



Healthy Trajectories

A Child and Youth Disability Research Hub



Best Practices in Early Childhood Intervention: Towards Effective Implementation

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Executive Summary

This paper calls for collaboration and action to ensure that the system of early childhood supports and services is aligned with, and delivered based on, the best available evidence. In this paper, we:

- summarise the evidence base for early childhood intervention and supports for children with developmental disabilities and their families
- review recent policy changes
- describe nine interconnected areas of concern identified with early intervention services in Australia, both for those children eligible for the NDIS, and those who are not.

A program of research is then proposed which aims to provide a deeper, more nuanced, understanding of the problems and provide an evidence-based platform to develop and test policies and strategies that can be implemented to improve existing early childhood intervention services.

Key Messages

1. The system for early intervention for childhood disability in Australia is falling short. Systems, policies, and practices do not align with the evidence we have for best practice approaches.
2. Best practice in early intervention is based on relationships. It is family centred, collaborative and strengths based. It is delivered in natural settings, with a focus on child and family capacity building. It is tailored to the needs of the child and family, giving them supported choice and control.
3. Since the introduction of the NDIS, there has been an increase in individualised, single-therapy services delivered in siloed clinical settings. Because there are so few services offered outside the NDIS, families are forced to push for access to the NDIS and maximum plan funding - even when that model might not lead to the best outcomes for their child.
4. The shift under the NDIS to give families more choice and control over funding and services has left many confused and in distress, as there is not enough support or information to help them make informed decisions; and a limited range of service delivery options to choose from.
5. Difficulty navigating the system of early intervention is especially pronounced for families at increased risk of vulnerability, including Aboriginal and Torres Strait Islander families. Culturally safe and inclusive supports are needed, and these should be devised through collaboration, engagement and communication with these groups.
6. The most recent changes to early intervention in the NDIS (with the move to the Early Childhood Approach) are creating more uncertainty, with few tangible signs that the model is moving closer towards best practice.
7. The challenges with providing best practice early intervention supports are exacerbated by shortages of experienced and appropriately qualified practitioners. There is a particular shortage in rural and remote settings, especially of practitioners who can provide culturally sensitive supports for Aboriginal and Torres Strait Islander children and families.

8. Change is needed, both within and outside the NDIS. This change must be underpinned by research and evidence, with the aim of developing, testing and implementing policies and strategies that improve early childhood services so that they align with best practice.
9. Co-design with families raising children with disability and developmental concerns is central to building this evidence base. This will ensure that changes to early intervention meet the needs of all children with disability and their families.

Authorship group

This position paper has been developed in collaboration and consultation among members of the Healthy Trajectories Child and Youth Disability Research Hub; the Melbourne Disability Institute, the Centre for Child and Community Health, and the Department of Social Work Disability Research Hub.

About this position paper

A recent survey, undertaken as part of a national disability research agenda setting exercise, found that the number one priority concern for the 973 respondents was the design and operation of the National Disability Insurance Scheme (NDIS) (1).

This document addresses one aspect of the NDIS: that pertaining to early childhood intervention. The system for early childhood intervention services in Australia has been broken for some time now (2). While there is a large body of evidence and collective knowledge on what constitutes best practice approaches and early interventions for childhood disability (3-7), policy and practice does not align well with this. The system is falling short, and children with disability and their families are not realising best outcomes (2). They are navigating a system that is fragmented, difficult to understand, and not necessarily optimally funded or structured. As a result, families are not receiving the support they need to make informed decisions in line with best available evidence (8).

In this paper, we define best practice in early childhood as that delivered using the best available evidence in accordance with the guiding principles articulated for early childhood intervention: family-centred and strengths-based approaches, that are coordinated, delivered in natural settings to focus on child and family capacity building, and appropriately tailored to child and family need (9). Currently, there is a lack of best practice universal / generally targeted disability supports, and a growth of individualised specialist services delivered in clinical settings.

In part 1 of this paper, we summarise recent advances in the science of early childhood development and current evidence for early childhood intervention and supports for children with developmental disabilities and their families. Historical and current policy changes in early childhood intervention services are then outlined, followed by nine interconnected areas of concern identified with early intervention services in Australia, both for those children eligible for the NDIS, and those who are not.

In part 2, we propose a program of research which aims to provide a deeper, more nuanced, understanding of the problems and provide an evidence-based platform to develop and test policies and strategies that can be implemented to improve existing early childhood intervention services and ensure they are aligned with best practice.

This paper is a call for collaboration and action to ensure that the system of early childhood supports, and intervention services, is delivered based on the best available evidence. Families raising children with disability and developmental concerns carry a deep understanding of their children's needs and capabilities and must therefore be partners in all decision making. Co-design therefore must be central to building this evidence base to ensure the research meets the needs of all children with disability and their families. Our team includes people with lived experience of child-onset disability, but we are also seeking a range of collaborators and partnerships to ensure the relevance and effectiveness of the approach to finding solutions. We seek collaborators from Disabled Peoples Organisations, researchers, governments, consumers from diverse backgrounds, and practitioners. Collectively, we will seek funding to implement the research and translation required to work towards the key issue of ensuring that best practice childhood intervention services are identified and implemented across the country and that children with disabilities and their families, in all contexts, are supported optimally.

Part 1

Background – Early childhood intervention in Australia

The science of early childhood development and current evidence for early childhood approaches

Evidence from child development and neuro-sciences support the important role of child and family related factors in influencing a young child's developmental trajectory (10-12). Early childhood is the period when the brain undergoes greatest structural change. g Neuroscientific evidence indicates that during this time the child's brain rapidly self-organises to develop increasingly elaborate neural circuitry that supports future development and learning. Active, robust neural networks are formed that resist change, alongside weaker connected circuits that are highly plastic and modifiable (13). Consolidation of the child's brain architecture and its capacity to respond and adapt to experiences is greatest in the early childhood years. This period is often referred to as the critical 'first 2000 days' (14)-- a time during which life circumstances can fundamentally influence the child's developing brain and life course trajectory (15).

Having the opportunity to develop positive relationships and experiences in early childhood reinforces the structural foundations of the brain that are needed for lifelong learning. Positive experiences can protect against the negative impacts from early childhood experiences of disadvantage and adversity, that can undermine early brain development with lasting impacts on learning, behaviour, and physical and mental health (10). Protective interventions that support parent and infant interactions and mental health can effectively buffer childhood experiences and enhance developmental outcomes (16, 17).

Children with developmental disabilities are at higher risk of adversity and poorer developmental outcomes in the early years. Associated impairments may be compounded by access barriers to early learning opportunities and higher risks of being exposed to trauma, abuse and neglect, stigma, and discrimination (18). Research evidence supports the need for timely family and child supports, to optimise child outcomes and reduce potential sequelae arising from a child's condition or family context (19-21).

Many types of intervention approaches exist, impacting different domains of child development and learning outcomes. For example, therapy interventions promoting child self-initiated movement through use of early power mobility in very young children, enables discovery and interaction with their environment, with positive impacts on cognition and social participation (22). Similarly, participation-focused (23) and parent-mediated strategies focussing on parent-child interactions have positive associations with enhanced social-emotional, communication and self-efficacy for children with delays (24, 25).

Achieving optimal outcomes, however, is predicated upon the early identification of need for early developmental support and services. Identifying this need has traditionally occurred late in the developmentally sensitive 'first 2000 days'. The likelihood of early diagnosis differs for particular conditions and in different contexts. Until recently, the average age for a diagnosis of cerebral palsy was 18 months of age. Cerebral palsy or high risk of cerebral palsy can now be detected accurately before 6 months of age (26). Similar shifts towards earlier identification and diagnosis exist for other developmental disabilities (27). Without early identification, the greatest developmental gains from access to timely intervention are missed.

Delayed diagnosis and access to services does not only affect the child. Evidence also demonstrates that it can negatively impact parent mental health (28). This is particularly significant as parenting behaviour (e.g., being attuned to their child's cues, parental warmth, family functioning) is more strongly related to the effectiveness of early intervention for children with developmental delays than the amount or intensity of therapy itself (24).

Delivering interventions within a family-centred delivery framework is key to effectively implementing supports during this significant early period (7, 29, 30). The widely agreed key features of family-centred practice include: an emphasis on child and family strengths rather than deficits, facilitating family choice and control, and creating a positive home learning environment that optimises the development of a collaborative family-provider relationship (7, 31).

As noted by Moore (4):

How services are delivered is as important as what is delivered... Relationships have a dual quality or function: they are both a means to an end and an end in themselves. Relationships are an end in

themselves in that they do not just lead to a better quality of life, they *are* quality of life. Positive relationships are central to our well-being (p. 8).

Opportunities for relationships and learning within and beyond the family are enabled through having timely access to informal and formal community supports with peers and other experts, delivered in accessible formats and locations with adequate resources and infrastructure.

Recent history of Australian service provision in early childhood intervention

Prior to the introduction of the NDIS, early childhood intervention supports were provided largely by State and Territory governments through block funding of specialist disability services, and through mainstream services. The Australian government entered the space with the Helping Children with Autism (2008) (32) and Better Start (2011) initiatives, with the aim of improving access to best practice early intervention, education and support for families of children diagnosed with autism and other disabilities. For those who could afford them, supports were (and still are) offered by private allied health providers.

After testing different approaches to early intervention during the NDIS trial period from 2013 to 2016, responsibility for early childhood intervention services started to shift into the NDIS utilising what was described as the Early Childhood Early Intervention (ECEI) approach. The purpose of the NDIS ECEI approach was to support children aged 0-6 years with a disability or developmental delay and their families based on their unique circumstances. It was intended that families be provided with information, emotional support, referral to mainstream services, short-term intervention, or help to access the NDIS for longer-term intensive supports as part of a funded NDIS plan (33).

To inform this approach, national guidelines on Best Practice in Early Childhood Intervention were developed in 2016 by Early Childhood Intervention Australia (34) (now Reimagine). The guidelines focus on providing children with developmental delay or disability, and their families, services to promote “the child’s development, the family and child’s wellbeing, and the child taking part in their community”. The ECIA guidelines (34) were developed based on eight best practice principles that address four quality areas:

- Family
 - Family-centred and strength-based practice
 - Culturally responsive practice
- Inclusion
 - Inclusive and Participatory Practice
 - Engaging the Child in Natural Environments
- Teamwork
 - Collaborative Teamwork Practice
 - Capacity-Building Practice
- Universal principles
 - Evidence Base, Standards, Accountability and Practice
 - Outcome Based Approach

The introduction of the NDIS ECEI approach triggered significant changes in the early childhood intervention sector, including in funding systems and planning procedures (35), and parental responsibility and decision-making (36). Indeed, the change began with the Helping Children with Autism and Better Start packages (which predate the NDIS).

In 2018, the National Disability Insurance Agency (NDIA) commissioned ECIA to investigate best practice in early intervention in Australia. Recommendations from the ECIA Best Practice Report (34) emphasised the need for streamlined, easy to understand and up to date information; a greater induction for families on what the NDIS can deliver, and how to tailor it to their specific needs. The report also recommended the NDIA develop strategies to stimulate parent-to-parent support mechanisms to empower parents/carers and foster family-centred support, and drive caregiver understanding of best practice to enhance outcomes for the child. Research shows that families value the support and advice they receive from other families who are in the same situation, but most families prioritise the needs of their child over the value of connecting with other families (37). This plays into parental decision making about supports accessed, especially when allocation of funds/resources are limited. Whilst best practice principles were developed and changes in funding systems and processes have been instigated across the Early Childhood Intervention (ECI) sector, the ECIA 2018 review has identified significant gaps in implementation and concerns exist about ongoing policy implementation shortfalls.

The policy landscape continues to change – the Early Childhood approach

The ECEI approach is changing. The NDIA launched an ECEI ‘reset’ in 2020 and a range of actions and approaches have been recommended or are in the process of implementation that may address concerns raised about the ECEI approach (see below).

The program is being rebranded to the ‘Early Childhood Approach’ (ECA). There is a documented focus on providing families with connections to information, expertise, supports and linkages to local specialist and mainstream community services so that children are supported to develop their capabilities to participate meaningfully in all aspects of their lives (38). In addition, as of 1 July 2023, the partnership of the NDIS and Partners in The Community (PITC) Program will extend early childhood services from 7 years of age to 9 years of age, to ensure that young children are supported throughout their transition to primary school, and align the Scheme with the World Health Organisation’s definition of young children, which is zero to eight years. The services will be for children younger than 9 years with disability, and children under the age of 6 with developmental delay (including developmental concerns).

The inclusion of terminology to identify children with ‘developmental concerns’ as eligible for the early childhood approach is new, as of late 2021. This identifier clarifies that children without diagnoses or identified developmental delay can receive support based on the concerns of a child’s carer/family. It is, as yet, unclear what impact these changes will have on the quality of early childhood intervention services or the sustainability of the NDIS. However, while the language in the latest guides from the NDIA align well with best practice early intervention, the forecast resourcing and priorities in the 2022 tender for the PITC program do not align so well (see further discussion below).

It was recently announced that the Australian Government will bring forward a planned independent review of the design, operations and sustainability of the NDIS, including the PITC program. This can be expected to result in further changes to early intervention in the NDIS.

Concerns about Early Intervention in Australia

The prioritisation and investment in early childhood intervention by governments has advanced in recent decades, but early childhood intervention services remain disjointed (34) and with significant gaps in implementation and access. Early childhood intervention services continue to be influenced and formed by divisions between health/clinical approaches and educational/capacity building approaches, and between child/family-centred models and clinically-based program models, as described further below. This appears amplified by the NDIA pricing structure. Services are also compromised by Commonwealth, State and Territory Government policy and program gaps in early education and care (34).

When a child is born with a disability or who has a disability diagnosed early in their life, this child may be the families' first lived experience of disability. There are many "unknown unknowns". Families do not necessarily know what constitutes best practice, or where to find out what is best practice and where to obtain services that align with best practice: indeed, parental access to quality information is a commonly identified need (36, 39). Children who face additional adversity or are from marginalised groups (such as those experiencing poverty, family violence, or who are from culturally diverse or Indigenous families) are further disadvantaged by the way systems are structured (36, 40). These inequalities pose significant barriers to accessing high quality early childhood services. Thus, the nine areas of concern about early childhood supports and interventions discussed below, relate to three core topics: (i) the NDIS model and funding; (ii) workforce; and (iii) practice and inclusion.

NDIS model and funding

1. Business model versus relational-based model

The issues with early childhood intervention have been compounded over recent years with the disruption of the relational-based approach by introducing the NDIS. The NDIS functions as a (quasi-) market-based and individualised business model and therefore incentivises a focus on achieving eligibility for the NDIS and obtaining and sustaining funding (35). At times, it appears that the objective of parents (and their service providers) can be to maximise funding. This can have adverse effects, as more funding is not necessarily optimal for children who need time to play and to be children.

Service provision situated within a family centred practice framework, on the other hand, rely fundamentally on the quality of the relationships established between the families and the ECI providers (4, 7, 29, 41). The effectiveness of family-centred approaches is related to participatory relational practices; practices that are individualised, flexible, situated in context, responsive to family concerns, and support informed choice (29, 42). These relationships are critical to success. However, the NDIS structure requires services to adopt an individualised 'billable hours' approach, which maximise income and thus incentivise centre-based clinical models of service delivery rather than home- or community-based capacity building models. This is not consistent with the overall aim of early childhood intervention, which is:

...to ensure that the parents or other key caregivers are able to provide young children who have developmental disabilities with experiences and opportunities that help the children gain and use the functional skills they need to participate meaningfully in the key environments in their lives (43).

Thus, the implementation of a largely transactional and individualised business model, has disrupted the nature of relationships between ECI providers and ECI recipients. Specifically, there does not appear to be a good understanding that optimal early childhood intervention does not equate to enrolment within the NDIS – as the services that are purchased may not be optimal for the child or the family, and because not all children needing support will be eligible for the NDIS. The failure to deliver appropriate support during the early childhood period is harmful when it deprives children of essential experiences that form the foundation for future development. The NDIS ECI approach, to date, has therefore resulted in administrative complexity (40) and both government failure and market failure – the worst of both worlds – at the same time as expenditure on early intervention services has hit record levels.

2. Gaps in service provision outside the NDIS

In the transition to the NDIS, existing Federal government-funded (both Australian and State and Territory) programs were rolled into the NDIS or discontinued. While governments committed to continuity of support for those people with disability not eligible for an NDIS plan, this largely did not materialise (33). The NDIS has, as a result, ended up as an “oasis in the desert” — outside the NDIS there is very little available to support children with disability and their families both in terms of specialist disability supports, and mainstream services. This is placing pressure on families to push for entry into the scheme, because they face little help if not found eligible: for families who have concerns about their child’s development, the pathway to receiving appropriate support is unclear and inconsistent.

3. Capacity and sustainability of the NDIS

There are many more children in the NDIS than originally anticipated (see Table extracted from the Taylor Fry report (44)). Children and young people tend to have lower support needs than the “average” participant. The other group of new participants are people with disability who did not previously receive support through the State and Territory disability schemes. Given that those with higher support needs were more likely to receive support from state schemes prior to the introduction of the NDIS, it is not surprising that increasing numbers of participants are reducing average package costs. This is also having an impact on the profile of scheme participants – including the disability mix/functional level/severity/age profile of those in the scheme. Nevertheless, it is clear from Table 1 (an extract from Taylor Fry,(44)) that higher participant numbers are the principal driver of higher-than-expected costs, especially given that exit rates are lower than expected. Children with developmental disabilities who qualify for the NDIS may always need support, as mortality rates are relatively low, however the level of support is likely to vary based on the effectiveness of early support for the child and family.

Table 1: Breakdown of increase in projected payments: Participant number and characteristics (\$b)

Change in assumption	2024-2025	2029-2030
Number of participants	6.8	15.0
Disability mix	-3.5	-4.0
Functional Level / Severity mix	-0.9	-4.0
Age Mix	0.3	0.7
Total	2.6	7.7

Note: Components may not sum to totals due to rounding. Table extracted from Taylor Fry (2021) Table 5.3, page 50.

Further insight into what has been happening to participant numbers since the NDIS commenced can be found in data provided in the December 2021 Quarterly Report to Disability Ministers. Table 2 compares data from the NDIS December 2021 Quarterly Report with the forecasts in the original Productivity Commission inquiry. The Productivity Commission in its 2011 report estimated that 120,960 participants would be aged 0 – 14 years out of an estimated 411,250 participants at full scheme, or 29.4%. At 31 December 2021, there were 502,413 participants and of these 207,930 were aged 0 – 14 years or 41.4%. This trend, if maintained, will undermine the sustainability of the NDIS.

Table 2: Comparison between Productivity Commission estimates of participants and actual numbers

	Productivity Commission Report Estimates of NDIS participants in 2018-19(a)	NDIS Participants, as at 31 December, 2021 (based on the Quarterly Report) (b)	Difference between Forecast and Actual
Aged 0-14	120,960	207,930	+86,970
Aged 15-64	290,290	275,413	-14,877
Aged 65+	0	19,340	+19,340
Total	411,250	502,413	+91,163

(a) Productivity Commission Inquiry Report, Disability Care and Support, No 54, 31 July 2011, Table 16.2, p 755

(b) NDIS Quarterly Report to Ministers 31 December 2021, Table, E16, p133

It should be noted that the comparison in Table 2 is not completely like-for-like. For example, the Productivity Commission forecast was based on population projections for 2018-19. Nevertheless, the comparison clearly highlights that almost all of the higher-than-expected number of NDIS participants are children. Part of this will be accounted for by a change in the NDIS eligibility criteria for children from significant developmental delay in the original Productivity Commission estimate to developmental delay when the NDIS was legislated and introduced.

The Taylor Fry (44) report notes “Behavioural aspects appear to be present.... for people with a reference package between \$10,000 and \$20,000, a substantial portion of packages have a total support package (TSP) that is 70% or less as a fraction of the reference package. Of these, the average TSP is \$5,300 but the average committed supports are \$16,300” (44). This helps to explain why participants are focused on demonstrating eligibility for the NDIS - if they are not eligible, they receive nothing but if they enter the scheme, they are likely to receive approximately \$15,000. While questions remain as to what level of support individual children and families need over time, the question of how much money is provided to a family should not dominate all other questions, such as what goals are to be achieved and how.

4. Transition to the Early Childhood Approach

There remains uncertainty over what effect the transition to the Early Childhood approach will have on supports and outcomes for children with disability and developmental delay and their families. Documentation describing the PITC tender requirements under the new approach (which was since terminated pending the upcoming review of the NDIS) raises many questions about ECA and whether it can hope to achieve its stated goal of best practice early intervention:

- Families who have “developmental concerns” about a child who is aged under 6 will be eligible for “early connections”. This will focus on “family capacity building” and “community inclusion”. However, support will be limited to 10.1 hours: not much will be realistically achieved in this time, especially while there are very few mainstream supports which children with disability and their families can connect to and access. This suggests there will be continued pressure on partners to make an NDIS access request or lead the participant to apply directly for early intervention access.
- According to the recent tender, children with disability or developmental delay will be eligible for “early supports”. They will receive a little more support – up to 17.2 hours per child, which is available over a maximum period of 12 months, but they will be limited to accessing these early supports only once and the NDIA estimates that only 4,200 children nationally will be eligible. Early supports are payable to the EC partner on a “part-variable payment” basis, meaning that actual provision of these services will be limited by the resourcing of the EC partner. Further, there is no assessment of outcomes from the “early supports” and amongst the potential suite of early supports there is no mention of assisting parent and family wellbeing: an essential element to creating optimal developmental environments for children. Therefore, again, there is likely to be continuing pressure for families to make an NDIS access request, especially given the much higher and ongoing supports that are likely to be made available in even a small NDIS plan.

The NDIA pricing structure, and the failure to apply any market interventions for allied health services, continues to encourage the delivery of clinically based individual therapy services. It is therefore difficult to conclude anything other than the current clinically based approach to early intervention will continue to dominate, families will not be properly supported to promote their child’s development and capacity building within their natural environments, and that pressures for more and more children to enter the NDIS will continue. What is needed, is further development of an embedded mainstream early childhood service system.

Workforce

5. Recruitment and retention of experienced health professionals

The quality of practitioners in early childhood intervention is paramount for achieving best outcomes (4). The national guidelines on Best Practice in Early Childhood Intervention describe that ‘Early childhood professionals deliver quality services and supports’, and that ‘early childhood professionals have qualifications and experience in early childhood development’ (34). Minimum qualifications and experience, however, are not required to work in the sector. Despite no requirements, a major shortfall exists. The recruitment of a workforce with adequate ECI experience is a challenge, both for EC Partners and ECI providers. There are not enough ECI services or experienced ECI practitioners to meet demand (2). Moreover, attracting and retaining health professionals in rural and remote areas is particularly challenging. Factors relating to extensive travel, burnout, lack of adequate support, lack of culturally safe practices and training, and financial incentives have all been identified as barriers to workforce recruitment and retention in geographically isolated areas.

While there is an overall lack of ECI services or experienced ECI practitioners to meet demand, there is also a lack of access to allied health professionals specifically for Aboriginal and Torres Strait Islander children. For those living in rural and remote settings, in addition to experiencing a higher incidence of adversity and risk factors associated with developmental delay(s), Aboriginal and Torres Strait Islander children are especially impacted by the shortage of qualified and culturally confident health professionals, resources, and accessibility (45). Aboriginal and Torres Strait Islander trial sites have found a lack of cultural knowledge to be the most significant barrier to engaging the Aboriginal and Torres Strait Islander community (2). There is, therefore, a need for greater sociocultural literacy of the service system. This has the potential to increase self-advocacy, engagement and support seeking for Aboriginal and Torres Strait Islander children and families (46).

In the tender for NDIS Early Childhood Partners, which has since been terminated pending the review of the NDIS, there are requirements that Partners recruit from a diverse range of backgrounds and cultures at a ratio representative of the community in which they work. They must also attempt to employ a minimum of 3 per cent of their workforce who identify as being First Nations People, and ensure their workforce includes people with specialist knowledge and understanding of diverse disability cohorts. This is likely to be a challenge for many employers, not least because the proportion of graduates across the professions, while growing, still falls well short of what is needed (47). General workforce issues are also likely to be exacerbated by the reduction in skilled migration in recent years.

6. Inconsistencies in provider regulation

Further exacerbating the delivery and quality of services and supports is the dual system of registered and non-registered providers in the early childhood space. As a result of differing requirements, this creates an uneven delivery of best practice in early childhood intervention. Practitioners in early childhood are not required to be accredited against the *Early Childhood Practice Standards* as articulated in the *NDIS Practice Standards* unless they are a registered service provider (48). Registered providers, accredited against the standards, are more likely to provide an approach consistent with best practice early childhood intervention

principles than unregistered providers who may provide more siloed clinical services. This variation in registration is a driver for lack of consistency in provision of evidence-based best practice.

However, it is also wrong to conclude that being a registered provider equates with “good” and non-registered equates with “bad”. There are potentially high quality non-registered providers who have chosen not to want all the red-tape and high cost of registering (49). Having a dual system of registration makes it even more complex for families to navigate and the inconsistency and inefficiency in services and supports can compound the existing distress, confusion and stress for families/ carers who are trying to navigate the NDIS service system. It also contributes to confusion over what is considered as ‘reasonable and necessary’ supports within a funded plan, adds to the scheme costs, and creates unrealistic expectations of services and supports to be funded (8).

Practice and inclusion

7. Decreases in the delivery and quality of family-centred and strengths-based practices

There is now a widely recognised loss of embedded inclusive family-centred and strengths-based service delivery and coordinated models of service, as well as inadequate consideration, funding and availability of parent/carer and family capacity building. With the interests of the child paramount,- tailored approaches that recognise the uniqueness of each child and family, and meet their specific needs are now difficult to obtain (8).

There is a lack (loss) of best practice universal / generally targeted disability supports, and a growth of individualised specialist services delivered in clinical settings. The policy shift under the NDIS to provide parents/carers greater choice and control over funding and services has resulted in challenges for both ECI services and for families of young children with developmental disabilities or delays (50). The opportunity and capacity for families to make informed choices about services is limited by: a lack of relevant, timely and independent information from reliable sources (about goal setting and what comprises good quality early intervention); a limited range of service delivery options from early childhood intervention providers; and a lack of genuine choice (perceived and actual) beyond varied specialist services (51).

Further, while the NDIS (38) claims that both family-centred and strengths-based approaches remain at the forefront of the original ECEI approach, the impact of the policy shift under the NDIS has seen a decrease in families engaging in family-centred coordinated services as families are exercising their choice to opt for single therapy and clinic-based service delivery models. The Victorian Department of Education and Training (DET), as well as other States and Territories, first received anecdotal evidence in 2017 – from peak disability organisations, NDIS Early Childhood Partners and ECI service providers – that the introduction of the ECEI approach has resulted in a reduction of families engaging in both family-centred and strengths-based practices (2). The lack of exposure to family centred services and strengths-based practices is a missed opportunity to build family knowledge/literacy about their child’s developmental capacities and to engage and advocate for appropriate support.

These limitations are leading to less optimal service experiences and have the potential to adversely impact health and developmental outcomes for children. In turn, they are causing stress, confusion and distress for parents/carers and risk entrenching longer term inequalities and vulnerabilities (37, 52). The results of this

policy shift are a clear indication of the disconnect between policy and best practice; which raises concerns as to the quality of practice in early intervention and the suitability and sustainability of the early childhood approach under the NDIS. It also raises the key question: ***What factors are driving the divergence between what is known through extensive research to be best practice and what is happening?*** This is a significant issue for both the prospects of children with a disability, and the sustainability of the NDIS.

8. Ineffective service delivery of assistive technology

Assistive technology is used to describe “assistive, adaptive and rehabilitative devices for people with varying degrees of disability” and is “aimed at assisting or expanding human function or capabilities” (53). Therefore, these technologies can range from computerised communication systems and software programs to a practical object such as a handle on a phone (53). Examples of computerised assistive technologies can be text to speech programs that convert printed text to voice, graphic organisers to help children and youth organise their writing, or voice recognition to convert spoken words to text on a screen (54). They are “produced specially or availed generally to prevent, compensate, relieve, or neutralise impairment, disability, or handicap and improve the individual’s autonomy and quality of life” (55).

Assistive technology is highly valuable for optimising the participation and overall development of children with disabilities (56). Assistive technology can facilitate children’s communication, mobility, and self-care. In doing so, assistive technology can empower children to further immerse into their worlds of family, friendships, education and play, thus enhancing their quality of life and that of their families. Assistive technology can also be transformative from a psychological perspective (57). However, for most children with disabilities, inadequate or no access to assistive technology can prohibit them from engaging in education, health, and social services, resulting in lifelong impacts on their participation and in realising social and economic independence (56, 58). For children with functional limitations associated with a wide range of disabilities, including cerebral palsy, developmental communication delays, and feeding difficulties, their participation in developmentally appropriate roles can be compromised by a lack of assistive technology resulting in further delay of their overall development, growth of independence, and a reduced quality of life (56, 59).

Currently, under the NDIS, subscriptions are required for accessing and using assistive technology. Further, if a subscription of an assistive technology resource surpasses six months, it is then considered owned by the consumer. This is a major shortfall in the service delivery and provision of assistive technology. For consumers who are children, after six months the assistive technology may no longer be suitable/appropriate for their developmental needs and trajectory, or be surpassed by rapidly advancing technical solutions. There are some options for renting assistive technology when this can be more cost-effective, such as for children who outgrow the technology (60). However, currently this does not cover children who receive early supports/connections and do not have an NDIS plan (60).

To address these challenges, we argue that there is a need for a better understanding of how best and most efficiently to support assistive technology provision (including child and family education/training in its use) during the early years of childhood. The importance of early access to assistive technology for children cannot

be understated; the earlier they can access assistive technology the better their short term and long-term outcomes of functioning, participation and quality of life will be (61, 62).

9. Need for better access to culturally safe practices

Aboriginal and Torres Strait Islander peoples have unique and diverse cultures, belief systems and world views. The strengths of Aboriginal and Torres Strait Islander cultures have continued to evolve and thrive despite the ongoing impacts of colonisation, systemic discrimination, and intergenerational trauma. In this context Aboriginal and Torres Strait Islander people are repeatedly impacted by structures that ‘continue to marginalise their human and legal rights and fail to address the social determinants of health’ (63).

The NDIS early childhood principles (38) include that ‘all families are different and unique’ and ‘early connections’ should be prioritised through the mainstreaming of community supports; practical developmental information; engaging other families for peer support; and access to early supports when there are developmental concerns. However, currently, there is limited collaboration, engagement and communication with marginalised families who are at increased risk of vulnerability, including Aboriginal and Torres Strait families (46). Aboriginal and Torres Strait Islander people have a right to culturally safe and responsive health care, free of racism and inequity. There is a need for culturally safe resources, and family inclusive language and literacy support strategies.

A key recommendation to address this need is to engage Aboriginal and Torres Strait Islander parents/carers in the co-design and re-shaping of ECI (2). This aligns with the long-held view that Aboriginal and Torres Strait Islander communities have had for their role in decision making in policies, programs and services to achieve better outcomes. In recognition of this inherent strength of Aboriginal and Torres Strait Islander people, all governments have committed to a new era of partnership and shared decision making under the new National Agreement on Closing the Gap (64).

Partnership and shared decision making should also be extended to other marginalised and vulnerable groups. Accessing and navigating the NDIS is known to be challenging for many families – Aboriginal and Torres Strait Islander families, culturally and linguistically diverse communities, families living in rural and remote areas, children in out-of-home-care, and families where the primary carer has a disability or requires complex mental health support (65). For some, these challenges reflect the fact that “Early childhood partners are not located in remote and very remote areas” (38). Additional access barriers can arise for vulnerable families when navigating the NDIS Portal. These can include limited internet access, the inability to read or write English, or computer literacy limitations. Other challenges relate to the demands on the parental role to navigate and advocate for services in a complex privatised system. Challenges may be exacerbated for parents with their own mental health or psychosocial challenges (36).

Summary

Nine key areas of concern have been highlighted that require intentional investigation if Australia is to realise an evidence-informed policy, system and service landscape that supports quality early years support for children and families:

NDIS model and funding issues

- Business model versus relational-based model
- Gaps in service provision outside the NDIS
- Capacity and sustainability of the NDIS
- Transition to the Early Childhood Approach

Workforce issues

- Recruitment and retention of experienced health professionals
- Inconsistencies in provider regulation

Practice and inclusion

- Decreases in provision of quality family centred services
- Ineffective service delivery of assistive technology
- Need for better access to culturally safe practices

Part 2

Building the evidence base

Early intervention in the NDIS currently operates in an evidence vacuum. To date, there has been little publicly available analysis and scrutiny of access, use and outcomes for young children in the NDIS. There is also little known about experiences and outcomes for children not eligible for the NDIS. We propose a research program is required to fill this gap and, ultimately, help advocate for better outcomes for children with disability and their families.

The proposed overarching research question

The overarching research question aims to identify:

What policy, process and funding changes are needed to the current system to optimise early childhood approaches that use best available evidence to meet the early childhood intervention guidance principles (i.e., best practice)?

Outcomes

Our intended outcome is to provide broad-based and in-depth evidence to inform policy, system and service design for the Australian Early Childhood Approach that aims to support families and children with developmental concerns, developmental delay or disability, including those who are, and are not, eligible for individualised supports under the NDIS.

For children outside the NDIS, those with developmental concerns and those not meeting eligibility criteria, we seek evidence to inform how community, mainstream and early childhood supports should be designed and structured for them, and what community capacity building is required. We need to identify whether the currently proposed supports and capacity building activities, which are now described as “early connections” and “early supports” in the ECA approach, are likely to be sufficient. For those with NDIS plans, we need to explore what supports, regulations and policies are needed to support choice and control to ensure good outcomes. We also need to explore which children will be best suited to receiving supports through the NDIS (an individualised package) and which children’s needs will be best suited to supports outside the NDIS.

Outputs

A broad-based dissemination strategy will need to be developed with our co-design partners to ensure results are translated in ways that support maximum impact and influence on policy and practice in Australia.

Methodology

Addressing concerns about early childhood intervention in the current funding and policy environment requires compelling evidence and repeated evaluation; including economic evaluation to establish efficiency credentials. We propose, therefore, that an iterative approach is needed, along with longitudinal data collection with embedded studies to understand specific issues in greater depth and/or to pilot alternate approaches. The design and implementation of these methods needs to be undertaken in partnership with a wide range of stakeholders including Disabled People’s Organisation, consumers, researchers, practitioners, and government. It also requires an underlying economic evaluation that has regard to multiple perspectives, including ‘societal’, ‘disability sector’, ‘third party funder’, provider, and ‘consumer’ perspectives.

All of these perspectives are essential because as noted by Moore (4), regardless of the focus or content of the intervention, effective programs

- are relationship based, involving partnerships between professionals and parents
- target goals that parents see as important
- provide parents with choices regarding strategies

- build parental competencies
- are non-stigmatising and demonstrate cultural awareness and sensitivity; and
- maintain continuity of care.

Data Sources

This research requires access to NDIA unit-record level data, to describe how parents/carers and families are currently using their NDIS funds, and explore what can be learned about service navigation and use from the characteristics of the NDIS early intervention population – for example, what do the clusters of package size, distribution of spending and outcomes measured tell us? It may be necessary to recommend additional or alternative data that should be collected to better inform policy improvements.

The research also requires direct engagement with parents/carers of young children who use early intervention supports and services, and with service providers, via surveys and interviews. Data collection is needed to provide evidence of the lived experience of the NDIS Early Childhood Approach and quality of life outcomes; to identify enablers of equitable and ethical policies, systems, services and supports; provide evidence about effective policies to guide systems, services and supports; and enable economic analyses to inform policy. Qualitative evidence can be combined with or situated within evidence gained through desk top review of existing empirical evidence and policy analyses.

Where to from here

Our Healthy Trajectories research team in collaboration with partners across the early childhood sector is positioned to progress a program of research like this, given funding. We have met with key interest groups including advocacy groups and early childhood providers who have expressed interest in ongoing collaborations in this work. We would welcome further discussion with the NDIS Review panel of this position paper and research proposal, and we can provide additional methodological detail.

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