WILEY

Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals

Gemma Carey | **Eleanor Malbon** | **James Blackwell**

Centre for Social Impact, University of New South Wales, Sydney, New South Wales, Australia

Correspondence
Gemma Carey, Centre for Social Impact, University of New South Wales, Sydney NSW 2052, Australia.
Email: gemma.carey@unsw.edu.au

Abstract

Over the last 30 years, governments have sought to give citizens greater choice and control of the public services they utilise. As a result, we have seen the creation of various forms of public sector markets, including through contracting and tendering processes and, more recently, by utilising individualised or 'personalised' care budgets. Under the latter, individuals are given money to purchase services that meet their needs. There is growing evidence that personalisation schemes may actually be entrenching administrative burden, due to their unprecedented emphasis on individual skills and advocacy. Moreover, reviews internationally have found that such schemes tend to be administratively complex. This paper uses a systematic review of existing research to explore experiences of administrative burden within the National Disability Insurance Scheme (NDIS). We found that the scheme is administratively cumbersome overall, and that burdens are exacerbated for particular social groups. We apply concepts of habitus and capital from Bourdieu to theorise why burdens are experienced differently by different groups, and how to address this in practice. In doing so, we can see that addressing exclusion within the NDIS requires us to move away from problematising individuals to including those individu-

als in different stages of the design and implementation of administrative systems.

KEYWORDS
administrative burden, disability, inequality and administrative systems, personalisation, policy implementation

1 | INTRODUCTION

The Australian National Disability Insurance Scheme (NDIS) is part of an international trend towards what is called 'personalisation' in social and healthcare services (Needham & Dickinson, 2018). Personalisation sees citizens playing a more active role in goal setting, while creating 'bespoke' services that better meet their needs through the use of individual budgets (Carey et al., 2018). Here, individuals are given budgets or vouchers by governments, and purchase services they need from quasi-markets: boosting choice, and driving innovation in service design through market supply and demand mechanisms (Carey, Dickinson, et al., 2020). Personalisation has been driven by two agendas: efficiency in government services and spending, and the human rights agenda with regard to people with disability (Carey, Dickinson, et al., 2020; Needham & Dickinson, 2018). Both emphasise service recipients as active agents at the centre of their own care. For government efficiencies, this emphasis comes from the market model and draws on logics of individualism which sit at the heart of neoliberal agendas. In human rights, this is driven by beliefs about the rights of individuals to exercise choice and control over their lives – including what assistances and services they utilise. Previous research has argued that there are considerable tensions between these twin drivers, which flow throw the design and administrative systems of these schemes (Carey, Dickinson, et al., 2020). For example, striving for government efficiency in service delivery does not necessarily fulfil the human rights objects of allowing citizens to be active participants in care processes – true participatory processes and supported choice can be costly (Glendinning et al., 2011). Additionally, a human rights approach sees service organisations play a supportive role in choice of services, whereas a marketised logic produces more transactional approaches (Carey, Dickinson, et al., 2020). Current research indicates that the NDIS is presently a hybrid model, with contestation over what role governments and service providers should play in supporting 'choice', versus a purely market approach (which would see participants negotiate complex administrative processes without much support) (Carey, Dickinson, et al., 2020). Although previous research has looked at the impact of this tension on the disability provider sector, this paper focuses on experiences of participants in negotiating the administrative systems of the NDIS (the complexity of which is further compounded by the aforementioned tensions).

In this paper, we provide a systematic review of the evidence on users' experiences of navigating the administrative systems of the NDIS, with a focus on the construction of administrative burdens. We draw on the approach to understanding administrative burden provided by Herd and Moynihan (2019), whereby administrative burdens and their uneven distribution across populations are not mere accidents but rather a form of 'policy making by other means', which are used to include and exclude particular social groups. In our review, we find that individuals need considerable skills and networks to successfully negotiate the scheme's complex administrative processes. These skills and networks are not equally distributed across the population, meaning

Key points

- Increased choice and control has been a growing priority for governments regarding social and health care services.
- In many countries, this has led to the creation of various forms of individualised and personalised systems, which rely on markets.
- These systems are being found to be administratively complex.
- This article outlines how personalisation systems are more complex for particular cohorts.
- It uses administrative burden theory, extended by notions of habitus, to examine how personalisation systems are calibrated to middle class norms and thereby can entrench or widen social inequalities.

that some groups are either entirely excluded from the NDIS or are able to derive less benefit from the scheme than others. We also find that for already marginalised groups, basic requirements of accessibility are not being met. Using these empirical findings, we expand upon theorising the relationships between administrative burdens and individual experiences in the context of personalisation policies. We suggest that although personalised budgets have in part been driven by human rights agendas (which in theory should see efforts to ensure equitable access and outcomes), the competing neoliberal market logics embedded in such programs assume a degree of agency regarding market actors which is not shared by all groups, leaving some excluded or experiencing more cumbersome burdens.

In order to expound on why some groups experience more administrative burdens than others, we draw on the work of Bourdieu. Specifically, we use the concepts of capital and habitus. Bourdieu famously outlined four types of capital – economic, cultural, social, and symbolic – which combine to create a person's habitus, which is a person's habits, skills, disposition, or ways of 'being in and seeing' the world (Bourdieu, 1984). According to Bourdieu, all people have a habitus – those designing administrative systems, and those having to navigate them, and these can differ significantly creating mismatches between systems and people. Applying the concept of habitus to the construction and experiences of administrative burden enables us to see that these systems reflect the social worlds of those who design them (i.e. middle-class policymakers). As a result, the habitus of the excluded becomes seen as the problem to be intervened upon, rather than the system and its design. To address exclusion, we therefore need to include individuals with different habitus (i.e. those from excluded groups) in the design and implementation stages of administrative systems.

We begin with an explanation of the NDIS and its administrative systems, before examining the findings and implications of the review.

2 | THE ADMINISTRATIVE PROCESSES OF THE NDIS

As noted, the NDIS reflects a broader trend in social care service provision towards individual budgets and personalisation (Carey, Dickinson, et al., 2020; Needham & Dickinson, 2018). In this section, we outline the NDIS systems through which individuals gain access to the scheme, and

organise services. It's worth noting though the NDIS launched in 2013, it is still very much in initial implementation (Australian Productivity Commission, 2011; Carey et al., 2018). This implementation has also been characterised by a host of problems, challenges, and disruptors (ANAO, 2016; Hansard, Commonwealth Government of Australia, 2018; Tune, 2019). This has meant that within the 'grand' reform of the NDIS, we have seen near constant waves of smaller reforms in response to political decisions and preferences, emerging issues in implementation, and complaints from participants (Carey, Nevile, et al., 2020). As a result, we outline the NDIS systems as they are described by the key implementation and oversight agencies – The National Disability Insurance Agency (NDIA) and the NDIS Quality and Safeguarding Commission – at the time of writing.

2.1 | Accessing the NDIS

To be eligible for the NDIS, a person must have a 'permanent and severe disability' and be aged 65 or under (Federal Register of Legislation, 2013). At full implementation, it is expected that around 500,000 Australians will be on the scheme.

Eligible individuals can apply to be an NDIS participant through the NDIA, who is main administrator body for the scheme. Individuals must complete an 'access form' which details basic demographic details and disabilities experienced. Although the form may appear simple, it makes assumptions about people's circumstances (e.g. that they have access to internet, a stable home address, a mobile phone number) (NDIA, 2020). Along with this form, applicants must compile evidence from their health and medical practitioners, other service providers, and government agencies to build a case for eligibility.

Numbers of individuals who are deemed ineligible are currently not reported, though it is known that some have gone through to the Administrative Appeals Tribunal to contest the NDIA's determination. Between the start of the Scheme in 2013 and December 2018, there were 1595 applications to the Administrative Appeals Tribunal with 80% settled before hearings, and 20% of those that have gone to trial have seen NDIA decisions overturned (Hansard, 2019). These fairly high numbers of complaints indicate that there are barriers to the scheme. The Administrative Appeals Tribunal (AAT) numbers likely underestimate the problem, because only the most persistent and resourced individuals are able to have their complaints heard given the costs and work associated with taking the NDIA to the AAT. The government has used extensive private legal representation in over a third of AAT cases, devoting close to $3million in 2019–2020 to fighting exclusion complaints (Henriques-Gomes, 2020).

2.2 | Gaining services from the NDIS

Once deemed eligible, NDIS participants undertake a planning meeting. Planning meetings are done either in person or over the phone, with a wide range of actors – from NDIA planners, systems as to Local Area Coordinators to other scheme coordinators depending on location and availability of NDIA planners at the time (Malbon & Carey, 2021; NDIA, 2018). In these meetings, participants set goals with the planner and decide upon necessary supports for achieving them. Plans are reviewed on a 12-month basis where the purpose is to allow participants to re-set goals and change supports, though there have been widespread reports of planning reviews either not occurring or resulting in reduced budgets for participants and in other instances participants seek more

frequent plan reviews but have been unable to obtain them (ANAO, 2016; Morton, 2017a; Tune, 2019).

In practice, planning has been highly convoluted, enacted without a clearly defined process (sometimes plans are prepared by Local Area Coordinators, then sent to NDIA planners upon which they are changed without discussion with participants), and subject to major complaints, audits, and changes (ANAO, 2016; NDIA, 2018; Tune, 2019).

Once a participant has a plan, it is then up to the individual to identify and engage service providers from disability service markets (Australian Productivity Commission, 2011). In the original design, service procurement was supported by Local Area Coordinators but during implementation these roles have become almost exclusively focused on creating plans rather than helping implement them (Malbon & Carey, 2021).

Participants experience administrative pain points throughout this process: from gaining access (e.g. compiling paperwork, chasing the NDIA for a response), through to obtaining a plan, ensuring it meets their needs, and implementing that plan (when little support is given to help navigate markets and make decisions).

Having outlined the administrative processes involved in accessing supports from the NDIS, we next outline the conceptual framework we will be applying to understand the experiences of these processes and how they are constructed as administrative burdens.

2.3 | Conceptual framework

In their framing of administrative burdens, Herd and Moynihan (2019) locate individual experiences in a network of interconnected political beliefs, state administrative capacity, and state construction of burdens, amongst other factors (Figure 1). As Herd and Moynihan (2019) argue, this framework is necessarily simplified. In this paper, we seek to expand just one part of this framework, in order to better explore the relationship between state-constructed burdens and individual experiences, using the concept of habitus (Figure 2).

Bourdieu was primarily concerned with class, equating habitus to a certain disposition produced by class positions (e.g. the ways of behaving which are socially consistent with one's class position) (Bourdieu, 1984). This class lens is useful, because different forms of capital are generally associated with different 'class' norms, for example tertiary education and access to 'bridging social capital' (the form of social capital most associated with social mobility (Yaojun, 2008)). Habitus refers to 'capital positions', with different people or groups having capital positions based on their access to multiple types of capital, including economic, social, and cultural. However, habitus can also be thought of as sets of cultural norms outside of class (e.g. Atkinson et al. (2010) and others (Radoll, 2009) talk about 'white habitus' and 'Indigenous habitus').

It is worth noting that human capital, as referenced in Figure 2, does not form part of Bourdieu's original concept of capital. Human capital has its roots in economics, emerging first in the work of Adam Smith (Smith, 1771) and later further developed by Gary Becker (Becker, 1993). It is generally used to capture the human elements of economic capital, such as labour or education and training (Becker, 1993). The critical difference between this concept of human capital and those of Bourdieu's, is that Bourdieu's encompass power. For example organisations or governments can invest in human capital when approached from Becker's perspective, and this is indeed the most common usage of the term (and that reflected in Figure 1). In contrast, with Bourdieu's lens one would examine human capital from the perspective of how education or training makes up part of an individuals' habitus; how does it enables a person to maintain their 'elite' social position? How
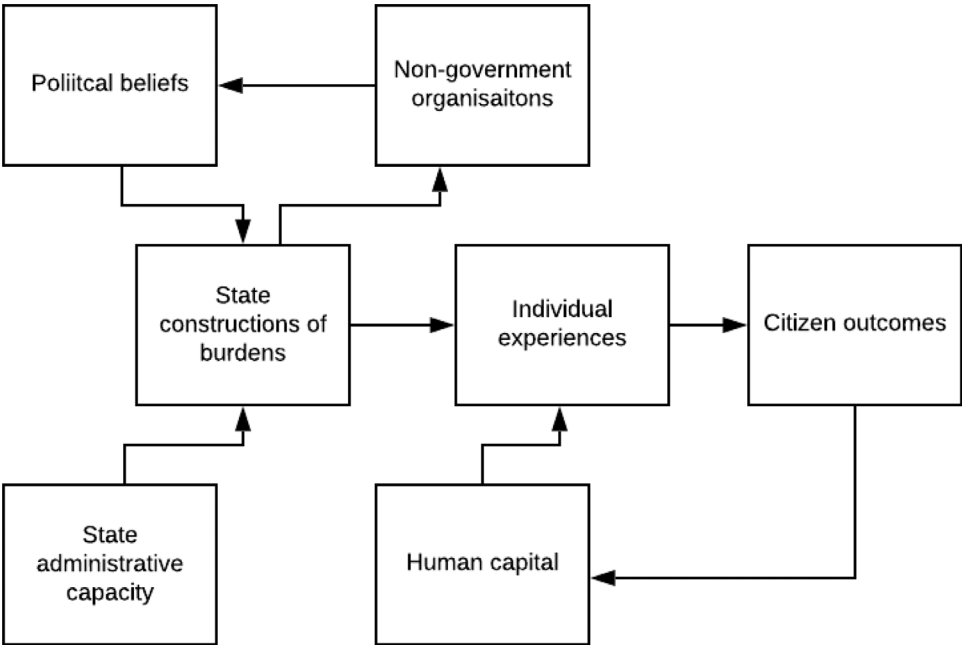
FIGURE 1 A framework for understanding state construction of burdens (from Herd & Moynihan, 2019)
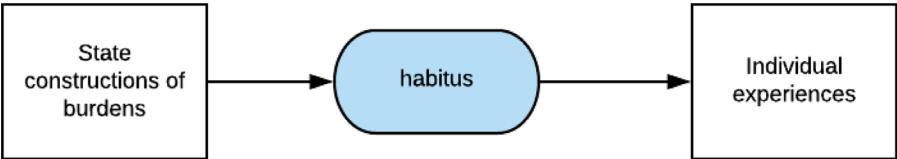

FIGURE 2 Unpacking the construction of state burdens and individual experience [Colour figure can be viewed at wileyonlinelibrary.com]

can one use education to move from non-elite position into elite positions? In this paper, we use Bourdieu's concepts of capital, linking them to power and social position. Recently, 'human capital' has been broadened within administrative burden debates to begin to overlap with Bourdieu. For example Chistenesen et al. (2020) unpack dimensions of human capital, as they pertain to administrative burden, with an emphasis on cognitive capital, thereby beginning to highlight the power dimensions of human capital. We do not expand or re-envisage human capital as depicted in Figure 1.

In the findings and discussion, we use habitus and Bourdieu's multiple forms of capital to explore the construction of administrative burdens within the NDIS, and what this theoretical position tells us about how we might go about designing systems where burdens are less inequitably distributed.

3 | METHODS

There has been wide-spread media coverage and internal government inquiries noting challenges with the administrative systems of the NDIA (ANAO, 2016; Joint Standing Committee on the National Disability Insurance Scheme, 2014; Morton, 2017a, 2017b; Productivity Commission, 2017; Tune, 2019). Despite this, there has been no systematic examination of how these administrative systems are experienced, their burdens, or whether such burdens are equally distributed. To address this, we conducted a structured review of existing empirical work on the NDIS to understand who is experiencing excessive administrative burdens, and the nature of these experiences.

We used a broad search term to capture general experience of the NDIS:

- (National disability insurance scheme, NDIS) AND (experiences or perceptions or attitudes or views).

We used two further search terms to target groups which inquiries and reports into the NDIS highlight as vulnerable:

- (National disability insurance scheme, NDIS) AND (choice, control, empowerment, marginalisation, social determinants, health, equity, equality, gender);
- (National disability insurance scheme, NDIS) AND (homelessness, migration, Aboriginal, Indigenous, women, girls, female).

The following databases were included in the search: ProQuest, Sociological Abstracts, PubMed, Web of Science, Science Citation Index, Social Sciences Citation Index, MEDLINE, Academic OneFile, ScienceDirect, Expanded Academic, and EBSCO. We also scanned the reference lists of selected articles to find other useful research and included government documents from relevant government websites (i.e. those charged with the design and/or implementation of the NDIS): The National Disability Insurance Agency and the Department of Social Services, and other sites of agencies that have produced work related to the NDIS, such as the Commonwealth Ombudsman, the Productivity Commission, and the National Audit Office. As the NDIS was established with the NDIS Act in 2013, our time frame was 2013–2020 (present). The search strategy is described in the PRIMA diagram (Figure 3).

Articles abstracts and executive summaries of the 102 articles were reviewed against the following inclusion and exclusion criteria:

3.1 | Inclusion criteria

- Research was empirical (qualitative or quantitative);
- Research focussed on NDIS in at least one case study;
- Papers described participant's experiences of administrative processes (whether accessing the scheme, planning, re-negotiating plans, or interacting with administrative bodies such as the NDIA).
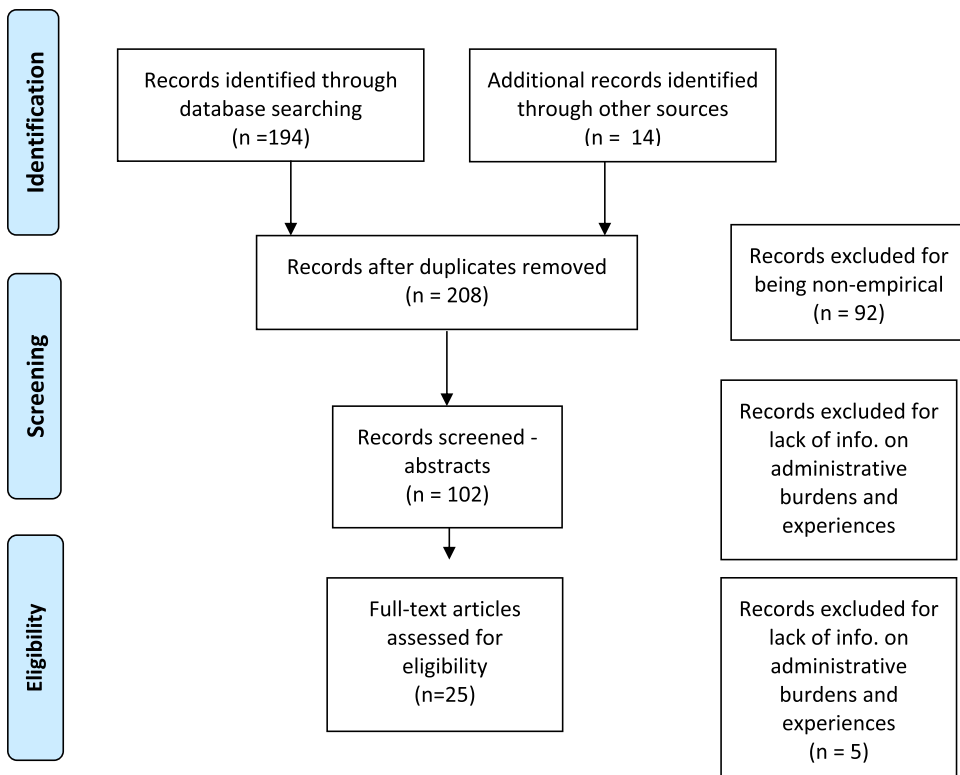
Identification

Records identified through
database searching
(n =194)

Additional records identified
through other sources
(n = 14)

Records after duplicates removed
(n = 208)

Records excluded for
being non-empirical
(n = 92)

Screening

Records screened -
abstracts
(n = 102)

Records excluded for
lack of info. on
administrative
burdens and
experiences

Eligibility

Full-text articles
assessed for
eligibility
(n=25)

Records excluded for
lack of info. on
administrative
burdens and
experiences
(n = 5)

FIGURE 3   Prisma diagram [Colour figure can be viewed at wileyonlinelibrary.com]

3.2 | Exclusion criteria

- No mention of administration or related issues (e.g. no mention of experiences of applying to the NDIS, planning meetings, complaints, or any other 'administrative' type interactions with NDIA agencies);
- Commentary pieces without empirical data.

  After culling from abstracts, 30 eligible papers were read in full, against the same criteria. A further five were excluded, for example an abstract did not indicate if an article was empirical, but on closer examination it was not; a number of articles included empirical work on the NDIS but did not discuss administration process, systems, or bodies.

  The 25 documents that met the full criteria and were analysed in full. All discussions related to administrative processes, bodies (e.g. NDIA), and structures were extracted. These were then analysed thematically, by what population groups the research looked at (e.g. Indigenous or CALD participants), and the nature of interactions described (e.g. positive, negative, and in what ways). The full list of papers can be found in Appendix S1.

  All papers portrayed a scheme which is administratively complex, with added complexity for CALD and Indigenous groups (noting these may not be the only groups to experience more administrative complexity, but they are the ones that current research has been published on). We analysed the descriptions of NDIS participant's experiences of the NDIS with an eye to what skills, networks, and resources they were either using or needed to successfully navigate the scheme.

This analysis was broadly informed by Bourdieu's notions of capital, that is what types of capital (economic, social, cultural) appeared to be needed to successfully navigate the NDIS.

4 | FINDINGS

Below we explore the administrative complexity of the scheme and the skills and resources the review identified as needed for successfully navigating that complexity. In our data, we present both direct quotes from participants in the reviewed studies, as well as summaries from the authors of these studies.

4.1 | Administrative complexity

Consistent with media reports and government reviews, the empirical research on experiences of NDIS systems paints a picture of administrative complexity. This complexity begins with initial planning meetings. As the largest and most extensive foray into personalisation in Australia, few participants are likely to have previous experience of planning meetings within such systems. However, beyond this the system itself is described as being onerous and convoluted:

> 'Focus groups noted that generally the language of the NDIS is complex, the paper-work confusing and the collation of material needed for planning meetings poses a huge hurdle for many potential clients'. *Author summary* (Heneker et al., 2017)

The scheme is so administratively complex that even participants who had attended information sessions felt unprepared to navigate it:

> 'Even when research participants had attended a NDIS information seminar, they reported a lack of NDIS understanding. Several research participants … reported being confused about what the NDIS would mean for the health and social support that is currently received'. *Author summary* (Lakhani et al., 2018)

It is also frequently described as time consuming by participants across the studies identified (Commonwealth Ombudsman, 2018; Heneker et al., 2017; Lakhani et al., 2018; Mavromaras et al., 2018; Warr et al., 2017). Confusion was exacerbated by inaccurate and inconsistent information given to participants and service providers, and has been noted in a range of reviews into the scheme (ANAO, 2016; Tune, 2019) and found across the studies in this research:

> 'Other parents said that they had received mixed messages…or inconsistent information in their contact with the NDIA, that the staff they spoke with did not have sufficient knowledge, or that the NDIA's technological systems did not work' *Author summary* (Meltzer et al., 2016).

As a participant in Mavromaras et al. (2018) demonstrates, the complexity of the planning process can be compounded by a lack of understanding of disability itself:

'Most NDIS participants expressed criticisms of the initial planning of their supports. Many had entered the planning meeting with a lack of understanding about the process ahead or the supports they needed; this was particularly the case for people who had more recently acquired a disability.

"You don't know anything because you have never been in this situation before. How do you know what [my husband] needs after you have a stroke? You've never lived with someone having a stroke…It was a very basic plan, and it wasn't a plan that included much thinking beyond the box. And I had yet to learn that we can use these plans to actually make changes and things within the life"'. *Author summary followed by participant quote*

In addition to being bureaucratically complex, experiences of planning and interactions with the NDIA suggest that participants had negative experience, requiring them frame disability and needs in a way which aligns with the scheme. This can also be a time-consuming process:

'My child is getting the supports he needs, BUT I fought for 11.5 months and all the way to the Commonwealth Ombudsman before his high support needs were taken seriously. I am anticipating having the same fight every year'. *Participant statement* (Purcal et al., 2018).

'A mother of a four-year-old child with a physical and cognitive disabilities explained the effort they go through in preparing their annual plans: When we go into a plan, we do a lot of preparation with our therapists, hours and hours of talking about what do we need for the next 12 months, what are we going to foresee, what shall we ask for in terms of therapy hours and time.

"My husband and I sit down together, and we talk about it … we go in and have this meeting with our planner… What I find frustrating is that you sit there, and you have a chat, … [the planner] sits their jotting notes. Then they give you a plan… I was horrified at some of the goals she came up with… I did not feel comfortable with these goals"'. *Author summary followed by participant quote* (Warr et al., 2017)

Compared to the previous system 'more time was required to do paperwork to obtain supports under the NDIS' (Mavromaras et al., 2018).

The following quote shows how these two elements can collide to disempower participants, within a scheme premised on the very notion of empowerment:

'One mother described hers as 'inefficient and demoralising'. She said that supports agreed during the meeting were rejected; that overall funding was reduced despite the child receiving an additional diagnosis after the last plan; that the review process was delayed, resulting in a funding gap of several months; and that during this time the family did not receive updates on the review progress'. *Author summary* (Purcal et al., 2018)

Problems with disempowerment were echoed in other research:

> 'A mother who had her planning meeting between the first and second interviews said she received incorrect information in the meeting. She said when she stated that she wanted to self-manage the package the planner replied, "well, it's up to the NDIS to determine how your plan is managed"'. *Author summary* (Meltzer et al., 2016).

As noted in the introduction to this paper, personalisation puts unparalleled emphasis on individuals to organise their own services and supports – purchasing them from disability markets. Although markets sit at the heart of the NDIS reforms, as a means of enabling choice and control (Australian Productivity Commission, 2011), in practice this presents major challenges for participants. As Heneker et al. (2017, p. 46) explain, the NDIS provides a 'unique challenge for participants who must navigate through complex systems and make multiple choices between providers and a myriad of different service options' *Author summary*. In their research on experiences of the NDIS, Warr et al. (2017, p. 46) note that:

> 'A lot of families of people with disabilities didn't really seem to know actually what they want to do because they're not practiced at making choices or making real choices. They're practiced at making choices from what's available, but not necessarily saying, "I don't like anything that you've got available for me, this is what I want cause that's what will make a difference to my quality of life"'. *Author summary*

The administrative structures through which choice is exercised appear to not be enabling (also noted in: Hansard, Commonwealth Government of Australia, 2018; Mavromaras et al., 2018; Tune, 2019; Warr et al., 2017). One participant in Ferdinand et al. (2019) described the experience of waiting for equipment, arguably one of the more simple things one can purchase through the NDIS (as opposed to finding a support worker, for example):

> 'The amount of time we're waiting for equipment to be available… You go through the assessment with the occupational therapist… Then from there turn to NDIS, NDIS probably will take a long time to approve that. When they approve that, then the supplier has to wait for the equipment to … It will be six months later before someone gets the wheelchair'. *Participant quote* (Ferdinand et al., 2019)

4.2 | Skills and resources required for successfully navigating personalisation schemes

The studies of NDIS experiences suggest that successfully navigating the administrative systems of the scheme requires a specific set of skills and resources. Dependent on one's access to such skills and resources, people may fare better or worse than others in terms of both how onerous the experience is but also whether they get the 'personalised' supports the scheme was designed to deliver.

In some studies, authors described participants feeling that they needed to take a deficit approach in planning meetings. For example:

'One mother said that because of going through the NDIS planning process for the first time, she had learnt more about how to frame what she asked for from NDIS services: "I think I'm a bit more clued up about how to ask for what I want. How to communicate what their needs are, in a very specific way that meets the NDIS framework"'. *Author summary and participant quote* (Purcal et al., 2018)

'Another difficulty with self-advocacy ... is the reluctance to emphasise the extent of formal support that a child may require. Throughout his interview, the parent of a child with autism... was very reluctant to detail or embellish upon his child's difficulties. Instead, he stressed his child's strengths and capacities. The need to discuss plainly all the difficulties faced by this parent and his child to receive adequate services and maximise his funding allocation, was clearly a challenge that caused him great discomfort'. *Author summary* (Heneker et al., 2017)

These last two quotes draw attention to notions of self-advocacy. Personalisation schemes put unprecedented emphasis on participants to be able to clearly articulate their goals, needs, and then access services/supports to achieve these. An early evaluation of the NDIS found that if participants could gain access to an advocate (which may be free or paid from personal funds, as these cannot be paid from NDIS funds), plans increased in dollar amount (Mavromaras et al., 2018). That paid advocates can result in larger plans for participants suggests that if one has more resources (e.g. personal funds to pay an advocate), they can maximise benefits from the scheme. In their quantitative analysis, Mavromaras et al. (2018) found that 96% of participants needed assistance from other people to navigate the planning process. Eighteen% of these people used advocates (though reasons for this number are not provided). The relatively low number of people accessing advocates is important when considering that engaging an experienced advocate is associated with larger plan budgets (Mavromaras et al., 2018). We also uncovered recurrent experiences of people being unaware of particular supports or services until they had engaged an advocate, for example:

'It was common for respondents to suggest that the NDIA remained reticent to suggest ideas for supports and services. One example of this was a respondent who wanted to enter the workforce being unaware that the NDIA was able to offer support in finding employment until she was informed by an advocacy agency'. *Author summary* (Mavromaras et al., 2018).

Challenges with skills and resources for navigating the NDIS appear to be exaggerated for already vulnerable or disadvantaged groups. Our review identified studies reporting these difficulties in people from culturally and linguistically diverse backgrounds (CALD communities) and Indigenous people (it's worth nothing that more groups may be experiencing heightened administrative difficulties, but research is not yet available).

For CALD communities, there is a lack of information in different languages or access to translators:

'... CALD people with disability there is the added barriers of a lack of flexibility to tailor NDIS information to different cultural languages, and the additional time a lack of translator adds to the already time-consuming process of guiding a partic-

ipant through all stages of applying for and utilising the scheme'. *Author summary* (Heneker et al., 2017)

> 'There are restrictions on use of translators …. Specifically, a translator is not able to be funded by the NDIA if the review request relates to a form of support that is not currently in the plan. The unfortunate irony here for CALD people with disabilities, then, is that the request for translation services to be included in a plan would not attract the assistance of a translator' [to the initial meeting]. *Author summary* (Heneker et al., 2017)

The CALD community makes up approximately one third of the Australian population, making the issue of access to translation a pressing issue (ABS, 2016).

For Indigenous communities, there appears to be a lack of cultural sensitivity in terms of what it means to have a disability and be part of an Indigenous community, or how government services are experienced (e.g. as an extension of colonial violence or surveillance). Although the NDIA has made efforts to have staff travel to remote communities, these visits were not foreshadowed or integrated with existing linking services:

> 'I was confused that time. They just popped up out of nowhere. I didn't know they were coming. I was surprised and a little bit frightened… I rang up …. and asked her who they were. We didn't know'. *Participant quote* (Ferdinand et al., 2019)

> 'I don't know who told me first about NDIS. It's very hard to think clearly about all those people when they came to see me at my house… They didn't tell me they were coming, and I wasn't sure what they wanted'. *Participant quote* (Ferdinand et al., 2019)

Participation rates of Indigenous people in the scheme are low, at just 5.7% of the scheme (NDIA, 2019), despite higher rates of disability amongst these communities (ABS, 2012). The NDIS notes that participation of Indigenous people in all age groups 'is lower than expected' (NDIA, 2019). Although the research reviewed in this paper suggests that rate is low because of the mismatch between the scheme design and Indigenous experiences or culture, the low rate of Indigenous participants is often framed as a lack of skills (rather than a need to redesign administrative processes or provide appropriate cultural training to staff), for example 'the inaction of this group of interviewees was attributed to a lack of skills' (Hui et al., 2018, p. 24). A review of how Indigenous communities are described in policy documents and inquiries into the NDIS similarly found that Indigenous communities are positioned as the problem, rather than emphasising system design or re-design (Gordon et al., 2019).

5 | DISCUSSION

The NDIS was explicitly established to replace an inequitable and fractured system (Australian Productivity Commission, 2011), suggesting that equity and ease of processes were priorities for the reform. At approximately 5 years into implementation, our review of the current evidence of participant experiences suggests a highly inequitable scheme, with individuals with markers

of disadvantage such as CALD background and Indigeneity more likely to be excluded from the scheme altogether or, if they gain access, more likely to face barriers to gaining services and supports.

To some degree, inequity may be built into personalisation systems, with their strong individualised philosophy stemming from the market principles which underpin the administration of such systems (i.e. personalisation of services is operationalised through market mechanisms) (Carey et al., 2019; Malbon et al., 2019). As noted previously, personalisation systems require unprecedented levels of self-advocacy with regard to social service provision (Carey et al., 2019; Malbon et al., 2019). They are also found to be administratively complex, even after they are fully implemented, suggesting that experiences presented in the findings section are unlikely to change at 'full scheme' (Fleming et al., 2019). Although personalisation, by design, may inadvertently create structures that favour some more than others, there have also been political choices that have been made in the implementation of the NDIS which amplify administrative burden and inequities for scheme participants. As Herd and Moynihan (2019) suggest, administrative systems are consciously designed with particular goals in mind. From this frame, the administrative complexity of the NDIS might be understood not as an accident of implementation but rather as a tool for reaching particular political goals.

Specifically, debates over 'cost blowout' and 'cost containment' of the NDIS have been rife since the scheme launched (Hansard, Commonwealth Government of Australia, 2018; Morton, 2017a; NDIA, 2017). The administratively cumbersome, and slow, processes of the NDIS are one way of reducing or deferring costs within the scheme – with supports either not provided, or provision being delayed, and costs pushed down the road. Similarly, the barriers to entry help reduce costs by excluding individuals from the scheme. Despite the NDIS being designed to help individuals with disability achieve their self-defined goals, in practice we are seeing a policing of what is seen as appropriate or not appropriate supports for people with disability, and by extension the goals people with disability are permitted to set. Overall, what should, and should not, be provided to people with a disability through the NDIS has become a point of significant political and community scrutiny. This, in turn, may drive administrative processes towards being more punitive and exclusionary.

Although the scheme is administratively cumbersome for all, our review suggests that burdens are exacerbated for particular groups. In particular, our review highlighted that CALD and Indigenous communities appear to have worse experiences of NDIS administration processes. For these groups, it seems that the system design is not respectful of specific needs or experiences – for example approaching communities without prior warning or introduction. This suggests that more training may be needed for engaging with Indigenous communities which have a long history of state-associated trauma. Such lack of understanding regarding Indigenous communities and embedded racism within organisations and agencies often leads to reduced rates of Indigenous healthcare participation, and a breakdown in partnerships with community (Hunt, 2013a). CALD communities, it seems, are often not being provided with the most basic requirements of accessibility (e.g. a translator), despite the NDIS being a scheme explicitly aimed at enhancing citizen accessibility.

Our review of existing research on the NDIS has sought to capture both the extent of the administrative burdens within the NDIS and how different groups experience those burdens. We found that experiences of the NDIS administrative systems differ for different groups. In particular, CALD communities lacked translators, making an already complex administrative system harder to navigate. Indigenous communities found the practices of NDIA representatives, for example arriving in the community or at houses without notice, traumatic. Although some people, while

unexperienced with the previous disability system, did not know the language required to get appropriate plans (e.g. presenting the strengths of their children, rather than areas needing support), the experiences of CALD and Indigenous communities in particular, as well as those who may lack requisite cultural capital for framing disability, speak to the unequal distribution of burdens as outlined by Herd and Moynihan (2019).

In the remainder of this paper, we turn our attention to theorising the relationship between the construction of burdens and differing experiences of them. Elsewhere, we have argued that successfully navigating personalisation schemes such as the NDIS requires access to particular types of capital (Carey et al., 2019; Malbon et al., 2019). Our previous work highlighted that certain skills for navigate administrative systems play an important role in how successfully individuals can gain benefit from personalised programs such as the NDIS. Skills identified in that review were 'education, being employed, having capable networks and support, knowledge and skills in navigating complex systems, household income, knowledge of where to access information and the capacity to self-manage individual budgets' (Carey et al., 2019, p. 4). The findings of the current review are consistent with these arguments, whereby skills in framing disability-based needs, social networks, and time and financial resources to gain access to advocates or supportive family/friends appear to play an important role in how successfully individuals are able to navigate (and in turn gain benefit from) the NDIS.

The skills and resources identified both in this review, and a broader international review (Carey et al., 2019), fall into Bourdieu's concepts of social and cultural capital (Bourdieu, 1984). For example, social capital is important in the form of networks that help gain access to information and assistance in navigating the scheme, noting Mavromaras' (2018) finding that 94% of people need assistance with planning meetings. While cultural capital appears to be important for operating within the norms of the administrative system, for example NDIS participants in this review talk about needing to frame disability in 'the right way' culturally. Cultural capital also captures implicit levels of administrative acuity one might have obtained through, for example, higher education or inherited in other ways such as family background or social ties (Carey et al., 2019).

With regard to the administrative burden and the NDIS, the concept of habitus can help to provide an explanation for how modes of behaviour or 'being' can differ systematically by social group in ways that might advantage or disadvantage them in dealing with state constructed burdens (ref Bourdieu, 1977). For example administrative systems might be better 'calibrated' to a particular habitus. In highlighting the struggles of particular groups with NDIS administrative systems and burdens, we can see that the NDIS is certainly not calibrated to the habitus of CALD or Indigenous communities – where disability has different meanings, and notions of individual and personalised services, budgets and advocacy do not align with their ways of being (Ferdinand et al., 2019; Heneker et al., 2017). Programs or administrative systems which lack appropriate co-development with these groups and long-term engagement with them create 'unnecessarily heavy burdens' on their ability to access said programs and systems (Hunt, 2013b). It is also likely that such barriers to Indigenous use and participation are not confined to rural and remote communities, but also to those in urban environments; Indigenous identity, and Indigenous barriers to healthcare, are also present amongst urban communities (Fredericks, 2013; Hunt, 2013b).

Arguably, introducing the notion of habitus (and associated forms of capital) helps us to understand more deeply why some groups experience excessive burdens or exclusion from state systems over individual change, which human capital approaches tend to emphasise. It also places the emphasis back on system change, over individual change. Returning to Herd and Moynihan's diagram (Figure 2), this would see changes occurring in the left-hand side: to state administra-

tive capacity and political beliefs – which flow into the construction of burdens. System change, over individual change, would require changing the state's administrative capacity (likely through shifting political beliefs), whereby individuals from diverse habitus are brought into the design process. Habitus, Bourdieu famously argued, is slow to change – it is complex, inter-generational, and speaks to the ways in which individuals experience and understand the world (Bourdieu, 1977, 1984). Expecting to be able to change individual habitus to make it compatible with administrative systems, as has often been suggested with regard to those groups excluded from the NDIS (e.g. training and capacity building of Indigenous people) (Hansard, 2019; Lakhani et al., 2018), makes little sense from this framing. Expecting a change of individual habitus can also further the oppression CALD and Indigenous communities feel regarding the healthcare and social care systems, and with the latter make them less likely to engage due to a longer-term pattern of government expecting Indigenous people to change behaviours or cultural practices in order to receive services (Anderson, 2015; Fredericks et al., 2011; Hunt, 2013b). Instead, we must make systems that can be adapted and flexible to a diversity of habitus if we want to avoid excluding or disadvantaging particular groups.

A step towards achieving systems which do not disadvantage groups would be to include those groups in the design of the administration (e.g. in the case of the NDIS, the planning process, community outreach/engagement around the scheme, requirements for access. In order for such co-design to be effective, in terms of its engagement with CALD and Indigenous communities, it must be respectful of culture, as well as being part of a sustained process which provides opportunity for active participation from development through to outcome evaluation (Hunt, 2013a, 2013b). As others have argued, administrative systems are primarily designed by white middle class people (Carey et al., 2019; Hastings & Matthews, 2015; Matthews & Hastings, 2013) and, perhaps not surprisingly, therefore tend to align best with the habitus of this same group – making them easier to navigate for those individuals, and unfairly oppressive on those outside this group of people trying to gain entry. Building administrative systems that are not overly burdensome or exclusionary for particular groups means building knowledge of diverse habitus into these systems. Given that one cannot easily 'learn' a different habitus (Bourdieu, 1977, 1984), this means including CALD, Indigenous, and women with a disability in the design and implementation stages of programs such as the NDIS.

6 | CONCLUSION

We have reviewed the available empirical work on the Australian NDIS as it relates to administrative burdens for social care recipients. Our findings reflect inequities at many intersections of the scheme, particularly for people with Indigenous of CALD backgrounds. Our findings emphasise the theories put forward in Herd and Moynihan that 'Administrative burdens are the product of administrative and political choices' (Herd & Moynihan, 2019, p. 8). By introducing the notion of habitus to Herd and Moynihan's work on administrative burden, we extend their theory to unpack how administrative systems can culturally misalign with already marginalised groups, thereby exacerbating burdens. If administrative processes are designed with and by those with diverse habitus, they are less likely to be exclusionary or unduly burdensome. The emphasis here is on changing the system, rather than changing individuals' habitus, as is often the case is social policies where by those most in need, and most excluded from government benefits, are framed as the problem (Jamrozik & Nocella, 1998). Habitus is typically slow to change, and has been shown to be passed intergenerationally (Bourdieu, 1997). This lens on personalisation schemes

and other administratively burdensome schemes puts emphasis on the importance of systems change, rather than looking to shift individual habitus.

ORCID

Gemma Carey https://orcid.org/0000-0001-7698-9044
Eleanor Malbon https://orcid.org/0000-0002-6840-498X

REFERENCES

ABS. (2012). Disability and work. Australian social trends (4102.0). Author.

ABS. (2016). Australian Census: Cultural diversity. Commonwealth Government of Australia.

Australian National Audit Office (ANAO). (2016). National Disability Insurance Scheme - Management of transition of the disability services market. Commonwealth Government of Australia.

Anderson, I. (2015). The crisis of Australia's indigenous policy. *Meanjin*, *74*(3), 54–59.

Atkinson, R., Taylor, E., & Walter, M. (2010). Burying indigeneity: The spatial construction of reality and aboriginal Australia. *Social & Legal Studies*, *19*(3), 311–330. https://doi.org/10.1177/0964663909345449.

Australian Productivity Commission. (2011). Disability care and support: Productivity commission inquiry report. Productivity Commission.

Becker, G. (1993). *Human capital: A theoretical and empirical analysis*. 3rd ed. The University of Chicago Press. Chicago.

Bourdieu, P. (1977). *Outline of a theory of practice*. Cambridge University Press. Cambridge.

Bourdieu, P. (1984). *Distinction: A social critique of the judgement of taste*. Routledge.

Bourdieu, P. (1997). *Outline of a theory of practice*. Cambridge University Press.

Carey, G., Malbon, E., Olney, S., & Reeders, D. (2018). The personalisation agenda: The case of the Australian National Disability Insurance Scheme. *International Review of Sociology*, *28*(1), 20–34.

Carey, G., Malbon, E., & Crammond, B. (2019). The personalisation agenda and inequality: Evidence review and early theorising. *International Journal for Journal of Equity in Health*, *8*(170). https://doi.org/10.1186/s12939-019-1075-2.

Carey, G., Dickinson, H., Malbon, E., Weier, M., & Duff, G. W. (2020). Burdensome administration and its risks: Competing logics in policy implementation. *Administration & Society*, *52*(9), 1362–1381. https://doi.org/10.1177/0095399720908666

Carey, G., Nevile, A., Kay, A., & Malbon, E. (2020). Managing staged policy implementation: Balancing short-term needs and long-term goals. *Social Policy & Administration*, *54*(1), 148–162. https://doi.org/10.1111/spol.12530.

Christensen, J., Aarøe, L., Baekgaard, M., Herd, P., & Moynihan, D. P. (2020). Human capital and administrative burden: The role of cognitive resources in citizen-state interactions. *Public Administration Review*, *80*(1), 127–136. https://doi.org/10.1111/puar.13134

Commonwealth Ombudsman. (2018). Administration of reviews under the National Disability Insurance Scheme. Commonwealth Government of Australia.

Federal Register of Legislation. (2013). National Disability Insurance Scheme Act 2013. Commonwealth Government of Australia. https://www.legislation.gov.au/Details/C2013A00020

Ferdinand, A., Massey, L., Cullen, J., Temple, J., Chamravi, D., Meiselbach, K., Paradies, Y., Baynam, G., Savarirayan, R., & Kelaher, M. (2019). Understanding disability through the lens of Aboriginal and Torres Strait Islander people – Challenges and opportunities. University of Melbourne.

Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F., & Stainton, T. (2019). Individualised funding interventions to improve health and social care outcomes for people with a disability: A mixed-methods systematic review. *The Campbell Collaboration*, *15*(1-2), e1008. https://doi.org/10.4073/csr.2019.3.

Fredericks, B. (2013). We don't leave our identities at the city limits': Aboriginal and Torres Strait Islander people living in urban localities. *Australian Aboriginal Studies*, *2013*(1), 4–16.

Fredericks, B., Adams, K., & Edwards, R. (2011). Aboriginal community control and decolonizing health policy: A Yarn from Australia. In: De Leeuw, E and Leahy, M (eds) *Democratizing health: Consumer groups in the policy process*. Edward Elgar Publishing, pp. 81–96.

Glendinning, C., Moran, N., Challis, D., Fernández, J.-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Netten, A., Stevens, M., & Wilberforce, M. (2011). Personalisation and partnership: Competing objectives in English adult social care? The individual budget pilot projects and the NHS. *Social Policy and Society*, *10*(2), 151–162. https://doi.org/10.1017/S1474746410000503.

Gordon, T., Dew, A., & Dowse, L. (2019). Listen, learn, build, deliver? Aboriginal and Torres Strait Islander policy in the National Disability Insurance Scheme. *Australian Journal of Social Issues*, *54*(3), 224–244. https://doi.org/10.1002/ajs4.73.

Hansard. (2019). Community Affairs Legislation Committee, Senate estimates. Commonwealth Government of Australia.

Hansard, Commonwealth Government of Australia. (2018). Joint Standing Committee on the National Disability Insurance Scheme: Market readiness for provision of services under the National Disability Insurance Scheme. Commonwealth Government of Australia.

Hastings, A., & Matthews, P. (2015). Bourdieu and the Big Society: Empowering the powerful in public service provision? *Policy & Politics*, *43*(4), 545–560. https://doi.org/10.1332/030557314X14080105693951

Heneker, K., Zizzo, G., Awata, M., & Goodwin-Smith, I. (2017). Engaging CALD communities in the NDIS. Australian Centre for Community Services Research, Flinders University.

Henriques-Gomes, L. (2020, 11 November) Government called in private law firms to fight a third of NDIS cases, figures show. The Guardian.

Herd, P., & Moynihan, D. (2019). *Administrative burden: Policymaking by other means*. Russel Sage Foundation.

Hui, F., Cortese, C., Nikidehaghani, M., Chapple, S. H., & McCombie, K. M. (2018). Hard to reach: Examining the National Disability Insurance Scheme experience: A case study in Wollongong. University of Wollongong. business.uow.edu.au/research/crop/ndis-research

Hunt, J. (2013a). Engagement with Indigenous communities in key sectors. Resource sheet no. 23. Closing the Gap Clearinghouse. Australian Institute for Health and Welfare.

Hunt, J. (2013b). Engaging with Indigenous Australia— Exploring the conditions for effective relationships with Aboriginal and Torres Strait Islander communities. Issues paper no. 5. Australian Institute for Health and Welfare.

Jamrozik, A., & Nocella, L. (1998). *The sociology of social problems: Theoretical perspectives and methods of intervention*. Cambridge University Press.

Joint Standing Committee on the National Disability Insurance Scheme. (2014). Progress report on the implementation and administration of the National Disability Insurance Scheme. Commonwealth Government of Australia.

Lakhani, A., McDonald, D., & Zeeman, H. (2018). Perspectives of the National Disability Insurance Scheme: Participants' knowledge and expectations of the scheme. *Disability & Society*, *33*(5), 783–803. https://doi.org/10.1080/09687599.2018.1442321.

Malbon, E., & Carey, G. (2021). Market stewardship of quasi-markets by street level bureaucrats: The role of local area coordinators in the Australian personalisation system. *Social Policy & Administration*, *55*, 18–66. https://doi.org/10.1111/spol.12607.

Malbon, E., Carey, G., & Meltzer, A. (2019). Personalisation schemes in social care: Are they growing social and health inequalities? *BMC Public Health*, *19*(1), 805. https://doi.org/10.1186/s12889-019-7168-4.

Matthews, P., & Hastings, A. (2013). Middle-class political activism and middle-class advantage in relation to public services: A realist synthesis of the evidence bases. *Social Policy & Administration*, *47*(1), 72–92. https://doi.org/10.1111/j.1467-9515.2012.00866.x.

Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L., Goode, A., Walton, H., Smith, L., Wei, Z., & Flavel, J. (2018). *Evaluation of the NDIS: Final report*. National Institute of Labour Studies, Flinders University.

Meltzer, A., Dickinson, H., Malbon, E., & Carey, G. (Online First). Why is lived experience important for market stewardship? A proposed framework for why and how lived experience should be included in stewarding disability markets. *Evidence and Policy*. https://doi.org/10.1332/174426421X16142714946996.

Meltzer, A., Purcal, C., & Fisher, K. R. (2016). Early childhood intervention review: Nepean Blue Mountains/Hunter trial sites. Social Policy Research Centre for Early Childhood Intervention Australia NSW/ACT.

Morton, R. (2017a, May 16) Families' NDIS support slashed in crackdown. The Australian.

Morton, R. (2017b, June 7) Reboot for flawed NDIS systems as agency acts on complaints. The Australian. http://www.theaustralian.com.au/national-affairs/health/reboot-for-flawed-ndis-systems-as-agency-acts-on-complaints/news-story/1b8a5f10c1c2a55e784594405294e375

National Disability Insurance Agenda (NDIA). (2017). 2017 Price Controls Review: Consultation on NDIS pricing arrangements. Australian Government. https://www.ndis.gov.au/providers/pricing-and-payment/2017review

National Disability Insurance Agenda (NDIA). (2018). Pathways review. Author.

National Disability Insurance Agenda (NDIA). (2019). Aboriginal and Torres Strait Islander participants. Commonwealth Government of Australia.

National Disability Insurance Agenda (NDIA). (2020). NDIA Access Form. NDIA. https://www.ndis.gov.au/how-apply-ndis/what-access-request-form

Needham, C., & Dickinson, H. (2018). 'Any one of us could be among that number': Comparing the Policy Narratives for Individualized Disability Funding in Australia and England. *Social Policy & Administration*, *52*(3), 731–749. https://doi.org/10.1111/spol.12320

Productivity Commission. (2017). *NDIS Costs*. Canberra: Commonwealth Government of Australia.

Purcal, C., Hill, T., Meltzer, A., Boden, N., & Fisher, K. (2018). Implementation of the NDIS in the early childhood intervention sector in NSW: Final report. https://doi.org/10.4225/53/5b2ae9c2563c5.

Radoll, P. (2009). The emergence of the indigenous field of practice: factors affecting Australian Indigenous household ICT adoption. Working paper. ANU.

Smith, A. (1771). *An inquiry into the nature and causes of the wealth of nations*. Legrand.

Tune, D. (2019). Review of the National Disability Insurance Scheme ACT 2013. Government Services, Parliament House.

Warr, D., Dickinson, H., Olney, S., Hargrave, J., Karanikolas, A., Kasidis, V., Katsikis, G., Ozge, J., Peters, D., Wheeler, J., & Wilcox, M. (2017). Choice, control and the NDIS Service users' perspectives on having choice and control in the new National Disability Insurance Scheme. Melbourne Equity Institute.

Yaojun, L. (2008). Social mobility and social capital in contemporary Britain. *The British Journal of Sociology*, *59*(3), 391–411.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.