Parental Experiences of Engaging with the National Disability Insurance Scheme

(NDIS) for their Children: A Systematic Literature Review

Abstract

The Australian National Disability Insurance Scheme (NDIS) reached full national implementation in July 2019. It supports Australians with disabilities via individualised funding packages for disability-specific services and assistive technology. This systematic review of literature presents research describing the experiences of parents of children with disabilities in accessing and participating in the fledgling NDIS and makes recommendations to assist the Agency in better supporting new participant families.

*Keywords***:** NDIS; parental experience; service provision; disability; individualised funding scheme

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Children with disabilities require a considerable level of care, support coordination, and advocacy. The Australian Bureau of Statistics' (ABS) 2009 Survey of Disability, Ageing and Carers found that of the 187,600 children aged 0-14 with disabilities living in Australia, approximately 108,000 reported a disability with a profound/severe core limitation. Ninety six thousand parents identified as primary caregivers for their child/ren with disabilities (ABS, 2013). In 2015, there were 129,300 Australian households containing at least one child aged 0-14 with disabilities and a primary caregiver (ABS, 2016).

Parental caregiving is considered 'informal care' in that it is nonprofessional and largely unpaid, however it was assigned an economic value in the United States of USD196bn almost twenty years ago (Navaie-Waliser et al., 2002). At the time, this figure far outstripped the total national spend on home health and nursing care. In the Australian context, the replacement cost of informal care leapt from AUD19.3bm (Winch, 2006) to AUD60.3bn (Deloitte Access Economics, 2015) over the past ten years.

Further levels of complexity surrounding the caregiving role for parents are that many parents caring for children with complex health needs are new to the world of typical parenting, let alone the additional demands of the caregiver role. Parents caring for children with complex disabilities spend significantly more time on direct child-care activities than their peers with typically developing children, and this occupational gap grows wider as the child ages (Crowe & Florez, 2006). Many children with disabilities will require basic self-care supports such as bathing, feeding, and toileting far longer when compared with their age peers. In addition to this, disability-specific developmental delays necessitate an increased level of care across all aspects of the child's daily life including social and educational

inclusion (Brown, 1999). The intensity of this care provision leaves very little time for leisure or social interactions (Green, 2007; Olsson & Hwang, 2003), which is to be expected of the first few years of parenting but in the case of disability often stretching relentlessly into the future. Many parents find that they are barely coping with this parent caregiver role without adding any further pressures (Glidden, Billings, & Jobe, 2006). Inevitably though, advocacy becomes a necessary component of the provision of care when needs are identified by parents and services must be sought, negotiated, and financed.

The Australian government will soon release recommendations stemming from the review of the National Disability Advocacy Program (NDAP), under which "people with disability are provided access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation" (Australian Federal Government, 2016b, p2). The NDAP acknowledges that not every person with disability is able to effectively advocate on their own behalf and funded 58 individual advocacy agencies across Australia in 2015-16, with a cost of AU$16.4M (Australian Federal Government, 2016b), to provide six types of advocacy support for persons with disability. The NDAP does not have a direct relationship with the NDIS, in part reflective of the conflict of interest inherent in providing fee-for-service advocacy support for participants of the Scheme through the funding approved and supplied by the Scheme itself. The NDAP review document summary, released ahead of the recommendations, conservatively projected that 12,000 people would be likely to seek individual advocacy support services (Australian Federal Government, 2016a) when engaging with the NDIS. Whilst the NDAP and NDIS are entirely separate policies, the NDIS is likely to further impact the NDAP as requests for advocacy related to the operationalisation of the NDIS increases. Individual support is just one of the six services provided by the program, Even if it was the only type of support funded under the NDAP, this would equate

to a little over AU$1,500 per person without taking into account the overheads incurred by each of the NGOs supplying the services. This makes it very clear that individual advocacy services are unlikely to be available to every family in need. Recent studies found that the overwhelming majority of parent caregivers are already engaged in advocacy through a wide range of activities resulting in varying amounts of success. A sense of frustration about systemic barriers facing the families of children with complex support needs was common (Green 2007; Neufeld, Harrison, Stewart, & Hughes, 2008; Resch et al., 2010; Ryan & Runswick Cole, 2009; Trainor, 2010). Another common theme was the identification of advocacy engagement as a drain on parental resources, including emotional (Brown, Anand, Fung, Isaacs, & Baum, 2003; Crowe & Florez, 2006; Neufeld et al., 2008), financial (Brown et al., 2003; Resch et al., 2010), and socio-cultural (Brown et al., 2003; Crowe & Florez, 2006; Green, 2007; Neufeld et al., 2008; Resch et al., 2010; Ryan & Runswick Cole, 2009; Trainer, 2010). Beyond these barriers, parents largely reported positive feelings and experiences when discussing their children with complex needs (Brown et al., 2003; Crowe & Florez, 2006; Green, 2007).

An Australian discussion of effective 'family-centred help-giving' (Dempsey & Keen, 2008) identified successful outcomes as being directly related to the locus of control, that is the extent to which parents/families felt in control of the events that impact them. This was as important as the extent to which parents/families felt they were positively influencing outcomes and their satisfaction with the support received. This aligns well with the National Disability Insurance Scheme (NDIS), which is being progressively rolled out across the country between 2013 and 2019 and represents a substantial change in disability policy in Australia (Bonyhady, 2014). An individualised funding scheme delivered within an insurance model, its central tenet is choice and control for persons with disabilities (Australian Federal Government, 2016b). Under the Scheme, a person with disabilities (or their agent) may

request any support or equipment that meets the "reasonable and necessary" test (Australian Federal Government, 2016a, p. 39). Individualised funding packages for disability supports and services have been available to eligible Australian children under the Better Start for Children with Disability (BetterStart) and Helping Children with Autism (HCWA) programs delivered by the Australian Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) since 2007 (Dew et al., 2013). These programs each provide up to AUD$12,000 for eligible children under the age of seven with which to secure therapies and equipment through a registry of approved providers. The NDIS will progressively replace these programs as children join the Scheme. Traditionally block funded supports for children with disability will also be replaced as the NDIS rolls out. This paper was prepared during the phased geographic rollout of the Scheme, which took place between July 2013 and July 2019. Any BetterStart and FaHCSIA funding being received prior to July 2019 is halted at the enactment of each individual child's NDIS Plan.

With respect to the current focus of this paper on children, the annual planning process for families within the NDIS requires the family of a child with disabilities to have a working knowledge of therapies, equipment, and supports available before they can request them. This systematic review presents the literature regarding parental experiences of the NDIS as it is implemented across Australia. The research question posed is 'How do parents of children with complex health needs experience their engagement with the Australian National Disability Insurance Scheme (NDIS)'?

Method

The systematic review was completed in accordance with PRISMA guidelines, an internationally recognised approach to conducting systematic literature reviews and meta-analyses (PRISMA, 2015). This ensured a rigorous and repeatable process to identifying and assessing articles for inclusion in the review. The search was conducted independently by

three authors to ensure reliability in the search outcomes from the databases. Articles identified in this initial search were then reviewed by two authors, then the final selection of articles were reviewed for final inclusion by two authors. Any disagreements were discussed and resolved through reference to the inclusion and exclusion parameters established before the search commenced.

Eligibility criteria

The search parameters were kept deliberately broad for this review due to the anticipated small numbers of articles currently published about parental experiences with NDIS service provision. The criteria for inclusion and exclusion can be seen in table 1 below.

Insert table 1 here

Search strategy

The databases selected for searching were PubMed, EBSCO Host (all databases), Psy Articles, Psych Info, Psychology and Behavioural Sciences Collection, Proquest, Web of Science, and the Cochrane database. In addition, given the relatively new research focus on the NDIS, a search was also conducted on Google Scholar to ensure the reach was as wide as possible. The searches were limited between 2013 and present due to the date of initial rollout of the NDIS, with the initial search taking place on 17th August 2017. The search was again repeated on 29th August 2019 and no new articles that met the inclusion criteria were identified.

Data extraction

A data collection form was created to extract the data following initial screening. This included the authors, date, full reference, and assessment decision with rationale for its acceptance or rejection to move forward for full inclusion or exclusion.

Quality assessment

Due to the focus of the review being that of parental experiences with the NDIS, the articles returned and selected for inclusion in the final review were qualitative or mixed-methods in nature. A quality assessment was conducted to assess the methodological quality of the articles. Given the mixed-methods and qualitative methodology adopted by the article authors, the Critical Appraisal Skills Programme (CASP, 2006) checklist was utilised. The use of the CASP enabled a review of the quality of the individual articles, resulting in an overall quality rating for each paper. The CASP quality score attributed to each paper can be seen in Table 2, which also summarises the main characteristics of the articles.

Results

Article selection

The initial search returned a total of 713 records from the search string NDIS, Aust*, Parent*, experie*. All records returned were considered for their merit in meeting the inclusion and exclusion parameters set. Six hundred and fifty records were subsequently excluded on the basis of not meeting the inclusion criteria. Following the removal of duplicates, 64 full text articles were assessed for eligibility. On reviewing the full text of these articles, 57 papers were excluded because they did not have a primary focus on the NDIS, were not research articles that presented empirical data, were not sufficiently focused on the voice of parents, and were not primarily experiential in focus. This resulted in seven articles being included in the final qualitative synthesis, which sought to identify themes common across the included research articles. Figure 1 outlines the flowchart of article selection and methodological decisions.

Insert Figure 1 here

Summary characteristics of included articles

The seven articles retained for inclusion in the final review were broad in focus on types of disability, with only one paper - Simpson, Stewart, and Douglas (2016) - focusing specifically on one disability type (hearing loss). Two studies - Howard, Blakemore, Johnstone, Taylor and Dibley (2015) and Johnston, Tracey, Mahmic, and Papps (2013) - adopted mixed methods; Ranasinghe, Jeyaseelan, White, and Russo (2017) primarily used a survey; and the remainder were qualitative in methodological approach, drawing on interviews and focus groups. The quality ratings of the articles retained for inclusion in the final review indicated a general high quality in research being undertaken concerning parental experiences within the NDIS. Table 2 below summarises the key aspects of each article and main findings from each paper.

Insert Table 2 here

Findings

Four major areas of focus emerged upon analysis of the articles included in this review. These are: (1) access to information and services; (2) system complexity; (3) family (self) advocacy; and (4) effective support systems.

Access to Information and Services.

All articles discussed the importance of access to appropriate and timely information for participant families in the lead up to, and implementation of, the NDIS. Dew et al. (2013) and Howard et al. (2015) reported that parents in their studies felt *'overwhelmingly uninformed'* and each discussed the perceived lack of information and advice available regarding the management of individualised funding. Howard et al. (2015), Johnston et al. (2013), Tracey, Johnston, Papps, and Mahmic, (2017), and Simpson et al. (2016) found that even when information was made available, parents found it indigestible, not tailored to their family or their child's needs, culturally inappropriate or insensitive, and often causing information overload. Parent participants in Howard et al. (2015) and Johnston et al. (2013)

further suggested that information for families needed to be offered in lay, jargon-free language and made available in easy English and other languages where appropriate. For example, "Families are keen to have more state-specific information regarding service providers on the NDIS website and more personalised interaction with the NDIA." (Ranasinghe, Jeyaseelan, White, & Russo, 2017, p. 26).

When seeking information, parents were likely to look to their peers (Johnston et al., 2013; Sheppard, Lefmann, & Crowe, 2013; Tracey et al., 2017), existing relationships with early intervention service providers (Simpson et al., 2016; Tracey et al., 2017), and the internet (Johnston et al., 2013; Ranansighe et al., 2017; Tracey et al., 2017). It was acknowledged that online sources were less able to be relied upon due to difficulties in judging credibility and accuracy (Simpson et al., 2016; Tracey et al., 2017). It was further noted by Simpson et al. (2016) that parents tended to procure information about the NDIS from third party sources rather than the National Disability Insurance Agency (NDIA) directly. Although the value of online information was generally acknowledged, every article reported that parents preferred person-to-person contact.

In the context of access to services, Dew et al. (2013) discussed the concerns of rural and remote families regarding the availability of local services. They identified a need for additional support in these regions to build capacity and skill in the local community, but added that financial support was necessary in the short term to enable people with disabilities and their families to overcome geographical barriers to service seeking. Parents reported a desire to have services aligned with their child's interests and related to their contribution to their community (Sheppard et al., 2013) – an issue compounded where choices were limited from the outset. Ranasignhe et al. (2017) found that better communication with local NDIA representatives could assist families to locate and choose appropriate service providers once their child's funds were in place. For instance, "According to participants in this study, a lack

of choice and limited capacity were associated with less access to therapy. Participants also reported increased costs due to the need to travel long distances to access services" (Dew et al., 2013, p. 440).

System Complexity.

Ranasinghe et al. (2017) surveyed parents of children under 7 years old about their experiences in entering the NDIS via referral from a health service and found that close to half of the families required follow-up or other support during the registration process. Dew at al. (2013) and Howard et al. (2015) found that families struggled with the complexity of managing individualised funding within the NDIS' difficult-to-navigate processes. In exploring parental experiences of an early NDIS trial site, Howard et al. (2015) also found that many parents cited the complexity of planning conversations and the eventual management of funds to be a source of stress and highlighted the need for support from local and consistent NDIS contacts. This issue was a central theme of the study by Simpson et al. (2016):

> I got to my meeting and there was a completely different person. I asked where my original planner went and they simply said oh they're gone now. I understand people move on and that work places have employee turnaround but to not even be told was rude and then the new planner knew nothing about my child. She seemed disinterested it made me really angry and it felt like a waste of all that time we had previously put in. (Simpson et al., 2016, p. 154)

Ranasinghe et al. (2017) found a relationship between the complexity of a child's needs and parental satisfaction with the Scheme. Parents whose children had complex disabilities reported higher levels of dissatisfaction with their NDIS experiences. Existing relationships with early intervention service providers were found to be extremely important

in navigating the complex processes of NDIS registration, assessments, and planning (Ranasinghe et al., 2017; Simpson et al., 2016; Tracey et al., 2017).

Family (self) Advocacy.

Parents reported growing tensions as responsibility for advocacy, coordination, and management shifted from the system to families themselves (Simpson et al., 2016). A sense of physical, mental, and emotional fatigue was reported by families with respect to attending multiple appointments and having to explain their child's disability and its functional impact over and over again to many stakeholders whose level of understanding, knowledge, or interest was often perceived to be minimal (Howard et al., 2015; Ranasignhe et al., 2017; Simpson et al., 2016; Tracey et al., 2017). For example:

> If I ever call the NDIS about a question, they never understand because they have no background in disability or have no idea who I am or know how to answer the questions so they get someone to call me back but they never do. (Simpson et al., 2016, p. 154)

Studies discussed the importance of keeping professional supports available for families who struggled to develop the skills or capacity to advocate for themselves and their children. Family advocacy services were considered necessary to combat the overreliance on families to identify and procure appropriate supports, equipment, and services (Howard et al., 2015; Tracey et al., 2017). For example, from the paper by Tracey et al. (2017, p. 7):

> There's a lot of parents with a high level of literacy who are very good at working on the system, but there are a lot of parents with a very low level of literacy who can't use the web who can't use those things, and that's what these case workers need to really be there particularly to support those people because they can't advocate for their children effectively.

Many parents reported satisfaction around the increased choice and control available under the Scheme (Ranasinghe et al., 2017) and expressed a willingness to develop the skills and resources needed to effectively advocate for themselves and their child/ren (Sheppard et al., 2013; Tracey et al., 2017). Parents spoke about the importance of peer relationships in sharing skills and knowledge to enable families to advocate for themselves and each other (Howard et al., 2015; Johnston et al., 2013; Sheppard et al., 2013; Simpson et al., 2016; Tracey et al., 2017), but also noted that the Scheme was limited in its support for parents and sibling caregivers (Howard et al., 2015). For example, Tracey et al. (2017, p. 6) found: "…the resource that has fed me best and nourished me and helped me has been getting together with other mums . . . I just share their experience of walking the same road, and that's where the resource is."

Effective Support Systems.

Every study included in this review highlighted the need for effective family supports in the context of individualised funding schemes like the NDIS. Supports discussed included professional services such as family advocacy programs (Howard et al., 2015), early intervention services (Sheppard et al., 2013; Simpson et al., 2016; Tracey et al., 2017), health services (Howard et al., 2015; Ranasinghe et al., 2017), peer groups and organisations (Howard et al., 2015; Johnston et al., 2013; Sheppard et al., 2013; Simpson et al., 2016; Tracey et al., 2017), and structured supports within the Scheme itself (Dew et al., 2013; Howard et al., 2015; Johnston et al., 2013; Ranasinghe et al., 2017; Simpson et al., 2016). For example, from Howard et al. (2015, p. 1378):

> …research demonstrates that any child and family initiative must recognise that already intensive everyday demands on parents and carers are compounded when their child's development and support is dependent on a convoluted system,

potentially based on inaccurate assumptions about what it takes to support and

develop parent and carer knowledge to gain the best possible results for their child.

Another key theme that emerged from every study was the strong preference for

direct person-to-person contact with support providers. These could take the form of face-to-

face local meetings (Dew et al., 2013; Johnston et al., 2013; Simpson et al., 2016; Tracey et

al., 2017) or online/telecommunication (Dew et al., 2013; Ranasinghe et al., 2017; Tracey et

al., 2017), but in all cases parents strongly asserted their need for consistent points of contact

– people with whom they could build relationships.

Parents also reported feeling that support was not always provided in an appropriate

way for families, citing jargon-heavy communication (Howard et al., 2015), and support not

tailored to their child's needs or stage of diagnosis (Johnston et al., 2013), and cultural

insensitivities (Tracey et al., 2017) as issues that must be resolved if the NDIS is to

adequately support the inclusion of young children and their families. For example: "…if it's

another Koori worker they just connect straight away, 'oh that's a Koori person', you know,

they know how we are in our culture everything, so it's just a connection" (Tracey et al.,

2017, p. 7).

Discussion

The Australian NDIS commenced in 2013 with four trial sites - including South

Australia, the first to include young child participants – which tested policies, systems,

regulations, and processes in anticipation of the full Scheme rollout from July 2016

(Reddihough, Meehan, Stott, & Delacy, 2016). It is therefore plausible that parents in these

studies experienced slightly different eligibility and planning processes as trials progressed.

However, the central themes of their experiences carried through the various iterations and

can provide valuable guidance for policymakers as the full Scheme is implemented across the

country.

Challenges for families have been demonstrated in the existing literature, as identified in the current review in terms of successful engagement with the Scheme. Parents whose children have participated in previous individualised funding packages such as the Better Start for Children with Disability (BetterStart) are more likely to have existing relationships with early intervention services than those who have received no funded supports prior to the NDIS. In the context of this discussion and the research findings, it is concerning that the eventual closure of these programs means that new families entering the NDIS are far less likely to have these important supports during the eligibility and planning stages. It is crucial that the NDIA acknowledges this gap and provides sufficient safeguards for early intervention engagement prior to Scheme entry. This has been partially addressed through the development of the Early Childhood Early Intervention (ECEI) pathway (O'Tarpey, 2016), but this concession still does not allow for the development of meaningful relationships with early intervention services prior to engagement with the Scheme. It will take time for this issue to be fully appreciated but it is likely to become apparent when families who have not had access to other services (closed as the NDIS reaches full saturation) join the Scheme.

It is plausible that families whose children have received services through the simpler Australian Department of Families, Housing, Community Services and Indigenous Affairs individual funding programs will have gained skills and experience that enables more confident engagement with the NDIS. However, the research presented here clearly demonstrates a shift of responsibility from the system to individual families, and the capacity of a parent to effectively advocate on behalf of their child/ren is influenced by many factors. Successful advocacy in this context requires a skillset (e.g., information management, health literacy, communication, and negotiation) and a mindset (e.g., family resilience and optimism) that advantages some families over others. There are many external factors that

also influence advocacy capacity such as socio-economic status, parental education, family structure, English proficiency, and availability of informal support networks.

Parents who are less able to advocate for their child/ren must be able to access advocacy support services to ensure that no child is disadvantaged. It is important that these services are available to all families who need them regardless of regionality and independent of the NDIS, and that these services empower families to develop their own advocacy skillset and mindset. This is in line with key themes from the Consultant Report on the Review of the National Disability Advocacy Program (Australian Department of Social Services, 2017), which will inform development of a new NDAP from 2018. Successful advocacy faces further barriers in the female-dominated parent-caregiver community. Female negotiators often suffer backlash because assertive behaviour is perceived as a masculine characteristic, viewed as arrogant or aggressive in a woman. Women who adopt a less assertive position are received negatively due to perceived feminine characteristics such as weakness and gullibility (Amanatullah & Tinsley, 2013).

The research presented in this paper demonstrates a clear preference among families to be provided with a consistent key contact throughout the process of application, planning, and Plan implementation. This will improve participant experiences by offering clear and consistent information tailored to families by someone with whom the family has established a working relationship. The NDIA has recently acknowledged this feedback by undertaking a pilot program in Victoria from December 2017 (National Disability Insurance Agency, 2017) that aims to improve communication and information channels for new and existing participants.

However, as the NDIS is fully realised, more work will need to be done in the area of facilitating family negotiations with the NDIS and service providers in order for effective and fitting individual packages to be crafted. Further thought must also be given to the supports

and services available to families prior to their engagement with the Scheme. These are important areas for future research as the NDIS continues to come into effect across Australia, and accompanying policy needs to support families in their building of individual support packages that enable positive growth.

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