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‘Faceless monster, secret society’: Women's experiences navigating the administrative burden of Australia's National Disability Insurance Scheme

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Abstract

Previous research has indicated that administrative burdens are particularly high in personalised funding schemes such as the Australian National Disability Insurance Scheme (NDIS), because these schemes are predicated on very high levels of self-advocacy. Administrative burdens tend to be inequitably distributed, thereby entrenching existing social inequalities. This is the first study to look at the lived experiences of administrative burden within the NDIS explicitly—and particularly those of women, who are underrepresented within the scheme. The research involved qualitative interviews with 30 women with disability who were either NDIS participants or had considered applying for the NDIS. We argue that like other marginalised groups, women with disability are experiencing significant administrative burdens within the NDIS, which are barriers to obtaining sufficient disability support. Based on this finding, we recommend the NDIS implement a gender strategy, as well as address burdensome administrative processes in general.

KEYWORDS
care management, disabilities, gender and health, gender and inequality, health and social policy implementation

1 | INTRODUCTION

Administrative burden on citizens who receive various forms of social and financial support from governments is a growing area of interest and concern for scholars of public policy and administration (Carey et al., 2021; Döring, 2021; Herd & Moynihan, 2019). Scholars are concerned with how excessive or cumbersome administrative burdens and processes are being used strategically as ‘policy making by other means’ (Herd & Moynihan, 2019). Moreover, these burdens tend to be inequitably distributed, thereby entrenching existing social inequalities (Carey et al., 2021; Chudnovsky & Peeters, 2021; Herd & Moynihan, 2019). This paper examines the experiences of women with disability, who are a marginalised group (UN Secretary-General, 2017), navigating the Australian National Disability Insurance Scheme (NDIS). It explores what these experiences tell us about administrative burdens and their construction within the NDIS and, in turn, personalisation schemes more broadly as they relate to women.

Previous research has indicated that administrative burdens may be particularly high in personalisation schemes such as the NDIS, because these schemes are predicated on very high levels of self-advocacy (Carey et al., 2019; Glendinning et al., 2008; Needham & Glasby, 2015). Within the personalisation model, which is growing internationally (Needham & Glasby, 2015), individuals must articulate their goals and needs to street level bureaucrats (Malbon & Carey, 2020). The more successful they are at articulating these needs in a way that aligns with ‘the system’ or bureaucrats' worldview, the more likely they are able to receive larger or better-tailored plans (Carey et al., 2021). For example, Mavromaras et al. (2018) found that people with advocates received larger plans within the

NDIS than those without, while Carey et al. (2021) identified that participants must 'learn the language' of NDIS administrators in order to get their needs met.

This is the first study to look at the lived experiences of administrative burden within the NDIS explicitly—and particularly those of women, who are underrepresented within the scheme. We draw here on the concept of administrative burden provided by Herd and Moynihan (2019), in which administrative burdens and their uneven distribution across populations are not mere accidents but a form of 'policy making by other means', which is used to include and exclude particular social groups. The research involved semi-structured interviews with 30 women with disability who were either NDIS participants, had applied for the scheme, or had considered applying.

Marginalisation of women with disability is a major concern in Australia and internationally. This manifests as both underdiagnosis and underservicing. Research from the United Kingdom and United States shows women with disability are more likely to have unmet healthcare needs than both people without disability and men with disability (Sakellariou & Rotarou, 2017; Smith, 2008). At present, the NDIS has a female participation rate of 37%, while ABS data indicate that girls and women under 65 form 49% of the disability population overall (NDIS, 2019). We argue that like other marginalised groups, women with disability are experiencing significant administrative burdens within the NDIS. These form barriers to scheme access or to accessing appropriate supports once on the scheme. To some extent, these experiences are gendered (following Risman's (2004) definition of gender as a social structure) and may partly explain the low numbers of women on the NDIS. Based on these findings, we argue that the NDIS needs to implement a gender strategy, as well as address burdensome administrative processes in general.

2 | BACKGROUND

2.1 | The NDIS

The Australian NDIS is an example of personalisation in social policy, in particular a variety that has been growing in Anglo-Saxon welfare states across social care (Christensen & Pilling, 2014; Glasby & Littlechild, 2009; Leadbeater, 2004; Needham & Glasby, 2015). The NDIS is Australia's most extensive foray into personalisation. It was legislated in 2013, after a significant community campaign which leveraged a human rights discourse and a goal to improve the lives of people with disability (Thill, 2015). Nearly 500,000 individuals who have a significant and permanent disability receive personalised funding budgets (Joint Standing Committee on the National Disability Insurance Scheme, 2021) from which they can purchase services and supports that meet their needs from disability markets, ostensibly giving greater choice and control to people with disability (Collings et al., 2016; Productivity Commission, 2011). Participants' budgets (known as 'plans') are negotiated with National Disability Insurance Agency (NDIA) staff or a contracted planner (known as Local Area Coordinators or LACs). The NDIA is a statutory body of government, and while LACs were initially planned to be employed through the NDIA, this role is now contracted out (though organisations which hold LAC contracts cannot also be providers in the market; Malbon & Carey, 2020; Productivity Commission, 2011).

In its original modelling, the Productivity Commission (2011) estimated that, for every 1% increase in productivity within disability services, scheme costs would be reduced by AU$130 million. In the original design for the scheme, it was acknowledged that the scheme would need to rely on effective planning processes and robust disability service markets. Since its launch, cost 'blowout' has been a major point of political debate (Henriques-Gomes, 2021; Morton, 2021; NDIA, 2017). This has led to a range of cost-cutting efforts, including reductions in support packages (Morton, 2017). It has also been argued that costs have been shifted onto providers and families, as a means to reduce the financial burden on government (Carey et al., 2020).

What is known about this topic

- Administrative burdens are likely to be high in personalised funding schemes
- Recent research shows that administrative burdens seem to be heaviest for marginalised groups
- Women with disability are a marginalised group compared to men with disability and people without disability

What this paper adds

- This is the first study to investigate the experiences of women with disability navigating the administrative burdens of a personalised funding scheme
- The results emphasise difficulties with time spent navigating the scheme, communication with scheme actors and barriers to scheme access

2.2 | Accessing the NDIS

To be eligible for the NDIS a person must have a 'permanent and severe disability' and be aged 65 or under (*NDIS Act*, 2013). Eligible people can apply to be an NDIS participant through the NDIA, which is the main administrative body for the scheme. Along with an application form, applicants must compile evidence from their health and medical practitioners, other service providers and government agencies to build a case for eligibility.

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, to LACs, to other scheme coordinators, depending on location and availability of NDIA planners at the time (NDIS, 2018). In these meetings, participants set goals with the planner and decide upon necessary supports for achieving them. In practice, planning has been highly convoluted, enacted without a clearly defined process, and subject to major complaints, audits and changes (ANAO, 2016; NDIS, 2018; Tune, 2019). When plans have been finalised, participants can then use their funding to purchase services and supports from non-government or private providers.

2.3 | The NDIS and administrative burden

Not all personalisation schemes are administratively burdensome, for example those in Austria and Finland are relatively basic in design and require little from participants regarding financial reporting (Gadsby, 2013; see also Dickinson, 2017). However, schemes such as those found in the United States and United Kingdom are complex and can be experienced as burdensome for both participants and providers. Herd and Moynihan (2019) have argued that administrative burdens 'hurt' some groups more than others. In the context of personalisation, Carey et al. (2021) have shown that administrative burdens fall disproportionately on groups who are already marginalised, thereby entrenching disadvantage and inequity. Carey et al. (2021) found that NDIS administrative burdens were heaviest, and systems hardest to navigate, for culturally and linguistically diverse and Indigenous people with disability. This suggests that those who are already marginalised, and least likely to be equipped to successfully navigate complex bureaucratic systems, are more likely to fare poorly in the NDIS (and potentially in personalisation schemes more broadly). Carey et al. (2021: 14) argue:

> 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).

While gender was not discussed as an impact on experiences of administrative burden in Carey et al.'s (2021) systematic review, this was due to a lack of research on the issue. There are good reasons to believe that women may be at a disadvantage in navigating personalised schemes, where the onus is on individual advocacy between a participant and a government planner. Participants need both skills and time to navigate these burdens.

A number of different literatures—including social psychology, management, economics and health—have examined the impact of gender on self-advocacy and negotiation. For example, Bowles et al. (2007) found that women's greater reluctance to initiate negotiations over resources could be explained by the fact that male and female negotiators are treated differently, and particularly that male evaluators penalise women more than men for attempting to negotiate for higher compensation. More recently, Pardal et al. (2020) found that men tend to hold implicit and explicit gender stereotypes about face-to-face negotiations and that this can predict lower performance in negotiations for women. Other researchers have argued that women are aware of these implicit and explicit gender stereotypes and that this can affect their behaviour in exerting power and influence when making requests or advocating for themselves (Amanatullah & Morris, 2010; Amanatullah & Tinsley, 2013).

There are also gendered implications of administrative burden when considering time and caregiving. Caregiving is a highly gendered activity that reproduces gender inequalities (Adams, 2010). Literature from across the world shows that women are the main providers of both formal and informal care for children, family members, and those with chronic medical conditions or disabilities (e.g. Adams, 2010; Revenson et al., 2016; Sharma et al., 2016; Swinkels et al., 2019). The caregiving literature has consistently shown that female caregivers experience higher levels of stress and depressive symptoms and are more burdened than male caregivers (e.g. Caputo et al., 2016; Marks et al., 2002; Pinquart & Sörensen, 2003). Recently Swinkels et al. (2019) examined gender differences in the burden experienced by those caring for partners and found, similar to previous studies, that women feel a greater burden from caregiving than men. Their results suggest this was due to women experiencing more secondary stressors, such as having to combine different tasks, and financial burdens. For women with disability, we can add the stressor of managing their own disability. Their capacity to take on the extra administrative burden inherent in personalised funding may thus be less than for male participants, adding not only to negative health and burden impacts of caregiving for women but creating gendered inequalities within individualised funding schemes themselves.

In the remainder of this paper, we examine the experiences of women and administrative burden in the NDIS.

3 | METHODS

This project was funded by the Disability Innovation Institute UNSW and received ethics clearance through the UNSW HREC (HC200195). We adopted features of inclusive research design, partnering with community organisations and employing a woman with disability to act as peer researcher. Our two partner organisations—Women with Disabilities ACT and Women with Disabilities Victoria—assisted with participant recruitment. As the larger study focused on gender inequality in disability support, inclusion criteria were women with disability over the age of 18 who had applied or considered applying for the NDIS. Invitations were sent through the partner organisations and women were invited to reply to our peer researcher, who conducted screening, talked participants through the project and its aims, and ascertained accessibility requirements. We conducted a combination of video and audio interviews, depending on participant accessibility needs. Participants were assured their contributions would be de-identified, and we gave them the opportunity to choose their own pseudonyms.

Interview questions covered participants' experiences with the NDIS, its administration, and whether they felt any of their experiences were gendered. The interviews were semi-structured and were transcribed verbatim. We employed reflexive thematic analysis (Braun & Clarke, 2006), working deductively to explore further evidence for findings generated by previous research on administrative burden. We did not work from a pre-determined coding frame, instead generating initial codes, reflecting on those codes and how they might aggregate into themes, and then returning to the data to refine our coding more systematically according to those themes. In reflexive thematic analysis, themes are 'patterns of shared meaning, united by a central concept or idea' (Braun & Clark, 2020: 14). This means themes are multifaceted and that data relating to those themes might appear disparate. However, each piece of data can be conceptually linked to the pattern of meaning that forms the theme.

3.1 | Limitations

The data presented here are drawn from an exploratory study intended to uncover and describe gendered issues with individualised funding, as no research published in English had done this previously. With a sample size of 30, it is not intended to be a comprehensive exploration of gender and administrative burden, therefore these findings should not be generalised to all women accessing or considering accessing the NDIS. Furthermore, due to recruitment through advocacy organisations, the sample skewed white and well-educated, so future research focused more on the inclusion of women across more diverse racial and socioeconomic groups will be important. Another helpful expansion would be the inclusion of men to allow for comparisons between the experiences of men and boys and women and girls, perhaps using a survey methodology to reach a larger group of participants.

3.2 | Participant profile

We encouraged interviewees to self-describe their disability. Some provided broad descriptions (e.g. 'neurodiverse'), while most provided more specific details. More than a third had multiple disabilities. As our research was informed by the social model of disability (Berger & Lorenz, 2016), we note interviewees' impairments, where they shared them, in an effort to improve understanding of where trends in NDIS access barriers may occur, and to clarify what types of disability experiences are and are not represented in this research. Examples of impairments participants identified are included in Table 1.[1]

4 | RESULTS

Two-thirds (20) of our participants spoke about the administrative burden involved in being on or applying for the NDIS. Our analysis

TABLE 1 Participant demographics

Characteristic	Details	Number
Location	Australian Capital Territory	12
	Victoria	18
Age	20s	4
	30s	6
	40s	8
	50s	8
	60s	4
Impairment types	*Examples*	#
Physical	Spina bifida, arthritis, amputation	17
Neurological	Multiple sclerosis, stroke, acquired brain injury	6
Cognitive	ADHD, autism, other impairments generally classified as intellectual disability or developmental delay	7
Psychosocial	Anxiety, post-traumatic stress disorder (PTSD)	10
Chronic pain and energy impairments	Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)	2
Sensory	Impaired sight, impaired vision	4
NDIS involvement	Current plans	24
	Applying	1
	Applying on behalf of children but not self	1
	Considered applying	4
Race and ethnicity	Caucasian or undisclosed	25
	Other backgrounds (Aboriginal or Torres Strait Islander, Asian (specific region undisclosed), Pacific Islander, Greek, Italian)	5

derived three major themes from the interviews regarding administrative burdens: time commitment, communication difficulties with the NDIA and other scheme actors, and the administrative complexity of gaining access to the scheme.

4.1 | Time: 'It's like a full-time job'

Many participants used words like 'exhausting', 'tiring', 'draining' and 'wearing' to describe their experience with the scheme and interactions with NDIA staff and other scheme actors such as LACs (contracted workers who undertake planning and activities) and service providers.

The work involved in being an NDIS participant is perhaps best summed up in the words of three interviewees who, independent of one another, told us that being on the NDIS is like 'a full-time job'. Other women made similar points, for example Peta reported: 'I'm always amazed at any interaction I have with the NDIS …how much I have to work'. She described her recently coined term 'death by admin':

> Peta: I called the NDIS the other day [and said] I just need some more therapy because my balance stuff is off after the radiation. She listed this litany of things you had to do. I was like, so I'll just add that to the list of death by admin tasks. And I said, thanks but no thanks, I'll just pay for it myself. And I just hung up.

That being on the NDIS is 'like a full-time job' is concerning on a range of levels, including that the financial model for the NDIS is predicated on moving people with disability into work (Productivity Commission, 2011). If the NDIS is so time-consuming, this has implications for participants' ability to also take on paid work.

There were some indications that women undertook more disability care administration than men. Ruby noted that while there were men in her Multiple Sclerosis Facebook 'troubleshooting, problem-solving' group, 'to be perfectly honest, it's often their wives that write, not them'. Maria, whose husband was also on the scheme, commented that she took care of the administration for them both. She felt that not wanting to deal with that kind of work was 'just a man thing', although she did not mind as long as it got done. But for other participants, the notion of women taking on the work of the NDIS for family members *was* worrying, as it meant they might not be able to prioritise their own disability needs:

> Dianne: I know of cases where women have been advocating for a child with a disability or an adult child with a disability, and they've had to fight all those battles, and then they're literally too exhausted to fight their own NDIS battle.

Theresa reported being in a similar position, telling us 'most of my world revolves around my children and my identity as a mother', which left her no time or energy to think about herself after advocating for the disability needs of her children.

Systems and processes being overly complex, too many forms to fill out, a steep learning curve, and the need to follow up on mistakes were commonly cited reasons for administrative burden. One participant reflected:

> Jean: Look it just takes a lot of work. …initially I did a whole lot of research to understand what it was and how it was going to help me. And of course, because it's new and it's evolving, and you just get to know what all the price rates are and then they all change. So you're constantly having to relearn how it works.

Some who were self-managed (i.e. responsible for organising and coordinating their own supports) felt that this added to their administrative burden, for example it could take significant time to find and manage service providers. However, being plan managed (i.e. employing someone with part of the NDIS package to manage and coordinate services) was no guarantee of reduced administrative burden:

> Melissa: I was plan managed, and I was managing my plan manager. Chasing up on invoices that they hadn't paid, or they paid the wrong person, or they'd reimbursed me. That was a huge barrier.

Melissa continued: 'It was meant to take away that burden of chasing up payments, or engaging services …all they did was actually make it worse'.

Participants talked about the balancing act involved in managing energy levels and completing NDIS-related administrative and self-advocacy tasks: 'So you sort of trade off. You know, what have I got energy to put towards, and what things can I live without because I just can't do it'? (Melissa). Likewise, Cat talked of 'choosing your battles', meaning that sometimes she had to prioritise her health rather than spending time on the phone chasing forms: 'It's all too hard and it shouldn't be'. Some participants had been through multiple internal reviews or escalated external complaints in order to receive packages that were more suitable for their needs, another time-consuming burden that is particularly difficult for people with low energy levels:

> Daphne: …every year I've been on the NDIS, 3 years, I've had to go up the chain and I've ended up having to go the Minister for Disability and the Minister for NDIS, the Commonwealth Ombudsman … to get a package that meets my needs.

Peta commented that it was 'wearing' and 'soul destroying' 'to be constantly questioned about, are you disabled enough? Are you disabled enough for us to give you something? Or do you really need this? Prove it to us 10 times'. These findings all point toward the time and effort required to manage participation in the NDIS, highlighting that this burden sometimes prevents participants from accessing adequate support through the scheme.

4.2 | Communication difficulties

One factor that contributes to administrative burden is how easy or difficult citizens and clients find it to communicate with public servants and other actors in relation to program participation (Herd & Moynihan, 2019). Over half of the women we interviewed used adversarial language such as 'push', 'fight', 'struggle', 'battle' and 'argue' to describe their or others' interactions with the scheme, indicating a significant need for self-advocacy. Furthermore, over half the sample, and two-thirds of those who had NDIS access at the time of interview, spoke of their communication difficulties in dealing with the NDIA. Two participants used evocative similes to explain their experiences:

> January: The NDIA is like dealing with…you know those octopuses that live a thousand metres down in the ocean, and no one's ever seen them? So we don't actually know how they work, just every so often they'll put a little piece of themselves above the surface and like, wreck a ship. But then you don't know which animal it's attached to [and] you've got no way of contacting it, to try and do peace talks. … They go out of their way to make sure that you can never phone or contact any specific person under any circumstances ever …So it just seems like this faceless monster.

Similar in theme, Theresa commented:

> Theresa: I would describe our experience as being like communicating with a secret society that grants you access but you don't know what that access is, and they can't tell you what that access is until they assess you, so you've got to put a lot of faith in them. And no, they haven't been supportive for me trying to navigate it. …And honestly I'm educated but I feel like I don't have the necessary skills to be navigating NDIS.

Both these similes emphasise the 'faceless', 'secretive' nature of the NDIA and the perceived lack of personalised assistance in navigating the scheme's complexities—which is arguably ironic for a scheme designed to meet the individual support needs of participants and enable them to achieve personal goals.

Other people also commented specifically on the difficulty of getting in touch with the right people at the agency, with one ACT participant explaining:

> Dianne: So you phone the NDIA and you're on hold for an hour. And then you get through to somebody who's in Perth and they have no idea …'Oh no, we're not allowed to put you through to the person in the ACT'.

These confusing and convoluted administrative processes have been noted in other research on the NDIA (Carey et al., 2020). Other participants noted combative behaviour from NDIS actors, for example Daphne described NDIA staff as 'unprofessional, incompetent, no understanding of disabilities, unhelpful, unkind, rude, disrespectful', and Marjorie reported 'you will get told something by one person who works as an LAC for the NDIS and then be told the complete opposite by another LAC'.

Another perspective on communication was the difficulty some participants had with understanding the right language they needed to use in order to get their message across to the NDIS. Jackie, who had an intellectual disability, said talking to the NDIS was 'shit', explaining further that:

> Jackie: They don't really explain what they're saying. We just had a plan review, and I will try to ask for a bit more, and the planner was just being like, you gotta explain to me why you need it, and I couldn't put it into words and none of my supporters could either.

Other participants commented on needing 'to use the right words with them' but not knowing what those words were, a disjuncture also noted in the systematic review by Carey et al. (2021). In the context of a disability scheme, it reflects an inability or unwillingness to adjust to accessible forms of communication.

Lastly, some participants reported a lack of reasonable adjustment from the NDIS to communicate with them in an accessible way. This was a particular problem for people with sensory impairments and intellectual disabilities, who reported a lack of access to adjustments such as: video conferences for the purposes of lip reading; Australian sign language interpretation; use of the National Relay Service for people with hearing impairments; electronic documents that were easy to use with screen readers; or the provision of documentation in 'easy English' for those with intellectual disabilities. These experiences made Nellie reflect, 'People who are non-verbal, how are their needs met in terms of communicating with the NDIS? I wonder how'.

These findings show that communication issues such as difficult or antagonistic experiences with staff; an inability to directly contact the right people; the effort required to use the right administrative language instead of staff accommodating their language to scheme participants; and a lack of reasonable communication adjustments by NDIS actors all added to the administrative burden of the scheme.

4.3 | Administrative complexity for entry

Accessing the scheme itself also presented administratively burdensome and complex processes, which as Herd and Moynihan (2019) suggest may be a way of gatekeeping program access. For example

Maria, whose personal experience on the scheme had overall been very positive, reflected of the application process: '…if [people] don't have any support to fill the paperwork out, that can be hard. Because that paperwork can be overwhelming'. Similarly, other participants who had applied for the NDIS spoke about insufficient information provision and the large amounts of documentation required:

> Marjorie: I just can't wrap my head around how exhausting they make the process and how difficult they make it, considering it is for people with disabilities and chronic illnesses, who are actually asking for support.

> Lisa: …there's just so much documentation that the NDIS wants you to come to the table with. Before you even meet anybody you have to supply so much documentation and so much proof that you are truly as fucked up as you say you are. And if you're a woman and you're trying to deal with every other thing in your life, if you're studying, if you're bringing up kids, if you've got a really serious disability …the idea of coming up with all this information is inaccessible and not compassionate.

Lisa had got partway through the application process and had needed to leave it aside for a few months while she dealt with other things in her life, but reported that when she re-started the process she was required to begin again from scratch, because 'all the stuff that I had given them last year somehow had disappeared'.

All the participants who had *not* yet applied were aware of the administrative burden involved in applying and reported that it formed a major barrier, particularly for female-dominated but poorly understood conditions such as ME/CFS (chronic fatigue) and Ehlers–Danlos Sydrome. For example Cyndi was involved in disability advocacy but did not know a single other person with Ehlers–Danlos Syndrome who had got onto the NDIS:

> Cyndi: I'm very likely to get rejected so therefore, it is such a burden to apply. It is just such a nightmare to get [all the supporting paperwork] in working order for the fact that it is probably going to be rejected.

Danielle, who faced a similar situation with her ME/CFS diagnosis, reported that her condition was not well-understood and had very few specialists: 'So to do an NDIS application, you've got to have reports from specialists that you might not even be seeing in the first place':

> Danielle: So you've got to argue [the] research basically …Some people have got onto [the NDIS] after going through a review process, but it remains a barrier. You've got to have the energy to actually go through that process as well which is very difficult for a lot of people with chronic fatigue syndrome, so they don't even start.

She felt that if the application process were less burdensome, she would already have applied at the time of interview.

Skyler pointed out that as someone in work and caring for children, she did not have time to attend all the appointments that would be required to gather the necessary evidence for an NDIS application, especially given that specialist appointments are expensive, difficult to organise and involve such long wait times: 'And that is part of the conversation, it's too much effort'. Finally, Sarah reported not being able to face the idea of spending the energy required for an NDIS application given that she could 'honestly say I've never had positive feedback' from others about their NDIS experiences, even if they had derived some benefit from accessing more services. These findings suggest that women, who are more likely to be diagnosed with conditions that are difficult to get funding for, and are more likely to be time-poor due to balancing childcare with work, could be more likely than men to be deterred from applying for the scheme based on application complexity and negative reports from others.

5 | DISCUSSION AND CONCLUSION

While previous research has examined the experiences of people accessing personalisation schemes, this study is the first to examine gendered dimensions of administrative burden from the perspectives of women accessing these schemes. The experiences of women described in this study suggest that, as an already marginalised group, women may be 'hurt' more by the administratively complex and burdensome nature of the NDIS. This stems from the gendered nature of time and caregiving (Revenson et al., 2016; Swinkels et al., 2019), through to self-advocacy (Amanatullah & Tinsley, 2013; Pardal et al., 2020) and bias in the medical and disability support systems.

Several participants had conditions such as ME/CFS or Ehlers-Danlos Syndrome, which are overwhelmingly diagnosed in women (Demmler et al., 2019; Faro et al., 2016), and for which it is very difficult (and therefore more administratively burdensome) to get NDIS support. On the other hand, men are more likely to be diagnosed with conditions that have more straightforward paths to NDIS access—such as autism and intellectual disability, which form the bulk of the scheme (NDIS, 2019: 6). Recent research has found that the NDIS application form is very long and administratively burdensome, with many questions that can be difficult to answer for those with complex lives or fluctuating support needs (Brown et al., 2021). Our findings suggest that some women are aware of these difficulties and may be deterred from applying as a result. As Chudnovsky and Peeters (2021) suggest, 'policy feedback' such as previous experiences with bureaucracy or knowledge of how bureaucracy works can affect people's willingness to interact with the state and apply for government programs, which has particular relevance for the experiences of marginalised people.

Caring responsibilities also have implications for women's ability to take on the administrative burdens inherent in both applying for the scheme and managing scheme participation. In Australia, women represent over 70% of primary carers to people with disability and older people. Of those providing primary care to children with disability, nearly 90% are female. Furthermore, 35% of female primary carers have a disability themselves (ABS 2019). This means that women are less likely than men to have the requisite time to successfully navigate complex schemes like the NDIS.

Resources matter when it comes to navigating and overcoming administrative burdens (Herd & Moynihan, 2019). Carey et al. (2019) grouped these resources into different forms of capital, from economic to social. These forms of capital are reflected in the major themes of the study: time (social and economic), skills (e.g. language, compiling paperwork, putting forth a 'convincing case'), and ability to navigate overly complex administrative processes (social capital, including having people to draw on for assistance). Our research suggests that burdens have either prevented some women with disability from accessing the NDIS, or made their lives harder (when this is opposite to the stated goals of the scheme).

Critically, emerging work on administrative burdens argues that they are a choice (Herd & Moynihan, 2019). The amount of paperwork required, the time involved, and also the decision not to invest in good systems and training of staff are *choices* that have been made regarding the NDIS, largely at a political level. There have been calls from a wide range of reviews into the NDIS to minimise administrative burdens (to name a few, ANAO, 2016; Joint Standing Committee on the National Disability Insurance Scheme, 2021; Tune, 2019). The evidence we present that these burdens continue to exist and are having tangible impacts on women's ability to both access and draw supports from the scheme, despite calls to address them, speaks to their political nature. As Herd and Moynihan (2019:8) argue: 'Such political choices are reflected in the maintenance of burdens, even when changing circumstances call for governments to minimise them'. Herd and Moynihan's (2019) theory of administrative burden does not include a gendered lens, nor has much research on personalisation adopted this perspective. The present study raises questions for both fields. That is, how does gender reduce or grow administrative burdens, under different policy contexts? Also, are services and support administered through personalisation schemes less accessible to women internationally? These are important equity questions for public administration as a field.

The disproportionately low numbers of women on the NDIS reflect both the marginalisation of women with a disability, which is an international problem, and the gendered dimensions of some administrative burdens within Anglo-Saxon personalisation schemes. To redress these inequities, we recommend the NDIS implement a gender strategy to purposefully ease access to the scheme for women, as well as address burdensome administrative processes in general.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

The lead investigator was SY. The co-investigators were GC, EM and JH. SY led the study design, supervised and jointly conducted data collection and led data analysis. JH recruited participants and jointly conducted the majority of the interviews. GC jointly conducted several interviews. SY and GC drafted the manuscript. GC, EM and JH all contributed to study design and revised the manuscript. The authors read and approved the final manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this qualitative study are not publicly available due to ethics requirements.

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ENDNOTE

[1] Categories largely based on those used by Centre of Research Excellence in Disability and Health (2020). We use 'psychosocial' rather than 'psychological' because this accords with NDIS terminology. 'Energy impairments' was used by our interviewees for ME/CFS and similar conditions.

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