Policy to practice: Implementing an Australian vision for children with disabilities

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Introduction

The next twelve months is going to be a critical time for children with disabilities and their families. Over the next 12 months the NDIS will be reviewed. The outcome of that review will decide if the status quo will continue or if there will be change. Whatever is decided, it is likely to last for the next decade. This means that the outcomes of the review will affect everyone with an interest in young children with disabilities, whether they are practitioners, researchers, Government administrators, service managers and, most importantly, families.

In thinking about this review, the first issues will be to make sure children get the attention they need. The NDIS is a huge venture. This means competing priorities. Many of the issues that the NDIS deals with have an urgency about them, for example making sure people have housing. Young children, who are cared for by their parents, can be seen as needing less attention. This is a long-standing imbalance that we need to address.

The second thing we need to do, is to change the conversation around. Since the beginning, the question seems to have been: how do children fit into the NDIS? For the review, we need to ask: Is the NDIS a good fit for children?

This question raises a difficult issue. What are our evaluation criteria? How do we decide what a good fit is? There are some lenses we can look at it through.

We have a vision for what we are trying to achieve. That is primarily documented through the conventions on the rights of the child and on the rights of persons with disabilities.

We have an accumulated knowledge about what practices best support children with disabilities and their families.

What we don't have is an agreed plan for how we support children in the community.

There is emerging information about the challenges of the implementation of the NDIS funding model.

So, is the NDIS a good fit for children and families?

Given the potential of the review to shape the future lives of young children with disabilities and their families, it is important that everyone engages.

The approach that I am taking is influenced by Cathedral Thinking, so let's look at that.

Cathedral Thinking

Cathedral Thinking has emerged as an idea in architecture and is also used in different ways in the debate about the environmental crisis. At the core of Cathedral Thinking is the need to take the long view, to think of what is sustainable, to think of what can be built over time. Cathedrals are remarkable because when they were commissioned, it was understood that they may take up to a century to complete and that when completed would last centuries. They were an investment for the future. To achieve these long-term projects Cathedral Thinking needed: a far-reaching vision, a well thought out blueprint, and a shared commitment to long-term implementation (1).

One of the modern examples of Cathedral Thinking is Antoni Gaudi's Basilica of the Sagrada Familia in Barcelona.

Gaudi started designing this project in 1883 and continued working on it until his death in 1926. At that stage it was less than a quarter completed. Its ambitious design combines cathedral Gothic with Art Nouveau. The building continued slowly through private donations and was stopped by the Spanish civil war, which it survived. Work slowly resumed in the 1950s. Modern technology, particularly computer aided design, then increased the pace of building. It reached the halfway mark by 2010. It was intended that it would be finished in 2025, but the pandemic has caused delays. While it is not universally liked, it is universally acclaimed for the scale and imagination of its design and its innovation in finding solutions to the challenges of its construction (2).

Structure of this paper

Why is Cathedral Thinking important for us? Firstly, it reminds us to take the long view. Secondly it provides a useful way of thinking about what needs to be put in place to have a successful outcome.

The structure of this paper follows Cathedral Thinking in that it looks at:

- Vision
- Blueprint
- Implementation

The section on implementation is divide between the development of practices and the NDIS funding model.

A timeline based on centuries

Why should we think about a timeline based on centuries? Cathedral Thinking is important because it helps us understand the foundations we build on and our decisions will have long term implications.

As it also happens, the current vision of children with disability and its predecessor, the institutional vision, follow almost the same timeline as the building of the Basilica of the Sagrada Familia. The institutional vision of disability lasted from the 1880s to 1960s.

In the end, it was recognised as a mistake.

From 1960s there was a human rights movement both in Australia and internationally to have people with disabilities out of institutions. For children this meant being included within their family, their community and alongside their peers.

The change from institutional care started a series of practical responses.

The 1970 Handicapped Children's (Assistance) Act (3) introduced the first payment of subsidies to organisations providing training and accommodation for children with a disability. In 1974, a Handicapped Child's Allowance Act was introduced, the first payment to a parent or guardian caring for a child likely to need constant care for an extended period.

There were further discussions nationally and internationally about human rights. These finally resulted in the development of international conventions on the rights of children and the rights of persons with disabilities.

A vision for children with disabilities

Australia adopted a formal vision for children with disabilities through its ratification of both the convention on the rights of the child and the convention on the rights of persons with disabilities.

Using the UN Conventions as the basis of our far-reaching vision has been endorsed by governments. The Act that established the NDIS specifically refers to the NDIS as part of the government's commitment to the Convention on the Rights of Persons with Disabilities (4) (CRPD). The Act also acknowledges that the government has responsibilities under the Conventions of the Rights of the Child (5) (CRC). The vision for children therefore comes from both being part of the population of children and part of the population of people who have a disability. The Early Years Learning Framework also speaks to the experience of young children.

Children with disabilities as part of the population of children

The first vision for children with disabilities was through the Convention on the Rights of the Child. The UNCRC recognises: the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children (Preamble).

Children with disabilities are covered by the general provisions for children and some specific provisions covering disability.

The specific provisions for children with a disability (Article 23) include that:

- A mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community
- A disabled child should receive special care and assistance to the eligible child and those responsible for his or her care
- A disabled child should be supported to achieve the fullest possible social integration and individual development, including his or her cultural and spiritual development.

The Convention on the Rights of Persons with Disabilities was created to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities'.

In sections specifically relating to children, governments who signatories to the CRPD are expected to:

- ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children
- act in the best interest of the child
- ensure that children with disabilities have the right to express their views freely on all matters affecting them on an equal basis with other children

- access an inclusive education system so they are not excluded from the general education system (Article 24)
- provide the support required, within the general education system, to facilitate an effective education (Article 24).

The final nationally recognised framework for children is for children in Early childhood education and care.

All children in Australia are entitled to attend early childhood services, which are now regulated through a National Quality Framework. This framework includes the nationally adopted Early Years Learning Framework (6). It requires services to promote the following outcomes:

- Children have a strong sense of identity
- Children are connected with and contribute to their world
- Children have a strong sense of wellbeing
- Children are confident and involved learners
- Children are effective communicators

Given these three frameworks are all recognised by governments, they contain significant commitments to children and a basis for considering if the NDIS is a good fit for children and families.

A Blueprint

The second component of Cathedral Thinking is a blueprint.

The name 'blueprint' derives from the copying of plans for a building. These plans were then given to everyone responsible for different components of the construction. It meant people were working towards the same end.

Australia has not had a plan on how to support children with disabilities to achieve the vision of living in the community. The lack of a plan about what we are trying to achieve has made it difficult to progress. It is still a problem.

National, State and Territory Disability Plans

The main mechanism for developing a national approach in disabilities has been through the national, State, and Territory Disability Plans. The focus of these plans has been almost exclusively on issues faced by adults with disabilities. They have proposed changes in areas such as accessibility, mobility, housing, health, wellbeing, safety, education and skills and employment. These plans did not address the issues faced by children and families, except in references to education. This lack of recognition has finally been acknowledged in the recent Australia's Disability Strategy 2021-2031, which includes an Early Childhood Targeted Action Plan 7. It is a welcome, although limited, response.

Young children and policy

The absence of young children from these plans is not unusual. Early childhood has not done well generally in terms of the development of plans. One explanation is that there remains tensions between what is a family's responsibility and the role of government. For example, different philosophies have been evident in debates about childcare. Is it about providing child minding for working adults? Or is it supporting children's learning and development? The Early Years Learning Framework took a century to be agreed on given preschools were first introduced in Australia in the early 1900s.

State and Territory Early Childhood Intervention Programs

In the absence of a national approach, the State and Territory governments preceded to fund services for young children with disabilities on an ad hoc basis. Each State and Territory government adopted its own approach. In all States and territories services were provided directly through government departments. Some non-government organisations were also commissioned to provide services, primarily in NSW and Victoria. Services for children with disability were kept separate from other services for children. (Kemp and Hayes (8), Sukar (9)). Services were managed through a range of different departmental arrangements. This contributed to different types of services in different parts of the country.

The guidelines for these services are the main indication of their purpose. Prior to the introduction of the NDIS these guidelines generally supported children's rights and the role of families in supporting their children.

For example, the NSW Ageing Disability and Home Care's approach was '*that every child regardless of their needs has the right to fully participate in their community and have the same choices opportunities and experiences as other children*'. Victoria and Tasmania's Education Departments' programs provided '*parents and families with knowledge, skills and support to meet the needs of their child and to optimise the child's development*' and to support them '*to participate in family and community life*'. The Western Australian Disability Commission described its services as using a '*family centred approach which recognises that every family is unique*'. in 2008 the Australian government became involved. Rather than playing a coordinating role and initiating a national planning process, the Commonwealth took its own ad hoc decision to become an additional service provider. Its services were explained as supplementary to those provided by the state. The new programs had a very different focus. The Helping Children with Autism and Better Start programs were described as '*providing grants for the purchase of professional therapeutic and educational services for a child with a specific diagnosis of disability*'. (Forster (10))

This approach can now be seen as a precursor to the introduction of the NDIS.

The ad hoc approach that has characterised the development of services for children with disabilities in Australia has contributed to different understandings in different regions. The NDIS has been implemented on top of these differences. A process to reconcile the different approaches is yet to occur. This makes it harder to agree on how to progress the vision for children with disabilities or the success or otherwise of the NDIS.

Implementation

The third and final component of Cathedral Thinking is implementation.

There are two components of implementation that are particularly relevant to the NDIS review. The first is the emergence of best practices. The second is what we are starting to learn about the NDIS through looking at the impact of its implementation.

After the agreement on a vision, the identification of best practices represents the most important progress.

The best practices developed from the interests of the professionals who started working in the services for children with disabilities. That group of professionals were pioneers. For 80 years, or four generations, children with disabilities were excluded from the community. Working out how to support children with disabilities in the community was new. There was an early commitment to using research to inform practice.

International research into young children with disabilities

As with the development of the vision, the progress on the development of best practices in Australia was linked to international developments. The primary driver of research on children with disabilities came from the USA. They started in the early 1960s, through the Kennedy administration. Leaders in this field have included Michael Guralnick (11) (12) and Carl Dunst (13). They, along with their colleagues, have continued to research and develop family systems models for supporting the development of children with disabilities. These combine a therapeutic understanding of what might help a child with a developmental disability with an understanding of the most effective ways to support a child's learning and development. While the streams of research into child development and children with disability began separately, they have converged over time. There have been significant advances in the scientific research into how children develop. President Clinton sponsored the National Research Council to undertake a major report: **From neurons to neighborhoods: The science of early childhood development** (14) in 2000. This synthesised the growing research on early development across many scientific fields. This report, and other work at the time, contributed to international interest in the importance of early years services. One outcome of that interest was the Australian Early Childhood Framework.

Best practice in Australia

In the lead into the NDIS, Early Childhood Intervention Australia 15 was commissioned to identify the best practices that support effective early intervention. This report was a combination of consultation with early childhood intervention practitioners and drew on the decades of research into the development of young children and young children with disabilities.

It themed practices into four quality areas and eight practices.

Quality Area 1: Family

- Family centred and strength-based practice
- Culturally responsive practice

Quality Area 2: Inclusion

- Engaging the child in natural environments

- Inclusive and participatory practice

Quality Area 3: Teamwork

- Collaborative teamwork
- Capacity building practice

Quality Area 4: Universal principles

- Evidence base, standards, accountability, and practice
- Outcome based approach

These practices are informed by what research indicates are the most effective way to work with children with disabilities. They have not been universally adopted. One of the reasons is that by design these practices are community based and largely occur in families' homes and other places children spend time. Other models of service have continued to provide services from a centre that families bring their child to, including in hospitals.

The best practices have been endorsed by the National Disability Services Agency (NDIA) and the NDIS. They have an important role in considering if the NDIS is a good fit for children.

Implementation of Practises and the NDIS funding model

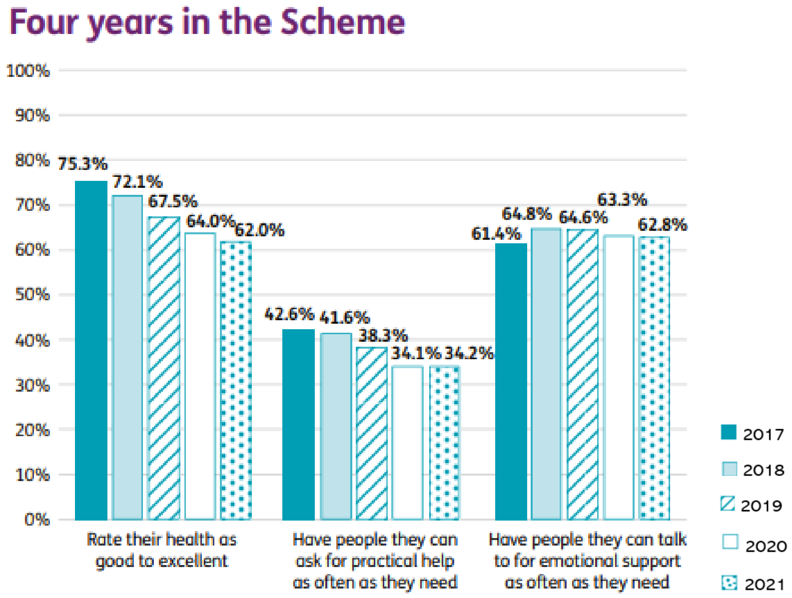
The final area I want to consider is what we have learnt so far from the implementation of the NDIS. I will look at three areas that are linked to Quality areas.

Firstly families.

Families: Is the NDIS bad for family health?

There is growing information that the NDIS is bad for the health or wellbeing of families and carers looking after children. The NDIA's 2021 report on outcomes for families and carers (16), which is based on surveys, indicates that for each year the parents of children aged 0 -14 years are involved with the NDIS:

- their rating of their health declines
- they have a declining number of people they can ask for practical help
- there is no change in the number of people from whom they can ask for emotional support



The table of parents rating of their health show ratings year by year. The baseline data comes from 2017. Between 2017 and 2021 families rating of their health declined by 13.3%.

These results correspond to the findings of the early evaluation of the NDIS (17), completed by Flinders University in 2018. That evaluation found that while the NDIS led to some improvement in the wellbeing of participants, there was no improvement in the wellbeing of families and carers generally, and it had a negative impact on the wellbeing of those caring for children.

The reporting must raise questions about the types of services that families are receiving. Our colleague Anoo Bhopti (18) found in a 2020 study, that families receiving early intervention services based on best practises had high scores in relation to quality of life. Factors that were important included family centre practices, a positive or strength-based approach and information and support.

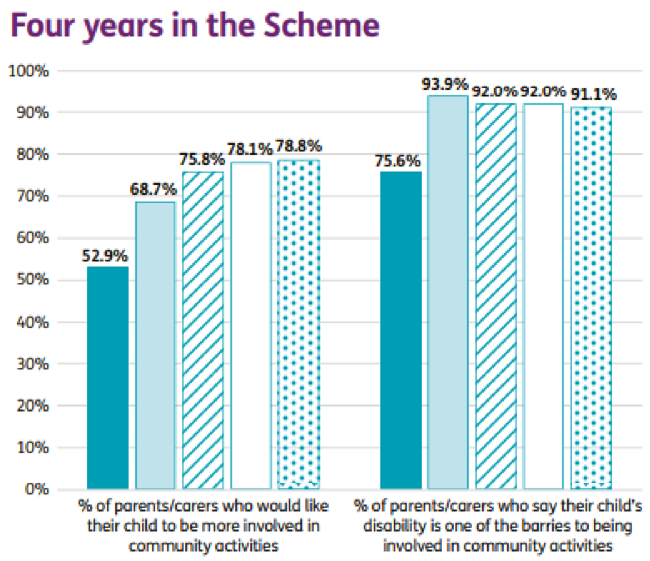
There may be more critical structural issues? Can an individualised funding model that does not include the family unit successfully work for families? There is lot to explore here.

Regardless of explanation, this is not a good result for the rapidly increasing funding packages experienced by children aged 0 -14 years since 2016. It's not a good result given the extended time parents spend supporting their children.

How does the NDIS support inclusion?

The model of funding through the NDIS supports the broad principles of participation. NDIS funding can support greater community involvement, which is a good thing. Whether a service has this focus or not rests with the family and service.

The NDIA has some limited data on community participation in its surveys (19). The main finding is that over time parents of children aged from birth to 6 years want their children to be more involved in community activities.



There are some areas of positive changes reported in family's sense of inclusion, in places like churches and other community settings.

The best practices highlight the importance of inclusion to children's development. The current NDIS funding model appears to have two limitations.

The first is that while parents want their children to be more involved, the individualised funding model does not support collective action to improve children's participation at the community level. The responsibility to negotiate access to activities, whether they are sport, art, or games, rests with individual parents or workers making representation on behalf of an individual child. A child's opportunities are influenced by their parent's networks and capacity to undertake such negotiations.

The bigger problem is that the two main places that children live in are at home and in childhood services such as preschools and schools. These are now split between the Commonwealth NDIS and the State run early childhood and school services. In the introduction of the NDIS the two levels of government committed 20 to: *working closely together at the local level to plan coordinated streamlined services for individuals requiring both school education and disability services*. Is this possible? The NDIS market model means there are no clear expectations about how NDIS funded services should interact with children's services or schools. Schools also make their own decisions. The result is one of three interactions between the services. These interactions are: no interaction; a service based on withdrawing the child from their activities; or a level of cooperation. The worst case scenarios we hear about include disconnects so severe that a child has one behaviour support program for school and a different one at home. Another child has one communication device at school and a different one at home. This type of situation compromises the child's development and should never occur.

Teamwork

In relationship to teamwork, the NDIS in general is creating problems. Hummell (21) and colleagues, in a 2022 report, have looked at some of the challenges arising from the way the NDIS encourages participants to have multiple providers. This is leading organisations to have to find ways of coordinating for individuals at the local level. The anecdotal information is that families with young children are now using multiple and disconnected services, which does not support teamwork.

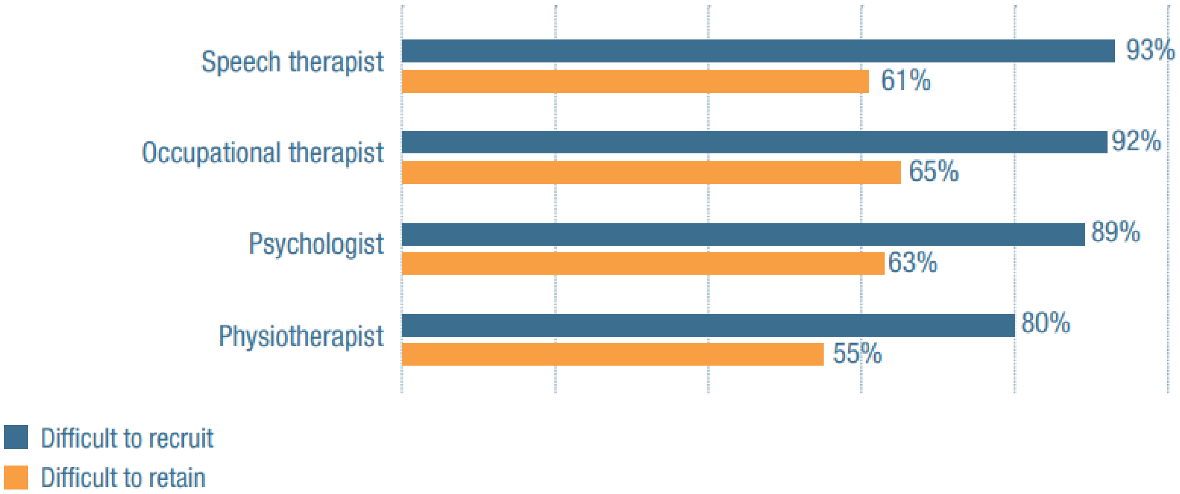
Workforce

I want to finish with a comment about workforce. Best practice needs a stable and sustainable workforce. To be effective, the professionals working with young children with disabilities need to be highly skilled. This can only occur if staff receive training and accumulate skills over time.

Since the introduction of the NDIS the workforce continues to experience high levels of workforce shortages and turnover.

In its 2021 report, NDS (22) reported that the top four hardest occupational groups to recruit into the NDIS were therapists.

Figure 15 Occupational Groups proving difficult to recruit and retain



Over 90 % of surveyed organisations reported difficulties recruiting speech therapists and occupational therapists. Over 60% of organisations had difficulties retaining speech therapists, occupational therapists, and psychologists.

The large increase in the demand for therapists was entirely predictable with the introduction of the NDIS and increased funding levels. This has been further impacted by the COVID 19 pandemic. There remains no NDIA initiated response. The NDIA 2021 workforce plan 23 barely raises the issue and does not comment on the specific situation for children, although there is a child on the cover. The current situation means services are unavailable, the quality of services cannot be sustained, and the viability of services is under pressure. In all, the situation is not sustainable.

Conclusion

In conclusion, let me briefly recap.

The next twelve months are critical time for people interested in the futures of children with disabilities. Whatever comes from the review of the NDIS will be significant.

We need to change the conversation. Instead of asking how children fit into the NDIS, we need to ask is the NDIS a good fit for children?

In making the observations I have about the NDIS I am wanting to look at structural issues we need to repair. The fact that we have an NDIS is unquestionably a great achievement.

I haven't tried to list all the things I think are right or wrong. Instead, I have observed the important information we have in place. We have an agreed vision. We have identified best practices. We have the start of understanding the operational outcomes of the NDIS model.

We still don't have an agreed plan for how we support children with disabilities and their families in the community, which will be essential.

There is another perhaps more fundamental problem. Who is representing the best interests of the child in all the decisions that will be made about them? If children's interests aren't represented, they are invisible in the decision-making processes. Without representation there is no recognition. Without recognition there is no action.

The disability advocacy groups are very strong in their call for '*nothing about us without us*'. Minister Shorten made a point in appointing additional people with lived experience onto the Board of the NDIA. The members on the Board with lived experience represent an adult's experience.

Children and their families are not represented on the Board. Nearly half the participants in the NDIS are children. Why don't they have proportionate representation?

Another example is there is no one with a professional background in early childhood disability appointed to the panel reviewing the NDIS. Early Childhood disability is a specific area of expertise. Most people who join the NDIS in the future will be children. Making sure the panel has the expertise to design the best entry is in the interests of the NDIS.

I recently joined some colleagues in writing to the Minister asking for the appointment of someone with early childhood disability onto the panel.

As the review gets underway, I am sure there will be many opportunities to contribute ideas to how the NDIS might improve. PRECI will have a place on its website for updates.

I hope Cathedral Thinking has added to your ways of looking at the NDIS. I will make the full version of this paper available soon. I'm sure you all have a valuable contribution to make.

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