

How do Families of Young Children with Developmental Delays and Disabilities Experience the NDIS?*

Dr. Gavidia Payne

Much anticipation existed regarding the implementation of the NDIS across Australia. It was designed to replace the long-standing difficulties of a fragmented service system and provide support to people with disability from birth to 65 years of age, their families, and carers. Scheme participants receive direct funding and are encouraged to purchase their own services and must understand, navigate, and source markets of private and non-for-profit providers. Howard, Blakemore, Johnston, Taylor and Dibley (2015) have suggested that the design of the scheme appears to assume decision-making and service planning processes more suitable for adults with disabilities. What does this mean for young children (birth to 6 years of age) with developmental delays and established disabilities (DD) and their families? The NDIS designed the Early Childhood Early Intervention (ECEI) approach to address the service needs of this population. However, several government reports as well as a limited number of studies have continuously revealed difficulties with its implementation. Among others, these have included problems in accessing the scheme, poor communication and coordination in navigating services, and early intervention workforce's challenges in using early intervention recommended practices. Since children under 18 years of age form almost half of the total number of recipients of funding (NDIS, 2019), it is urgent to describe and understand more precisely the barriers and enablers to early intervention service provision. In this study, I aimed to add to this evidence and examine the scheme's implementation with young children with DD, grounded in families' experiences of the ECEI in the State of Victoria. It is important to note that the NDIS provisions in this State are catered for by two metropolitan ECEI partners and five regional ECEI partners. A range of private and non-for-profit service providers deliver services and supports across the State.

The study

Seventeen parents participated in the study, most of whom were mothers (96%), aged between 31 and 53 years. Except for 4 parents, all were born in Australia. About one-third of participants were employed outside of the home working an average of 4 days a week. About 50% of participants had a university degree. Participants' children with DD (14 males and 3 females) were aged between 2 years 2 months and 7 years 1 month (M = 53.05 months, SD = 20.07 months). Children's primary diagnoses included autism spectrum disorder (n = 12), Global Developmental Delay (n = 4), cerebral palsy (n = 1), and language delay (n = 7).

A qualitative research design was adopted whereby participants' lived experiences of the NDIS and ECEI approach were explored through semi-structured interviews and focus groups. All in-depth interviews were audiotaped and transcribed and the written transcripts cross-checked with the audiotapes for reliability purposes by an experienced doctoral student. Thematic analysis was used to systematically explore participants' views about their experiences with the implementation of the NDIS.

Findings

Study findings indicate that the promise and potential invoked by the NDIS legislation's core tenets are yet to be realised for children with DD aged birth to 6 years. Even though families were satisfied with the potential availability of funding, problems identified in the NDIS trial phase and earlier studies about its roll-out persist. Three main themes were identified reflecting parental perspectives about access and planning; choice and control; and family well-being and community life.

Accessing, waiting and planning

At this crucial access point into the service system, ECEI service responses were delayed, confusing, laden with

continued next page

administrative language, and ultimately lacking in sensitivity. As Participant 7 indicated, "...The wording. It's not people-friendly, it is too clinical...sometimes they throw words at you...it's just French to you..." (P7). Parents faced challenges related to delays in assessment, plan development and coordination of plan implementation (and therefore funding), as well as a plan emphasis on child individual goals, which were largely limited to therapeutic services. One parent from a culturally and linguistically diverse (CALD) background faced particularly long delays, which led to the family's temporary departure from Australia, "...so I'm waiting for that message to approve...so I thought why don't you go to [country of origin]..After two years almost..so nobody's came over and asked why is happening. Meanwhile there's nobody tell where to go..."

These experiences are not only inconsistent with the application of effective early intervention practice but may also be an indication of more systemic and structural barriers. Links among mainstream health, education and community-based systems supporting young children with DD, the ECEI and the NDIS implementation more broadly were reported to be non-existent or weak at best. Furthermore, parents' reported difficulties in navigating these systems may reflect how the absence of a dedicated support coordinator for all families, to guide them before and after entering the ECEI stream, can limit access to resources that would otherwise promote optimal child developmental outcomes.

The challenges of choice and control

While choice and control constitute one of the pillars of the NDIS legislation, the implementation of the ECEI approach was reported to hamper parental decision-making. In asserting the types of supports they perceived a need for, participants experienced limited information and guidance, poor availability of services, or no approval for funding of needed supports. Parents' confidence, particularly those who could not make informed choices given their limited resources, was further challenged as they had to provide constant justification for funding, as well as having to advocate for their rights and needs.

We know from the literature that personalisation schemes, such as the NDIS, can entrench rather than level existing inequalities and prevent the application of good practice given the implicit administrative burden and accountability issues. Furthermore, the exercise of choice and control is also more complex for families of young children as they weigh a number of parental, child or program-related factors in deciding among the service options for their children. As Carlon, Carter and Stephenson (2013) indicate, all these decisions can be made more difficult by the limited capacity of the service system and the attributes of staff involved in it. It is then not surprising that parents' choice of services may have been skewed, often selecting some services such as allied health services above team-based approaches and special education, all of which are essential to effective early intervention practice. The crucial role of these interventions in linking children to mainstream services may have been also missed in the design and implementation of the ECEI, thus jeopardising parental choice of effective resources and supports. This finding is noteworthy given its inconsistency with (1) policy recommendations regarding the need for the interface between the NDIS and mainstream supports in achieving participant outcomes as stated by the Productivity Commission (2017); and (2) best practices regarding young children's participation in everyday natural environments (Early Childhood Intervention Australia, 2016).

The impact on family well-being and community participation

Parents overwhelmingly described the extent of the perceived effect of their ECEI experience on themselves and their families. They reported feeling undermined in their competencies, often doubting their knowledge and confidence to support their children. Often expressed were emotional responses consistent with mental health concerns such as stress and anxiety in accessing services, having to advocate for their needs, asserting their rights, and uncertainty in finding and funding service providers, "...There is a lot of shopping around [for service providers]... "...It's really stressful...you don't have a life anymore."(Participant 8). These concerns went generally unrecognised in their interactions with ECEI planners and more formally, in the goal development and planning phase.

continued next page

Similarly, parents reported difficulties in participating in the community such as going shopping and recreation, given the limited emphasis on these areas. It is argued that the ECEI approach, as it currently stands, has amplified the distress and restricted community life often experienced by parents of children with DD. It is pivotal that local planners and service providers understand the uniqueness of everyday family life as well as the adaptations (physical, emotional, informational) they must make to accommodate their child's disability. Central to this aim is the adoption of promotive and competency-enhancing strategies to empower families and strengthen family interactions as demonstrated in numerous research studies for the last four decades.

Conclusion

The NDIS promise for children aged birth to 6 years of age is yet to be fulfilled. Families experienced a challenging system that was decidedly designed for adults with a disability, and that lacked most of the distinctive qualities that make an effective and efficient ECI system of support. A reduction of family choice is evident through the introduction of a therapy-based approach, which has not only replaced, but weakened the implementation of ECI best practices in Victoria. Families faced less control over resources given unpredictability in NDIA service responses, support to identify and gain access to services, and fragmentation in service planning. This has resulted in the amplification of parents' experiences of diminished capacity and increased mental health concerns, which are detrimental to their caregiving role, family, and community life. Overall, the chasm between NDIS policy and its implementation is of great concern, clearly underscoring the pressing need for the scheme to review and reconceptualise the current ECEI approach to ensure that the potential of the NDIS is accomplished for young children with DD and their families. While some changes have been introduced to address access and planning delays (NDIA, 2019) in particular, consideration must be given to the development of a revised strategy for the implementation of ECEI under the NDIS (Joint Standing Committee on the National Disability Insurance Scheme, 2019) that provides clear direction and policy and practice. This can be pursued based on well-known evidence-based early intervention models, already in existence, that address implementation as well as intervention strategies that maximize child and family benefits (Dunst & Espe-Sherwindt, 2017; Guralnick, 2019).



Associate Professor Susana Gavidia-Payne B.Psy., M.Sc., Ph.D

Dr Gavidia Payne is an Adjunct Associate Professor in the School of Education at RMIT. Her expertise in the development, delivery, and evaluation of programs has led her to form close research collaborations with early childhood intervention agencies. More recently, this work has involved the joint development of conceptual models and methodologies with service agencies to guide the implementation of evidence-based practices in the NDIS context.

References

- Carlson, S., Carter, M., & Stephenson, J. (2013). A review of declared factors identified by parents of children with autism spectrum disorders (ASD) in making intervention decisions. *Research in Autism Spectrum Disorders*, 7, 369-381. <https://doi.org/10.1016/j.rasd.2012.10.009>.
- Dunst, C. J., & Espe-Sherwindt, M. (2017). Contemporary early intervention models, research, and practice for infants and toddlers with disabilities and delays. In J. M. Kauffman, D. P. Hallahan, and C. P. Pullen (Eds.), *Handbook of Special Education* (2nd ed., pp. 831-849). New York: Routledge.
- Early Childhood Intervention Australia. (2016). *National guidelines: Best practice in Early Childhood Intervention*. Retrieved from <https://www.ecia.org.au/Resources/National-Guidelines-for-Best-Practice-in-ECI>
- Guralnick, M.J. (2019). *Effective early intervention: The developmental systems approach*. Baltimore, Maryland: Paul H. Brookes Co.
- Howard, A., Blakemore, T., Johnston, L., Taylor, D., & Dibley, R. (2015) 'I'm not really sure but I hope it's better': Early thoughts of parents and carers in a regional trial site for the Australian National Disability Insurance Scheme. *Disability & Society*, 30, 1365-1381. doi:10.1080/09687599.2015.1093462.
- Joint Standing Committee on the National Disability Insurance Scheme (2019). *NDIS planning interim report*. Canberra, ACT: Parliament of Australia. Retrieved from https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/NDISPlanning/Interim_Report
- NDIS (2019). *COAG Disability Reform Council, Quarterly Report*. Retrieved from <https://www.ndis.gov.au/about-us/publications/quarterly-reports>
- Productivity Commission (2017). *National Disability Insurance Scheme (NDIS) Costs*. Canberra, ACT: Productivity Commission. Retrieved from <https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf>

* You can access Dr Gavidia-Payne's full report as follows:

Gavidia-Payne, S. (2020). Implementation of Australia's National Disability Insurance Scheme: Experiences of families of young children with disabilities. *Infants and Young Children*, 33, 184-195. doi: 10.1097/IYC.000000000000169