIS] does chip away [at a sense of self] if you allow it to. That's why I appeal it. (WA3 –female)

Barriers relating to choice in the context of the NDIS

A number of significant barriers were identified in relation to both the NDIS and support services. These barriers affected people's experience of choice and form the context for the labour of choice that people are required to undertake as NDIS participants.

The key barriers that limit people's capacity as choice-makers as identified by research participants can be categorised as those relating to the NDIS and those relating to services and supports. The number of participants who reported

each barrier is indicated in brackets following the description of the barrier.

Barriers relating to the NDIS

Three major areas emerged:

4. Limitations and inadequacies of the plan that limit or deny choice:
   - lack of choice in structuring funding and what to spend it on; not funding what is required (16)
   - inappropriate plans that do not address a person's real needs and goals (11)
   - lack of psychology provision (7)
   - increased broader life participation choice required – especially education, employment (5).

5. Lack of information and communication that undermines choice:
   - lack of information about entitlements (13)
   - lack of communication from the NDIA, including delays in processing applications (11)
   - lack of information/clarity about what an individual's plan and funding mean (10).

6. Personnel and meeting processes do not foster choice:
   - dealing with different staff and the anonymity of the NDIA (14)
   - an impersonal system where people do not feel listened to or supported to make decisions – are made to feel unimportant (12)
   - arduous/intimidating meetings and a confusing/complex application process (12)
   - staff do not understand mental illness and psychosocial disability – are often rude, condescending, focus on physical aspects of health/life (11).

Two other themes emerged:

- uncertainty and worry over reviews and the possible reduction of funding (11)
- inconsistency with funding across recipients (4).

Barriers relating to services and supports

- delays in adequate response and/or service establishment (10)
- inefficiencies of support coordinators (10)
- lack of choice and flexibility of services (9)
- unsatisfactory support workers (8)
- lack of choice of support staff and/or inconsistency of regular workers (8)
- uncertainty of what they are entitled to from services (6)
- difficulties in taking control and/or liaising with support workers (5).

The following section discusses these barriers in more detail, drawing on quotes from the interviews with the 22 NDIS participants.

Barriers related to the NDIS

1. Limitations and inadequacies of the plan that limit or deny choice

Lack of choice in structuring funding and what to spend it on; not funding what is required

People's most common grievance was frustration at the lack of choice resulting from funding not being provided for items that they considered to be necessities – sometimes urgently required necessities. The restrictions on funding packages meant that people may have money but lacked control in being able to spend it in ways they deemed 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. It was sort of given to me as a necessity. I had to spend $6,000 on such and such, for such and such a period. (Hunter2 –male)

> Maybe it should be a couple of interviews before you actually put a package in place rather than putting one in place right away. Let's get a package

– then they're going, 'Shit, I could've been using the money for – I'm with this other person I don't want – it's making it even harder for me being with this person [support worker] than being alone. I'm more fatigued and stressed and anxious after being with that person for two or three hours than I would've been if I didn't have them. But it's like I'm forced to have them now'. I hear that quite often here, so that's a biggie. (Hunter7 –male)

Because it's a psychosocial disability – that's why I only got two days of weekend support for the whole year. Because they don't have the level of money per hour to pay somebody to work on a weekend for a psychosocial disability. (WA2 –female)

Apart from psychology provision, education and employment (these are addressed separately in this report), items that were not funded but that participants regarded as essential to ensuring their wellbeing included assistance/companion dogs, peer support, gym memberships and assistance for transition to work/volunteering.

To get one service I need a microwave but I'm not entitled under core support for that microwave … So, I have to save money up to get that microwave, which took me almost two months – because money's tight at the moment, especially with two 16-year-olds. I'm finding the stuff so difficult at the moment. (Hunter 1 –female)

Dental is something that is a constant drain on money. And I've got some limited health insurance but it covers sort of half the costs of my dental costs every year and stuff. So, if there was some sort of dental plan, that would be terrific. (Hunter2 –male)

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. They're getting big, they're getting fat, they're getting heart conditions. (Hunter7 –male)

But I just keep coming back to the choices that I did ask for that I'm not getting at times – which was around the physical stuff and the peer support. Because … that was probably the best level of functioning that my body had when I did the weekly physio. (WA2 –female)

Spend [NDIS funding] on a good Chinese massage therapist or on things that the literature show works for people with bipolar and PTSD – that's a social rhythm exercise program, that's massage touch therapy. There's all sorts of things. They [the planner] just said it can't go in [the funding package]. And the only one that I became very immovable on was the [name omitted] lifestyle club that I go to. And I said from a perspective of social rhythm, from a perspective of exercise, from a whole set of – from informal support – I said this is an incredibly valuable service to me. I want it funded out of the 60 hours or whatever. And that's the one I'm appealing. But all the other therapies I have either got to try and find the money myself to continue or else I'll discontinue them … It's an essential part of keeping me out of hospital. (WA3 –female)

Not having my doggie is really getting to me now because she was, like, a big part of my recovery. Even realising that I dissociate – and so badly – it was only because of her that I realised she could bring me out of it. Whereas people and that don't. Once I dissociated when my daughter was there and they didn't let my dog near me. The minute they did, I snapped out of it … The thing I wanted was an assist dog. But again, that's really expensive. And I've asked them [NDIA] about that – they won't do it. (WA2 –female)

The local coordinator goes, 'I can get you an occupational therapist. I can get you a physio. I can get you a dietician.' Physio for my head, neck and shoulder pain, which I get from stress. I have chronic head, neck and shoulder pain. So she got me all excited, and then I came to the next one and she goes, 'No, we can't get occupational therapist, we can't get physio, we can't get dietician.' But I need to keep podiatry because I'm a diabetic. If you're a diabetic you can lose a limb, or a foot, or something like that. And with a GP you get five visits a year with a specialist so I spend all five visits on podiatry to look after my feet. (WA9 –female)

Inappropriate plans that did not address a person's real needs and goals

A number of people spoke of having plans that not only failed to address their needs but contained items that they did not necessarily require. This ties in with not being listened to and understood, and with not having more choice as to how funding should be allocated and spent.

> By the time I got there [NDIS meeting], I was livid – and I was hot and tired and shaky. [Looks at NDIA letter.] So she's given me $5,000 transport that I didn't ask for … I thought she'd given me funding for professional services but she hasn't … But it's certainly nothing I asked for. But she obviously thought I really needed it. So now I've got it – oh, funding for allied personnel – there it is. Supporting, assisting you to meet your goals in independence. I didn't ask for allied health professionals because I see a psychiatrist. (Hunter5 –female)

> They're used to planning with people that have more traditional intellectual and physical disabilities. The choice I get given is home care, garden care, taxi services. A lot of it's about mobility and access and participation – which is not specifically relevant to my condition, which is more about cognitive and emotional support. (WA3 –female)

> I thought, 'I don't need that. I don't need that', and she [the planner] kept pushing it a bit – the interviewer did. After we came out of the meeting, I talked to the person I was with: 'Do you think that's really necessary because I don't think I need that. I'm not getting that funding that I actually need.' And she said, 'I don't think that's necessary either.' So we just didn't follow up. She said – and we took it to [the coordinator] – and she said, 'No, that's not necessary.' A lot of people felt a bit like they're over-managing – and some people will need to be over-managed because for any number of reasons and I understand that – but I wasn't one of them. But that person sort of thought I was. (Hunter7 –male)

Lack of psychology provision

Many people spoke of their frustration at not being able to use NDIS funding for the provision of psychology, noting that this was an important service in supporting and assisting them through difficult times.

> Well, I have given thought to that because we actually tried to get a review earlier on this year for psychological support because I've actually been through quite a difficult year this year psychologically … And I have to pay to see my psychologist. I'm paying $30 each month out of pocket. My psychologist wanted me in there every fortnight. And I thought that if I could get NDIS support for that I might be able to see him fortnightly and not monthly, and not be up for all that extra. But they wouldn't look at it. (Hunter2 –male)

> When I sent in the first review, I got a call from a lady and she said, 'Your package is adequate.' And I said, 'So, I can't use the services for psychology'? She said, 'No'… I just felt like I haven't really had an opportunity to spend that money doing what I need because my needs have changed greatly now. I'm not unwell and I don't need that social-type support. I just need psychology … I didn't get the psychological support I need at this point in time. (Hunter4 –female)

> I don't think I suggested any supports aside from asking, 'Can you fund psychiatry?' and that was basically being told no ... So perhaps if psychiatry could be funded, that would be very, very helpful. (WA8 –male)

Increased choice required in terms of broader life participation, especially education and employment

While some people noted that their immediate daily needs were often being met, they also expressed a desire to be able to participate in aspects of life beyond those, such as education and employment.

> Like, my basic needs are being met at the moment … But I was hoping that there might be some sort of higher-level needs met – like helping me with studies and things. (Hunter2 –male)

> In particular, I really want to study – I've started twice and just not been able to keep going. And if I could get some help – someone to kind of walk alongside me, doing the degree, it would make a huge difference. And it's something I really want to do – and it's something I'm not getting at the moment. (Hunter5 –female)

There's 60 hours of support in there – the support worker ... But I want that support in a different service – I want employment support. Because what I was trying to do was get work where people would recognise my disability and make work adjustments … It's assisted employment. It's basically somebody assisting you to get into employment. (WA3 –female)

2. Lack of information and communication that undermines choice

Lack of information about entitlements

Many participants indicated that they were unaware of what they could choose and what they were entitled to. The lack of information meant that many people were attending planning meetings and reviews in a state of ignorance about their rights and the options open to them, and were therefore unable to exercise choice at this important stage of the process.

I don't even know what I want because I don't know what's available. I don't know what's out there … Because with mental health there's so many different grades of it – and there's nothing out there. I don't know if I'm entitled to this or I'm entitled to that … It's what makes the situation so frustrating. That's why I'm here today because something has to be said. We don't know what we're entitled to; we don't know what's out there … 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 and work with the support workers on the ground to actually do the things I want to do. Like the shopping, or going to the gallery and stuff like that … I don't know what to ask for. I don't know what's available – I try to just ask for a general thing. (Hunter5 –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 – if that makes any sense … Like I don't know what to choose, I don't know what to say, because I'm not – I don't know what I actually need. And I think that's why I stuck with [support service] and with

[support service] was because I knew that that was something that I genuinely needed. And I didn't realise that I needed exercise help until after the fact. It didn't occur to me in my head to ask for exercise help … But I didn't know what choices to make because I didn't know what choices there were. (Hunter8 –female)

I wrote down a few bits and pieces [prior to NDIS meeting] that I thought of. And then I went through things what I thought I might want – but the rest of it was like, 'I don't know.' You need someone. Even then, it's, 'Well, I don't know what I want really' … You just go into a meeting and they just ask you and such, and they don't say, 'Be prepared' or 'Get someone to help you.' (Barwon2 –female)

But they got all the information on the internet. See, I'm not on the internet. You know what I mean? (WA5 –female)

Lack of communication from the NDIA – including delays in processing applications

Participants spoke of a lack of communication from the NDIA. In some cases they mentioned specific instances, while in others there was a more general sense that communication was inadequate and/or infrequent. This left people uncertain about their status with the NDIA, a situation that was exacerbated by the anonymity of the NDIA (which is discussed in point 3).

I had no questions, sat down with no one. It was a case of – there's the application, come back, it's approved and that was it. They did not even write a letter to me to say that I needed to go out and find my own coordinator. Nobody even said to do that. (Hunter1 –female)

When I put a request in for a review earlier in the year, we got no response at all. We got no response. None at all. I understand that they're flat chat, but they should really respond at least with a one-line email to somebody – 'Unable to do it at this time' – something like that. They shouldn't leave us hanging all the time – waiting for a review which never comes. (Hunter2 –male)

We handed them in [application forms], and then six months passed. And nothing had happened ... And

somewhere they got lost. So we had to do it again. (Hunter3 –female)

We put in a subsequent review about five months ago and haven't heard anything. Not even documentation to say they received it … I did call them after about three months and they said, 'We're still in the process because we've been inundated.' (Hunter4 –female)

So, I went and applied. About 14 months later, I said, 'I haven't heard from you' and they said, 'Oh.' Didn't hear from them for 14 months … So, if I hadn't recontacted them I probably never would've heard from them. (Hunter7 –male)

I've only had one meeting. That was the very first one and then I went back myself – made an appointment. That's so hard to get – the appointments. I've got 50 days before my plan runs out and I still haven't been told when my next appointment is. So I rang up, left messages and later rang up for my son – because he's on it as well – and I'd thought I'd ask her when's mine coming up because I hadn't heard anything about it – no letters or anything. And she looked, couldn't find it on her system. So she went, 'Look, can I ring you back later and I'll find out what's going on?' She did ring back and she said, 'Oh, it's the 11th of December.' And I thought, 'Well, that's when my plan ends' … But they said it rolls over so it's no big issue. But they've stopped it and nothing else happens. (Barwon2 –female)

Lack of information/clarity about what an individual's plan and funding means

People were often unaware of how their package was constructed, what funds they had received and what the funding related to. They were also uncertain about how the money had been spent (this was a criticism of the NDIA for not informing people clearly about these matters; it may also amount to a criticism of services and coordinators for not informing those they support about how their funding is being spent).

> Nobody explained any of the plan to me whatsoever … Because I wasn't going to go and instigate conversations not knowing what the hell my plan means. Nobody explained what the plan meant to me. (Hunter1 –female)

But I still look at that core amount on a daily basis and go, 'Well, other than the three services, what else can I do with that money?' I don't know what to do. Everybody's situation is different. Everybody's entitled to different things and I'm not being told what my choices are. I'm not being told what's out there. So I've done a lot of finding out things myself to the point where I just throw my hands in the air and go, 'Yeah, it's just helping with the usual – there's nothing more I can do.' I'm not going to ask any more questions because nobody really understands how to answer them anyway. So, the majority of the time they don't even know what the options are for us. So, these companies are given these clients but they don't know what to do. (Hunter1 –female)

They might do it different [review] because I've got $7,000 sitting – the core ones which I haven't used … I didn't know what 'core' was. They don't explain to you what things are … We've got work and then we've got the Salvo lady, the support work and then we've got core … So, we weren't quite sure if they went together… Even the support lady, as I call her, doesn't know … We can now go into NDIS online and we've got portals – we can go into there and I can just have a look. But I've got no idea what's what. (Barwon2 –female)

3. Personnel and meeting processes do not foster choice

Dealing with different staff and the anonymity of the NDIA (including phone planning)

Participants mentioned a general inconsistency in dealing with NDIA staff. They spoke of having to deal with a different person each time they engaged with the NDIA, which meant having to tell their story over again. This did not lead to participants feeling that they were understood and being supported in addressing their needs. Participants were also critical of phone planning as they felt that it contributed to the lack of understanding of the individual.

> I point blankly refused to do one [phone planning] because you can get so much information from people's body language and stuff, and so there was no way I'm ever going to do an over-the-telephone plan …. Yeah, it's a pretty big thing too for a lot of people to say, 'No, that's not what I want to do.'

But, just out of experience, from what I've seen and heard – I've met people where it's just all gone terribly pear-shaped and it's been that they've lost funding. (Hunter5 –female)

I think that definitely the telephone thing is crap because you can't see what goes on between people. You don't see and I don't think you can advocate for yourself very well on the telephone either. Certainly, you can't have a support person with you. (Hunter 4 –female)

He [nephew] had a little bit of NDIS funding but then something happened – they left the paperwork or something and couldn't get back on. She [mother] had meetings with the providers and [they] said, 'No, he can't have it' … And my Mum's ringing them up all the time, trying to get them – she can't get a hold of them. And they say, 'We left your paperwork. You have to refill the paperwork out. You've got to do this. You've got to do that.' (Hunter9 –male)

I did have a few issues with that … you thought you knew who your planner was, but then you find out that they've gone or moved on. (Barwon4 –male)

An impersonal system where people do not feel listened to or supported to make decisions

The NDIS was often viewed as impersonal and more of a hindrance than a help. People were made to feel unimportant; they often felt that they were not listened to and that the planner made decisions that did not reflect their individual life and needs. Rather than exercising choice and control, people spoke of being compliant and passive recipients of funds that were regarded 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. (Hunter4 –female)

I feel like I'm not important and that's what I've been tempted to tell them – to stick it. Because it's been more of a hassle than it has been a help, which isn't the way the system should be. (Hunter1 –female)

They [the planner] just slam the phone down. They've got tempers – you know what I mean? (Hunter6 –male)

I wasn't told at my planning meeting what services I would get and I was not allowed to find out what they were – because I had an LAC, who was part of [service agency], but seconded by the NDIA. And she wouldn't tell me at the planning meeting, or a follow-up telephone call from me three days later, what she was going to submit to the planner at the NDIA – which I think is dreadful. I have a right to know. So this plan has got things in it that I didn't ask for. (Hunter5 –female)

The bureaucracy [gets in the way of making choices]. I honestly feel like there's no way to say what I need – and to have it listened to and enacted on. Though I'm grateful for what I get offered. So, what is offered to me will be useful. I'm grateful for that and I'll take it – the bits that I think will be useful for me. I probably won't use the other bits. I'll see what happens. Or it will depend whether they allow me to use it for things like advocacy and other sorts of things. But, yes, it's the bureaucracy. (WA3 –female)

And I don't fit into that system. And I never want to. Because it's not about me being independent and risking life. It's about me being compliant and fitting into a slot so people don't have to bother about me anymore. My goals had just shrunk – you know – down to nothing. And now I think people listen but they can't help putting their own stamp of what they think a good-enough life is on it. I think it's [the problem] fairly universal. (Hunter3 –female)

Arduous/intimidating meetings and a confusing/ complex application process

Given the nature of psychosocial disability, consideration should be given to how challenging people may find the application process and the subsequent meeting/planning. Participants found NDIA processes confronting, intimidating and confusing, all of which added to their anxiety and uncertainty.

I've only ever had one meeting with the NDIA – and at that time it was just so nerve racking to go into the first meeting. I don't recall if we discussed

anything other than what the planner put to me as I recall. (Hunter2 –male)

It was actually quite easier without the NDIS because you get your money from Centrelink and then you pay for your stuff in person. And I was just doing day programs at the time – so that was easier. But then NDIS has confused a lot of people. It confused me. So, it did confuse some people. (Hunter9 –male)

They already know that I've got a disability. There's two sections on there [NDIS application]. There's one for mental and one for disability. But they still ask for all the paperwork … But they've already got – already know all my disabilities. So why can't it be one mental and disability, instead of making one of this? And then you've got to get more papers for this when they already know what you got. (WA5 –female)

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)

Well, it's very impersonal, and if you're suffering it's a very difficult way to have to reveal things about yourself. (WA8 –male)

It needs to be made a lot more simpler … the whole thing. And like some aspects of the NDIS not even the average Joe would be able to understand … And especially as they keep on changing the goalposts – like you think that you understand something, and then all of a sudden it's changed. (Barwon4 –male)

Staff do not understand mental illness and psychosocial disability

Research participants often felt that the NDIA staff they engaged with did not understand mental illness and psychosocial disability and were therefore ignorant about how they can affect a person's life. Staff could be rude and dismissive. In particular, participants felt that there was a

focus on the physical aspects of people's lives, that NDIA staff – especially planners – were more comfortable in discussing the physical aspect of disability, reflecting a view that it was frequently regarded more as a physical phenomenon.

But what I don't understand was that my application was all about mental health but all they cared about is the injury because it's the physical – 'Well, we can fix that' …. They can see it. Because they can't see it, they don't … But ours – it's not so much physical but mental. (Hunter1 –female)

I said I really want to get a companion dog – you know one of those dogs – but with official certification so I can have it in my unit. And she just gave me this really big long lecture about how I'd have to think really carefully about having a dog and did I know how to feed it, and would I know that it had vet fees? … It was really inappropriate that she spoke to me as though I was a five-year-old and hadn't thought those things through. It was half-way through the interview so she knew I wasn't having any trouble understanding things. (Hunter5 –female)

The lady at the NDIS was a bit kind of disrespectful in the way that like mental illness is not considered a proper disability. Like, if there's a person with a missing arm or leg, you can see that they're missing an arm or a leg and you know. But if they've got a mental illness, you can't see it. And this woman was being really rude to my sister because 'Oh, you're all right, there's nothing wrong with you, you look fine.' But she's got a mental illness. And I am very kind of okay with standing up for myself and speaking out and stuff, but my sister's not. And she couldn't stand up for herself in the face of being told that she didn't really have a disability because it was a mental illness and not a physical one. I think that is so wrong. And I've heard that from other people, too, saying that the NDIS people are not as nice to them because they've got a mental disability – not a physical one. And I've even heard workers say, 'They just don't understand that people with a mental illness have a genuine disability.' Like we're not putting it on. Don't you think that I would love to have a full-time job and be normal? Of course I would. I'm not pretending. It makes me angry that, like, mental illness is not really seen as a proper disability. (Hunter8 –female)

There is no choice. You get presented with something that fits the funding model and whatever they can do that fits you into there … There is no clear understanding. It's like a social disability. And I'm one of the few people that sit there and say I have a psychosocial disability rather than a mental illness. Because most people want the mental illness with the concept of recovery … When I talked about being recovered, I don't think they [the planners] understand mental illness recovery. I think they said is this no longer permanent – rather than seeing that you can have both. It can be both permanent and you can recover. (WA3 –female)

You lose a lot of self when you fall mentally ill – and especially if you get left with a disability out of it. Because, for example, work was a very big part of my identity. So, you want to retain the bits you've still got. And I don't find the process of NDIS conducive to me retaining my bits of self that I've still got … Parts of it chips away. My psychiatrist made an interesting point when she said it is actually disabling for them to push me into a system of support. So, a support service like, for example, the one where they put me on a bus and do whatever else in comparison to the one I'm already in that has been self-selected through choice. And I think that's probably true. So it does chip away if you allow it to … I do believe there is lack of awareness … I think it's just a system – I know there's the interplay at the moment between the mental health sector and the disability sector and I see bonuses for both. I think the disability sector's much better in terms of getting you to focus on abilities and getting people to see the whole and not the parts. (WA3 –female)

4. Other themes

<u>Uncertainty and worry over reviews and the possible reduction of funding</u>

Given that there are no guarantees that people's funding will remain consistent, participants expressed anxiety about forthcoming reviews and the fear that their funding could be reduced.

I have bad days, but I'm going so well that I'm scared when the renewal comes around. It's only three months away. And I don't feel I've used enough of the core support to warrant them giving me anything

again. I'm already a disaster thinking about how the review's going to go. (Hunter1 –female)

I'm really lucky because I've heard horror stories of other people. They didn't – they got their funding cut or things like that have happened to them. And I'm just like, 'I hope that doesn't happen to me.' It is a concern that your funding – because people have had their funding cut smaller because they're not using it or something. And then someone else I heard of had their funding cut completely because they'd ploughed through the whole lot. And I'm just like, 'Oh gosh, that's a real concern. What if my funding runs out? What do I do then?' Yeah. It makes you feel uncertain about what are you going to do with yourself if the funding disappears because you become very reliant on it … I haven't done much planning ahead because – I'm not even certain when my next review is. And I like to know ahead of time when things are happening. (Hunter8 –female)

I panic a bit, because it's like, 'Okay, my plan finishes on this time.' I wasn't quite sure that if I don't get a meeting, does it stop? Do we have to redo it all? You don't want to do that again. (Barwon2 –female)

It's a worry if there is hardly any funding left – what are they going to do? Are you going to be left with nothing? (Barwon4 –male)

[I was worried because] we were thinking because I broke my ankle … for three months I didn't use that funding towards the support worker for most of that time. There was a bit of concern around whether I would get that money again for a support worker to come and visit me – which is very important. But then if you don't spend the money that's on the NDIS package, you might lose that. Which means I don't have a bloody support worker. (WA6 –male)

<u>Inconsistency with funding across recipients</u>

While recognising that funding packages will vary according to individuals' needs and circumstances, some people expressed frustration at what they saw as inconsistencies in funding.

Funnily enough, my funding is quite a bit less than other friends of mine … I felt I was really blessed to get in early because of the trial zone here. But it's

funny because some people I know got $37,000, $68,000. (Hunter2 –male)

I've had trouble getting financial assistance. I don't know why, because I know some clients have received that financial assistance to do courses and things like that. For some unknown reason, I don't qualify. (Barwon3 –male)

Barriers related to services/supports

Delays in adequate response and/or service establishment

Participants identified inadequate response and/or service establishment as key barriers to exercising choice. These inadequacies related to things such as providing support coordination, organising supports and services, recruiting support workers and replacing them when they went on leave. Inadequacy of response was also related to resolving issues/disputes and concerns about billing.

> The first experience I had was with [service provider]. I wasn't rung for almost a month, nobody rang me, nobody sent me a letter, and that's when I rang another mob. (Hunter1 –female)

> 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)

> I think what's hard is you don't know where the funding is going. You've got these figures and you think, where is it going? What I've said to them – I wanted transparency … Especially when my worker wasn't there for a month. No [replacement]. Well, she was away and then their boss said to me he'll get – Clare would bring a list of the hours so I could see what was owing to me. And still nothing has

come to me … And that drives me crazy. I like transparency … still nothing has come through. And I'd ring up, she'd be away – 'Oh, she's on two weeks annual leave now.' And then her boss was away. So, there's always someone away or something was happening – personal situation. So, I thought maybe she's had a tragedy in the family so I'm not going to ring her. But apparently that didn't happen – it was just 'whatever.' So, it's no communication. (WA4 –female)

Inefficiencies of support coordinators

Support coordinators were recognised as being valuable enablers of choice but also barriers when their performance in the role was unsatisfactory. Participants noted that sometimes there was a lack of contact/response from coordinators as well as a lack of organising supports. It was also noted that they often took control of decision-making inappropriately, or could lack adequate knowledge of the NDIS and how its funding works. Some participants also said that they were uncertain about the parameters of the coordinator role and what it was reasonable to expect from them.

> I've just recently changed coordinator of supports ... I wasn't satisfied with her because she was talking about my NDIS packaging with somebody else who doesn't – shouldn't have known anything about my NDIS package. And that person said to me, 'Oh, you're ploughing through your package too quickly. You're spending your money too quickly.' She had nothing to do with me or my package – and I was a little bit put out by that. And I thought, 'Well, that's not right, my – like, coordinator of supports – should not be talking to other people about my package.' (Hunter8 –female)

> 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. (Hunter1 –female)

Lack of choice and flexibility of services

Participants often found that services had not changed following implementation of the NDIS and that there was a lack of choice and flexibility with regard to them. Some spoke of being 'boxed

in' with others – that there were only groups available in which people had little choice over which activities were undertaken and when. Often, when they did wish to engage with a particular service, there were no places available, leaving people without the supports they required. The lack of flexibility resulted in some people finding themselves without a support worker at important times, leaving them stranded and vulnerable.

> What's the point of having support workers if you've really got nothing that you can do mental health wise other than sitting down and having coffee with someone – then what? They're not helping. And there's nothing that they can do – they don't know what to do themselves. They're told, 'This is what we're doing for a month if you want to take part in any of that.' I said, 'No, I don't want to pay.' There are choices out there but there's just not enough. When it comes to mental health, there's not enough out there. (Hunter1 –female)

> Day programs might work for some people, but for most – for some people – they don't work because they're trying to fit in – a one-size-fits-all thing. But where I came from – it just doesn't work…. What happened is, they [support service] had two groups – TTW and then the CP group, which is the general public people. TTW is Transition to Work. Well, this year they got rid of TTW and I said, 'Okay, what are we doing?' 'Oh, we're going to colour in today. We're going to do this. We're going to do that.' I'm thinking, 'If I want to colour in, I'll go colour in at home.' I want to go try to get a job. I want to learn how to budget. I want to be able to support myself in the real world. (Hunter9 –male)

> I was put into that box … I'm put into that – [service/support name] – 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 or … If I could be able to mingle with normal people, as such but, like I said, we're all together – all the same. We've all got different issues but we're all boxed in the same thing. But I want to do a cooking course. Well, I can't find a cooking course anywhere – unless I go – like Jamie Oliver or something like that. Or the [TAFE] – which I have to pay myself. There's nothing there with mental health. Even the groups – there is nothing there. (Barwon2 –female)

> Just say if I got a hospital appointment or something like that – a couple of times if that time's [shift] up they [support workers] just leave you there and then you've got to find your own way back. Yeah, they just do their three hours and that's it. So, wherever you are if you're not back they charge you – on my time. They charge for time limits from their work … so if it takes her half an hour, she's got to leave an hour early – so half an hour to me, half an hour back – so you're only getting two hours. (WA5 –female)

Unsatisfactory support workers

It is evident that support workers have a significant impact on people's daily lives. A good-quality worker could greatly enhance choice while an inadequate worker could diminish a person's autonomy and personal wellbeing. Issues with support workers included lack of knowledge related to mental illness, inappropriate and unacceptable behaviour and a lack of attention to participants' needs.

> Because it's not so much physical but mental, I don't feel like the support workers even understand the people that they're working with. My support worker often talks to me about her illnesses and what happens and stuff. She suffers bipolar as well. But there's tiny things – like I'll be going to say something and she talks straight over the top of me. And it's like I'll never get my side, I'll never get it right. But it's just that – oh, my God – some days I've just got to tell you all to go away. (Hunter1 –female)

> A lot of workers – I've had workers who want me to go and sit in the park and listen to them play guitar. I had one worker turn up for an interview here at the house and he brought his wife. I mean, yeah, these are trained people by the way. This is why I get so worried when people talk about training. Mandatory training – that's not going to stop anything from happening. (Hunter3 –female)

> A lot of people have NDIS carers. The carers come. They're with them for three hours. The carer's just talking about themselves half the time – most of the time to the person that's on NDIS. The person's struggling because they're not feeling particularly good. The person, the supporter, is often just using them and getting paid to use them often – and a lot of the time they're on the phone or taking

messages. They're not there for the client. When they're with the client, they should be with the client. That is so important. That's so discouraging for people on NDIS. Sometimes, half the time the person's on the phone, or they're answering their texts, or they're doing their Facebook or whatever they're doing. They're not working with their client. They're using their time with the client to catch up with their stuff. And they think the client – because they're a bit mental, or they're a bit dumb or they're not too bright – they think they don't notice the person. But people notice. They notice. They've been pushed around all their lives. They've been taken advantage of – and here they've got NDIS and you've got this person taking advantage of them again. They're supposed to be helping them. That's a biggie. That happens a lot. (Hunter7 –male)

My first worker that I had through NDIS – I don't like talking about him. I didn't think of him as a friend. I saw him as a person that I had to get up and spend five hours with. And … yeah … I had a mental breakdown and had to go to hospital. And then they said, 'Okay' – because I told his boss what he used to do. Nothing to me, but he used to go for [country name omitted] and … boys and stuff like that. And he'd tell it openly to me. I'm thinking, 'I don't want to know that.' And he called me gay and all that stuff because I carry a bag around because I had all my medication in it. Yeah, so I went to hospital. His boss rang up – because we're really good friends with his boss. And she goes, 'Yeah, he's not working with us anymore. You should have told me sooner. He has other clients that he used to do that sort of stuff to as well.' (Hunter9 –male)

She [support worker] wasn't really listening to me today when – or kind of interested that I haven't had any fruit for six weeks. Like my body is screaming and I was saying my body is screaming – I've got to go to the chemist. And she's sort of more talking to the new person instead of attention to my needs. It's like she doesn't want to go shopping – she's happy next week because we're going to Bunnings because she likes Bunnings … She's very good, but I just feel that my hours are not going on working with me – they're going on running my agenda, the coordination, instead of my practical stuff. So, I'm wondering what the coordinator is actually doing. (WA4 –female)

With the support workers, that went very, very badly. I had two very bad experiences with the first two support workers and ended up leaving that organisation. And I've actually put in a complaint. I made a choice on my own against one of the support workers in that organisation. (WA8 –male)

Lack of choice of support staff and consistency of regular workers

Participants considered the choice of support worker and ongoing regularity in dealing with the same person as being vital in enhancing the quality of support they provide and maximising the possibility of a good, supportive relationship. Being unable to choose one's support workers was commented on by many participants, as was the inability to deal consistently with the same worker. Participants noted unfilled staff absences, ad hoc changes of staff with no notification, high staff turnover and poor organisational systems for managing this.

> Consistency is the main one – we've got a worker one week, then it's changed the following week, and then it's 'We're not even going to tell you. We're going to send this different cleaner.' And obviously with my mental health and dealing with a teenager at the moment on my own – I'm not finding it easy at all. So, I found that even harder … Because of the inconsistency [have to tell story over and over again]. Like, I started with my support worker and then because she was only a casual worker – not permanent – I could only have so many sessions with her then I had to go with someone else. And then I had to go to someone else and it was just – my support worker was home one day when the normal cleaner was supposed to show up – that I've never had a problem with. I'd had a big drama with [name omitted] the night before. I'd had a massive fight and this strange cleaner pops in and I'm a disaster as I already was. And I just had to say, 'There's the kitchen, just sort of clean.' Like I was dealing with my own dramas, but nobody rang me, nobody messaged me, nobody emailed me to tell me that that was going to happen. And being, like I said, with the dramas that happen with mental health on a daily basis, you can't do that, you can't. You're getting used to one person – 'Oh no, we've got to give you this person' … It's full-on inconsistency.

And it's only that I stomp my feet up and down with the support coordinator that he emailed them and said, 'Come on, guys, get your finger out of your butt. This needs to stay consistent.' They then put the staff all – like the temporary staff – on permanent part-time. But then I was still fighting with them because – the system's just a mess, absolute mess. (Hunter1 –female)

Now, this is a biggie. You get a person. You get comfortable. You get secure. You get feeling this will work out. And that person leaves – and they give you another person. Then you have to kind of retry and get it all going with a new person. Then that person leaves. This happens a lot – and that's real … People on NDIS – again, they might just give up and say, 'It's just hopeless.' That's a biggie. It's really important that you get someone who's going to stay around that's managing their stuff. (Hunter7 –male)

Well, as far as [support service] is concerned, you get allocated one – and if they disappear you have no support worker. They just don't have the numbers to do it. (Hunter5 –female)

I still don't actually know everyone that provides NDIS support in [Perth region]. Even, like, last year – because the three weeks that I went over there and the NDIS worker being sick and them not replacing her in that time – I ended up with 50 hours over that I couldn't use. (WA2 –female)

Well, I don't know why, if someone's going to go on four weeks leave, why you have to have no support for four weeks. It just boggles my head. (WA2 –female)

I was ringing up the bosses saying, 'Well, look, you're saying you're going to ring me back and nobody is ringing me back …' And then they told me this guy had left this organisation and someone else had taken over – so there were people coming, people going. And they said, 'This is what happens – human nature, like people change jobs.' And then unfortunately I was the one that fell in the cracks. (WA4 –female)

Uncertainty about what people are entitled to from services

Participants expressed frustration and uncertainty about what supports they could request from services and what their funding entitled them to. Enacting choice and control was said to be extremely difficult as it requires a degree of assertiveness that is not always consistent with people's experience of mental illness.

I have to say, I waited about three months before I had the courage to go up to the coordinator – because I don't know what I was asking. I don't know what to ask or I don't know what he's supposed to do. I don't know what their job is. It just wasn't clearly stated and you just – with mental health, you don't want to go to this mob and this mob. 'Oh, you've got to go and find your own – you can talk to as many as you want.' Well, I'm having trouble trying to talk to you let alone going to each individual place and asking what can they do for me – and I still feel that they don't understand. It's just not the support coordinator – it's the system itself … (Hunter1 –female)

I'm a bit confused about how they said something – It said, 'Taking money out for the day program', which I haven't been to for three weeks now … I had to sign it so I don't lose my one-on-one support with them. But I'm going to write a letter to them and saying, 'What does it mean by you taking $10 out a day for something that I'm not using?' (Hunter9 –male)

Difficulties in taking control and liaising with support workers

It was often difficult for participants to take control in their exchanges with support workers, to take a more active role in terms of 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 and reach satisfactory arrangements. Many said that such difficulties were common among people with psychosocial disability as many find confrontations difficult or even impossible.

Since day dot, I haven't felt like that at all in this whole situation – I've never felt comfortable enough to be able to say, 'Can you do this, can you do that?' … I just find it hard to ask people to do things. (Hunter1 –female)

A lot of people on NDIS, they'd be given somebody – 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. (Hunter7 –male)

Yeah, I don't speak out because I think – like, my mental health [counsellor] has said I'm worried about what people think of me. And I pretend I'm not worried about what people think of me but for some reason I must do because they said it was ambiguous what I said. So, I do really worry about what people think of me because someone mightn't like me. (Q: So, there are times when you keep your mouth shut with your support worker or the coordinator?) Yeah, and I get resentful sometimes … So, it's a personal situation of the worker and the client and it's going to be variations right across the board depending on how high-functioning you are, how low functional and how assertive you are. Which I'm not always very assertive because some of us might be working with a personality who's got a stronger personality so my voice is not being heard. (WA4 –female)

I'd feel very uncomfortable doing that [dismissing a support worker]. I'd really struggle with that. Rejecting somebody because I – having mental illness your whole life's about rejection and not fitting in, so for me to reject somebody else and say, 'That's not working for me' – I'd really struggle with that. That'd be tough. (Hunter7 –male)

The NDIS – making life easier and better

Despite these barriers to choice-making, it is important to recognise that – although the point was not specifically investigated as part of the research – many people (13) explicitly stated that funding from the NDIS had made their life easier and/or better. For many, it was the first form of financial assistance they had received and it had given them more control over their lives and enhanced their capacity to make choices. Significantly, some people acknowledged that adequate financial support and greater

control over their lives had the advantage of enhancing their health and reducing the need for hospitalisation; this is beneficial both to individuals and those closest to them. It also benefits the health system and the wider community. Having adequate financial support increased some participants' confidence. Many expressed their appreciation for the support the NDIS provided them in meeting their basic daily needs.

Keeping people well

Well, I think the Government saves out of it because she's [friend with psychosocial disability with NDIS funding] not going into hospital every 12 months for three weeks. And she's been out of hospital now for three years and she's been through the deaths of both parents. I think the result has been a remarkable about-turn in her mental health. So I think it was actually worth it in that regard because it probably saved the Government money in the long-term. (Hunter2 –male)

I've been able to get out more and been able to do what I wanted to do, and I've been able to get fitter, which is what I wanted … Because I'm getting out and I'm doing things and I'm meeting different people. And, you know, because we see so many people in the pool all the time and we say hello to them and make friends with them. I used to be going to hospital all the time – frequent visits to the hospital. As I say, the going out and doing things, getting away from here for a little while, has made a difference as well … I get out more and I'm meeting different people and they're helping me getting out and meeting new people – helping me get jobs. (WA1 –female)

Increasing confidence

Yes, that's [NDIS] given me a lot more confidence. Now I have choice. Now I'm on top of it. I can decide what I do during my day. I have choices. I can do or not do a thing. I can contribute or not contribute. I can help people. I can come here a bit. I've got lots of choices. But with mental health there's not a lot of choice there – You just can't say, 'Well, I'd like to choose my mental health to go away or stay.' You don't have that choice. It's not going anywhere. (Hunter7 –male)

Meeting basic needs

> This was actually the first assistance I received. And I tell you what, I'm very grateful for it because it has made life a lot easier for me … My basic needs are being met – exercise, cooking, house-cleaning … They're all being met so I'm grateful for that. (Hunter2 –male)

Many of these benefits of the NDIS can be attributed to the enablers to choice that are examined in the following section, along with participants' suggestions for improvements.

Enablers and suggested improvements relating to choice in the context of the NDIS

A number of significant enablers (things that aided participants in choice) and suggested improvements that affected people's experience of choice were identified. These relate both to the NDIS/NDIA and to support services.

The key enablers and suggested improvements identified by research participants are summarised below. In each case, the number of participants is indicated in the bracket at the end of the description.

- skills and qualities of personnel – support workers/coordinators (19)
- the importance of specific funding for a wider range of services, both as an enabler where currently provided and as an area for improvement (14)
- more flexibility and control required in spending the total package (13)
- the importance of having an advocate and supporting documentation from family/general practitioners/therapists (13)
- self-efficacy – individuals knowing what is good/best for them, identifying clear goals and the ability to change supports (12)
- resource information – list of clear options with cost attached and profiles of staff to choose from; getting information by direct face-to-face contact (6)

- more overall clarity required from the NDIA and improvements needed in being able to contact it (5)
- support of peers (5)
- pre-planning – aid in identifying goals; support of service in accessing the NDIS (5)
- competent NDIA planners (4)
- individual choice considered important, though often this is in collaboration with others, who may make choices for the person (4)
- review and appeal processes to be quicker and easier, with certainty regarding future funding (3)
- planning process – all interviews to be face-to-face, with questions relevant to person's life (3).

Skills and qualities of personnel – support workers/coordinators

People emphasised the value of having a good coordinator and support workers they could trust and rely on. NDIS participants valued knowledgeable and empathetic staff who could support them with planning, managing funds, knowledge of the NDIS and services and problem-solving. Having regular, ongoing contact with staff who know the client well and follow their instructions is a key enabler. Equally important to participants was getting to choose their support staff. Skilled support personnel are credited with facilitating significant life outcomes for participants, contributing to their quality of life and having 'life-changing' impacts. Skills particularly valued were identified as: vigilance in providing care; experience in mental health, including lived experience; listening skills; the ability to teach skills and support life-planning and organisation; the ability to suggest but not coerce; consistency; the ability to support decision-making through asking questions and presenting options; and the capacity to become a friend.

> I have a worker from [service agency] who visits me once a week, just to enquire after my health you might say. He sort of keeps a walking brief on my behaviours and he's very good. He's terrific. He's really good, really kind. Tough when he has to be, but kind. He's really kept me motivated with my diet and stuff. I've been blessed. I've been blessed. I've actually had four workers. My worker is absolutely

terrific. And he is very, very humble and very strong and he's very decent. Before him, I had a South African worker and I only had her for two weeks. Prior to that, I had a consumer worker who was very good as well – she was very direct. All three of them were excellent. And then with the other agency I have someone who's had a lot of experience in mental health and she's actually just funny. She's a funny person … The planner worked for years in [support service] on the front desk sort of thing – in the actual implementation of the program. She's worked there 14 years or something so she's very au fait with how mental health works. And she understood what my needs were. So, all four I've been happy with. (Hunter2 –male)

And had it not been for getting a fantastic specialist coordinator of support … They got this guy who is an ex-addict and he works with some of the people out at [hospital] and things like that. And like I've worked with him for about – it's over a year-and-a-half now. And he's changed my life. And he's listened to me … But what's been great is that he's witnessed. I've had a witness. That's pretty much – I've had a non-judgemental witness. (Hunter3 –female)

I've got a woman in Sydney who I meet and we go to see the theatre – she'll book things for me if I can't and she'll work out how to get there. And through her I've managed to use Uber, which I just couldn't. I was terrified. And with [support worker], I managed for the first time in my life to go overseas by myself – and experienced life not afraid for the first time in my life that I remember. And it was literally because of [support worker]. I said, 'I wish I could go to Scotland and visit my friend.' And he said, 'When do you want to go'? And then he – over eight months – we meticulously went through all of the – you know – absolute no bullshit CBT, think positively. It's like, 'Okay, what's the worst that can happen'? And then problem solving. Like, to me, that's so much more positive than pretending life's great. (Hunter3 –female)

I had money from the [support service]. I had someone two hours a week – it actually ended up four hours a week. And we were doing exercise like walking. And I used to walk up and down the hills here, with [support worker], to get a bit fitter. But then she left and I got cancer – and that was the end of the walking at the moment. But I'm looking for someone to do that walking. And then

I've got [support worker], who I see twice a week for two hours – she's the one I go shopping with and do that sort of thing. We've got four hours – at the moment I've had a whole lot of doctor's appointments, so she's taken me to the doctor and those sorts of things. Takes me to get my scripts filled, which is – I live about six or seven kilometres from here. So, we do that kind of mundane stuff but we also do the other stuff on the other two hours … Having the support has made a huge difference to the quality of my life. (Hunter5 –female)

You have to get the right coordinator of supports – someone with experience. But my Coordinator of Supports has been absolutely fantastic. He meets with me fairly regularly. He has found me the cleaning, the exercise person … Oh, he's good. He's really good. He listens. He has suggestions, but doesn't force it on you. (Hunter5 –female)

I applied and I said, 'Would it be possible to get somebody with these skills or that can help me with this or this?' And they found different agencies and they said, 'Try this person for a while.' Yeah, I'm pretty happy with the three of them … The music guy and the other lady comes – they both do computers with me. I always have a list for them of things I can't do or things I need them to help me with. Once I've got those sorted, I can get on with my week and do more things on the computer. But if I didn't have them coming, I pretty much wouldn't touch the computer. Because when you have mental health and anxiety, the last thing you need is no computer skills. And trying to get your computer to work because that's when you just really implode. That can bring on a massive anxiety attack. But I know that even though I'm getting very stressed with something on the computer or managing my appointments or something, that there'll be people coming during the week that can talk me through that – get me back on track again. And I know they're coming the following week and the following week and the following. (Hunter7 –male)

He's a really, really good caseworker. I've had him for about two or three months now. He asks me questions, he says, 'How can I help you better?' (Hunter8 –female)

[Caseworker] and I are really good friends now. And so it's more like spending time with a friend than it is spending time with a caseworker … because if I

have a problem, I'll say, 'I've got a problem – help me.' And we'll discuss it and she'll say, 'Okay, what are the options? How are you going to do this?' So, yeah, I would say she was the person that helps me decide things the most. (Hunter8 –female)

Yeah, we have a good time. I don't see her as a worker. I see her as a friend. I see them all as friends. (Hunter9 –male)

Well, as I say, it's good because I get on with the people that support me and they do the things I want to do. So, it makes me feel good inside and, you know, it uplifts me. (WA1 –female)

Going back to the first support coordinator who I said I think is wonderful, but was a little coercive, she did actually help me way beyond her job description in getting admission to TAFE. She sat down with me, went through forms, got me on the internet to actually look at the courses that are available – that is why I thought she was wonderful. And I do think she went well and truly beyond her job description. (WA8 –male)

My original support worker – she was an occupational therapist, so she was really, really great. And she was a Christian too – and I am a Christian so that was really good. And then she left and there was another lady who came on – and she was okay, but she wasn't as good as [the OT]. She was great. She got me going from the beginning when I first moved to WA. (WA9 –female)

The importance of specific funding for a wider range of services, both as an enabler where currently provided and as an area for improvement

People identified a range of specific items that enabled them to exercise control over their lives and contributed to their wellbeing. There were many items that were not funded, and participants felt that funding them would contribute significantly to the quality of their lives and wellbeing, which in turn would bring social benefits in both the individual and the wider contexts.

Employment I'd probably put above education … Dental is something that is a constant drain on money … So, if there was some sort of dental plan, that would be terrific. (Hunter2 –male)

I really want to study … It's something I really want to do, and it's something I'm not getting at the moment. (Hunter5 –female)

I'd really encourage them to have health programs in place … If the NDIS really pushed to say, 'Well, we'll get you a personal trainer at the gym for a couple of sessions and then we'll give you a gym membership' – that'd be very, very empowering for a lot of people. They'd probably have to go along with their handler for a while or their supporter – but once they got confident, they'd want to go and probably it'd be more of a social outlet for them … I think gym memberships and personal trainer – just to get a person confident doing that … and, you know, when you're – you look pretty fit – you know, when you exercise you get the happy – the endorphins. (Hunter7 –male)

I would really like some extra funding for fitness and health. Like, maybe even going to a gym or something. I mean, I know we've got a gym here, but maybe, like, to have somebody with me in the gym. Like, for physical health things – I'm worried. I don't want to get diabetes. I'm a bit concerned that I'm overweight – and so help for getting – losing a bit of weight would be really, really good, yeah. (Hunter9 –female)

One thing I'd like – I would like to see a psychologist on a monthly basis. That'd be great. (Barwon3 –male)

The other thing I wanted was an assist dog, but again, that's really expensive. And I've asked them about that – they won't do it … Well, I feel like I've tried to tell them what I needed, and I've just felt that they haven't been able to fill that. (WA2 –female)

I'd ask for advocacy. And everybody says you don't need an advocate because you're one yourself – which is wrong because I do need one when I'm not well. I'd ask for some sort of allocation for respite for my husband or my family in terms of sometimes they need something. (WA3 –female)

We just had a thing at the [restaurant] with all the family because it might be the last time we'll get together with Dad alive. And if money was no problem, I probably could have got him [son who also has a disability] out and sent him back in a taxi and he wouldn't have to spend the night. If you have a special family occasion and you've got to get a

taxi that's not really local, and you've got to travel a little way, you can't afford to do it … Yeah, you can do stuff that's close but not far away. (WA4 –female)

I've just applied for a new job, which is on a different route to what I normally go to so I'll have to try and find out what the route is there, or I can catch a taxi. Because I've got the taxi vouchers from NDIS so I can do that. (WA1 –female)

Probably more hours with a worker, I'd say, and maybe – I don't know – maybe more hours to help with [son with disability's] stuff. (WA4 –female)

Being given the access to greater psychological resources – resources and psychology is very helpful … I'm not sure without sounding greedy – I think some of the other things I asked about they said, 'We consider those kinds of things to be ordinary life.' Medications and things like that – and that's fair enough. Beyond that, I'm not sure. I think there's a fairly good range of – things that are core supports and not core supports. So, being able to assign some of that flexible funding towards extra psychology would be helpful. There were other organisations that run different programs – I could allocate some of those funds to those programs. But apparently, no, you can't. It's got to be under the strict – I think they call them – 'line items.' (WA8 –male)

I'd really like to have a pet for some company and to motivate myself to take the pet for a walk every day … It has to be a girl. It would make me really happy. She can sleep on my bed. But I'm concerned about the cost. I want to have enough money in the bank for vet bills. I'm worried about my money management. (WA9 –female)

I have three people coming to my place from different agencies. One's teaching me music and computers – a bit of each. He's helping me with computer skills and teaching me guitar. Another lady, her job is mainly to help me organise my week and get my appointments in the phone, and other computer stuff and just general stuff around computers – but also getting my life in order and checking that everything's being paid or not being paid. Now, I've just started going to another music guy and he's teaching me harmonica and ukulele and he'll teach me mandolin eventually. At first, I don't think NDIS accepted music tuition, did they? I think they're doing it now and I think they're okay

with it. For me, it's massive. A lot of people with Asperger's, the only way they can communicate is with music. Finally, I've got some people that are helping with the music and that's massive because that helps me here – because I bring the music here [to the service agency] and I help other people here that want to get involved in music. It's something I can pass on – so the music's really good. I like kind of paying it forward. If I get something from somewhere, I'm happy to share it or to give it to other people. I'm teaching a few other people how to play guitar and I've been teaching – showing people the ukulele for years. Once I learn the harmonica and the guitar properly, I'll be able to do that. So, it gives me a purpose. It gives me a skill. It settles me down. Music's very calming when I'm anxious or depressed … There's one guy, he comes in here and it settles him down … And it's good for my self-esteem too. It's good for who I am. (Hunter7 –male)

The need to fund a holiday or short break was seen as important by some people who valued the possibility of taking 'time out' from the demands of daily life.

I'm finding the stuff so difficult at the moment. 'We can send you away to a retreat for a few days and be one with yourself.' I know that sounds pathetic – but something, little things like that, like a retreat, we all need time out. And that's what mental health people want … It would be a brilliant idea to send people with mental health – similar mental health disorders on – I know it sounds stupid – but, like, a retreat or, like, a camp, just so that we can get a break from everyday life. (Hunter1 –female)

I haven't had a holiday for as long as I can remember. And even if it was just a week by the sea or something – or even the bush. I'd love it. But apart from the occasional weekend – I'd love a holiday. And I think a lot of people with disabilities fall into that role. (Hunter5 –female)

[What like to choose to do] I'd choose to fly to Italy. I heard a long time ago there's a five-week trek through Italy … So that was one thing if I ever got enough money. I would like to do that because it's – it doesn't sound too expensive except for the flights, of course. And that would just be life-changing. (WA6 –male)

More flexibility and control required in spending the total package

People expressed frustration that they did not have flexibility in how they chose to spend their funds. They saw this constraint as overly restrictive and denying people the ability to make the choices that would be most valuable to them. Participants discussed the need to be able to spend a larger proportion of their funds flexibly, to have more choice in what to spend their funding on and the capacity to change their choices. They also discussed the need for a more simplified budget that has fewer constraints.

> I don't understand why there's so many divisions of the NDIS. The plan is divided into so many divisions. It just needs to be one as a whole. There's this for technology and this for therapies, and then the core support; it's not consistent with individual need. It needs to be given as a whole and say, 'Well, you can use this for everything and then that's how that works.' (Hunter1 –female)

> Yeah, if I was given an option of what's available and not just, 'Well, what do you want?' Well, let me know what I'm entitled to before I can tell you what I want – because nobody with mental health can give guaranteed information on what they want. Like, we want this, we want that – but it changes on a daily basis. (Hunter1 –female)

> More choice [required] … there's some sort of conception of psychosocial disability which doesn't allow a great deal of flexibility. I'm just saying that generally – I'm not saying that individual planners think that way or anything. Just saying that the system seems to have a one-size-fits-all response to things. (Hunter2 –male)

> I think that the current format doesn't suit that [provide choice and control]. Take out control and just more choice around how you spend that money. Yeah, just choice about how you spend it. (Hunter4 –female)

> The music guy I got at the moment took almost two months from the time I asked him if I could go there to him putting the application in, the NDIS sorting it out – to take some funds from one thing and putting it into there. Took nearly [two] months to change

over, and I thought 'That can't be right'. Well, I probably had all the money in certain things so they had to take the money from one other thing I was doing and give it to him – but that took nearly eight weeks to do. So, yeah, there must be a bureaucratic backup or something in there. It'd be good if that was a whole lot more efficient. (Hunter7 –male)

> [Other choices like to make?] Probably around the physical health. For me, it's a see-saw all the time with my physical health. Trying to maintain that level of wellness when I feel like I'm going to die, in a way, with all the pain and everything else. So, yeah, probably more around the physical health. So, like the things that were helping were, like, weekly remedial massage – because I've got the fibromyalgia and the chronic fatigue as well. And they don't see that as any part of the disability, of course. (WA2 –female)

> And the other side is that you just get presented with this framework of these are the providers to use. Which is difficult for me because I had some private providers that I've been supported by for ten years that I would have ideally liked to continue – because they were providing me with a service that was, I think, reasonable and necessary and working. But it didn't fit the framework. So, I wanted that service funded [a mainstream service that was supportive and in which she had established friendships] because it was an incredibly vital service from my own perspective as one of the things keeping me well. But what they would fund is me going with another service provider that's a mental illness agency of some sort or other that takes you on a bus on social excursions. And I couldn't understand the rationale for the difference. (WA3 –female)

> I think the most useful and most practical [to enable choice] is that out of the pot of money there's something that's called innovation or something else. And so, there is the flexibility for planners to actually provide services that don't fit within the round hole. (WA3 –female)

> That's what they [support workers] do. They do their three hours. That's it. So that's why I need longer times. Even if she took me to any kind of meetings – right? Like [unofficial peer support] going to take me to one on the 13th. It starts from half-past 8 and goes to 12:30 – right? She could change her times

around. But she won't. We'd have to leave half-way in between that session … So anything to get right with NDIS, you need more hours. (WA5 –female)

I need the flexibility … At the planning meeting – so we'll go back to there – I managed to get away with – having fairly open-ended goals. I didn't want to sit down and say, 'Okay, I will join four community groups and I will learn swing dancing.' I wanted – 'I just want to be actually able to enjoy life, to – I don't know – just to get better.' So what was put in place was the support work and the psychology. (WA8 –male)

The importance of having an advocate and supporting documentation from family, general practitioners and therapists

Having an advocate was seen as being most important to ensure that any engagement with the NDIA was successful, less stressful and more responsive for the individual.

I would advise everyone to go with someone. An advocate – someone who will speak up when you're being railroaded. (Hunter5 –female)

Well, it's a good thing [having an advocate] because sometimes I forget about a few things and they might bring something up and I say, 'Oh, that's right, I did that but I didn't know it at the time.' Stuff like that – you know? But it's good to have one, in my eyes anyway, especially with the way my mind is … I try not to make the wrong decisions – that's why I get my advocate in to give me something to think about. (Hunter6 –male)

She [caseworker] could also come with me into the NDIS review as well. So that makes me feel good because I've got her there – and if I forget something, she can remind me. I'd be happy to talk to her and to [my coordinator] about it. And the next review I would love for them to be there at the same time – that would be really good. Because that will make me feel supported and less like to have forgotten something important, yeah. (Hunter8 –female)

I did [attend original planning meeting alone], which is probably not – I think you need someone to come with you. (Barwon2 –female)

Having supporting statements and documentation from family, friends and professionals was also seen as a valuable advocacy strategy.

And this was actually done [planning/assessing with NDIA] with a lot more supporting material. My brother wrote a letter, my sister-in-law wrote a letter, my mother wrote a letter, my doctor, GP, psychiatrist and everybody else – psychologist – were all involved. So, there was much more support for me. (Hunter2 –male)

Self-efficacy – individuals knowing what is good/best for them, identifying clear goals and having the ability to change supports

People appeared to be more likely to achieve successful outcomes from the NDIS when they were clear in what they required and, with the support of advocates, were not just passive and reactive in dealing with the NDIA.

I think I was guided very largely by what they were willing to offer. But I had set the ground rules in so far as I had given my goals and so forth, so they tried to work in with those, I think. (Hunter2 –male)

When I went and applied for the NDIS, they asked me what I wanted and I said, 'Well, I really want [specific service provider], because that's important to me. And I really want Home Care because that's important to me as well – and also my caseworker.' So those are the things that I asked for. (Hunter8 –female)

So, the NDIS – when we have the meetings, we and our helpers, whoever it is, needs to be able to go, 'Right, this is what I want.' And they just have to write it down – because they don't really know how … We need to go, 'You need to write it down', and say, 'This is what I want.' (Barwon2 –female)

My NDIS plan – and I can say this unequivocally and I've said it to them – is a crisis plan. When I'm in crisis it provides me support services. Will that keep me out of hospital? Not necessarily. Will it make my crisis more comfortable? I hope so. It depends how safe I feel … If I don't do those emergencies, that will be a successful outcome from the plan. It's that crisis person ringing me up and just saying 'Are you okay?' Or dropping in is sufficient. (WA3 –female)

I was given choice in choosing this organisation. My support coordinator said, 'Okay, there are these five organisations, perhaps you should do some research.' And I did actually make, to the best of my capability within the scope of those organisations, a fairly informed choice. I met with, I think it was three representatives from three organisations, and made a choice to not go with two of them. I'd heard some negative feedback about one of the others – and I made a choice on that basis not to go with them. And so far, so good. (WA8 –male)

When I was going for my first interview with my local coordinator officer, I wrote my wish list down of what I would like, and I put them first – I put them ordered. So: cleaner fortnightly, episodic care when discharged from hospital – because when you get out of hospital, you're still not right; you're still crazy. And I'm very anxious just for at least – for ages, for about two or three months to settle back down … It was good because she said, 'You need to be very, very clear about what you want with the NDIS.' So, that's when I decided to make a list. (WA9 –female)

Resource information – list of clear options with cost attached and profiles of staff to choose from; getting information by direct face-to-face contact

People were often unclear about what was available to them through the NDIS. They noted a number of ways of improving this situation, and in doing so identified the need for clearer information about their options. Other suggested improvements included lists of what was available through the NDIS, and profiles of staff of support services that they were considering engaging with.

I'd love to see lists and stuff that we could have choices on and know what we're entitled to do – but nobody knows. So it's just playing it by ear. We're really in a category that NDIS don't know what to do with us … Know what our options are. Tell us what that money entitles us to. Let us know what's available and what's not available. (Hunter1 –female)

Just a greater awareness of what you can have. What difference it can make to your life. I don't think there's any sense of that and I've got very dull – what do you call it – requests – no, goals. (Hunter5 –female)

What could be improved? I think it'd be good for a person to be able to say, 'What is available?' And then have them – instead of the thing being on us, instead of being like, 'You need to tell us. Choose, blah-blah-blah.' But we don't know what to choose from. So, if the NDIS person said, 'Look, here's all the range of things we can help you with. Here are all the different range of suppliers. And tell me – 'Have a look at these, see what you think you might need.' That would have helped me out so much – if they'd done that before we did the first NDIS package. Because I was just like, 'I don't know what to choose. I have no idea what's going on.' And, yeah, they were lovely, but it would have been nice to have been aware of that there are other things that you can choose from … And it would have been better if there was some kind of clearer statement of what you can and cannot get through the NDIS … Like, some kind of structured list would be so much better than just sitting there with a blank look on your face, not knowing what to choose because you don't know what the choices are. Yeah, that would help a lot, it would help me a lot anyway. I like lists. (Hunter8 –female)

I had the idea support workers had a profile. Like, 'I've got three kids. I've done this work, that work. I enjoy doing this and that and the other.' So you didn't have to sit in front of this person … 'These are the ten support workers that have got available time that you've got allocated. They've got that flexible three-hour shifts that they can still fit in their roster.' And a picture of them, of course. (WA2 –female)

They didn't give me a choice or a list of who I can have. You know what I mean? That's what they should do. You know – give you a list … I reckon they should give you a list of who you can go through and what your choice – and then they should have up there whether they're peer workers or whatever. That would help. (WA5 –female)

More overall clarity required from the NDIA and improvements needed in being able to contact it

People spoke of the need for more overall clarity from the NDIA, stating that it was hard to get in contact with the Agency, and that the information that was available was often confusing and ambiguous.

> And, sure – it is confusing. If they maybe dumb it down a little bit for people who do have learning disabilities and mental health that don't really understand money and the figures – and stuff like that. (Hunter9 –male)

> Just easier contact would be great. Because you ring up, and you've got to ring an 1800 number which goes to Canberra or wherever it goes, and then they email Geelong for them to ring you. Which could be – I don't know when. You can go in there, but I went in there to do something and I had to make an appointment. So, I went in there and they just said, 'Yep, come back in two weeks.' But it would be nice if you could just walk in and say, 'Can I go and see Jeff, who's my coordinator' or whoever … Okay, well, why do we have to ring up? Because we can't actually ring the Geelong office, which is a bummer, because if you need something today – like something's not working out, well, then I have to wait … Easy access would be great – to be able to just ring up someone … and it would keep us on track as well. (Barwon2 –female)

> They need to make the information a bit more simple for a start. That's a certainty … And, like, some aspects of the NDIS not even the average Joe would be able to understand. (Hunter4 –male)

> Whoever is looking after your funding or your planner – actually needs to keep a bit more contact and be a bit more accessible. (Barwon4 –male)

> Planners are no longer with you for the duration of your plan. If you want to contact the NDIA, you come in the generic way and you speak to whoever is available is my understanding. I understand why that's done – so you don't get attached to a particular planner, you're not calling them and bothering them all the time. But if you were able to develop a relationship with one particular planner for the duration of your plan, your choices would be facilitated because you could discuss them with someone you were familiar with. (WA8 –male)

Support of peers

People found it empowering when they could engage with – and have the support of – their peers. Many felt that funding peer support would be valuable in assisting people in a manner that was enhancing both to their lives and their wellbeing.

> It's using peers. It's using in the early stages. But people should not go in [to planning meeting] alone. They should have peers. Are not peers who know what's best? (Hunter3 –female)

> That's why we all come in here [community based mental health service]. Even I've talked to the other – I won't say patients – but my mates. We sit down, we have a chat about things, what's going on in their lives and what's going on in my life. It's a pretty close community here and that's why I've stuck with this community. (Hunter6 –male)

> Coming here is very big for me [service provider]. Aspergers tend to isolate themselves. I find I'm very comfortable here because everybody else has got some level of mental illness and I fit right in … out there I don't. In here – I'm – we're a family. We'll have bad days, good days – and this place has been massive to help me come out of myself, become more social. (Hunter7 –male)

> So, the thing that has changed everything was peer support. When me and my husband split up … somebody said about going to [service provider] with my girls, because, as far as they were concerned, I didn't want to be here and I didn't love them and I was just acting badly. I had choice in that. So, I did a family-to-family program and one of the facilitators there was a peer that actually heard voices but was working – there was a lady that she must have worked with previously in one of the groups. She just talked outright to her and sort of gave her some guiding questions about her voices and what they were doing, and that she was safe regardless of what they were saying, and she belonged. That just opened my – blew my mind. Like, they can talk to her like that, yeah. So that was the start of everything … So that worked really well. (WA2 –female)

I'm a part of a peer community. It's all voluntary and it's all just people getting together, really. But the self-worth I get out of people seeing me as intelligent, wise, yeah, that's really good … But I really feel, like for me, the choice of and being able to choose and find peer support and having so much value out of that. Knowing I can go through the distress, it's like, 'It's a feeling, it can't hurt you.' Like, no doctor ever told me that. To value and hopefully being able to provide that choice to other people – to having a community of people that can help support you, and you can choose who you work with or who are your friends … Well, it's definitely the one thing that changed everything. (WA2 –female)

I'm doing this study to hopefully get paid as a peer worker. So, I'm hoping that eventually NDIS will put peer support on their list of support workers that can work with people with mental health issues and others as well – like mums that have got disabilities that look after kids … So, definitely, I'd like them to be able to provide peer support. (WA2 –female)

It's always a different [support worker] person. So, I don't feel safe there. I feel safe with [unofficial peer support person] because we're friends as well. You know what I mean? We've gone through a lot. She's helped me a lot. (WA5 –female)

Pre-planning – aid in identifying goals; support of service in accessing the NDIS

Not all respondents had undertaken pre-planning. There was recognition that when it occurred it was beneficial in assisting people to enhance the value of their planning meetings and ensuring a viable funding package.

Well, the best thing I did was actually come in here [support service] – this is where they done all my paperwork and all of that for the funding. And all of that come about was through just being here and listening to what was going on in the groups and that. (Hunter6 –male)

Yeah, because I spoke to a few people – what I can and can't have and what I have. But – and I know what I want. So, my goals are now as such, so I can sit there and say, 'Can I have …? or, 'I'd like this' or whatever. So, yeah, I've written down goals myself as well. (Barwon2 –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, 'This is what she needs' … those couple of pages was all it took. (Hunter1 –female)

Competent NDIA planners

People appreciated planners who had significant knowledge of the NDIS and wider services, as well as of psychosocial disability. Being empathetic and understanding were valued traits.

My planner was actually very good. She was very kind and very understanding. And when I said I had a household management issue, she understood exactly what that meant … Newcastle had been running for, like, a year-and-a-half of the trial zone by then. And I think this particular one, she – I can't even remember her name – but I think that she was quite gentle and relatively understanding, which made a big difference. (Hunter2 –male)

I think we went to the [NDIS] office and we sat down with a lady. And she just went over everything and said, 'This, this, that. And here's how you apply, and this is what you need to do.' So, lots of filling out forms and stuff like that. And they gave me a bit of help with the filling out of forms because sometimes I find forms difficult. But, yeah, so that was really – and they were really nice to me. I mean, I hear lots of stories – other people saying, 'Oh, my NDIS person's mean and blah-blah-blah.' I haven't had that – haven't had that experience at all. (Hunter8 –female)

She's good because she rang Mum the other day saying I can come back to a group – to do the individual support working. So, I don't know who my new handler [or] whatever you call them are. So … yeah. So, she listened and then she got to know the family and got to know me. (Hunter9 –male)

The girl [planner] was really good. Yeah, she probably wrote about ten pages – what I was just blurting out. Basically, I think that helped me get in as well – because I was talking like we are at the time. So, it was good. (Barwon2 –female)

Individual choice considered important (although this is often in collaboration with others, who may make choices on behalf of the person)

Overall, people valued having choice while recognising the need to collaborate with and be advised by those who can provide specific knowledge. Many stated that there were times when they needed to be supported to make choices, and even sometimes to have choices made for them. In part, this was because many people felt they had never enjoyed the right of exercising choice. What is important is that people are listened to and have their choices and preferences respected, even when they cede some control to those who support them.

> When they [support workers] sit me down and – they actually sit me down and had a straight-out talk with me when I do my plan – I've got the freedom of choice and they explain it to you. They don't talk down to you, they're just telling you straight, you know what I mean? They tell me what's going on and plan it. It gives me time to think, and I'll say 'Oh, I'll think about this idea.' They go, 'No, that's not a good idea and I'll tell you why.' That's what they're like – with me, anyway. I don't know about other people. The support workers are pretty good, you know what I mean? ... But, like I said, I've got to take things pretty slowly because it takes a lot to get into my head to figure things out, but I'll go with that. They do help me out in more ways than one. Like I said, I never thought about it at the time, but now when I start thinking back my life's got a lot better than what it was. Because where I was going wasn't a very happy road to take … And they'll sit me down sometime, whenever, and they'll tell me what's going on. (Hunter6 –male)

> I'm really happy for [coordinator] to be in charge of all of that – because like I have a hard-enough time dealing with my own personal grocery budgeting. Because every fortnight I do my budget and, like, blah-blah-blah. And if I had to do that with the NDIS stuff as well – I think that would be too overwhelming. And, yeah, it's hard enough to budget for household things than to calculate the budgeting for the NDIS. I think I will just let [coordinator] do that. (Hunter8 –female)

> I'm happy that it's managed by somebody else because it's too much information for my brain to handle and I get confused. (Hunter9 –male)

> It's really important to have choice, but in some cases you just want to be told what to do. (Hunter1 –female)

Review and appeal processes to be quicker and easier, with certainty regarding future funding

Many people identified this as a significant concern, and hence a barrier to choice and a cause of significant anxiety about the future. Some specifically cited it as an area for improvement that would give people more certainty.

> Yes [more certainty about ongoing funding] – and not have to worry that it's going to run out or you're going to be cancelled. Because that is the thing that worries me a lot about the NDIS – is that the funding is going to be cut and then I'll be stuffed. Yeah – and I don't want that to happen. (Hunter8 – female)

> My friend who had planning – he lost his funding this year. And not even half-way through the year – and I'm thinking, 'How the heck do you go from having money, then one day you get up and go to your group – we can't go to group, or you can't have one-on-one support, or you can't do this, or you can't do this' … To have a routine changed automatically under him … (Hunter9 –male)

> And that's not good to cope with when you're changing routine. Especially with autism and things like that. They just have meltdowns and then you have behaviours. (Support worker for Hunter9)

> [Reviews to be] a lot more quicker and easier, yeah. [If funding was cut?] Well, that would mean things would be restricted a lot more. Yeah, that wouldn't be good. (Barwon4 –male)

Planning process – all interviews to be face-to-face, with questions that are relevant to the person's life

Some people suggested improvements to the planning process. Their suggestions highlighted a need for all interviews and planning to be face-to-face and for questions to be relevant to the individual applicant's life.

> I didn't get any choice over the planner, though I think if I'd gone a different route I would have – because I know through [support service], for example, that they have individual planners. And I know through other organisations they have individual planners. So, I guess if I'd gone to the support organisation first I would have been choosing a planner. (WA3 –female)

> 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. (Hunter5 –female)

Discussion

Two key principles of the NDIS are choice and control. Its participants' understanding of choice, and the issues associated with exercising it, are the focus of this research. If choice is regarded as central to the NDIS, attention must be paid to ensuring people have the opportunity and capacity to maximise their choice-making capacity under the Scheme. This research identifies that doing so is complex, especially for people with a psychosocial disability.

Choice was considered to be essential by the participants in this research. They regarded it as central to providing their ability to voice what was important to them, their sense of self, their autonomy and their right to make decisions in their lives. They considered it to be vital to their physical and mental health. They also saw choice as being key to their being part of a community to which they could contribute. Human rights advocates and conventions such as the CRPD emphasise the right to choice for people with disability, and this attitude is understood to be positive and important in disability policy. However, choice is also a central discourse and policy driver in free-market economies, and this is more problematic for people with disability. The design of individualised funding programs such as the NDIS is premised on the assumption that the market is functioning at an optimum level offering high-quality and relevant goods and services. In this context, emphasis on individual choice, on being able to exercise one's right as a consumer, is to be an active citizen of society. The experiences of participants in this study identify that the market is not necessarily conducive to them enacting choice, nor does it always meet their needs. Indeed, participants are required to enact choice in a poorly functioning system that, together with ongoing issues related to mental illness, acts to constrain and deny choice and negatively affect outcomes.

Choice is also not an automatically positive, or even neutral, experience and is affected by a variety of factors both personal and within the social and policy contexts. Many participants' history of choice-making is fraught, leaving a legacy that affects their ability to engage in choice-making of any kind. Many discuss the impact of psychosocial disability on choice-making, and its variable impact at different stages of the individualised funding life cycle, in different contexts and at different points in the recovery journey. Previous research has indicated that factors such as 'age, gender, socioeconomic status, residential location and household structure' can restrict potential for choice and control for people with disability (Warr et al., 2017: 31). Significantly, many participants discussed individual circumstances that highlighted how personal trauma such as mental and physical abuse had a long-lasting and profound impact on their ability to make choices for themselves. This was often compounded by financial hardship and lack of sufficient resources – including inadequate support services – that left people disempowered. Our research reveals that a raft of elements – personal, interpersonal, organisational and systemic – can make choice-making difficult.

Within the context of the NDIS, factors that affect people's choice-making capacity are: the application process; the planning process; the amount of funding; the things that will and will not be funded; the skills, knowledge and personal characteristics of planning/NDIA personnel; the accessibility of planning/NDIA personnel; review processes; and uncertainty regarding future funding. Equally, the quality of support services, including coordinators, support staff and the variety of services available, will have a significant impact on how NDIS recipients exercise choice. The extent to which people with psychosocial disability are able to go beyond the limitations of disability/mental health support services and access mainstream services that meet their needs will also affect their choice-making experience. Choice-making is therefore not easy to undertake and is reliant on a number of factors that need to be considered when evaluating and understanding how the NDIS can best enhance people's experience of doing so.

Consideration also needs to be given to the manner in which the NDIS can support recovery for people with psychosocial disability. It is critical that recovery is seen as being fundamentally allied to psychosocial disability. Many participants

discussed the way in which individual funding was vital to their recovery journey, and the need for planners and services to support them through the provision of services that assist them in recovery. In 2011, the Productivity Commission recommended that people with psychosocial disability should be supported through the NDIS. However, the Productivity Commission's study into costs (2017) recognised that there are concerns from various stakeholders about the need for disability permanency under the NDIS Act being incompatible with recovery models. The Commission claims, however, that the investment approach of the NDIS is well aligned with the recovery model of mental health and that the NDIS Rules and Operational Guidelines 'accept that a permanent condition may be episodic requiring different levels of support at different times' (Productivity Commission, 2017: 23). Individual funding could potentially enable people to exert more choice and control in achieving their aspirations – effectively taking a strengths-based approach rather than approaches that seek to focus on managing people's deficits or illnesses (Tew et al., 2015). Any consideration of enhancing choice under the NDIS needs to consider the importance of the recovery approach and the ways in which all aspects of NDIS processes and individual funding must be in line with it. This also means providing funding and support arrangements that allow for contingencies such as mental distress and other forms of crisis.

Choice across the life cycle of individualised funding involves different sets of tasks, including among others: seeking information; applying; being assessed; justifying; representing; explaining; organising; selecting; contracting; liaising; coordinating; managing; supervising; correcting mistakes; appealing. Each of these tasks can be associated with specific competencies such as a person's knowledge, skills and personal attributes. These will vary for each individual. Participants reported that choice comes at a significant price, bearing in mind the labour involved at all stages. This extends well beyond the planning moment to include implementing the package of funds. It then includes selecting services and staff,

which, alongside funds, have to be managed, and preparing for and participating in reviews and appeals. Participants also identified an associated emotional effort that can be detrimental to people across the NDIS process. Not all participants want to undertake this labour at all stages of the NDIS life cycle, and the majority indicate a desire for support in this process. Choice in itself is not a panacea to all problems; however, when the NDIS works well for people and they have sufficient support to enable them to enact choice, the Scheme can enhance people's lives and contribute to their wellbeing.

The research indicates that for people with psychosocial disability there are many barriers to choice to be overcome. This set of barriers becomes the context in which they are required to undertake the labour of choice. The barriers correspond with the concerns identified in mental health and individual funding schemes in other countries, particularly the United Kingdom, and in the limited research on the NDIS to date (Mavromaras, K., Moskos, M. and Mahuteau, S., 2016; Warr et al., 2017; Productivity Commission, 2017). The barriers to choice identified by participants have been outlined in the body of the report and will not be reiterated here. What is worth outlining here are the issues to be dealt with in order for the NDIS to enhance the choice-making capacities of people with psychosocial disability. This means addressing the barriers to choice and enhancing the enablers that participants have identified. Significantly, key enablers included: the skills and qualities of personnel, including support workers and coordinators; flexibility of funding, including specific funding for things such as education, employment, transport, exercise, psychology and holiday/respite. More flexibility and control in spending the total package required was a key enabler. Having an advocate and supporting documentation was considered vital in accessing the NDIS. In brief:

• An NDIS application process that is not arduous and that minimises delays at all of its stages is needed. This requires clear and ongoing communication between the NDIA

and the applicant. The applicant should have access to a person that is allocated to them to provide a more personal and less bureaucratic process. To this end, the Productivity Commission (2017) has recommended a 'Psychosocial Disability Gateway' involving specialised staff to improve the way the Scheme engages with psychosocial disability. Work has since been undertaken by the NDIA in conjunction with Mental Health Australia (MHA) to improve the experience and outcomes of participants with psychosocial disability. Improvements are primarily focused on the launch of a new 'tailored stream', which recognises the episodic nature of psychosocial disability and embeds a recovery-based approach. The aim of the tailored stream is 'to make access criteria for those with psychosocial disability clearer, ensure individuals are connected with other services, and have flexible arrangements incorporated into their plan' (Council of Australian Governments, 2018: 28).

- All planning processes are to be undertaken face-to-face by staff who communicate clearly, listen to the applicant and work with them collaboratively to devise a plan that addresses their needs. Applicants are to be encouraged to have an advocate with them throughout the planning process (it must also be recognised that it is their right to engage with the NDIA alone). The Productivity Commission acknowledges that 'the quality of planning processes is a key determinant of the success and long-term sustainability of the NDIS' (Productivity Commission, 2017: 25) and that face-to-face planning should be the default approach.

- There should be very clear guidelines on what will be funded – they are currently opaque at best – and these guidelines must be available to applicants. Participants uniformly requested a clear set of guidelines about available options and where the limits are. This will determine whether people's choice is limited to everyday choices or can incorporate more pervasive choices such as those relating

to work and education (Ramcharan, 2012), which can assist in recovery and a sense of meaning and purpose. Throughout the whole NDIS life cycle, there needs to be increased clarity and resourcing about what choices are available, such as those regarding service providers, service types, support coordination, fund management and staff selection. This is recognised by the Productivity Commission: 'Providing timely, accessible and useful information to participants about providers will help people with disability access their NDIS supports, and better exercise choice and control' (2017: 39). There also needs to be more flexibility about how people spend their money to enable more choice in meeting their needs. The lack of flexibility meant that people could not spend their funding on things they considered important – even critical – to their wellbeing. This may mean there is, at times, a tension between what the NDIS will fund and what people would like to spend their funding on. This is felt to be a significant limitation on both meaningful choice and life outcomes of participants. What is most essential is that the NDIS addresses people's needs and goals as identified by them (possibly with the assistance of advocates) with a whole-of-life approach rather than a limiting 'one size fits all' arrangement. While it is acknowledged that some limits need to be set on items/goals eligible for funding, at present the logic of what is 'ordinarily' a responsibility of citizens to self-fund is inconsistent with the financial capacity of many participants with psychosocial disability to do. Equally, limitations around funding activities that are the responsibility of other service jurisdictions, such as health, rely on participants having access to these systems. Both limitations incorrectly imagine an ideal state of adequate personal finances and mainstream service access. As a result, participants miss out on necessary supports that greatly affect their outcomes, as well as the effectiveness of the NDIS.

- Planners/NDIA staff must be trained to understand psychosocial disability. Staff should have good communication skills that

encompass listening, understanding and talking to people with clarity and respect. Empathy and upholding the dignity of people with psychosocial disability must be utmost at all times. Efforts must be made to ensure the ongoing employment of staff to enable more certainty for NDIS recipients. NDIA staff and planners working with/for and supporting people with psychosocial disability need to understand the psychological and emotional burden that may accompany people on a daily basis. They must also understand the impact this may have on people's lives. Such understanding includes recognising that people have often experienced trauma, or are indeed experiencing it currently (they may choose not to reveal this) and may have had a lifetime of financial hardship and lack of the resources necessary to support their wellbeing. This requires the recognition that people's levels of distress and capability vary over time, and that the NDIA and supports need to be flexible in assisting people to manage during periods of crisis, including flexibility in the use of their funding during such times.

- The review process needs to be straightforward and function without major delays. NDIS participants require more certainty about their ongoing funding and the knowledge that future supports will continue to be available if required. The uncertainty over future funding creates anxiety for people and is detrimental to choice in their lives.

- Finally, choice can only be enhanced when the services available and the support staff provided have the flexibility and the capacity to meet the needs of people with psychosocial disability. This requires ensuring that available services do not simply continue with a standardised approach (for which they have been criticised) but that consideration is given to ensuring that they meet a diversity of needs across a diversity of locations. While the Harper Review (2015) suggests that individualised funding leads to services becoming more relevant as they respond to demand, this fails to take into consideration the difficulties

people with psychosocial disability have in advocating for their needs and holding services to account. At the interpersonal level (as with planning/NDIA staff), meeting the needs of people with psychosocial disability requires personal qualities that ensure empathy and understanding. These qualities must also ensure that the person being supported can have confidence in, and certainty of, the person supporting them. People need to be supported as required by trusted and reliable people – as determined by the NDIS participant – to assist in day-to-day decisions. Peers have a unique role to play here: 'their personal experiences may be valuable in giving people permission to have their own aspirations and in suggesting ways in which personal budgets could be employed to support personal and social recovery' (Tew et al., 2015: 84).

The above discussion points have been outlined broadly and are not exhaustive. How they would be implemented requires further attention, however, the outline here provides a basis for consideration in further enhancing choice for NDIS participants.

Conclusion

Choice and control are key – yet somewhat vaguely defined – principles of the NDIS. This research has sought to consider the issues that participants face in exercising choice, including how they define it and the value they place upon it. If choice is to be successfully exercised by participants in the NDIS, a range of issues needs to be addressed throughout all stages of the NDIS process – from application (including pre-planning) to accessing supports and ongoing engagement with the NDIA and support services. Importantly, processes must be clear and smooth, with staff available to support people throughout their NDIS application and beyond. Most vital is that the quality of people who support them – whether in the NDIA, support services or the wider community – is integral to exercising choice and ensuring that activities are undertaken successfully.

Addressing the issues identified in this study is not straightforward and there is no prescriptive way for doing so. However, drawing on the experiences and understanding of people with psychosocial disability provides insight into issues relating to choice under the NDIS and serves as a guide to commencing the work to be done to maximise people's choice-making potential.

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Appendix 1: Literature: The experience of people with psychosocial disability / mental illness as choice-makers in individualised funding contexts

Author, date, title	Purpose/aim	Method	Findings	Recommendations/themes	Quotes/notes
Brophy et al. (2014) 'People making choices: The support needs and preferences of people with psychosocial disability'	To establish which supports people with psychosocial disability require for a good life, how to allocate funding and whom to rely on to help with decisions and choice.	Forty-one people with a psychosocial disability who met NDIS eligibility requirements – select top five life goals, allocate resources (hypothetical funding).	Top five life goals: 1. health 2. economic security 3. social connection 4. housing 5. personal life (intimate relationships).	• Can make rational choice re: life goals; open to purchasing support and advice but wanted choice and assistance to navigate system • Support, relationships and social connection vital; providers to address range of challenges in innovative ways • Access to information vital re: systems, especially health and welfare.	People saw choice of provider as important.
Coyle (2011) 'Impact of person-centred thinking and personal budgets in mental health services: reporting a UK pilot'	Pilot of Individual Recovery Budgets in 2007 using PCA. Evaluation considered individuals' experience of using personal budgets.	Uses narrative approach (progressive, regressive – seven recipients and staff focus groups (early intervention teams)).	• Perception that 'recovery budgets were doing something that could not have happened by other means' (p799) • Often unanticipated outcomes, with outcomes chosen by individuals having a greater effect than those chosen by staff (no detailed listing of outcomes other than items bought, especially sport, computers, gym) • Staff – support planning helpful in richer assessment of person and what is important to them • Staff recognised modesty of requests.	• Challenge is for staff to see SDS and DPs as a right rather than a gift • Staff need to embrace flexibility and individual response other than 'one size fits all'.	'A key feature of the IRB was a perception that the recovery budgets were doing something that could not have happened by other means…It might be that some of the outcomes observed through the narratives may have been achieved by other means and over time regardless of the IRB. However, for the participants, the fact that the budgets were there and accessible at the time they felt most needed them meant change occurred' (p799).

Author, date, title	Purpose/aim	Method	Findings	Recommendations/themes	Quotes/notes
Glendinning et al. (2008) 'Evaluation of the Individual Budgets Pilot Programme' (adult social care including mental health) Also see Manthorpe et al. (2008) 'Individual budget projects come under the microscope', (an outline of conclusions for the above project)	Evaluation to examine merits of individual budgets (IBs). Covered 13 IB pilot sites for adult social care 2005-7.	Uses 130 in-depth interviews to explore first experiences of new processes as well as variety of staff responsible for BPs. (Only 14% were using mental health services.)	• Mental health group more likely to view their budget as higher than previous support • After personal support, leisure most popular (66% of MH users) • MH service user reported higher quality of life than other user groups – 'saw an IB as an opportunity to access more appropriate support' than previous conventional arrangements • Better overall social outcomes • Complexity of paperwork, agreeing support plan, changes to level of budget during planning process • Staff – struggling to decide acceptable levels of risk and how manage • Difficulties in distinguishing between health and social care needs • Those with learning difficulties found IB processes stressful but 'had more social care resources allocated to leisure or social participation than any user groups, leading to greater well-being overall' (43).		'The evaluation suggests that IBs offered a greater range of flexibility of support arrangements than are available for this group from standard services' (p43).

Author, date, title	Purpose/aim	Method	Findings	Recommendations/themes	Quotes/notes
Griffiths (2013) 'Personalisation: Direct Payments and Mental Illness'	To investigate self-reported barriers, facilitators, problems and successes, and provide recommendations.	Nine carers and 12 people who experience mental illness (seven who have not been able to access DPs).	• Motivation to apply: widen social networks and interests; knowledge of DPs; dissatisfaction with existing care and services • Success factors: supportive and proactive carer; level of self-confidence; social care professionals • Barriers: biased and uninformed professional staff; lack of knowledge about DPs • Benefits: social life; standard of living; improved health • Issues: stressful process; disappointment resulting from rejection of application; challenges to managing DP and PA; complex appeals process.	• Among many: simplify application process; ensure security of DP funding for individuals; provide high level of information to applicants.	Confirmed advantages of having the power to choose and manage a PA. 'Direct payments were reported as having the potential to benefit the mental health of the person receiving them, as well as that of their carer, nevertheless the six month reassessment process was reported as being damaging to mental health' (no page number available – web source).
Hamilton et al. (2016) 'Power, Choice and Control: How Do Personal Budgets Affect the Experiences of People with Mental Health Problems and Their Relationships with Social Workers and Other Practitioners?'	To identify issues linked to experiences of power, choice and control in the process of accessing, arranging and using a PB.	Interviews with 52 service users and 28 MH practitioners across three sites in England.	• Majority of service users talked of being grateful to receive a PB rather than feeling entitled • Some professionals concerned about individuals' lack of capacity • Responsibility for managing PB could increase sense of control and power • Most practitioners recognised choice and control but prepared to use authority and override individual • Lack of clarity with staff about how funding decisions made • Local authority managers have ultimate decision.	• 'We found evidence that some service users were able to take control over their budgets and, in those situations, personal budgets did offer people with mental health difficulties a genuine experience of choice and empowerment. In some instances, this gave people more control over personal support and daily living, but, for others, the personal budget offered routes to recovery through further education or self-employment' (p14) • Evidence that meaningful choice compromised by pressure on workloads and bureaucracy – avoid offering PBs or take over decision-making process (p15).	The process of exercising choice through a PB may be important in itself in terms of contributing to a recovery 'mindset' – reclaiming control ...' (p4). 'With local authorities facing very rapid cuts in funding, policies and procedures governing implementation need to be frequently revised, so approaches to practice have little chance to bed down' (p14).

Author, date, title	Purpose/aim	Method	Findings	Recommendations/themes	Quotes/notes
Hamilton et al. (2017) 'The role of family carers in the use of personal budgets by people with mental health problems' (its focus is negotiating budgets)	To explore experiences of family involvement in accessing and managing PBs.	Interviews with 18 family carers and 12 MH service users.	• All carers having active role in managing a PB were also providing other ongoing support and care • Common belief was that a PB would never have been offered without the carer • Carers commonly involved in decisions and planning – saw their role partly as protecting the service user from decisions not made in their best interest • Reviews not being used to make best decisions but to reduce the amount given • Perception from both service users and carers that they could not manage a PB by themselves.	• Carers take on crucial role in 'fighting', especially when LAs seeming to be trying to save money • Can assist in increasing support levels • 'Carers make it possible for people to receive DPs where otherwise the service user is considered likely to struggle with managing and monitoring money' (p7).	'Carers can play a number of important roles to enable most effective use of personal budgets; however, they often found the process of negotiating budgets with practitioners and agencies to be adversarial rather than collaborative – with processes and procedures seeming unnecessarily obstructive and unresponsive' (p8). 'A powerful theme to emerge from carers' accounts was their experience of having to 'fight' both practitioners and the agencies for which they worked in order to secure an appropriate budget for their family member against an agenda that seemed to be dominated by an imperative to save money, rather than supporting the service user in achieving outcomes that were meaningful to them' (p7).
Larsen et al. (2013) 'Implementing personalisation for people with mental health problems: A comparative case study of four local authorities in England'	'Research is lacking about PBs for people who have severe, enduring and fluctuating mental health problems' – aims to understand factors influencing the introduction and take-up of PBs by people with MH.	Study of four Local Authorities – interviews with 58 staff and range of stakeholders, including local service providers.	• Two key themes: 1. responsibility and power – lack of clarity for staff re: decision making 2. vision and leadership – clashing values and need for effective, knowledgeable leadership (varied).	• Managers need to give voice to its [personalisation] values and find ways for staff to own 'change'.	'…the difficulty of joining up LA means tested services and free NHS services. It remains to be seen whether personal health budgets offer opportunities for health and social care to integrate personalised funding' (p180).

Author, date, title	Purpose/aim	Method	Findings	Recommendations/themes	Quotes/notes
Larsen et al. (2015) 'Outcomes from personal budgets in mental health: service users' experiences in three English local authorities'	To identify positive and negative outcomes attributable to PB.	Semi-structured interviews – 47 people (over 12 months) receiving a personal budget due to social care support needs linked to mental health problems.	• PBs = positive outcomes related to recovery (mental health and wellbeing, confidence and skills, physical health, self-management and coping strategies, social participation, education and employment, family and friends) • Negative = stress of applying for and managing PB.	• 'Only a minority of participants described outcomes in terms of greater control over their daily lives and support arrangements, or enhanced ability to self-manage their mental health problems. Indeed, for some participants the demands placed upon them in this regard could be stressful and adversely affect their mental health' (p224).	Confirmed advantages of having the power to choose and manage a PA. 'Direct payments were reported as having the potential to benefit the mental health of the person receiving them, as well as that of their carer, nevertheless the six month reassessment process was reported as being damaging to mental health' (no page number available – web source).
Ridley & Jones (2002) '"Direct what" – A study of direct payments to mental health service users' 'Ridley & Jones (2003) Direct what? The Untapped Potential of Direct Payments to Mental Health Service Users'	To explore the obstacles facing, and support needed by, mental health service users in relation to receiving DPs.	Six-month study – interviews with range of stakeholders, including nine mental health service users.	• Little progress in implementing DPs over past two years – little awareness, even among managers • The anticipated benefits were that DPS might mean greater say over the support and life they choose • Perceived disadvantages were having to manage payments and finances, especially during worsening mental health difficulties (unaware of managing options) • Main barriers: lack of knowledge about DPs; uncertainty about eligibility; ability to manage finances and PAs.	• More information and publicity (including eligibility) required • Need for contingency planning and planning for the future • Easier procedures and management of payments required.	

Author, date, title	Purpose/aim	Method	Findings	Recommendations/themes	Quotes/notes
Ridley et al. (2011) 'Evaluation of Self-Directed Support Test Sites in Scotland' ('SDS' = umbrella term encompassing many concepts and practices, including DPs)	Three local authorities as test sites – aims to assess the development and impact of interventions to improve uptake of SDS (self-directed support).	Interviews with range of stakeholders, including 30 service users.	• Those with mental health problems less likely to access DPs • SDS had expanded choice and control for the vast majority interviewed (across range of adult services). Unsure if this is due to model of SDS or greater levels of funding during the test sites.	• Identify local authority barriers to DPs • Increasing knowledge • Review of eligibility and funding criteria.	'While the early evidence base shows that those in receipt of DPs generally consider the benefits far outweigh the challenges, implementation has been slow in Scotland' (p4). 'SDS had expanded choice and control for the vast majority we interviewed. More flexible support was being offered under SDS than had been the case even with past DPs, which were often linked to purchasing specific activities or inputs rather than outcomes' (p7).
Spandler & Vick (2006) 'Opportunities for independent living using direct payments in mental health'	National pilot project (2001) to promote independent living through DPs for people experiencing mental distress (five local authorities). Mid-way evaluation of experience of accessing and receiving DPs.	Twenty-seven interviews with DP recipients who took up option during pilot.	• Use of DPs diverse – approximately half purchasing PAs, education, leisure • Packages rarely included additional costs for admin and contingencies • Self-referral rarely successful • Barriers – take-up slow due to low level of knowledge and awareness; attitudinal and practical barriers • However, recipients identified significant benefits, especially choice and control, autonomy, social, cultural and physical activities, self-worth.	• DPs offer choice and control • Restrictive eligibility criteria may limit access • Many mental health professionals yet to grasp principles of DPs • Services often purchased through DP based on 'services' rather than 'needs' – local authorities 'operated limiting criteria concerning what DPs could not be used for and decided in advance how they could be used' (p112) • More accessible contingency funding – 'It may be necessary to provide for a greater level of flexibility in payments to allow for self-directed support during crises' (p112) • '"Control and choice" are not all or nothing fixed points but rather a process' – professionals need to relinquish control, with support for users to take control – training, planning.	Debate over what constitutes community care or mental health needs: 'In mental health, the boundary between health or medical and social needs is perhaps even more complex and contested' (p112). 'Some recipients reported difficulties arising in actually making decisions, especially if there were constraints and pressures limiting their ability to make choices' (p113). 'Many mental health service users may feel that their capacity for exercising choice and control has been undermined by their experience of mental distress and long-term use of mental health services. This means that the benefits of direct payments and independent living may take some time to realise' (p113) – control and choice not all-or-nothing fixed points but a process.

Author, date, title	Purpose/aim	Method	Findings	Recommendations/themes	Quotes/notes
Tew et al. (2015) '"And the Stuff that I'm Able to Achieve Now is Really Amazing": The Potential of Personal Budgets as a Mechanism for Supporting Recovery in Mental Health'	Paper to develop an 'Ideal-type' model [PB model] as a mechanism to promote recovery.	Reviews existing research and interviews with 52 service users and 28 MH practitioners across three sites in England.	• Peer support for assessment and planning processes • DPs but contingency arrangements for times of distress • Planning based on supported change and what required for the journey (building up recovery capital).	• Study has provided some initial validation of this ideal type • PBs may need to be constructed to take account of potential variability of people's distress and capability.	'Overall, the evidence from this national study suggests that personal budgets can and do provide a valuable mechanism through which to enable the process of social recovery for people with serious MH difficulties – although not in all instances.'
Webber et al. (2014) 'The effectiveness of personal budgets for people with mental health problems: a systematic review'	Systematic literature review of empirical data/research re: PBs and outcomes.	Reviews all pubs up until 2013 – 15 studies (UK and USA).	• Identified and synthesised four outcome domains: 1. mixed results, with some feelings of uncertainty 2. impact on life – improved quality of overall 3. decrease in community health service use 4. only two cost-effectiveness analyses (divided).		'It has found generally positive outcomes for mental health service users in terms of choice and control, impact on quality of life, service use, and cost-effectiveness' 2014, p153) Findings insufficient to inform policy and practice – methodological limitations.

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Appendix 2: Interview discussion guide

Demographic questions

- age
- gender
- location
- mental health diagnosis (plus any other impairing condition/disability)
- extent of support needs
- size of funding package and types of things it is spent on
- number of plans/reviews
- funds management arrangements
- Guardianship/administration arrangement, if any
- living arrangements (with parents/own family/ alone/shared accomm.)
- Community Treatment Order, if any.

Question discussion guide to choice

1. What does it mean to you to have choice?
   a. Is it important to have a choice? In what areas?

2. Do you have choice (as much as you would like)? In what way?
   a. How does it play out in your life?
   b. What choices do you make?
   c. Are there other choices you would like to make?

3. Tell me about the choices you have in the NDIS. (Prompt: What does choice mean to you in relation to your funding/planning or in dealing with the NDIA?)
   a. What is different to before? What's it like for you now? (What's the process like?)
   b. Are you getting what you need from the NDIS/in your plan? (Prompts: The amount of funding, what gets funded, how you get to spend it?)
   c. Is there anything in your plan that you don't need?
   d. Have you got enough money in your plan?
   e. Do you get to spend it on what you want?
   f. Are there other choices you would like to make?
   g. (For people with multiple plans) Have things changed in how you make choices from when you first came into the NDIS?

4. How do you know what to choose (in planning, in spending)?
   a. Is it hard to make choices?
   b. How do you make choices?
   c. What helps you make choices? (Prompt: Are there particular things you need to know?)

5. Who helps you make choices?
   a. How do they help?
   b. What choices do they make for/with you?
   c. What are the other enablers or things that help you make choices?

6. What gets in the way of you being able to make the choices you want? (What are the barriers?)
   a. Other people
   b. Lack of information
   c. Fear/risk/past experience or lack of it
   d. Other.

7. Do you get to choose the people who support you? (Prompts: Planners, support worker/support coordinator, service providers)
   a. Is this important to you? (In what way?)
   b. Are you confident in changing any of these if you wanted to? (Prompt: Including if you need more support because your mental health changes).

8. Given all that you have told me about choice – what are your dreams? Are these different from before you got your own funding from the NDIS? Has having more choice made your life better? (Prompt: How do you think the NDIS will help you achieve your dreams? What do you need to bring these to life?)

9. What needs to happen or change so that you can make the choices you want?
   a. What would help you make choices?

10. Is there anything further you would like to say?