

Controlled choice, not choice and control: Families' reflections after one year using the National Disability Insurance Scheme

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Abstract

Introduction: At least 40 percent of children with cerebral palsy and their families rely on access to allied health services, assistive technology, and require funding and expertise to achieve skills and participate in daily life. Implementation of the National Disability Insurance Scheme (NDIS) has resulted in a shift to public funding and emphasis on choice and control of services, support and assistive technology to promote social and economic participation. Families of children with cerebral palsy are invested in scheme success and their subjective experiences require consideration if the NDIS is to meet participation targets.

Objective: The aim of this research was to explore the experiences of families with a child with cerebral palsy, who have been in receipt of the NDIS for 12 months, comparisons to previous funding systems, and recommendations for the NDIS going forward.

Methods: Purposive sampling was utilised within one specialised paediatric setting. All families received occupational therapy intervention for their child. A qualitative approach using semi structured interviews was employed. Braun and Clarke's six phases of thematic analysis was utilised to analyse the data and explore participants lived experiences.

Findings: Eight ($n = 8$) mothers of children with cerebral palsy were interviewed. Three overarching themes were derived from the data: *Equipment impacts on all areas of life*; *Frustration navigating the National Disability Insurance Scheme*; and *Gratitude, hope and suggestions*.

Conclusion: Families reported challenges navigating the NDIS including administrative challenges and extensive wait times for assistive technology, as well as gratefulness for increased opportunities for support. Occupational therapists and other allied health professionals can assist by: being proactive in service delivery and advocating for the needs of individual families and children; and finding ways to increase the preparedness of the NDIS to better understand the needs of children with cerebral palsy and their families.

KEYWORDS

National Disability Insurance Scheme, NDIS, families, consumers, cerebral palsy, assistive technology, service provision

1 | INTRODUCTION

The National Disability Insurance Scheme (NDIS) was a recommendation by the Australian Productivity Commission to create a universal national disability support scheme in Australia (Thill, 2015). The move from block funding is the biggest reform within the disability sector, since the Disability Services Act 1986 (Kendrick et al., 2017). Australia is following the trends of governments who have implemented similar systems throughout Europe (Carey & Dickinson, 2017).

The NDIS is a social insurance model that is centred around personalised funding, (Kendrick et al., 2017) and aims to support approximately 460,000 Australians with a permanent disability under the age of 65 years (National Disability Insurance Agency [NDIA], 2018). As the scheme rolls out across Australia, there has been an assurance that the scheme intends to provide people with a disability more choice and control over decision-making that impacts on the services they utilise, therefore increasing opportunities for economic and social participation (NDIA, 2018). In real terms, scheme participants (children and adults who meet the disability criteria) meet with an NDIS planner, and an individualised plan is developed to meet the participant's goals. Plans may be approved by the NDIA, and some participants receive access to funds quickly. A longer administrative process is required for more extensive plans. For example, when participants have extensive or complex assistive technology (equipment) needs, the administrative processes may be extended due to more rigorous approvals required by the NDIA (2018). Once approved, scheme participants then have choice within an open market of suppliers including allied health and equipment providers.

Early qualitative research investigated NDIS participant experiences and found issues with NDIS planning support and expertise, and lack control over decisions and resources (Perry et al., 2019). This qualitative study investigated the perspectives of eight adults with intellectual disability and found that participants also experienced better social and economic participation. Consumer perspectives are important, especially when they represent people with intellectual disability who will make up the vast majority of scheme participants. Thill (2015) emphasised the importance of listening to the lived experiences of those utilising the system to ensure that the scheme embodies a responsive and flexible approach to address arising issues. Hence, ongoing research that captures participants' experience as the scheme rolls out provide service providers and participants with an update on participant experiences.

The largest group of NDIS participants with physical disability will be children and adults with cerebral palsy. People with cerebral palsy can have a range of mild to severe physical impairments, although 38 percent of children with

cerebral palsy in Australia have a Gross Motor Functioning Classification System rating of III, IV or V (Palisano et al., 1997), meaning that they have significant mobility and movement issues (Australian Cerebral Palsy Register Group, 2018). Children with cerebral palsy and complex needs utilise health and allied health services such as occupational therapy, speech pathology and physiotherapy services with high frequency across childhood, requiring assistive technology such as communication devices, seating and mobility devices (Beauchamp et al., 2018; Bourke-Taylor et al., 2014; Hayles et al., 2015). The complex nature of the condition means that a multidisciplinary approach to therapy is needed to enhance the participation and inclusion of children with cerebral palsy (Cadwgan et al., 2019; Rosenbaum et al., 2007). Hence, many children with cerebral palsy are likely to be lifetime participants in the NDIS (Graham et al., 2016). Occupational therapists play a key role in enabling access to play, leisure and productive occupations as well as environments such as home, school, and the community (Beauchamp et al., 2018; Bourke-Taylor et al., 2018; Chantry & Dunford, 2010).

One key source of support for children with cerebral palsy is their parents who provide the majority of care. Mothers are known to spend up to six hours per weekday in direct care tasks with the child, which is two to three times more than that of other mothers (Bhopti, 2017). Other research with families of children with multiple and complex needs emphasised the far ranging family impacts of meeting a child's health and participation needs and overall reliance on assistive technology, supports and a team of professionals (Davey et al., 2015). Families raising children with cerebral palsy play a large role in service access, care provision, assistive technology and enabling participation, often exercising choice and control in interactions with the NDIS (Kendrick et al., 2017). Family-centred practice (FCP) involves collaborative partnerships with families. Service providers (therapists) who practise from an FCP approach understand children within the family context, their needs and resources, and that family priorities and goals drive planning and service provision (Rodger & Keen, 2010). Family-centred practice paradigms are essential for the child and family unit (King et al., 2004). Therefore, service providers such as occupational therapists are invested in further understanding how the NDIS is perceived by families, in order to achieve best practice and align with FCP principles.

The aim of this research was to explore the experiences of families who have a child with cerebral palsy who has been in receipt of services which they have purchased with funding from their child's NDIS plan. The research questions were: What are the experiences of parents of children who have been NDIS participants over the past 12 months? How do parents reflect upon previous funding systems since utilising the NDIS? and Based on parents

experiences, what are some future recommendations that they believe the NDIS should incorporate to improve service delivery?

2 | METHODS

2.1 | Design

Qualitative methodology was selected for this exploratory study that sought to understand participants' perspectives. A pragmatic approach utilising thematic analysis was selected to explore participants' opinions and lived experiences relating to the research questions (Creswell, 2013). The experiences of participants were analysed to identify common themes and sub-themes. Ethical approval (Project 17641) was granted by the Monash University Human Research Ethics Committee.

2.2 | Research setting

The Cerebral Palsy Education Centre (CPEC) is the setting in which this research study was conducted and is recognised as a registered NDIS provider. All participants were recruited from the same centre to improve the homogeneity in the sample, that is, families of children with multiple disability with approximately the same access to services prior and since implementation of the NDIS. The centre is a not for profit organisation based in Victoria, Australia that provides specialised services to support children, aged 0–18 years, with cerebral palsy or similar conditions (CPEC, 2018). The centre comprehensively provides occupational therapy, speech pathology and physiotherapy to service users, either individually or in a group setting. The therapeutic approach includes lifelong learning and aims to integrate skills into the children's everyday life activities at CPEC, within their homes, and at their schools and kindergartens. All authors had prolonged engagement with the population of families of children with disabilities ranging from six months (first author) to four decades (third author) as occupational therapists. Prolonged engagement improves the dependability of the data, and enhances trustworthiness (Liamputtong, 2009).

2.3 | Sampling

Participants were recruited from CPEC, using purposive sampling methods. Researchers collaborated with one facility that served high populations of families raising children with cerebral palsy as parents would have unique insight into the specific experiences required for this

research (Liamputtong, 2009). This process began with CPEC clients being screened by CPEC staff to determine if they met the inclusion criteria. All clients received regular allied health services: occupational therapy, physiotherapy and speech pathology at CPEC. The inclusion criteria were a parent of a child: aged 12 months to 18 years with cerebral palsy or similar physical condition: in receipt of CPEC services; in receipt of an NDIS plan for at least 12 months; and were the parent most involved with coordinating their child's NDIS plan. Centre staff sent information about the study to families meeting the inclusion criteria and families then contacted the researchers. Additionally, advertising posters were displayed around CPEC. As CPEC is an NDIS service provider and participant involvement was not intended to impact upon service delivery, CPEC staff members were blinded from the consenting participants' identity as Monash University conducted the research and de-identified data prior to sharing results.

2.4 | Data collection

Participants were provided with an explanatory statement and consent form and if signed informed consent was received, demographic information was collected and appointments scheduled. Semi-structured interviews consisted of open-ended questions to gather in-depth data about participants' experiences, thoughts and opinions based around the

TABLE 1 Sample interview guide for participants

Questions for participants

1. Please describe what a typical day is like for you.
2. Please tell me about how your child participates in the activities at childcare/school etc, the support they need from another person, assistive technology, etc...
3. Please describe your experiences of the processes you have been involved in with the National Disability Insurance Scheme over the past 12 months.
4. Please reflect upon your experiences of pre-National Disability Insurance Scheme services that you received and share your previous experiences.
5. If you had to compare the service schemes, can you tell me a bit about how you think the National Disability Insurance Scheme processes compare to that of pre-National Disability Insurance Scheme schemes?
6. If you had the chance, what information would you share with the National Disability Insurance Scheme about their service system and what are the core things they need to address for families?
7. If you could provide feedback to the National Disability Insurance Scheme, what are the top three things you would tell them?
8. Can you think of anything else that is important for me to know about your family's experience with the National Disability Insurance Scheme?

research aim and questions (see Table 1 for interview guide). Lead questions were asked and prompts included to derive more detail (Liamputtong, 2009).

Interviews were conducted by the first author either over the phone ($n = 6$) or face-to-face at CPEC ($n = 2$), as preferred by participants, in April and May in 2019. Interviews ranged from 60 to 90 min. The interviews were audio-recorded and then transcribed verbatim. Transcribed interviews were provided to participants to ensure accuracy and credibility of the data, and no changes were received.

2.5 | Data analysis

Pseudonyms ensured anonymity of participants and their children. Demographic data provided context for interviews. Analysis of interviews occurred using an inductive process, where the codes and categories were developed from the data by utilising thematic analysis, as outlined by Braun and Clarke (2006). This method was utilised to identify, analyse, and report patterns or themes within the data collected (Liamputtong, 2009). Records were meticulously kept

ensuring that detailed steps outlining data analysis were recorded to add dependability to data analysis. These detailed steps outline the iterative process where the authors considered and discussed the refinement of the codes and themes emerging from the data and their relationship to the research questions. Further detail and examples of this analysis process can be found in Table 2.

2.6 | Trustworthiness and rigour

This research addressed strategies that strengthen the trustworthiness and rigour of qualitative research, including credibility, transferability, dependability, and confirmability (Fossey et al., 2002). Credibility relates to the truthfulness of the findings and this was enhanced through the prolonged engagement of the research team, as well as constant contact between researchers across the project, and the first author keeping a notebook of reflections and observations. Further, correct representation of participants experiences and minimisation of researcher bias was achieved through reflexivity (first two authors maintaining frequent discussions regarding objectivity

TABLE 2 Steps of data analysis adapted from Braun and Clarke's (2006) phases of thematic analysis with examples

Step	Stage	Example
The first and second authors were involved in the data analysis process. The third and fourth authors reviewed results. The third and fourth authors did not contribute to data management due to the potential power relationship involved in being service providers.		
1	Familiarise yourself with your data	The first author familiarised herself with the data by listening to the audio recordings before transcribing the interviews. Each transcript were then re-read prior to making any notes about initial codes. .
2	Generate initial codes	By reading through the data, each transcript at a time, ideas that seemed to be frequently occurring throughout the data were highlighted by the first and second authors. With further re-reading of the data, initial codes for these highlighted sections were then created. A sticky note system was produced to record frequency of codes appearing within interviews. Across each interview the sticky note system was supported by codes reoccurring in differing interviews throughout the data.
3	Search for themes	The first author then reviewed the codes and discussed reoccurring codes and their relation to the research questions with the second author. Therefore, through in-depth discussions relating to context of codes, broad initial themes were generated. From this, the three key themes were further analysed to gain an understanding of the concepts within these and thus, sub-themes were derived.
4	Review themes	The first author then revisited the transcripts to ensure that the themes were a true representation of the codes and that utilising the sticky note system the participants quotes could truthfully sit under the themes and sub-themes.
5	Defining and naming themes	Upon discussion between the first and second author the concepts of themes were then clarified. The authors specified the meaning behind the themes by naming and them and defining what they mean with reference to the context of the data. Once themes were explained, sub-themes were named and defined also, outlining of how they fit under their respective broader themes with concepts that have been derived from the data.
6	Producing the report	The first author then proceeded to write the report, outlining the themes and sub-themes and how they relate to the data, ensuring that quotes were utilised to ensure credibility of results. Quotes were meticulously selected to draw on the most common ideas that were stated during interviews by participants. This was completed by the first author who read the transcripts and utilised the sticky note system to identify matching quotes with themes. Once these quotes had been tabulated across all the participants, quotes were compared and selected based on how best they explained the themes that were derived from the data and to ensure that all participants were included. All authors reviewed this and agreed upon use of quotes and findings produced.

and suspending judgements) and keeping a detailed audit trail in the form of written notes to record researcher feelings and experiences. Further, interview transcripts and audio recordings were also utilised and scrupulous records were kept of all steps of the data analysis process. Transferability, or the extent to which findings might be applied to other situations, was enhanced by the explanation of the background of the study, description of participants and their families and the research design and data analysis process.

3 | FINDINGS

Eight mothers participated in the study. All were partnered and parenting children with cerebral palsy. Mothers described having one ($n = 1$), two ($n = 4$), or three ($n = 3$) children. Mothers were mostly educated to university level including Bachelors or equivalent ($n = 6$) and post graduate ($n = 2$). Mothers worked part time ($n = 7$) or not at all ($n = 1$). Mothers described their child's physical capabilities and needs for assistance to communicate, with mobility and transfers, and assisting with self-care tasks (see Table 3).

Three overarching themes were derived from the data: *Equipment impacts on all areas of life*; *Frustration navigating the NDIS*; and *Gratitude, hope and suggestions*. Sub-themes were identified within the overarching themes to categorise concepts that were drawn from the data, the relationships between themes and sub-themes can be seen in Figure 1.

3.1 | Theme one: equipment impacts on all areas of life

All participants highlighted the importance of assistive technology (referred to as “equipment” by

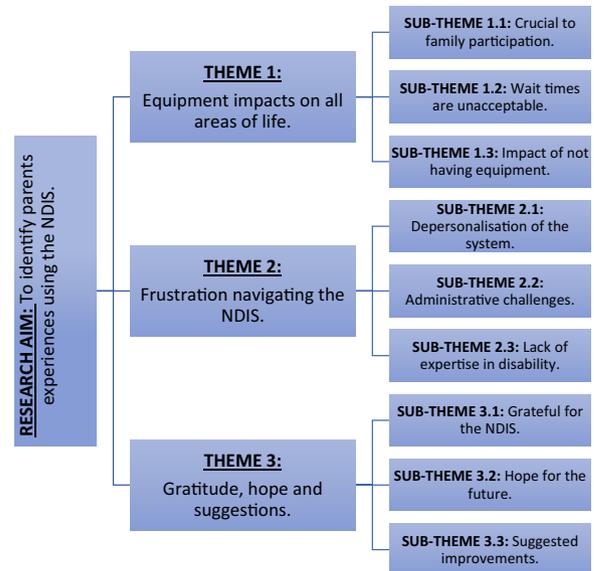


FIGURE 1 Thematic map of themes and sub-themes derived from the data

participants) to engage in occupations of their everyday life. Regardless of the level of care their child required, all participants viewed assistive technology as essential to support their child to actively live a meaningful life and their ability to control and choose their level of participation in varying occupations. However, all participants expressed similar frustrations that “there has been enormous issues with equipment” (Kate). Assistive technology limitations placed on children reduced the family's ability to exercise the choice and control that the NDIS aimed to provide through providing funds for assistive technology. Encompassed within this theme were three sub-themes that arose; *crucial to family participation*; *wait times are unacceptable*; and *impact of not having equipment*.

TABLE 3 Participants, children and characteristics of care

Participant	Child's age (years)	Child's GMFCS ^a	Type of care provided			
			Assistance to communicate	Assistance to mobilise	Assistance with self-care	Assistance with transfers
Tammy	11–15	5	X	X	X	X
Simone	0–5	3			X	
Bonnie	6–10	5	X	X	X	X
Celeste	11–15	5		X	X	X
Kate	6–10	3				X
Amy	6–10	5	X	X	X	X
Charlotte	6–10	5		X	X	X
Sam	6–10	2	X		X	X

^aGross Motor Functional Classification System: 5 = wheelchair mobility and limited postural or extremity movement; 3 = hand-held mobility device inside and wheeled mobility long distances; 2 = walk in most settings and climb stairs holding onto a railing, or may walk with physical assistance, a handheld mobility device or used wheeled mobility over long distances (Palisano et al., 1997).

3.1.1 | Crucial to family participation

Five participants explained that, without the correct assistive technology in place, the whole family experienced limitations in their ability to engage in family leisure and other quality experiences causing “social isolation” (Charlotte). Four participants also stated that they did not believe it would be “fair” for their children “to sit on the sidelines and watch” (Bonnie) if the family were to participate, which often meant that the family would not get actively involved. Sam further questioned the insight of the NDIA about their understanding of “how much we really need those things”, such as assistive technology to engage as a family. However, the true lack of family engagement was stated by Charlotte when she said “...she's little and we are a family. So, what Laura can't do, we all can't do... It's not like we are going to leave her behind and say you can't go”.

3.1.2 | Wait times are unacceptable

Additionally, all of the families made it apparent that under the NDIS they were “still waiting” (Sam) for assistive technology. Seven participants stated that they had been waiting “more than half a year” (Simone) to receive assistive technology that would help their child to participate. Some even stated that they found the assistive technology process to be a “black hole” (Kate), leading parents to believe that “you have to get to breaking point before it's being moved through quickly” (Amy). One participant in particular expressed that after the hoops that participants have to jump through and all of the exhaustive efforts and rejection that she had experienced that she felt as if “...it's almost like they take a long time to provide what you need because it's almost like they are sort of hoping that your daughter or son might die in the meantime so that they can save some money” (Sam).

3.1.3 | Impact of not having equipment

All families highlighted some of the impacts that the lack of assistive technology was having on their child. Five participants felt that it often “took the risk of injury” (Bonnie) for assistive technology to become a pressing issue in the eyes of the NDIS. Three mothers directly reported a time that their child was injured experiencing issues such as “pressure sores on his ear from an old wheelchair” (Tammy), “choking incident at school” (Amy), and “[falling] off the front porch and smash[ing] her face” (Charlotte) due to the fact that they were waiting on assistive technology. Parents also highlighted that not only does the lack of assistive technology impact their child's safety, but it also impedes their sustained ability to care for their child. One parent in particular stated that:

“...they focus only on the child and the child's needs. But when you've got a daughter that is entirely dependent on you, you are almost a part of your daughter...she can't do anything without you, so your health really matters” (Sam).

Six parents who assisted their children with mobility and transfers also commented on “back injuries” (Tammy) and how life without the equipment is “more difficult and time-consuming” (Celeste) for them as a family unit. However, Amy, a parent who had been waiting two years, stated that there were also financial burdens that were placed on the family as a result of equipment not materialising and the potential risk to children:

“...we have ended up \$1000 out of pocket with hiring fees. But you're in such a really bad situation because you are like, what do you do? Do you put your child in an unsafe situation? Or do you just pay it? So, we're like well, we don't really have a choice”.

3.2 | Theme two: frustration navigating the NDIS

While speaking about the NDIS, all participants re-stated that it was frustrating to navigate. Some participants used emotive phrases such as “horrendous” (Bonnie), “life-destroying” (Charlotte) and “antagonistic” (Celeste) to describe the new system. These feelings were also linked to participants having the sense that they were being caught in a system where they were promised the idea of choice, however, when they tried to exercise this, they were limited by the challenging systems in place under the NDIS. Therefore, three sub-themes emerged: *depersonalisation through the system*; *administrative challenges*; and *lack of expertise in disability*.

3.2.1 | Depersonalisation through the system

When comparing the NDIS to previous systems that were in place in the disability sector, six participants stated that they felt as though the system is “faceless” (Celeste) and that the system lacks personalisation that was previously present with a localised system. One participant stated that “I always knew I could depend on the local physio and occupational therapist...they would be really focused on the steps needed” (Tammy) and this gave a feeling of greater support. Parents compared the localised system to the centralised NDIS and felt that they were having to “go through your whole story over and over again” (Amy), which made them feel “hollowed out” (Sam) and as though “they [NDIS] just don't get it” (Celeste). Four participants

stated that there were people who “were making decisions about what was best for [their] child without ever meeting [them]” (Bonnie). One participant even stated that even though the system was set up to help participants, they felt as though:

“it seems like such a hassle for them, like rather than them having to really help you they are sort of rolling their eyes, ‘oh we have to do that, we have to do this’ and it makes you feel really bad” (Sam).

3.2.2 | Administrative challenges

All participants experienced a level of difficulty interacting with the NDIS. Some participants specifically stated that it “hasn't been a very successful process” (Amy), that it has been a “nightmare experience” (Celeste). While another participant stated the processes and paperwork involved in participating in the NDIS has been “unnecessarily convoluted and problematic” (Tammy). Charlotte went on to describe that she felt “...so much documentation is getting lost in translation or in the system and no one [is] able to find things”.

Seven participants highlighted that these administration challenges were often due to the feeling that they were “going around in circles” (Amy) when “you have to redo the same assessment multiple times” (Simone) which three parents noted is a “waste of money that could have gone into helping us or someone else” (Sam). Parents often related this frustration to “poor communication with the participant” and a lack of clarity regarding the processes involved as suggested by Sam when she stated that “it's really hard to find out exactly what to do and how the system works, and it seems like even the people who are supposed to guide us through the process don't know the answers”.

Five participants also spoke of the lack of flexibility within a plan and how when it came time for a new plan, there was a feeling of there being “no consistency because it's year by year you're being reviewed and you don't know whether you get approved or not. So, it does cause anxiety to the family” (Simone). Families felt insecure knowing that future years may not provide the support that they required and received in the previous year.

3.2.3 | Lack of expertise in disability

Seven participants felt that when communicating with NDIA planners, that they were “speechless at their lack of training to even understand what cerebral palsy means, let alone quadriplegic” (Charlotte), with another parent stating that

planners “have no idea about what having a child with severe and complex needs entails” (Celeste). Simone went on to say that “because they are not familiar...they wouldn't know what we can ask for” to aid families in getting the best out of their plans. Five participants also highlighted the difference that a knowledgeable planner can make, this is evident when Kate stated that “Both my planners have been therapists in their past lives, and I felt like they understood the language I was speaking”.

Bonnie also experienced both a therapist and an administrator as planners, and noticed that the administrator “didn't seem to have the same understanding of the needs of a child with a disability”. Half of the participants stated that they also felt baffled that “the therapist put together a fantastic report for the NDIS...and they just ignored it” (Bonnie) just because “someone else needs to approve it that has no information about those conditions and no expertise” (Sam).

3.3 | Theme three: gratitude, hope and suggestions

Throughout data collection, participants often outlined a mixed range of emotions towards the NDIS. Participants expressed that “the NDIS is never going to solve all of the problems, it's just going to correct some of the disadvantages” (Sam). In correcting some of the disadvantages, participants were hopeful that they would be heard and be able to exercise the promised choice and control over the services and assistive technology they need in the future. Therefore, the following sub-themes were derived: *gratefulness for the NDIS*; *hope for the future*; and *suggestions for improvements*.

3.3.1 | Gratefulness for the NDIS

Although participants outlined frustration at some of the processes that they had experienced under the NDIS, four participants expressed that they knew they were “incredibly privileged...to live in Australia and to live in a society where this is even on the table” (Tammy). Seven participants expressed that in the areas of consumables and capacity building, the NDIS was providing more opportunities than the previous systems. Charlotte said “the new system, the core supports and having [help at home]... it has been great having funding for that under the NDIS”, a statement which was echoed by Kate when she said “I think that the NDIS is a much bigger improvement on the previous schemes”.

However, four families expressed that the processes and wait times around assistive technology caused “extra strain to families that is unnecessary, and it's undermining the good they are doing” (Sam). This can lead to families feeling

conflicted over how to feel about the system in that “they are giving [with] one hand and adding more difficulties with the other” (Celeste).

3.3.2 | Hope for the future

Six participants also expressed that they had hope that “next year will start to be a lot better” (Amy) because “there is a lot of room for improvement” (Simone), and that “maybe this is just a system trying to find its feet” (Tammy). However, two participants could not see the light at the end of the tunnel and were highly unsure of how this system was ever going to improve. Bonnie stated that her family “don't know how we're going to survive”, and Charlotte stated that they were “at the point where if this next plan doesn't come through... [they're] pulling out of the NDIS and going back to fundraising and getting things for [themselves]”.

Hope was the dominant experience among participants, although four mothers expressed fear such as Bonnie, “we all know it's not sustainable” and Kate, that “the conversations in the media around that funding may not continue are terrifying for families on the NDIS”. One participant in particular noted that “if it's not sustainable it's not going to help us long term because the condition of my child is permanent” (Simone) and the participants of the NDIS “need to have a system that will continue to care and look after [them] into the future” (Sam).

3.3.3 | Suggestions for improvements

Participants expressed ideas for improvements, with many coming up with similar concepts. Six participants felt that there needed to be clarity around the processes under the NDIS, with five participants pleading that the NDIS “please fix the equipment process” (Kate), and “streamline the assistive technology process” (Amy). Seven participants also suggested that there needed to be “experienced planners on board” (Celeste) who “have a clearer understanding of what disability means and what different disabilities mean for people” (Tammy). Another participant stated that they need to have planners that “specialise in cerebral palsy or maybe specific with certain conditions” (Simone) so that participants can feel valued and understood so that the NDIS can be “a good, comprehensive, caring scheme” (Celeste).

Six participants also highlighted that they think “the communication between families and the system needs to be better” (Sam) and that “they need to listen to us as the people who have lived it... listen to the therapists, support workers, people who have experience in the sector” (Bonnie). Because as one participant highlighted:

“...it's not the families that are having a hard time that are going to make a difference, it's when the service providers all stand up and go “Who are these people rejecting our letters? What qualifications do you have above us?” ...they are the ones who are going to make a change in the system for us” (Charlotte).

4 | DISCUSSION

This study explored the experiences of families raising children with cerebral palsy who had been NDIS participants for 12 months. The study sought participants' opinions and comparisons to past funding, as well as recommendations for improvements to the NDIS. Eight mothers of children with cerebral palsy described common experiences: drawn out wait times for assistive technology, termed “equipment” by families; lack of appreciation of the essential role that technology and equipment plays in the lives of children with a disability and their families; navigation difficulties; feeling de-personalised and managed by planners who did not understand their child or family needs; and uncertainty about future support.

Participants used emotive and powerful phrases to express their experience of immense difficulties and overwhelming sense of not having support within the system. In the current study, some families also found benefits in the NDIS, including the promise of a suitable system for their child, more supports at home and improved opportunity for their child if the scheme was ongoing. They compared past (localised) and the current centralised scheme, noting that the past localised scheme was more personalised and skilled compared to the NDIS, with mixed reviews as the system matured and improved. This concept was supported by Barclay et al. (2020) where participants found that the NDIS planners ability to support choice and control was largely impacted by their knowledge of disability and corresponding needs. Previous literature further supports the notion that participants are more likely to feel supported when their planners demonstrated knowledge of the NDIS and offered advice about options (Collings et al., 2019). Further, Howard et al. (2015) previously reported on the need for better understanding of family needs including provision of assistive technology and complex care requirements.

Recommendations for improvements to service delivery included reducing wait times for essential equipment, upskilling planners, including using experienced allied health practitioners as planners, better training for NDIS administrators in the area of communication, disability knowledge, family impact and more collaboration with allied health practitioners who knew the child/NDIS participant. It is widely known that

children with cerebral palsy rely on an enabling environment and supports. Chien et al. (2017) conducted a cross-sectional study in Australia, with children with developmental disabilities and found that environmental restrictions within home and community settings were crucial to minimise negative effects on community participation. The impact of not having assistive technology to support a child's engagement resulted in the child and family missing out on opportunities to participate in family occupations.

Furthermore, participants stated that the lack of assistive technology often had detrimental effects on all members of their family. Bourke-Taylor et al. (2014) supported the notion that assistive technology are a requirement to aid families and enable children to participate in their usual daily occupations. This concept resonated with participants as many stated a decreased level of physical health between themselves and their partners as a result of executing care duties that are deemed unsafe but could have been safely executed with assistive technology. Participants in this study reported that, while waiting for assistive technology, they had no choice over the situation and felt that they had to perform duties or else they might be placing their child at a greater risk of decreased participation. Mothers reported emotional distress related to inappropriate or unavailable assistive technology and described injuries to themselves and their children, noting their own need to stay healthy to maintain capacity to care. Past research has acknowledged the stress that mothers experience providing care, attending to numerous family responsibilities, navigating their child's service system, accessing assistive technology and therapy, advocating and managing the financial and participation issues related to their child (Bhojti, 2017; Bourke-Taylor et al., 2010; Davey et al., 2015).

The findings in this study emphasised the repercussions of poor communication between the NDIA and participants. Mothers experienced a lack of understanding about the needs of children with complex disabilities which often made it hard to feel like they were at the centre of decision-making. Karlsson et al. (2017) identified that lack of alignment with families reduces experiences of family-centred care. Although previous literature supported the notion that families require support or training when navigating the NDIS support (Lakhani et al., 2018), findings in this study suggest that families did not receive adequate training. Further, families in the current study would have benefited from past research findings advising the provision of reliable and consistent information to nurture families to develop the capability to exercise choice and control over their child's care (Brien et al., 2017).

Participants in the current study expressed being thankful, hopeful, and still fearful that such a system was being implemented in Australia. The current system was preferred by participants. Past research has suggested that there are more disability supports in place under the NDIS than there were

in the previous system (Collings et al., 2019). The findings concur with the Australian Productivity Commission (APC, 2011) that appraised the previous block funding model as fragmented, inefficient and underfunded. Most participants in the current study were hopeful that the NDIS would improve, however, families still doubted the level of sustainability of the scheme, a valid concern, given that the government let the previous scheme get to a level deemed unsustainable (APC, 2011).

4.1 | Implications for practice

The outcomes of this research suggest that allied health practitioners might consider how their role in service provision may change in accordance with the implementation of the NDIS. Occupational therapists provided direct services to all participants in this study. There is a clear role for occupational therapists in supporting families through the navigation of the NDIS, as supported by Barclay et al. (2020), so that families and their children experience greater choice and control. Of note, the findings of this study indicate that occupational therapists have a vital role in supporting parents to achieve an effective NDIS plan for their child. Further, they have a key role as service providers for children and families represented in this study. The findings suggest that occupational therapists must continue to provide services to children and their families using a family focused framework as participation for the child and family are interconnected, reliant on assistive technology and appropriate supports for the family (King et al., 2017). Occupational therapists have a duty of care to be coherent in managing the NDIS parameters for appropriate services and to be proactive preparing and assisting families to manage. It should be the utmost priority to assist families with temporary assistive devices to prevent injury from ill-fitting and outdated equipment, as well as exclusion from every day activities preferred by the family that results from a lack of appropriate equipment.

Past research suggested that preparation was key to getting more out of planning conversations, which forms a crucial part of navigation (Collings et al., 2019). Therefore, occupational therapists might assist families to prepare for planning meetings by encouraging clients and families to consider their goals that they wish to achieve. Supporting families to gain a good understanding of their circumstances and future needs will aid them in thinking about things such as potential assistive technology that may be needed as their child develops. This process will be critical moving forward so that requests can be placed in advance in an attempt to combat some of the implementation delays that were noted throughout this study.

Finally, occupational therapists who are experienced in the needs and trajectory of likely service, assistive technology, and modification needs of children with cerebral palsy

might have an important role in the training of NDIS planners and administrators to better meet the child's individual needs and the family's needs to care and support the child.

4.2 | Limitations and future research

There were some limitations noted in this study. This project had a small sample of only eight participants from one setting. This was attributed to the nature of requiring participants with at least 12 months experience utilising the NDIS as per the inclusion criteria. However, at the time of data collection the NDIS was still in its rollout phase and amongst service users in the research setting, some families were not eligible to meet these requirements. Moreover, the participants from this singular setting were targeted for the rich content of their consumer experiences. Utilising one setting allowed for the assurance that support provided was the same for each of the participants, allowing the potential variances in their experiences to have a greater reflection of their interaction with the NDIS. It is noted that although a small sample size, data saturation was achieved, as participants were identifying the same emerging themes, with no additions of new concepts.

Future research with consumers of the NDIS remain a crucial and important aspect of further streamlining the scheme to participants needs, expectations and meeting the aspirations of children and young people with cerebral palsy to experience of a future with social and economic participation as desired.

5 | CONCLUSION

This study explored families' experiences and revealed excessive wait times for assistive technology with substantial impact on their lives. The NDIS was frustrating to interact with posing administration challenges, communication issues and a lack of personalisation. Families mostly highlighted how grateful they were for the system and expressed fear as well as hope for improvements in the administration of the scheme. Service providers and families can collaborate to share consumer feedback with the NDIS to contribute to a responsive, successful system of support for children with cerebral palsy and their families.

KEY POINTS FOR OCCUPATIONAL THERAPY

- Consumer experiences provide occupational therapists with insights into where and how families raising children with cerebral palsy need assistance related to the NDIS.

- Occupational therapists need to advocate for more timely provision of assistive technology because delayed availability promotes the child and family's exclusion and may cause injury and increased stress for parents.
- Occupational therapists have a vital role in supporting parents to achieve an effective NDIS plan for their child.

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CONFLICT OF INTEREST

The authors have no conflict of interest to declared.

AUTHOR CONTRIBUTION

All authors contributed to the study design of the project. The first author conducted the data collection process and first draft of the manuscript. The data analysis, interpretation of results, and critical evaluation of the manuscript was completed by the first author with guidance and review by the other authors. All authors were involved in revising and approving the final manuscript prior to submission to journal.

DATA AVAILABILITY STATEMENT

Research data are not shared in this study as permission was not received from participants to share raw data, that is, interview transcripts. Participants agreed to their data be amalgamated and shared and their identity confidential.

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