

First an autism diagnosis then a clinician's office—how the evidence supports a different approach for families

July 2 2024, by Andrew Whitehouse, David Trembath and Sarah Pillar



Credit: Unsplash/CC0 Public Domain

Minister for the National Disability Insurance Scheme (NDIS), Bill Shorten, has proposed a number of [policy changes](#) to the scheme. It is

hoped these will ensure its sustainability for future generations.

The proposals and legislative amendments follow a nationwide discussion on the need for reform so the NDIS can achieve its original aim to support and empower Australians with disability. Currently, [one in ten children](#) aged between five and seven years are participants of the NDIS.

Less discussion has focused on how the introduction and roll-out of the NDIS may have shaped community expectations around early support. For example, many families are now seeking supports that do not align with what experts know is best practice for children with developmental delays or who are autistic.

So what does the evidence say works best for [young children](#) diagnosed with autism? And how could reframing community expectations be critical to the success of any policy reform?

Support can come in different forms

Around 20% of children in Australia experience developmental delay, and around 3% of children are autistic. Many of these children will require additional support to meet their developmental needs at some time.

Depending on its aims, support can be delivered in many places, including within [clinical settings](#), or in settings embedded within everyday life.

Within the NDIS there has been dramatic increases in the delivery of support in specialized clinical settings, such as the clinics of speech pathologists or occupational therapists. But best [practice guidelines](#) consistently call for community-embedded approaches.

[Best practice guidelines](#)—consensus statements within a specialist area that summarize evidence and describe what reflects the best approach—emphasize the importance of building capacity within the child's everyday routines and environments.

This might be at home with parents, in childcare and early schooling with educators, or in their [local community](#) with playgroups, sport coaches and other important people in the child's life.

Within the current NDIS funding model, these types of supports are either underfunded or unfunded, and therefore not prioritized.

The [NDIS Review](#) that completed its work last year highlighted a range of policies which incentivize the delivery of services within clinical settings. These include the dominance of individual support packages, an activity-based fee-for-service funding model and rigid funding categories—all of which preference clinic-based service delivery as a way of controlling costs.

Specialized services within clinical settings have an important role to play, particularly when children are presenting with developmental challenges that are having a substantial impact on their daily functioning.

However, this model of care is [not what is best](#) for the majority of children.

The three Rs

Three core tenets of [best practice](#) are the delivery of support at the right time, in the right amount and in the right context.

Right time

Development is a sequential process. Skills are built up over time, with later skills often relying on the firm foundation of earlier skills. Because of this, early delays can cascade into greater challenges over time. Effective support must move quickly to provide support early. This is also when support needs may be lower.

Right amount

Many people assume more intense support will result in better outcomes for children. But research does not bear this out. A [recent meta-analysis](#)—a type of study that uses statistics to compare different studies—found no evidence outcomes improve with increasing amounts of therapy.

Instead, the right amount should be individually determined and should vary across a child's life as their needs and environment change over time.

Right context

One of the [primary goals](#) of childhood disability supports is to enable children to participate fully and meaningfully in family and community life. To achieve this goal, supports must be delivered in the right context.

Wherever possible, supports should be delivered in naturalistic settings (home, childcare, school) and focus on [family and community capacity building](#).

Policy changes need community shifts

The NDIS reform bill currently before parliament makes provisions for more flexible use of personal funding. This may make it easier for clinicians and families to adapt the type of support to the changing needs

of the child over time.

The other major proposed change is the development of a "[foundational support](#)" system. State and territory leaders, who will be responsible for delivering this support, have asked for more detail on the cost of this shift. But the government hopes such a system could support the "missing middle" between children receiving intensive therapies and no therapy at all.

But policy changes alone will not be enough to realign the system.

The NDIS was established in 2013, and many families' and clinicians' knowledge of what represents best practice supports for children is framed by the "specialist" model of care. The success of any policy change will also likely hinge on a community reappraisal of the importance of community-based supports.

Building capacity

Naturalistic supports decrease the distance between therapy and everyday life. This helps ensure supports are immediately translatable to the child's daily life.

So prioritizing supports that can be brought into community settings, like childcare, the community library or the local sports club is vital. This focus might be different to what families and those providing a diagnosis have become used to expecting.

Family and community capacity building is a powerful way to support children. Through identifying the key people in a child's life and empowering them with knowledge and skills, children can receive high quality [support](#) from those who know them best. When non-specialists are equipped to deliver supports, children can be supported wherever

they are by people who will have deep and lasting bonds in their lives.

This article is republished from [The Conversation](#) under a Creative Commons license. Read the [original article](#).

Provided by The Conversation

Citation: First an autism diagnosis then a clinician's office—how the evidence supports a different approach for families (2024, July 2) retrieved 21 July 2024 from <https://medicalxpress.com/news/2024-07-autism-diagnosis-clinician-office-evidence.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.