

Exploring the lived experience of the National Disability Insurance Scheme for school students with disability in NSW Australia

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Abstract

To improve efficiencies in disability support funding, including support for people with vision impairment, in 2013 the Australian Government initiated the National Disability Insurance Scheme (NDIS). The impact on participants' lives has been widely documented, however, many of these studies have focused on adults with disabilities and related issues. But what of the situation for school students? Five purposely selected recent studies which investigated the experiences of Australian parents of school students with disability as they sought to access NDIS support are reviewed. Common themes identified in these studies confirm that families are frustrated with the reality of accessing less (not more) school-based support for their children as they grapple with the rules of the NDIS scheme in NSW. Parents are seeking more choice, more control, and more school-based services.

Keywords

Disability, student, National Disability Insurance Scheme, funding

Introduction

Australia's approaches to supporting people with disability reflect a chequered history. Various attempts at implementing suitable disability support models have been made including government funded services which are frequently delivered by private providers. The recent national approach to disability support designed to revolutionise the Australian situation has not necessarily achieved this outcome. This paper will introduce the Australian National Disability Insurance Scheme (NDIS) and draw on examples in the literature where the voices of students and parents highlight policy shortfalls and unresolved funding issues for Australian school students, living with disability in New South Wales (NSW).

Things begin to change in Australia

The early 1970s are recognised as a time of critical global change in social disability policy approaches, with the emergence of the Human Rights movements (which included people with disabilities) and the United Nations advocating in 1971 and 1975 for the rights of people with disabilities (Kendrick et al. 2017). However, prior to the mid-1980s, Australian families of people with a disability chose either placement in an institution or family-led care for the person. This situation remained largely unchanged until the Australian Government commenced programmes in 1986 to support community living for both people with a disability and older people (Kendrick et al. 2017). At this time, people with disability had no voice, were not treated

fairly, nor were they represented when important decisions were being made (Kendrick et al. 2017).

To this day in Australia, it continues to be illegal to discriminate against people based on their disability. Recognising the need to combat discrimination against people with disability, the Australian government created the Disability Discrimination Act 1992 (Cth) (the DDA) and the Disability Standards for Education 2005. Both reflected the Australian government's commitment to end discrimination of people with a disability and to create equal opportunities, including in education (Duncan et al. 2020). In 2009, many hundreds of people across Australia, including those with vision impairment, contributed to consultations as part of the development of a National Disability Strategy. For the first time in Australia's history, all state and federal governments agreed on a national policy to enhance the quality of life for individuals with disabilities, their families, and caregivers (Cowden and McCullagh 2021).

The need for a national disability support scheme

Due to pressure from the disability sector to address service and support gaps, in 2009 a report was commissioned which presented the findings of the National Disability Strategy (Buckmaster 2017). This report titled *Shut Out The Experience of People with Disabilities and their Families in Australia: National Disability Strategy Report* (National People with Disabilities and Carers Council 2009) found that the existing disability system was broken and failed people with disability, with insufficient and poorly coordinated services. Further, rigidity in services and a lack of tailoring for individual needs led to dissatisfaction with the block funded approaches of the time (Buckmaster and Klapdor 2010).

In 2011, the NSW Ombudsman reported on consultations held with families of children with disability (Ombudsman NSW 2011). Families noted significant problems with access to disability supports and challenges with finding services and accurate information, including access to trained professionals in the disability sector. Meanwhile, disability service providers complained of resource shortages, multifaceted administrative requirements and a system that was weighted to complex and emergency needs, leaving many without support.

The National Disability Insurance Scheme begins

While the provision of disability services of the past might best be considered as government controlled, many countries such as England, Germany and the Netherlands have adopted consumer-controlled funding as a means for catering for the disability sector (Foley et al. 2020). Aiming to make services easier to access for eligible people, and to shift towards "personalization and individualization" (Meltzer and Davy 2019, 251), Australia adopted this "social insurance approach" (David and West 2017, 332). The NDIS, labelled as a "complex social reform" (Foster et al. 2022, 141) was first implemented by the Australian Government in 2013. After a trial period of three years in seven trial sites around the nation, the Scheme's Transition Phase began in 2016, with the full roll-out by 2019-2020 (Buckmaster and Clark 2018).

Underpinning the NDIS, people with disabilities have a right to support, more choice and control over how that support is provided, with more individualised service delivery, and funding portability across the nation (Kendrick et al. 2017). People are considered eligible for the NDIS when they are aged from birth to 65 years, their disability is permanent and significant, or when they have developmental delay; people over 65 years are supported by the aged care system. The impairment could be intellectual, cognitive, neurological, sensory, physical, or psychosocial. Evidence of this status is required and provided by clinical professionals registered under the Health Practitioner Regulation National Law Act 2009 (Cth).

A report titled "People with a Disability in Australia 2022" noted that 4.4 million people in Australia, or around 20%, had a disability (Australian Institute of Health and Welfare 2022). Therefore, the number of people applying for NDIS support is likely to be significant. This includes people with vision impairment whose numbers were predicted to increase as early as 2015 with an ageing population and a high prevalence of eye disease (Ah Tong et al. 2015). The prevalence of vision loss is now predicted to increase from 6.7% to 7.5% by 2050 (Foreman et al. 2020).

The NDIS was established to improve the quality of disability services (Kendrick et al. 2017), and the Australian Government committed to providing \$33.9 billion to over 500,000 Australians with permanent and significant disability in 2022-23,

growing to \$44.6 billion in four years (Australian Government 2022). The increased investment aimed to improve choice and control over services to meet people's individual needs; to create more jobs and opportunities; and to encourage new providers to join, to increase the supply and quality of service for NDIS participants. At the time, the NDIS was reported to be more effective and individualised than previous approaches, creating freedom for participants (Kendrick et al. 2017) and favourably influencing the health and well-being of people with disability by ensuring equitable access to health services (Lakhani, McDonald and Zeeman 2018).

Reflections from the literature on the NDIS policy implications for education

Over the NDIS operational journey, policy implementation challenges have emerged related to definitions of care, collaboration, self-management, and the Scheme's remote reach. Early in the NDIS infancy, the capacity of NDIS policy to achieve reasonable and necessary care was challenged by Foster et al. (2016) in their study of 25 adults with acquired disability, including their families and providers. The study flagged the difficulties in reaching accepted definitions of reasonable and necessary care without compromising opportunities for people under the NDIS.

Collaboration is critical for the success of any person-centred support. Foster et al. commented in relation to the NDIS approach that "individualised funding is one attempt to ease problems of fragmentation and unmet needs, but perversely, it introduces further interface complexities" (2021, 127). These authors discussed the trend by organisations towards differentiation to ensure viability, during transition to the somewhat market-like system of the NDIS, with an unintended impact on interagency collaboration. Such a lack of collaboration has not worked in the favour of people with disability. In fact, rather than being person-centered, the operational culture of the NDIS has been labelled as a provider-centered practice (Green et al. 2018).

A key feature of the NDIS policy is the capacity for NDIS participants or their nominee to self-manage or "directly choose, control and purchase their support services" (David and West 2017, 334). Self management requires the person to make agreements with service providers, managing funding, and keeping records (NDIS, 2025). However, the success of this approach has been

shown to have had mixed benefits. David and West (2017) discussed a reduced benefit for people with intellectual disability, older people with disability and those from culturally and linguistically diverse backgrounds. The same issue was identified for Aboriginal and Torres Strait Islander people by Veli-Gold et al. (2023) and Smith-Merry, Gilroy and Watharow (2023). In choosing to self-manage it is important that an NDIS participant has the capacity to self-advocate, or "stand up for themselves" (Australian Institute for Health and Welfare [AIHW], 2024). However, in 2024, the AIHW reported that only 37.3% of NDIS participants felt that they could advocate for themselves. This number moved marginally in 2024 to 38.1% (AIHW, 2024).

The NDIS is available for all Australians with disability, yet access remains challenging for Australians who live remotely. A literature scoping review conducted by Veli-Gold et al. (2023) found access was complicated by a transient health work force, inexperienced NDIS workers, poor communication, the burden of travel costs and the emotion burden associated with the NDIS planning process.

The NDIS and school students

There is no question that NDIS challenges continue across the spectrum of people eligible and accessing the NDIS, and this includes children. The rights of students with disabilities and the obligations of education providers to assist these students are enshrined in the Disability Standards for Education 2005, which is part of Australia's DDA 1992. The standards overarch five areas: enrolment, participation, curriculum, support services, preventing harassment and victimisation. Standards uphold among other things, education providers' obligations to make enrolment standards clear and accessible, and to ensure that curricula are inclusive enough to allow students with disabilities to participate.

In 2019-2020, the NDIS supported over 337,000 individuals and created more options in housing, service provision, assisted travel and medical needs (Australian Bureau of Statistics 2019). Of the 337,000 individuals who accessed the NDIS, over 65% were under the age of 35 (Australian Bureau of Statistics 2019), with those under 18 years old (i.e., those of school age) making up almost half of the total number of recipients who received funding (Gavidia-Payne 2020).

NDIS participants under the age of 18 years old are entitled to funding for transitioning from school to

the workforce and can be linked with a job agency who will help them find employment (Foley et al. 2020). Having funding available for independent travel, being part of a social group, going to outings, accessing respite and many other purposes has provided new opportunities for participants. Caseworkers, NDIS providers, parents and other key stakeholders work together in creating a plan to cater for the individual needs of the participants. The goal of the funding is to support the needs of each participant, to help individuals become more independent and to ensure suitable supports are in place (Foley et al. 2020).

Since the Scheme's launch, the effects of the NDIS on participants' lives have been widely documented. However, many of these studies have focused on adults with disability and related issues (Bigby, 2020; Dowse et al. 2016; Wilson et al. 2020) rather than children. It is estimated that 1 in 10 students (about 380,000) in Australia has a disability; of this group, two in three have an intellectual disability. In general, it can be said that participants under 18 years old have benefited greatly from NDIS funding. However, according to a report by Strnadová, Cumming and Lee (2021) not all NDIS funded allied health professionals and Government funded therapists achieved collaboration. Despite a "wraparound" approach being implemented, Strnadová, Cumming and Lee (2021) reported a "siloeing" effect, resulting in obstruction of equitable and quality professional practice, and implications for care integration and care co-ordination for children with disability.

The responsibility for reasonable adjustments that enable participation, versus supports that address the functional needs of the student's disability (which are described in the Disability Discrimination Act, 1992), remain firmly within the remit of the education system (Australian Government, 1992). The current responsibility of education systems for in-school educational supports includes providing specialised itinerant teaching support, and providing materials in alternative formats by submitting requests for braille and large print services and dispatching these to the student (NSW Government 2023).

The NDIS has heralded a change in the involvement of allied health services with schools. Previously allied health services for areas such as everyday living skills, social skills, transition to the workforce, and independent travel were usually only offered outside of the school day.. This changed during the NDIS transition phase pre 2020, and

NDIS support during the school years has translated to access to a wide range of services which work collectively and collaboratively within the student's school (NSW Department of Education 2024). For example, NDIS funded professionals (such as Orientation and Mobility Specialists, Occupational Therapists, Behaviour Therapists, Psychologists or Support Workers) support students in school, building beneficial relationships with school staff.

In NSW, the Department of Education recognises that "some therapies may be best delivered in school during school time" (NSW Department of Education n.d.), and provide clear guidance about how schools will work with NDIS providers. A four step process must be followed including parents asking the school in writing and then meeting with school staff; the school principal considering the request in terms of the needs of the child, other students and the operations of the school; and final approval (made by the school principal) for the NDIS funded allied health professional to deliver their services in the school (NSW Department of Education n.d.).

While welcomed, the shift to permitting NDIS funded professionals to work in schools has come with challenges. The National Disability Services commented that the "interface between NDIS funded services and education is at best clunky. This means that the planning which can set students up for success does not occur" (p. 12). The recent review of NDIS pricing (NDIS 2025) has also brought into question the sustainability of allied health professionals' capacity to deliver services, including those in schools (Allied Health Professionals Australia 2024).

The NDIS and people with vision impairment

People with vision impairment and low vision/blindness service organisations have also reported challenges with NDIS including issues with navigating the Scheme, ensuring NDIS plans are tailored to individual needs (Guide Dogs 2025) and launching appeals when funding is denied. Service organisations such as Guide Dogs Australia, Vision Australia and NextSense, and advocacy groups such as Blind Citizens Australia and Vision 2020 remain vigilant for opportunities to provide feedback on the NDIS experience, and active in submitting to NDIS reviews, and parliamentary enquiries. For example, in 2022, the Orientation and Mobility Australasian Association (OMAA) challenged the National Disability Insurance Agency Commission

regarding a lack of recognition of Orientation and Mobility specialists as a group belonging to an autonomous profession (OMAA 2025). In 2024, the NSW Parliament Legislative Council review titled “Children and Young People in NSW in Educational Settings” (2024), referenced a survey conducted by Vision Australia with NSW students and families. The survey findings indicated “...a lack of consistency in the educational supports and services being provided to students who are blind or have low vision in NSW schools” (p. 119).

So, how well is the NDIS supporting school students? The next section identifies themes raised in recent studies which have investigated the lived experience and provision of disability support services in rural areas; socio-economic disadvantage; remote learning due to the COVID 19 pandemic, access to reasonable and necessary support funding and the impact of transitioning over to the NDIS for school students with disability in NSW.

Lived experience of disability support services in rural areas

A research project conducted by Prowse et al. (2021) investigated whether the NDIS could be easily accessed by families in rural Australia, and whether NDIS funding was benefiting the participants who were eligible. The participants in the study consisted of six parents/carers of children receiving NDIS services who resided in rural NSW. In a semi-structured interview, participants talked candidly about the impact of raising a child with a disability in a rural and remote location, and the immense difficulties involved in locating and utilising relevant services under the NDIS. This study posed the question: You now have access to NDIS funding - Is there sufficient choice of school-based support services and service providers available to participants who live in rural and remote regions of the country?

Three themes emerged from the data. Theme 1 ‘More than a disability’ referred to the lack of awareness of caregiver and family issues during the development and implementation of NDIS policies. Theme 2 ‘Fighting for funding and services’ identified that while funding had increased via the NDIS, due to limited services, parents/caregivers only actually received minimal assistance utilising that funding. Theme 3 ‘Cold as Ice’ included details of the interactions between parents and caregivers and NDIS officials. The restricted availability and resulting lack of choice of health service providers

in rural areas was a consistent source of difficulty (Prowse et al. 2021).

This study is important as it identified the experiences of families raising individuals with disabilities in rural areas and what should be changed in the NDIS to make it easier for them to have more choices for services. The NDIS was designed to cater for all Australians who have a disability and who meet the eligibility criteria, to provide once in a generation chance to change how people with a disability are served (Kendrick et al. 2017). This project identified major flaws in the NDIS, resulting in lack of choice, control and support services for individuals living in rural and remote locations.

Lived experience of disability and socio-economic disadvantage

To qualify for a support plan and NDIS funding, applicants must adhere to strict eligibility criteria. A study conducted by Cortese et al. (2021) reported on the experiences and success rate of families attempting to apply for NDIS funding. The study participants consisted of 32 individuals with disability, deemed potentially eligible for NDIS funding. Each applicant was interviewed about their experiences of applying for NDIS funding. Parents reported that they were omitted from the Scheme due to the complexities of understanding the rules for applying, disability classification, having limited computer literacy, and due to financial hardship, and limited internet access (Cortese et al. 2021). Unfortunately, some applicants reported being excluded because their cases were too complex. While the study was not able to verify these reports, it did reveal the problems that some parents experienced when attempting to complete the funding application, emphasising the need for an accessible application system.

Lived experience of access to educational support services

Whitburn et al. (2017) conducted a study which focused on whether the NDIS funding scheme articulated inclusive educational opportunities for children and young people with disabilities. The participants of the study were five families whose children had a variety of disabilities and were NDIS participants since its commencement in 2013. Each family was interviewed on the impact of the NDIS on support services for their children’s education and whether they were able to access additional educational support.

Participants within this study noted that although their children were enrolled in inclusive education programs, they could not use NDIS funds for specialist education or allied health services to support their child while attending school. Parents were disappointed that the funds on offer could only be used for post-school services. This did not allow for a consistent approach as in some cases, the post school therapist offered different advice to school based experts (Whitburn et al. 2017). The study concluded that more investment needed to be focussed on in-school professional support for children with disability.

According to NSW Department of Education (n.d.), approval of professional support for a child during school hours is left up to the school principal. The principal is responsible for deciding when and how therapy services are delivered in the school. The principal will make decisions that ensure that the school is able to run to benefit all students and without disrupting learning. The principal will manage any services that come into the school in a way that supports children to continue to take part in classes and school activities (NSW Department of Education n.d. 2). Robust communication between principal, staff and parents would be key to the success of continuity of professional in-school support.

The NDIS funding scheme was designed to cater for the individual needs of its participants based on the availability of services and health care providers available. The Whitburn et al. (2017) study is important as it raises concerns that the NDIS appears to have fallen short of one of the strategic goals of the Scheme which is to improve a child's educational program by integrating funding for their education (Whitburn et al. 2017).

As the NSW government allocates a limited budget for each school, the NDIS has benefited individuals for certain services such as access to Psychologists, Occupational Therapists, Behaviour Specialists, gaining support for transition, respite, transport, and social outings. However, to benefit participants who are enrolled in school, adjustments must be made, and funding for education needs to be given more attention. Applying for extra funding to cater for the individual needs of each student can be difficult and time consuming. Having NDIS funding available to parents to fund educational specialists who could cater for the individual special educational program requirements of children enrolled in school would improve their learning,

social skills and help to improve students' independence (Tait, 2020).

Lived experience of remote learning for students with disability during COVID-19

Yates et al. (2020) conducted a study which investigated how parents fared seeking NDIS funding for remote learning support services during the COVID-19 pandemic for school-aged children. In this study, over 700 families of children with disability reported on their experience of NDIS approved support for remote learning during the pandemic. The study identified a range of results, with some people able to make the necessary changes while others described how they were left with a huge service gap (Yates et al. 2020).

Parents reported that during the global pandemic (or in any emergency), individual funding schemes were not necessarily more flexible than traditional systems. There were many factors to consider, such as effective system flexibility, the participants' capacity to quickly navigate a complex system, the clarity of the information being given, and all stakeholders sharing a common message (Yates et al. 2020). Challenges, such as the way the NDIS interacts with traditional services like education, were highlighted in this study.

According to Yates et al. (2020) although all families were approved applicants of NDIS funding, many respondents experienced significant barriers during the COVID-19 lockdowns when trying to access NDIS support for remote learning for students with disabilities. In essence, during lock down, NDIS funding transferred service provision responsibilities from school-based education experts to parents and caregivers at home (Yates et al. 2020). However, a school-based service could have been achieved by increasing funding and allowing NDIS participants to have more frequent visits from individual support staff at home or regular Zoom sessions by class teachers during lockdown (Yates et al. 2020).

Lived experience of funding transition to the NDIS

The final study selected for this article, conducted by Boaden et al. (2020) focused on the funding transition experiences of families, (i.e., how effective was the experience of transitioning to NDIS and what areas of improvement could be made). 344 people (153 family members and 191 service providers) were invited to recount their experiences and opinions using a mixed

methodology of survey and interview. A similar set of disappointments were expressed by these parents as have been previously identified in the other studies addressed in this paper. That is, many families reported experiencing delays and issues with communication while transitioning to the NDIS. This was most notably reported by those families who identified from a low socioeconomic background or who acknowledged having a lack of adequate technology skills or limited technology access (Boaden et al. 2020). Participants who had positive experiences were associated with better system navigation skills, support networks, and service providers. These findings indicate that there is likely to be an increased chance of social inequities if risks are not managed during the transition to NDIS for some families (Boaden et al. 2020).

The NDIS has dramatically transformed how disability services are offered by personalising, individualising, and marketing the services (Boaden et al. 2020). People with disability and their families not only have to navigate the system directly, but the system also operates like a marketplace for health care services and new providers in the disability sector (Boaden et al. 2020). Reflecting on the personal experiences of these families and making the necessary changes for an effective transition to NDIS is important. Creating a process that is fair to all applicants, that avoids social inequities is vital as the aim of the NDIS is to provide better overall services, funding, and supports for people with disabilities (Boaden et al. 2020).

Policy Implications

The effects of the NDIS have been widely documented since the Scheme's launch. However, many of those studies have focused on adults with disabilities (Bigby, 2020; Dowse et al. 2016; Wilson et al. 2020). The purpose of this article was to highlight the importance of lived experience of parents/carers when seeking funding support for school-based services for children with disability in NSW, Australia. Eight years ago, Warr et al. (2017) noted that it was difficult for people with disabilities to use different funding systems since there were not enough resources available to support them. Consequently, the NDIS scheme was built to simplify funding processes and make a positive impact on the lives of recipients.

Recent studies conducted by Prowse et al. 2021; Barr et al (2021) and Cortese et al. (2021) identified

that it remains difficult for parents of children with disability to access and apply for NDIS funding. Many of the participants in those studies recalled the negative experiences and the problems with applying for funds via the NDIS scheme. Difficulties such as not having access to technology, not having any access to service providers or health services in rural and remote locations and not understanding how to apply for NDIS funding should have major implications on policy.

The third and fourth studies addressed in this article were conducted by Whitburn et al. (2017) and Yates et al. (2020). These studies investigated the impact that the NDIS had on school aged children's education, inviting parents to comment on the ways in which they were permitted to use NDIS funding to benefit their child in an education setting. In both studies (albeit for different reasons), parents reported that they felt the NDIS did not deliver on its core element - that of helping their children with their education. Specifically, during the COVID-19 lockdowns, parents reported being overwhelmed by their responsibility to self-cater for their child's home learning due to the lack of support by the NDIS to support their child's remote learning needs.

Warr et al. (2017) found that there are strong policies in the NDIS that separated it from the Department of Education in any state or territory in Australia. These policies explain and confirm parent's perceptions that the NDIS does not work closely enough with Education Departments, resulting in a deficit in the provision of reasonable and necessary special education service support for school-aged students with disability.

The final study conducted by Boaden et al. (2020) focused on the transition experiences of families from the early childhood setting to NDIS funding. This study addressed social inequities which arose during the application process. Results of this project indicated that families from low socioeconomic backgrounds or from migrant backgrounds were at a disadvantage due to a lack of support during the application process. The results of the Boaden et al. (2020) study also supported the outcomes of the study conducted by Cortese et al. 2021, which described the experience of parents of low socioeconomic means. These parents were tasked with meeting their families' most basic day to day requirements, including acquiring sufficient food, shelter, safety, utility bills, social inclusion, medical, and transportation needs. These parents recounted that allocating long periods of time to navigate the complicated NDIS

process was simply outside of their day-to-day considerations..

Clearly, the implementation of the NDIS has been complex. Confusion, misunderstanding and anxieties have emerged from providers, employers, and people with a disability (Green and Mears, 2014). The results of the five studies reviewed in this paper raise many implications for the NDIS and suggest that significant changes need to be made to the NDIS to permit in-school services for school aged children with disability. This sentiment was clearly articulated in a 2024 report by the NSW Parliament Legislative Council with the statement that "...supports funded by the scheme often fail to integrate with the supports in the classroom, and a potential misunderstanding of the requirements of schools to meet the learning support needs of students regardless of their access to NDIS support" (p. 54).

Conclusion

The NDIS is a scheme currently designed to give applicants a choice of services by transferring power to the participants rather than receiving government-controlled decisions. Like other countries, Australia has a moderate population of people with disability including people with vision impairment, all of whom have the right to a good life. However, the assumption that Australian services are suitable and in place, along with being desirable for people with disability to achieve this good life, could perhaps be questioned.

The outcomes identified in the five selected studies reviewed in this paper address the need for changes to the NDIS funding scheme to better cater for service recipients and service providers. Currently the NDIS funding scheme only permits support of services such as personal care, transport to school, and out of school hours specialist support (NDIS, 2022). There needs to be much more done to support school aged children with disability during their school day, including students with vision impairment (Tait, 2020). Specialist education support during the school day can promote improved strength based educational outcomes via individualised education programs, using consistent learning approaches such as evidence-based teaching practices, improved self-confidence, social skills, and independence for students with disability (Tait, 2022). If changes and improvements are not made to the current system to support students in school, then parents of children with disability will continue to feel abandoned and alone, and

Australia's attempts to meet the obligations of the United Nation Convention on the Rights of the Child will remain inadequate.

Conflict of interest statement

The authors report there are no competing interests to declare.

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