

# 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

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





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