

A comment on the family experience of the Australian National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is a scheme that the Australian Government designed to fund costs associated with disability (NDIS, 2021a). The scheme was legislated in 2013 and went into full operation in 2020 (Olney & Dickinson, 2019). Prior to 2013, disability funding in Australia had typically been a block type system, where agreed funds were distributed directly from the government to the service providers according to predicted output (Green & Mears, 2014). The aim of this article is to shine a light on the current consumer experience of parents of young children with a disability. When addressing families' challenges and needs – does the NDIS offer families control, controlled choice or do support needs remain unmet?

The design and scope of the NDIS

From the moment that the National Disability Insurance Scheme (NDIS) was established, a new form of organisation, 'disability support organisation', was designed to offer people brokering services. Services supporting families raising children with disability were faced with the unfamiliar world of severe disability and families were suddenly permitted to exercise choice, access to management services (such as dealing with the administrative aspects of self-directed funding, were a person to go down that route), personal planning, and orientation supports (Gavidia-Payne, 2020). In other words, this national system of disability service support was calling for the establishment of a market in disability services that would provide the flexibility and choice needed by people with disability and their families.

The National Disability Insurance Agency (NDIA) website provides examples of persons who can provide evidence of disability (Buckmaster, 2017). These are clinical professionals required to be registered under the *Health Practitioner Regularly National Law Act 2009* (Cth). There is a list of 'best practice' evidence alongside those health professions deemed best able to provide such evidence for different categories of disability, while specific evidence types are listed as 'good evidence' of disability (Australian Government: Department of Social Services, 2018). This provision refers to the potential functional problems a person with disability will have in order to attract NDIS support.

For individuals who do not meet the NDIS criteria for admission into the scheme, the NDIA website provides a list of alternative state and federal government services that people may be able to access (NDIS, 2021a). That page of information states that the NDIA's Local Area Coordinators may be able to assist people with referrals, as can a services linkage program administered by the Department of Social Services. Otherwise, the website provides a list of potential service providers ranging from advocacy services to My Aged Care, Legal Aid, as well as information about specialty services for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse Communities. If an application is rejected, the applicant can seek an internal review and can appeal to the Administrative Appeals Tribunal.

Effectively, this arrangement created a two-tier system of disability supports. This system depended on the NDIS working in parallel with state and territory disability services – services provided by the NDIS to those who were eligible (Tier 1), and services provided by the states and territories to those who were not (Tier 2). This, in fact, had been what the Commission had envisaged in recommending the establishment of a national disability scheme (NDIS 2021b). The Commission maintained as part of its underlying assumptions that the NDIS would have a positive economic impact on employment both in the disability sector and for persons with disabilities themselves. According to Venning et al. (2021) it was presumed that this would offer an overall lift in the economy, social inclusion, and standard of living for many with disabilities. This surplus was supposed to generate the Tier 2 services which would support those without a disability if they were not qualified for the NDIS. According to Dowse (2016), these services would also prevent the NDIS being oversubscribed or people with less complex needs going without support.

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However, it is highly debatable whether many of the Commission's planned Tier 2 services will ever eventuate because this model relies on creating a market for disability services. This marketplace would be composed of businesses that wish to make a profit (or, at the very least, an operating surplus, if they are a charity). The reality has been that this marketplace has been difficult to create and sustain (Johnson et al., 2020). On the one hand, there have been difficulties with staffing. The disability support workforce, predominantly made up of women and migrants, is ageing faster than the general workforce. Further, the impact of low pay rates has also led many workers to reassess their involvement in the sector (Cortese et al., 2021).

Opportunities provided by the NDIS

Notwithstanding the plethora of findings into what barriers were identified during the NDIS roll-out, very little has been written about what elements of the scheme have been helpful to parents. The kinds of support the NDIS might fund include: support for daily personal activities and household tasks, transport to enable someone to participate in the community, social activities, work or education; help for someone to get and keep a job, and the development of a behaviour support plan (<https://www.health.nsw.gov.au>). There are three main support purpose categories in the NDIS. These are core, capital, and capacity building. Examples of **core supports** are assistance with everyday needs, household cleaning and/or yard maintenance, and everyday consumables (such as continence products or low-cost assistive technology and equipment to improve independence and/or mobility). **Capital supports** include higher-cost pieces of assistive technology, equipment and home or vehicle modifications, and funding for one-off purchases participants may need (including Specialist Disability Accommodation). **Capacity Building Supports** include budget development and training to increase an individual's skills so they can participate in community, social and recreational activities. Examples of capacity building supports include employment-related support, training and assessments that help with finding and keeping a job, such as the school leaver employment supports (<https://www.ndis.gov.au>).

Challenges, concerns, and unmet needs

Nonetheless, and regardless of disability, whether transitioning from previous funding, being completely new to funding, or after 12 months in the scheme, it is vital for inclusive support teachers, special educators, and allied health professionals to understand what barriers may still exist and what elements of support have collectively proven helpful to parents in overcoming these challenges. The following section reports on insights identified in six recent studies addressing the experiences of parents of children with disability (both ECEI and school-aged children) as they engaged with the NDIS.

The importance of developing trust

Recognising the growing importance of family "capacity" and obvious need for information to assist with newfound choices, Tracey et al. (2018) investigated how parents of children with disability access information. It was noted that parents' need for information was twofold, both to understand their child's disability to assist their child, and to best relate to individualised funding schemes such as the NDIS. At the beginning of a family's journey with their child's disability, there is often an element of grief. Consequently, the development of trust in parent-service provider relationships is extremely important. Results from this study showed that overall, parents were neither trusting of, nor proficient with the internet as a source of information, regardless of the website chosen. Certain cultures too, experienced mistrust of the government and, therefore, saw word of mouth and community connection as a more reliable form of information (Tracey et al., 2018).

Lessons learned from this study include how incredibly key it is to successfully communicate information to parents in a way that reaches them and for the need for websites to be more user-friendly. Further, the results of this study also showed that relationships with ECEI services and past professionals are paramount in assisting families to access

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information about the NDIS and, as such, need to be protected as a source. According to Tracey et al. (2018), they promote connection, provide families with emotional support, and help grow parental capacity to navigate the system.

Simplification of the registration process

A study by Ranasinghe et al. (2017) researched the experience of parents of children aged between 0 and 7 years old, with developmental disabilities, in accessing NDIS support. The Child Development Unit (CDU) attached to the Women's and Children's Hospital in South Australia provides assessments for children with complex needs. Of particular significance was the "unique opportunity" that the CDU had with the NDIS, in that they regularly referred clients to the NDIS after assessment. Ranasinghe et al. (2017) noted a correlation between the primary diagnosis of ASD and the "ease of process accessing funds" and "approval of funding" (p. 27). Additionally, most of the parents who had heard about the NDIS prior to referral had been those with children with ASD. Nonetheless, it was suggested that the registration process was not as easy as predicted, as 45 % of parents needed a health professional to help them register.

Parents who did not have an up-to-date diagnosis for their child experienced longer wait times. These parents reported barriers such as system complexity, lack of information, not being heard by NDIA planners and not having the necessary computer skills. It was communicated by some parents that the NDIS website was inadequate and that it would be beneficial to have service providers listed according to area. Parents made many suggestions to improve the NDIA and NDIS – common suggestions included having a single point of contact per child, simplifying the application process and better training for NDIA staff, an improved website with more information about what to expect in the process.

The importance of advocacy skills

In a 2021 study conducted by Barr et al., families who had previously accessed funding (pre-NDIS) and those transitioning to the NDIS or who were new to funding altogether, highlighted the importance of advocacy skills. Barr et al. (2021) investigated the experience of parents of children with hearing loss from all states except NT, with 48% being from NSW. Results showed that parents struggled to access funding due to poor communication of instructions and a lack of information about their eligibility. Barr et al. (2021) reported that 71% of parents did not know how to find information about the NDIS or how to begin the application process. Parents in this study felt that they had a lack of adequate advocacy skills to negotiate for their child, which became even more necessary when it was evident the NDIA planner, who had lack of education about hearing loss, was changing plans designed by the hearing professionals (Barr et al., 2021).

Restricted rural and remote support services

Tait et al. (2020) conducted a study with parents of children living in rural NSW and reported that families from remote areas were extremely dissatisfied by the severity of restricted disability support and thus limited choice of services, partly due to service providers being reluctant to travel to rural and remote locations. A lesson learned from this study was yet again that communication between the NDIA and parents needs to be improved, as does NDIA staff education of disability.

Accessing support under the ECEI approach

Gavidia-Payne (2020) researched the experiences of parents accessing support under the Early Childhood Early Intervention (ECEI) approach, in the state of Victoria. Most families reported being positive about the fact that funding was available and held hope for future access when their child grew in age. However, Gavidia-Payne (2020) summarised that most parents also reported that "serious difficulties" prevented best Early Childhood Intervention practice, negatively affecting the way parents were able to relate to the ECEI pathway and successfully make informed choices. Examples of these difficulties included insufficient and hard to understand information from planners. Parents who had

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had experience with previous ECEI funding found that in comparison, the new system had lengthy, confusing wait periods. Transition gaps were reported of up to 18 months, during which no services were available.

Families found the planning phase impersonal and brief. Many parents felt unable to advocate for their child due to lack of information, and support and restriction of choice and control of service providers. Interestingly, parents who were previously accustomed to the old funding scheme were seen to have some advantage over those who were new, as they knew to ask for things such as a “transdisciplinary package” as part of advocating for their child (Gavidia-Payne, 2020). This study highlighted the significant emotional stress and anxiety experienced by parents. Though the barriers already listed above cause stress, the author advocated that parents of children with disability are already having to accommodate in many ways for their child’s disability. Having to advocate for their child’s rights and explain to be understood only exacerbated parental distress. There is clearly a need within the NDIS framework for strategies that build family capacity and support in this regard.

Twelve months experience

In contrast to the previous studies, a study by Smethurst et al. (2021) researched parental experience with the NDIS after involvement for a time frame of at least 12 months. This study documented the experience of Victorian parents of children with Cerebral Palsy. Findings showed that despite children having been accepted and having had access to a NDIS plan for at least 12 months, similar levels of parent distress were reported.

There was some hope expressed by parents for better assistance to come, though many had concerns about the sustainability of the scheme. Barriers experienced included parent frustration navigating the system including many communication issues (e.g., rule interpretation confusion, not understanding procedural requirements, and a lack of empathy for families’ personal situations). Further conflict between the NDIA and parents was caused by administration challenges, lack of NDIA expertise with disability, and feelings of depersonalisation.

Parents reported a need for advocacy to better exercise more control and more choice for support services. One of the most pertinent issues raised was the excessive wait times, especially for equipment (assistive technology), which for a child with complex needs is highly problematic. In several studies addressing rural and remote families’ support service needs, Tait et al. (2020) and Hussain and Tait (2015) have reported that raising a family member with a significant disability can impact on the quality of family life. Parents concurred reporting concerns such as financial impact, emotional distress and, if their child had a physical disability, the need for constant lifting and carrying, over time, which caused back injuries for 6 out of 8 parents involved (Smethurst et al., 2021).

Common challenges and unmet needs

While each of the reported articles in the above section addressed individual emphases and insights, they also highlighted similar barriers experienced by parents accessing support from the NDIS for their children. Communication, lack of information, complex processes and a perceived greater need for advocacy were amongst the common issues. As a result of their reduced capacity, many parents experienced emotional fatigue. Parents requested a more personalised system, with a single point of contact and greater understanding and communication between all parties involved. The ECEI Pathway was seen to be a definite step forward.

Conclusion

The goals of the NDIS to provide increased choice and control, reasonable and necessary high-quality support, national consistency, and participant independence, are admirable. However, these goals are quite far reaching when one reflects on the day-to-day needs of children with disabilities and their families. Time delays in enacting significant reform are somewhat noted in Tune’s review (Australian Government, 2021). While reform may have been implemented in certain

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areas, this may not be the case in others. For these reasons, generalised judgements about NDIS improvement or lack thereof need to be interpreted with caution. The magnitude of the roll-out and the widespread barriers must be considered. However, it is important that the complexity and vastness of this undertaking does not overwhelm nor stunt progress.

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