

Flexibility in individual funding schemes: How well did Australia's National Disability Insurance Scheme support remote learning for students with disability during COVID-19?

Sophie Yates¹  | Helen Dickinson¹ | Catherine Smith² | Massimiliano Tani¹

¹Public Service Research Group, School of Business, UNSW Canberra, Canberra, Australian Capital Territory, Australia

²Melbourne Graduate School of Education, University of Melbourne, Melbourne, Victoria, Australia

Correspondence

Sophie Yates, Public Service Research Group, School of Business, UNSW Canberra, Canberra, ACT, Australia.
Email: s.yates@unsw.edu.au

Abstract

Individualized funding schemes are designed to offer people with disability greater choice and control over the services they receive. In this research, we report on a survey of over 700 families to explore how Australia's National Disability Insurance Scheme (NDIS) supported children and young people and their families to learn remotely during COVID-19. NDIS funding to support education during the first COVID-19 lockdown period forms an important case study of the flexibility of individualized funding schemes. Our results suggest that participant experiences varied widely, with some people able to make the changes they required and others left with a significant service gap. This shows that individual funding schemes are not necessarily more flexible than traditional systems in an emergency situation—useful flexibility depends on many factors, such as clarity of information giving, all actors having a shared message, proactive support of flexibility initiatives, and participants' ability to quickly navigate a complicated system. This research also highlights problems with the interface between the NDIS and mainstream services such as education.

KEYWORDS

care, personal budgets for, and purchaser–provider relations, children and young people, coronavirus, disability, education, early years and schooling, individualized funding schemes

1 | INTRODUCTION

The Australian National Disability Insurance Scheme (NDIS) is an individualized funding scheme introduced to fundamentally transform the quality of disability services and ultimately the life chances and outcomes of people with disability. In contrast to traditional services, the NDIS was designed to offer people with disability greater choice and control. Children and young people comprise more than half of current NDIS participants (NDIS, 2020). In comparison to their peers, children and young people with disability face significant inequities. This group is more likely to experience poorer health outcomes, be excluded or suspended from school and less likely to be employed (Cox & Marshall, 2020; Hall, Fildes, Liyanarachchi, Plummer, & Reynolds, 2019). Evidence from previous pandemics suggests that these events worsen inequities (Quinn & Kumar, 2014).

In this research, we explore whether the NDIS was sufficiently flexible for children and young people and their families to gain the kinds of support they required during the COVID-19 pandemic. Earlier research demonstrated that children and young people with disability and their families experienced significant disruption to their lives during the early stages of the pandemic, and for many this had detrimental impacts on their wellbeing (Dickinson & Yates, 2020). In this article, we report the results of an online survey that generated over 700 responses from children and young people and their families regarding the types of educational supports they received during COVID-19 and the impact this had on their lives.

We begin by describing Australia's move to individualized disability funding in the form of the NDIS. While the aims of this scheme are ambitious and it has achieved some service and wellbeing improvements for people with disability, research has shown the implementation of the NDIS to be patchy, with inequalities in participant outcomes and problems with accountability, flexibility for participants, and the market-based delivery model (Carey, Malbon, Reeders, Kavanagh, & Llewellyn, 2017; Gavidia-Payne, 2020; Malbon, Carey, & Meltzer, 2019; Malbon, Carey, & Reeders, 2019; Tune, 2019). However, we note that much of this research is based on adult populations rather than services to children and young people. We then outline our research methods before presenting our findings with respect to educational support for students with disability during COVID-19. Our results suggest significantly changed needs for NDIS funding during the pandemic, primarily due to responsibility for children's education shifting from teachers to parents and carers during the lockdown. While about half of respondents reported that students with disability needed changes to their NDIS plans and supports, only a tiny fraction had been able to alter their plans. Many respondents described not being able to access the supports they needed. Barriers to flexibility as perceived by respondents included confusion and sometimes inconsistent information about whether the NDIS could fund educational supports; previous negative experiences with the NDIS; administrative burden; and inability to move funding between different support budgets.

Our evidence suggests that while some people received proactive and flexible service, a core NDIS principle of choice and control was not realized for all scheme participants and their families during this global emergency. The ability to achieve flexibility is not a given of the scheme and depends on a range of stakeholders having similar messages about use of funds, and participants' skills in navigating complex systems. This research points to the importance of capacity building in participants, family members and those on the front line of the scheme. Moreover, emerging evidence suggests that individualized disability funding schemes may have significant equity implications, with some able to achieve better outcomes than others. We argue that advocacy is important to ensure that the scheme operates in an equitable way, and yet these services have seen considerable cuts recently.

1.1 | Individualized funding and Australia's NDIS

Over the past few decades, disability policy has become increasingly internationalized, not least through commitments such as the 2007 UN Convention on the Rights of Persons with Disabilities, which set out a powerful imperative to support people with disability to live active and meaningful lives in the context of their communities. These

articulations have taken hold in different nations, broadly tied to a personalization agenda (Pearson, Watson, & Manji, 2018). Australia has followed such a trajectory, embarking on significant reform of care services through the NDIS. A key component of individualized funding schemes such as the NDIS is offering people with disability control of a budget that can be used to purchase services, allowing people to tailor their care. This is intended to expand choice and control of services so they are more flexible to individual needs, which in turn should help to integrate individuals into society, restoring people's rights as citizens (Oliver & Sapey, 2006).

In Australia, disability services have traditionally been the responsibility of state and territory governments, and a range of models had been developed across the eight jurisdictions (Fisher et al., 2010). The funding and organizing picture for disability across the country was complex, with splits between state/territory and federal responsibilities. In making the case for the NDIS, advocates argued that disability services were underfunded, inflexible and built around the needs of the system rather than the individual (National People with Disabilities and Carer Council, 2009). Therefore, disability services were "fragmented and inefficient and [gave] people with a disability little choice and no certainty of access to appropriate supports" (Productivity Commission, 2011, p. 2). In addition to these organizational complexities, research found Australians with disability fared worse than those in other developed nations (OECD, 2009), had low levels of labour force participation (Milner, Lamontagne, Aitken, Bentley, & Kavanagh, 2014), experienced social exclusion at high rates (Mithen, Aitken, Ziersch, & Kavanagh, 2015) and experienced significant rates of violence (Krnjacki, Emerson, Llewellyn, & Kavanagh, 2016), with these inequities becoming worse over time (Kavanagh, Krnjacki, Beer, Lamontagne, & Bentley, 2013).

The NDIS offers greater investment in early intervention and community-based support for people with low support needs, and individualized funding packages for people with higher support needs. While Australian disability services have historically been predominantly block-funded, the NDIS brings them closer to much of Western Europe and North America, where variants of individualized funding are available (Purcal, Fisher, & Laragy, 2014). The NDIS will ultimately provide approximately 460,000 individuals who have significant and permanent disability with individualized funding budgets (Carey, Nevile, Kay, & Malbon, 2020). Of the 412,543 current NDIS participants, 56% are children and young people aged under 25 (NDIS, 2020).

Once accepted to the scheme, participants develop a plan that includes their life goals and the budget allocation available to support achieving these. Participants may receive up to three types of support budgets: core (support with everyday activities), capacity building (to build independence and skills), and capital (to buy assistive technology, equipment or home and vehicle modifications). The plan articulates the types of services agreed in relation to these different budgets. The NDIS is not intended to replicate services that are already provided by other systems (e.g., health, transport, education). Importantly for this study, the NDIS funds support to help students engage with education, but will not pay for items deemed the responsibility of schools or education departments. Individualized funding might include things such as: support for daily living activities at school like eating or getting around; equipment or technology; and support for transitions between schooling levels and into post-school options. This has led to confusion and challenges for some people about where particular technologies or services should be funded from (Warr et al., 2017). Participants can manage their budget in three ways: the National Disability Insurance Agency (NDIA) manages the funding, it is self-managed or a plan manager is provided. Plans are reviewed annually (or in some cases every 2 years) to ensure they are still appropriate. If there is a significant change in circumstances, participants can request a plan review at any time.

The NDIS has previously been criticized for being inflexible in accommodating changes to plans, for example in using funds for different types of therapies to those agreed in plans (Tune, 2019). In late 2019, the federal government announced a series of changes to try and make plans more flexible. The NDIS announced additional flexibilities as the COVID-19 pandemic began to take hold, such as planning processes happening by telephone rather than in person, more ability to shift capacity-building funding into core supports, priority access to home delivery of shopping, and the ability to use existing funds to purchase low-cost assistive technology to engage with telehealth and telepractice. The NDIS also began to reach out to participants identified as 'high risk' via a special team of planners, to assist people in organizing their care during the pandemic.

Having set out this background in relation to individualized funding systems and the NDIS, we now provide an overview of the methods used in this study.

2 | METHODS

The survey reported here was devised by Children and Young People with Disability Australia (CYDA), in consultation with disability and education scholars, to interrogate the educational experiences of children and young people with disability during COVID-19. CYDA is the national representative organization for children and young people with disability. The survey ran from 28 April to June 14, 2020 (nearly 7 weeks). It therefore provides vital information on respondents' experiences when schools had been mostly closed to students and covered the period of transition back to face-to-face teaching for the majority of students. CYDA shared the survey to its membership of over 5,000 people and it was also promoted via social media by a number of other disability advocacy organizations.

CYDA sought the assistance of researchers from UNSW Canberra to analyse the data, a summary of which was published by Dickinson, Smith, Yates, and Tani (2020). We received ethics approval from the UNSW Human Research Ethics Advisory Panel, reference HC200411.

The survey asked about supports that students with disability had received both before and during the COVID-19 pandemic. It asked whether their needs for NDIS supports for educational purposes had changed during the pandemic, whether respondents had been able to alter their NDIS plans, and if the students had received adequate support for their education during the pandemic. In this article, we report mainly on the NDIS-specific results of this survey. We present quantitative data using simple descriptive statistics. Twelve questions included boxes for free text responses, and many respondents provided extra information to contextualize or enrich their answers to the quantitative questions. We analysed the qualitative data thematically using NVivo. One researcher developed the coding scheme using a combination of directed and conventional content analysis (Hsieh & Shannon, 2005) and conducted the initial analysis, with cross-checking undertaken by a second researcher. Directed analysis flowed from the survey questions themselves (respondents were asked to specify the changed needs of children and young people with respect to NDIS funding for education), so simple analysis focused on the types of changes respondents reported needing and whether and how they had been able to make these changes. Further codes were created to aid understanding of the barriers to flexibility respondents reported experiencing. We assigned a number to each respondent and provide this number when reporting direct quotes.

2.1 | Findings

Having outlined the background and methods for this study, we now present the findings. First, we describe the respondent sample, including how many were NDIS participants and received NDIS supports for education before the pandemic. We then describe how many respondents reported changed needs for NDIS funding to support education during the pandemic, and what form these changed needs took. Next, we outline the changes respondents reported being able to make, such as making extra purchases and receiving higher funding amounts. Lastly, we consider the changes respondents were *not* able to make and the perceived barriers to accessing flexibility in NDIS plans.

2.2 | Participant profile

A total of 719 respondents completed the survey, 95% of whom were a family member of a child or young person with disability. The remaining 5% of respondents were children and young people with disability. Respondents came from all Australian states and territories, with the largest proportion being from the three most populous states of

Victoria (31%), New South Wales (25%) and Queensland (24%). Six hundred and twenty-nine respondents gave information about whether the student with disability represented in their answers was an NDIS participant, and as Table 1 shows, nearly three quarters of these indicated they had an NDIS funding plan.

Respondents were also asked whether students had received NDIS-funded educational supports before the COVID-19 pandemic. As Table 2 outlines, of those who responded to this question, just under a third were in receipt of such funding. To some extent, this demonstrates the division of responsibility concerning access to education, as outlined earlier. The NDIS is restrictive in the degree to which it will fund education-related supports, seeing these as a responsibility of state and territory education services.

2.3 | COVID-19 led to shifting needs for services

The survey asked respondents whether they perceived responsibility for provision of education to have changed after the pandemic hit. As Table 3 indicates, respondents felt that responsibility for providing the education routine of students had largely shifted away from schools and teachers to parents and carers.

Numerous respondents described the increased educational responsibilities of parents and carers during the lockdown, many of whom were trying to juggle schooling students with disability and their siblings with work and other responsibilities. Free text responses indicated how challenging many families found this:

No guidance on how to manage the curriculum at home with a child with ADHD [Attention-Deficit/Hyperactivity Disorder]. I taught what I could trying to manage my workload as well (participant #190).

Yes	460	73%
No	169	27%
Did not answer	90	

TABLE 1 Is the child or young person an NDIS participant?

Abbreviation: NDIS, National Disability Insurance Scheme.

Yes	143	31%
No	316	69%
Did not answer	260	

TABLE 2 Were there any supports that the NDIS funded for the child or young person to assist in accessing education before the COVID-19 situation?

Abbreviation: NDIS, National Disability Insurance Scheme.

The student	29	5%
Parent or carer	489	78%
The same teacher/educator as before	76	12%
A different teacher/educator	7	1%
The same education aide/support person as before	8	1%
A different education aide/support person	7	1%
Other	15	2%
Total	631	

TABLE 3 Who is the adult mainly responsible for providing the child or young person's daily education routine during the COVID-19 situation?

Being a parent with a disability, plus caring for an 8-month-old baby, remote learning and supporting my son who also has a disability has been a struggle. ...my son has autism and ADHD, so learning and focussing is a struggle as it is, let alone when the "parent" needs to all of a sudden become the supervising "teacher". That's against the black and white unwritten rules. School and teachers are for learning, home is for relaxing and parents are parents, not teachers (participant #333).

Parents and carers' new responsibilities went beyond assisting students to access materials and supervising them while they completed work—many respondents reported needing to adjust materials to suit students' needs, as schools had provided the same materials for students with and without disability:

School provided learning material. But minimal modification. We spend on average 5-8 hrs a week modifying plus an additional 15–20 hrs (at least)/per week in helping (most of the work set by school is unable to be done independently by our child) (participant #213).

The student received the same materials as the rest of the class which had to be adjusted/modified by parent so student could access the content (participant #25).

This shift of responsibility from school-based education professionals to parents and carers in the home resulted in significantly changed needs for NDIS support, as we will outline further below.

The survey asked about a number of potential impacts of the pandemic on the lives of students with disability and their families, beyond specific educational impacts. Relevant to the NDIS, 22% of respondents had cancelled support workers coming to their home (e.g., due to fear of infection), 19% had had support workers cancelled by the service provider and 31% had experienced cancellation of other NDIS-funded services. Cancellation of support workers meant that students either received no service at all, or that parents and carers were required to take up the slack, for example "Lost support due to COVID 19 so have gone months 1 to 1 continuously with high needs child" (participant #40). As this quote illustrates, many families found themselves under significant pressure with schools closed and usual supports cancelled.

2.4 | Types of changes required

The NDIS is designed to provide support for people with disability only in areas not covered by mainstream systems (e.g., education, public transport and health) (Whitburn, Moss, & O'Mara, 2017). As we have demonstrated, pandemic-related school closures meant that many supports previously provided by the education system ceased, meaning parents and carers became responsible for the day-to-day educational management of students. This led to changed needs for NDIS supports as parents struggled to balance work, caring and education. Of the students with disability who received NDIS funding represented in this survey, the needs of 45% had changed with respect to accessing education (Table 4).

Although not all participants provided free text responses to specify what changes were required, some did provide detailed information. The most commonly reported needs centred around equipment (particularly technology) and support workers. Because families were expected to engage with schooling, health services and therapy appointments remotely, many people found that they needed a device such as a laptop or iPad to do this. Families that had previously managed with one computer between them now needed more devices or updated devices to access the new platforms schools were using to deliver educational content. Other technology needs included assistive technology, apps (e.g., speech to text) and other software, and hardware such as keyboards, monitors and printers for making hard copies of educational materials (which is necessary for some students with disability who struggle to engage with material on a screen). Some respondents also needed to purchase materials to enable therapies:

Yes	203	45%
No	252	55%
Did not answer	264	

TABLE 4 Have the child or young person's needs for NDIS funding to assist in accessing education changed since the COVID-19 situation?

Abbreviation: NDIS, National Disability Insurance Scheme.

Unable to utilise NDIS funding on materials, purchased education, speech, music, OT [Occupational Therapy], physio and art materials to run education therapy and medical management from home. Significant debt. Zero support (participant #273).

As responsibility for education had largely shifted to parents and carers, respondents reported more need for support workers in the home. Before the pandemic, 56% of students had had access to an individual support worker (e.g., education aide, learning support worker) to assist them in the classroom if they were unable to complete tasks independently. During the pandemic, this dropped to 12%, often due to Occupational Health and Safety restrictions not permitting school-based supports workers and aides to work in students' homes alone and unsupervised by a teacher. Parents reported needing NDIS-funded support workers in the home to supervise students and tend to their needs while parents worked, or to assist them with learning activities:

Need for worker to assist with keeping student focused, and assist with behaviour (participant #309).

Schools are closed for most. Thus we needed to have been given enough funding to cover school hours or at least enough for 1:1 home based for 3 hours every day. Not going to happen! (participant #552).

The impacts of insufficient support extended beyond students with disability and their carers. In some cases, increased support worker hours were required because the demands of home schooling were impacting other siblings. Some students with disability required significant assistance with schooling, to the extent that parents were not able to also tend to the needs of their siblings without disability:

My son needs a person to support his learning, I am at home with him and his sibling and for both of them their learning is impacted by his support requirements (participant #536).

Many respondents also reported increased needs for supports to assist with mental health, behavioural challenges, social skills and connection, communication skills and occupational therapy:

Needed more psychologist and support worker support. Suffered a great deal from isolation and routine changes (participant #263).

My son's learning will be significantly impacted, he needs intensive therapy and intensive support to learn, we are only maintaining what he has learned at school while we are at home, his therapy is starting to foster developmental skill but this has taken two weeks to establish and his daily living skills therapy has had to be delivered by his family who are not skilled therapists. His NDIS plan needs to be more flexible at this time so we can use his funding to suit his needs at home in this stressful time (participant #544).

Other needs reported related to teacher's aides or tutors, non-technological equipment such as desks and chairs, and personal protective equipment. A small number of respondents noted that some NDIS support needs had

reduced, for example, lower transport costs due to school closures, or fewer support worker hours since support workers had been used only on school grounds.

2.5 | Respondents' ability to make changes to NDIS supports

Here, we discuss whether and how respondents were able to make changes to their NDIS arrangements to support education. As the foregoing demonstrates, just under half of respondents experienced a need for changes to their NDIS arrangements, for a variety of reasons. However, Table 5 shows that only 36 of those needing changes had requested a plan review; of these, 9 had been approved and 7 had not. Sixty-five respondents reported not needing a plan review, perhaps because there was enough flexibility in their current plan to meet their changed needs. Worryingly, about half of respondents with changed needs had not yet requested a plan review, and 10% were still awaiting the result (although some may not have been waiting very long at the time they filled out the survey, as the data collection period was 7 weeks relatively early in the pandemic, and reviews can take months).

It was also clear from respondents' comments that some had managed to make changes to their NDIS funding arrangements to support the remote education of students with disability, while some had not. A small number reported useful, proactive service from NDIA staff and Local Area Coordinators (people who provide planning and coordination supports), for example:

They told me just to use my plan however I wanted and when it got low to ring and they would bring a plan review forward (participant #541).

Another respondent agreed:

NDIS was very good for us. Our [Local Area Coordinator] checked in and we moved our funds around (participant #17).

A very small number of respondents reported receiving extra funding (e.g., "core supports were increased by 50%"; participant #217), and some had been able to redirect funds from their flexible 'core supports' NDIS budget to purchase equipment or services to support education. One respondent mentioned that self-management made for greater flexibility: "I self-manage my daughter's plan and used her funding to support her" (participant #70). However, another self-manager had only heard by accident that flexibility was possible:

I self-manage my daughter's NDIS and had no information as to flexibility available. It was only when I happened to have a call with the [Occupational Therapist] for advice regarding my daughter's issues

TABLE 5 If [student is NDIS participant], have you needed to request a change in the NDIS plan due to the COVID-19 situation to assist in education?

Yes—Have requested a plan review and it was approved	9	5%
Yes—Have requested a plan review and it was not approved	7	4%
Yes—Have requested a plan review and are still awaiting the outcome	20	10%
No—Did not need a plan review	65	32%
Have not yet requested plan review	100	50%
Total	201	

Abbreviation: NDIS, National Disability Insurance Scheme.

experienced during online learning that I was informed of some changes to funding allowing for flexibility in purchases. The OT had only discovered this through an OT chat group (participant #248).

Another had heard that support budget flexibility might now be possible but had not been told so directly by the NDIS:

I have recently heard that there are changes in the way NDIS packages can be now used, that core & therapy packages can be combined—this is a phonecall I am yet to make to confirm. But there has been zero contact at all from the NDIS if this is the case (participant #200).

Lastly, some people who had been able to use more of their funding to support students at home were faced with a significant shortfall before their next plan review. As one respondent reported:

Our plan is up for review in December, and we have nearly no money left as we did not get enough anyway, so it is stressful, as we are now going to be hugely out of pocket (participant #17).

Running out of money may not be a huge issue for some families with economic resources, but for families in lower socio-economic brackets it would be very concerning. Many respondents mentioned financial concerns in comments, either related to the NDIS or to the pandemic situation more generally.

Some respondents outlined the specific changes they had been able to make. The most common change to support arrangements for education was the use of support workers to assist students with remote learning, for example: "More support hours required/used from NDIS plan budget to support education at home" (participant #510). Another parent, upon responding to a question about whether the student receives adequate support with their education, commented:

Our daughter does receive adequate support with her learning, but it is only because we are using her NDIS funding to employ extra support workers to act as her aides at home (participant #304).

There was some evidence that respondents were getting around restrictions on education funding by using support workers originally approved for other purposes:

Due to no support from the school and parents still working we utilise "in home respite" to gain assistance with our daughter's education. Note NDIS do not fund education assistance and hence the fact we have categorised this assistance as "in home respite" (participant #524).

I was lucky enough to have had funding to support in-home supports, which I used to assist with schooling during COVID-19. I am the sole parent of two children with disability, plus an essential worker. Without this support my children would have received no quality schooling at all during the school-closures (participant #218).

The other main way respondents were able to use NDIS funding to support education related to the purchase of technology, for example "They helped fund a suitable touch screen computer" (participant #63), or "The NDIA changed the AT [assistive technology] criteria to allow for the purchase of a laptop" (participant #385). However, this did not always happen quickly enough, as one parent reported: "...purchase of an iPad with NDIS funds was only approved yesterday after waiting nearly 2 months" (participant #265).

Having discussed the changes some respondents were able to make, we now consider what barriers respondents perceived to accessing the flexibility they needed.

2.6 | Barriers to receiving adequate support through the NDIS

Many respondents experienced barriers to accessing NDIS supports to assist in the education of students with disability. One significant barrier related to the interface between the NDIS and the education system: 25 respondents from four jurisdictions (Victoria, New South Wales, South Australia and Queensland) commented that NDIS rules do not allow for funding to support education. This is not necessarily the case—as reported earlier, 143 respondents reported that children and young people already received NDIS funding for educational needs prior to the pandemic. However, not all respondents were aware that funding was available for education, or they had not been able to access it. Most described this as a general principle, but one respondent reported being refused educational support and being told by the NDIS directly that this was the responsibility of the education department:

NDIS declined to provide additional support as they viewed it as a double up of supports and stated education [department] had received funding for him and they should have been supporting him (participant #425).

A second barrier to flexibility reported by respondents was the effort required to interact with the NDIS. One parent explained their decision-making with reference to the difficult experience of NDIS plan reviews:

Our son needs assistance from experienced educators but this is where NDIS fails. They say it's "educational" and the responsibility lies with Dept of Education. ...It was my understanding NDIS does not provide assistance for education so I have not submitted a plan review. Why go through the excruciating pain of a review when they'll just tell me it's not NDIA's responsibility?? (participant #557).

Several other people who needed changes to their funding and supports reported that they did not feel able to meet the anticipated challenges of making these requests of the NDIS, with one single parent commenting "That takes time and energy I don't have. Easier to struggle on" (participant #579), and other respondents reporting "I don't have capacity for that battle" (participant #95) or "I've basically given up" (participant #280). One parent commented that she needed extra support but had no time to investigate this as she was too busy actually implementing home learning arrangements for her son. Another parent commented that their needs had also increased but they were experiencing burnout from previous interactions:

...we have little energy and time to approach NDIA, and have recently had to advocate and lobby to get our child's NDIS plan reviewed as there was insufficient funding despite our request and rationale. We were successful in getting some additional funding (still insufficient and much less than requested). We should fight again and request again, but we are exhausted and feel broken by school, the Catholic Education Organisation, and the NDIA (participant #213).

The foregoing quote also demonstrates that students with disability and their families interact with many different systems, each of which adds to the complexity of their service experience.

Administrative burden (e.g., 'ridiculous' complexity and 'red tape') was also perceived as a barrier by a number of respondents, as well as frequent rule changes and delays. A participant who had been able to buy a computer worried about the lack of information provided to NDIS participants about flexibility during the pandemic, the self-advocacy it had taken to get the computer ("I had to get a report from her OT...the computer was not offered. I needed to ask"), and whether others in need would have been able to do the same:

How many people with disabilities who are unable to advocate for themselves are there?? The system is difficult, as specially for those with a disability and no support and they are the ones that need the help the most (participant #63).

As reported earlier, some respondents had been able to use their various support budgets flexibly, but others had less success, for example:

Absolutely no additional assistance has been provided by the Education department or NDIS to support my child in access or additional assistance to learn from home nor has the NDIS been flexible enough to allow more flexible use of support budgets. It's still the families struggling to make it happen (participant #427).

We needed more support and NDIS did nothing proactive or clear and simple (participant #95).

Another respondent reported the problems they had experienced with lack of flexibility while they were unable to use some services in lockdown:

Running out of Capacity Building supports budget while Community Participation budget untouched due to COVID-19 lockdown. As self-managed NDIS plan, we are hoping further flexibility to use Core Support budget for payments for speech therapy appointments post-COVID (participant #209).

A third had asked their Local Area Coordinator for a flexible approach, but had been instructed to use funds according to plan goals set before the pandemic:

The NDIS needs to adjust their filter questions as pinning reasonable and necessary decision making on goals created prior to COVID-19 is dangerous and inappropriate. The LAC I spoke to took a rigid approach when I asked about flexibility in my son's plan. I was told to use his goals, largely social and community inclusion focused, during a time when we are being asked to not be social or move freely in our community. It was a silly and dangerous approach during a pandemic (participant #576).

We will now consider the implications of our findings for the question of whether individualized funding schemes are sufficiently flexible to support participants during emergency situations.

3 | DISCUSSION

COVID-19 is an event that has exacerbated and shone a light on many existing challenges and inequalities (Deslatte, Hatch, & Stokan, 2020; Martin-Howard & Farmbry, 2020; van Barneveld et al., 2020). This has extended to people with disability (Dickinson et al., 2020; Sakellariou, Malfitano, & Rotarou, 2020). The goal of a personalized disability funding scheme is to achieve a higher degree of choice and control—that is, flexibility—than a traditional block-funded model. Thus, a successful individualized funding scheme should reduce inequalities by allowing sufficient flexibility for people with disability and their families to alter arrangements to receive the support they need during times of emergency. Our results suggest this has often not been the case during the early stages of the COVID-19 pandemic.

Children and young people with disability and their families, like society in general, experienced significant disruption to their lives and their support services due to the pandemic. However, the families of children and young people with disabilities often have complex needs and carefully balanced service arrangements, and the consequences of disruption to this can be severe (Dickinson & Yates, 2020). These disruptions led, in many cases, to changed needs for NDIS-funded supports. Respondents did not report a singular experience, as individual circumstances, levels of school support and NDIS service experiences all varied widely. In our study, about half of respondents reported changed needs to support students' education during COVID-19. But they also reported very variable

service responses and flexibility from the NDIS. Some respondents were able to change their plans and there were instances of good proactive service from the NDIS. However, other participants reported not being able to access the flexibility they needed, despite announcements from the NDIS about changes to the scheme to support changed needs during the pandemic. It appears that for many respondents to our survey, these NDIS initiatives were either inaccessible, not communicated well enough or inadequate for their needs.

Service inconsistency raises equity issues: not only does it imply differing levels of service between families, but the existence of a significant service gap is more problematic for families with lower socio-economic resources, particularly single parents. Families with financial reserves may be out of pocket from having to purchase supports with their own funds, but are less likely to be significantly financially disadvantaged or to go without supports. Equally, families with more resources are less likely to worry about using more funding now and running the risk of not having enough at the end of the year—if they run out, they can purchase supports using their own funds. Or if they redirect funding for purposes they are not sure will be permitted, they are financially stable enough to pay the NDIA back if required. Equity issues with individualized funding schemes have largely been explored with respect to adult services (e.g., Carey et al., 2017; Malbon, Carey, & Meltzer, 2019; Owens, Mladenov, & Cribb, 2017; Slasberg, Beresford, & Schofield, 2013) but our findings suggest similar issues apply to children and young people.

Our results also suggest some respondents were better able to navigate the system to get what they needed than others. For example, some respondents redirected the efforts of support workers employed for personal care and community access so that they were supporting education instead, or engaged extra support worker hours but categorized them as something other than education. Others did not know this was an option. Some reported being discouraged by earlier experiences with the NDIS to the extent that they did not even try to make the changes they needed, which may have led to students with disability missing out on plan flexibility that would in fact have been possible. The administrative burden associated with the NDIS has been well documented, for both scheme participants and service providers (Carey, Dickinson, Malbon, Weier, & Duff, 2020; Foley, Attrill, McAllister, & Brebner, 2020; Mavromaras, Moskos, Mahuteau, & Iskerwood, 2018; Olney & Dickinson, 2019). Research has shown that individualized funding schemes, which rely on participant and carer self-advocacy and ability to navigate complex administrative systems, are more accessible for well-educated, native English-speaking, and assertive individuals and families (Heneker, Zizzo, Awata, & Goodwin-Smith, 2017; Mavromaras et al., 2018; Owens et al., 2017; Russo, Brownlow, & Machin, 2020). This was likely a factor in some of the variation in support our respondents experienced with the NDIS during COVID-19. Such a finding points to the importance of high-quality advocacy to support individuals to navigate the scheme. The NDIS was designed with Local Area Coordinators playing an important role in undertaking this function, although in the implementation of the scheme these individuals have become more involved in creating plans than undertaking this type of role (Malbon & Carey, 2020). Moreover, governments have substantially cut funding to disability advocacy organizations since the introduction of the NDIS (Innes, 2015). This means there are fewer independent sources of support and advice for those experiencing difficulties in accessing and navigating the NDIS.

Another potential factor impeding flexibility and information dissemination is the broad array of different actors forming the NDIS service system. The scheme is administered by the NDIA, but most families deal with Local Area Coordinator for planning purposes, who may be an NDIA employee or externally contracted depending on the location. Families also interact with service providers such as Support Coordinators who help with plan implementation, as well as those directly delivering services, and finally there are a number of advocacy organizations working on behalf of people with disability and their families, often with limited funding. In an emergency situation, consistency of messaging is important if scheme participants and their families are to learn what changes are available—but this is difficult to achieve across such a large constellation of system actors.

These results also expose significant ongoing issues in the interface between the NDIS and the education system, which Whitburn et al. (2017) note is the mainstream service most accessed by NDIS participants. When a large-scale disruption such as a global pandemic affects participants' access to a mainstream service, where does the responsibility lie for addressing the resulting changes to service needs? Our findings clearly demonstrate that the

split of responsibilities across educational departments and the NDIS is not meaningful for many families and causes big issues for NDIS participants in practice. When school-based support workers were no longer able to provide in-person support, or did not transition to supporting students 1:1 in remote arrangements, students and their families were left with a service gap. The education department provided funding for a service families were now not receiving, and many respondents were unaware the NDIS could provide anything to bridge that gap—and in some cases, reported being refused flexibility to cover what they needed for education.

For children and young people with disability, we know that early intervention is crucial for improving outcomes and reducing service needs throughout the lifespan (Productivity Commission, 2011). While the first Australia-wide lockdown only lasted a few weeks, schools in Australia's second most populous state of Victoria were subsequently closed for Term 3 following a resurgence of the coronavirus. Further individual school closures may continue to occur and more widespread lockdowns are possible before the pandemic is brought under control. Even when all school campuses re-open some students may not be able to attend until there is a vaccine, due to being immunocompromised. If important educational supports are removed from NDIS participants for long periods, this has implications for participants' and families' wellbeing, participant outcomes both immediately and over the longer term, and the long-term success of the scheme as a whole.

4 | CONCLUSION

NDIS funding to support education during the first COVID-19 lockdown period forms an important case study of the flexibility of individualized funding schemes. This research has shown that individual funding schemes are not necessarily more flexible than traditional systems in an emergency situation—useful flexibility depends on many factors, such as clarity of information giving, all actors having a shared message, proactive support of flexibility initiatives and participants' ability to quickly navigate a complicated system. It is worth noting that the establishment of the NDIS has been used as justification for stripping away advocacy funding in Australia's disability system, on the basis that greater choice and control for participants negates the need for advocacy organizations. The research presented here shows that if the disability system does not provide effective capacity building or provide better support for people in individualized funding schemes, rule changes to allow for greater flexibility will not make enough difference for those accessing services. Moreover, without such supports it is likely that there will be unequal outcomes, with those less able to navigate the complex system less able to access appropriate resources.

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ORCID

Sophie Yates  <https://orcid.org/0000-0003-1912-8509>

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