



# Review of Best Practice in Early Childhood Intervention

## Findings from the ACD Consultation

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Version 1.0, 21 November 2024  
The University of Melbourne



Association for  
Children with a  
Disability



## Acknowledgements

The University of Melbourne acknowledges the Traditional Owners of the unceded land on which we work, learn and live: the Wurundjeri Woi-wurrung and Bunurong peoples (Burnley, Fishermans Bend, Parkville, Southbank and Werribee campuses), the Yorta Yorta Nation (Dookie and Shepparton campuses), and the Dja Dja Wurrung people (Creswick campus).

The University also acknowledges and is grateful to the Traditional Owners, Elders and Knowledge Holders of all Indigenous nations and clans who have been instrumental in our reconciliation journey.

We recognise the unique place held by Aboriginal and Torres Strait Islander peoples as the original owners and custodians of the lands and waterways across the Australian continent, with histories of continuous connection dating back more than 60,000 years. We also acknowledge their enduring cultural practices of caring for Country.

We pay respect to Elders past, present and future, and acknowledge the importance of Indigenous knowledge in the Academy. As a community of researchers, teachers, professional staff and students we are privileged to work and learn every day with Indigenous colleagues and partners.

This document has been developed by a University of Melbourne-led Consortium as part of an independent review of best practice in early childhood intervention in Australia.

Funded by the Department of Social Services, the consortium is led by Professor Christine Imms of the University of Melbourne in partnership with Murdoch Children's Research Institute (MCRI), Professionals and Researchers in Early Childhood Intervention (PRECI), SNAICC - National Voice for our Children and Children and Young People with Disability Australia (CYDA).



## Recommended citation

This is one of four consultation reports. The recommended citation for this report is:

Dimmock, K., Rees, N., Kakoschke-Moore, S. (2024). *Review of best practice in early childhood intervention: Consultation report from the Association for Children with a Disability*. The University of Melbourne, funded by and provided to the Commonwealth of Australia's Department of Social Services.

*In addition to named authors, we acknowledge the Consortium Leadership Team including Christine Imms, Denise Luscombe, Bruce Bonyhady, Kirsten Deane, Gretchen Young, Tim Moore, Anita D'Aprano, and advice from the SNAICC Policy and Research Team, national and international expert advisors.*

The project team is very grateful to the many families, young people, practitioners and other professionals and organisations who so generously shared their experience and knowledge, and for their ongoing commitment to the wellbeing of families and children living with developmental concerns, delay or disability.

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# 1. Introduction

This Consultation Report has been prepared as part of an independent review of early childhood intervention (ECI) best practice commissioned by the Department of Social Services (DSS). The review is being undertaken in fulfilment of Action 2.4 of the Early Childhood Targeted Action Plan, which is part of the implementation of Australia's Disability Strategy 2021-2031.

The purpose of the action is to:

*review guidance for best practice in ECI and prepare a framework for best practice in ECI that reflects current research and evidence.*

This project will contribute to the second objective of the Early Childhood Targeted Action Plan (TAP):

*to strengthen the capability and capacity of key services and systems to support parents and carers to make informed choices about their child*

The primary objective of this work is to co-produce an Australian Early Childhood Intervention Practice Framework that is founded on the best available evidence, is practical and can be implemented and evaluated for effectiveness and impact. The goal is that all children growing up in Australia live in thriving families and communities that support their health, development and wellbeing, and that children with developmental concerns, delay, or disability receive the support they need to participate fully in their families and community.

## 1.1 Aim

The aim of the consultation was to use the results of the desktop reviews (the first stage of the independent review) to support the consultation and co-production processes to inform and to contribute to development of the new Practice Framework.

## 1.2 Our overall approach

Our goal was to provide the right conditions for participation, collaboration and engagement in the consultation, which includes providing space (opportunity to participate), voice (support to express views), audience (access to decision makers) and influence – that decision makers are open to being influenced by the views expressed (Lundy, 2007). The consultation activities were completed in four parts, each aiming to reach differing groups with the goal of broad reach across Australia to those with an interest in ECI.

The four consultation processes were led by different members of the project consortium:

- Professionals and Researchers in Early Childhood intervention (PRECI) conducted consultations with early childhood practitioners and providers, professional organisations, peak bodies, advocacy groups, researchers and academics
- SNAICC - National Voice for our Children (SNAICC) convened targeted engagements with Aboriginal and Torres Strait Islanders state and national

peak bodies, Aboriginal and Torres Strait Islander community-controlled organisations and families

- The Association for Children with a Disability (ACD) undertook consultations with parents and caregivers
- Healthy Trajectories undertook a qualitative study with young people aged 15-30 years to explore their experiences of childhood interventions and supports.

The draft consultation reports were shared with our national and international expert panel members for their input thought engagement in a 3-hour workshop or individually in writing.

### 1.3 Report structure

The findings of the different consultations are presented as separate reports, which will be available on the [Healthy Trajectories ECI website](#).

Section 2 of this report provides the findings from the consultations conducted by the Association for Children with a Disability.

Now that this round of consultations has been completed, the next step of the project is to bring together what was heard in the consultations with what was synthesised in the desktop reviews to inform the development of the framework. We will seek stakeholder input, via consultation, to the draft framework and proposed resources through the next phases of the review.

## 2. Findings from the ACD consultations

### 2.1 Background

Association for Children with Disability (ACD) is the leading advocacy service for children with disability and their families in Victoria. We are a not-for-profit organisation led by, and for, families of children with disability. Our vision is an inclusive community where children with disability and their families thrive.

To inform the Review of Best Practice in Early Childhood Intervention (ECI), ACD is coordinating engagement with families and carers of children with disability and developmental differences.

For the first phase of engagement, almost one hundred families and carers took part in interactive sessions held in August-September 2024. Seven family-led online sessions were conducted. These were hosted by family-led organisations ACD, Kindred and Kiind, and Autistic-led organisation Yellow Ladybugs.

Key topics discussed included:

- the type of ECI supports children and families are accessing
- what families and carers understand by the term best practice
- experiences of key elements that are considered to be best practice
- experiences of where and how ECI supports are working well
- ideas about opportunities for ECI supports to better reflect best practice
- how families and carers know if ECI supports make a difference.

### 2.2 Overview of key findings

Families and carers are heavily invested in lifting the bar on the quality, coherence and connection of ECI supports. Having a child with disability or developmental delay puts families and carers on a steep learning curve to work out how best to support and nurture their child's wellbeing and development in the context of their broader household and life circumstances.

Families and carers are desperate to do what's best for their child and broader family. Those we spoke with overwhelmingly referred to the importance of seeking ECI supports at the earliest opportunity. Loud and clear across all consultations was the message that families want best practice to be the norm and to feel confident that any and all ECI supports are consistently of high quality. They do not want best practice ECI to be something they have to specially search out, advocate for, or be lucky to receive.

Nearly all families reported receiving a combination of different types of ECI supports, delivered across various settings – in clinic and community, individual and group-based.

Making sense of how these practically interact with universal services - like kindergarten and schools – is a live challenge for families and carers with many children continuing to experience marginalisation and exclusion in these settings.

Many are struggling to navigate the minefield of competing advice and the challenges of accessing therapies – to inform decisions about the best types, mix and intensity of supports for their child’s situation. Some of those we spoke with are battling to secure allied health therapists in a confusing market.

Families and carers mostly reported positive experiences with ECI professionals, many of which are reflected in this report. We highlight what is working well, alongside ideas for improvement.

Key themes from the consultations included the need to:

- empower families and carers with reliable and relatable information about best practice ECI by including family and carer voices, insights and real-life examples
- overhaul the interface of ECI supports and education settings as a priority, to help tackle Australia’s substantial inclusion challenges
- make a child’s everyday environments – education settings, community and home - the default location for delivery of ECI supports
- position families and carers as partners in ECI and equip them to translate and embed effective approaches in day-to-day life
- nurture family wellbeing through ECI, including by involving and supporting siblings
- expect the sector to deliver child-centred and affirming practices as the norm
- guide families and carers about the best mix, intensity and staging of supports for their child and circumstances
- require ECI professions to deliver supports in an aligned and coordinated way – including the key worker model
- consider measures that matter to families and carers when developing outcomes for the ECI Best Practice Framework

The first phase of engagement with families and carers for this project underscored the value of lived experience insights and the empowerment and safety created through peer-led consultations. Nearly all attendees have put their hands up for involvement in the next phase of the review. ACD looks forward to continuing on the journey with this dedicated and passionate community.



## 2.3 Summary of participant demographics

97 parents and carers participated in consultations held via seven online sessions in August and September 2024.

- Nearly all attendees were female; 8.2% were male, and 1% non-binary.
- 20.6% identified as being culturally and linguistically diverse with backgrounds including Filipino, Chinese, Vietnamese, Lebanese, Japanese and Cypriot Turkish.
- 3.1% identified as First Nations.
- 15.5% identified as having disability themselves. Autism was the most prevalent.
- Attendees came from across Australia, representing a mix of metropolitan, regional and rural postcodes. Victoria was the most heavily represented (56.7%), followed by New South Wales and ACT (23.7%), West Australia (11.3%), Queensland (5.1%), South Australia (1%) and Tasmania (1%).

Attendees all had a child or multiple children with disability or developmental delay. Ages of children ranged from 2–16 years, with the average age being 6-7 years. Nearly all has a child with disability aged under 12 years. Attendees were asked to identify their child's *primary* disability:

- autism (49.5%)
- genetic/chromosomal disability (12.4%)
- developmental delay (9.3%)
- neurological (7.2%)
- intellectual disability including Down Syndrome (7.2%)
- ADHD (4.1%) - also frequently mentioned as co-occurring condition
- deaf and/or blind (4.1%)
- acquired brain injury (2%)
- speech impairment (1%).

Just over 3% of attendees did not identify a primary disability type because their child was awaiting diagnosis or they preferred not to say.

### **Some caveats**

#### **The language of “Intervention” is concerning for some**

Some concerns were raised about potential negative, intrusive and ableist connotations associated with the term intervention. We understand this terminology is being considered as part of the review.

#### **Supports can be helpful at any age and stage**

Some expressed concern that much emphasis is placed on the early years, noting that some children are not identified as having disability until later and that for many children allied health therapy continues to be beneficial beyond the early years.

## 2.4 Thematic analysis of the consultation

### 2.4.1 Range of ECI supports

#### **Families and carers reported engaging with a wide range of supports**

A wide range of ECI supports are being accessed by those we consulted with. Allied health therapies were by far the most commonly mentioned.

Supports included:

- OT
- Speech
- Physio
- Psychology
- Behavioural therapy
- Feeding therapy and dieticians
- Play therapy
- Auslan - sign language
- Art therapy
- Music therapy
- Equine therapy
- Orthotist
- Hydrotherapy
- Parkour
- Personal training
- Naturopathy

#### **ECI supports are being delivered in a mixture of settings and formats**

Most families and carers reported receiving ECI supports in a mix of settings.

Allied health therapies appeared most likely to be delivered in everyday settings (particularly homes, kinder and school) – at least some of the time. Clinic visits were also widely reported, including community health and hospital outpatient clinics.

*Mainly clinic visits but therapists try to provide at least one community visit (generally to early childhood centre).*

Having supports delivered in everyday environments is highly regarded by families and carers. It means the child is building skills in regular settings.

*Understanding the child outside of the therapy room their strengths and growth areas. understanding that capacity differs from home to therapy room where it is a controlled environment.*

*We found the best ways to work on social skills and participation were in natural environments like preschool.*

*Therapist worked across settings, home and school, so could see my child in different environments. This was also good when my partner and I separated and there were two different homes.*

*I changed therapy to everyday settings. Last week, so cute speech pathology was at a cafe. She used her AAC to ask for a baby cino and then said thank you*

It is convenient for, and often preferred by children.

*OT, Speech go to school as my son hates leaving school.*

*It was really helpful for us because it removed that demand of having to get an overtired kid after kindy to a session.*

However, the cost impact of delivery of ECI supports in everyday settings can be an issue.

*When my son started Kindy, the therapists started coming to the school for therapy instead of us going to their office. This resulted in the therapy fee doubling as we are charged the same rate for their travel... it is almost as though the [real value] NDIS funding has been halved because of this.*

Delivery of supports via telehealth or video call came up across all consultations. In some circumstances, this was because of distance. In others, because of preference, including child preference.

Some therapies are being delivered individually, others as part of a multi or transdisciplinary initiative.

Many attendees are engaged with ECI supports delivered in small group settings including:

- Family sessions
- Social skills groups
- Group speech therapy
- Supported playgroups
- Music groups
- Early intervention preschool program

## 2.4.2 Understanding best practice

### Families and carers have varied understandings of the term best practice

Families and carers used various descriptors to articulate their understanding of best practice including:

- highest standard
- evidence based
- most effective
- age appropriate
- tried, tested and proven
- gold standard
- a standard that people have to meet
- the interventions have been researched and evidence shows they work the best to achieve the desired outcomes.
- Best practice combines family's knowledge of their child and family with evidence based and research backed intervention approaches
- proven it works and helps to give child the best result
- what is accepted as the best way to do therapies

The term best practice was also met with some caveats, caution and even cynicism.

*I personally think evidence based is quite a loaded term.*

*Research based, but also taking under consideration new community recommendations as research is often behind and misses participatory input.*

### It is critical that ECI supports are best practice

Attendees at the consultations made a very strong case for the importance of ECI supports being best practice.

- It will mean **better outcomes and lives for our children**  
*Good support from the start will reduce poor mental health outcomes, improve engagement in education/services long term.*  
*Can have lifelong gains if done in the right way, at the right time.*  
*To give children the best chance to thrive.*  
*Sets the child and family up for success.*
- **The early years are vital**  
*Important because a child's brain is so plastic at the early stage of their life.*  
*Make the most of neuro plasticity mind and body.*  
*The early years are the most important for development.*

*Establish effective foundations / scaffolding to support the child as they develop.*

Families and carers also tempered this point by acknowledging that supports at any age and stage are valuable and noting that some children do not have their disability diagnosed until later.

- It should mean that **harmful treatments are stopped**

*The 'wrong' therapy is at best costly but can be traumatising and regressive.*

- **Time and money are well spent**

*It's important in terms of return on investment. You don't want to waste money on something that won't help your child.*

*So that you get the best out of the therapy you are in.*

*It's important because accessing therapy takes a lot of resources - from parents and child - and it's got a cost in terms of what the child doesn't get to do with that time - so it needs to be worthwhile.*

- Best practice will **improve consistency and fairness**

*... to maintain the standards of therapies, to make sure all children have access to the best outcomes.*

### 2.4.3 Family and carer experiences of best practice

#### **ECI has a vital role in promoting inclusion**

The urgent need for greater inclusion, and the importance of ECI enabling – even turbo-charging this - was amplified across all consultations.

There were different views about what inclusion looks like, including varied perspectives on disability specific education settings. Differences aside, there was clear common ground and practical examples of how ECI supports are promoting inclusion.

- **Building connections with other children**

*A new OT has included the other kids in play-based learning sessions at school during lunch break and it's made a huge difference in engagement.*

*Speech Therapist put together a play skills group to support my daughter in her social emotional goals as identified by school.*

*Group based fun activities have worked well ... Not many available though. Most seem to be one-to-one.*

*Inclusion at special needs playgroup works well... all the volunteers and therapists are very familiar with kids with complex needs...Having access to multi-disciplinary team to assist in meeting milestones.*

*Our physio helped my son participate fully in his first school sports carnival.*

- **When ECI professionals and educators cooperate and share approaches**

*The school is great. They coordinate with deputy principal, teacher, OT and internal EA to provide support.*

*Kindy- extra supervision, PECs, extra help with toileting and changing issues, they were very open to therapists visiting and assisting them in making any changes necessary.*

*Communication boards were added to the room, staff educated on use, and so he was able to communicate with others...he was given seating that supports him correctly at mealtimes and play, so he could eat and drink safely.*

*My daughter had a quiet corner set up to decompress upon arrival to help with the anxiety. Staff were educated on what triggers were, how to manage drop-offs, etc.*

*Educators helped us put together an "About Me" book and it went everywhere with my child at kinder and we even still use it and update it now to use when meeting new people.*

*Physio discussed with preschool staff about seating requirements for 'mat time' so my daughter can sit well-supported/aligned with the group.*

*Our childcare educators welcomed OT, speech and keyworker suggestions for accommodations.*

*The behaviour consultant is very helpful as she provided strategies after observation done in class to the educators and parents.*

*Works well when therapist helps to build the skills of the people who spend the most time with our children.*

*Teaching teacher and other kids in kinder how to use the IPAD communication device to communicate with child.*

*Our therapists go into kinder and observe and provide recommendations ... an Allied Health Assistant [linked to the therapist] goes in weekly to provide support... kind of a bridge between those 2 services.*

*OT and speech have been absolutely incredible in helping me both within childcare and also at home... I was really surprised that they're able to come to the childcare to assess everything and make suggestions as to how to better support my son.*

## **ECI supports should more intentionally turbo-charge inclusion**

Challenging experiences in mainstream early learning settings was a dominant theme across all consultations. Families and carers are endlessly navigating the gap between commitments to inclusion and its practical implementation – and continue to report not being welcomed, a lack of universal learning approaches, failure to provide reasonable adjustments, use of exclusions, restraint and expulsions.

Education system inclusion supports (such as kinder and school disability funding) are a critical part of the equation. However, these are heavily rationed, and families report that effective implementation is hampered by a range of issues.

While acknowledging the Review of Best Practice in ECI is not a solve-all magic wand, families and carers identified opportunities for this process to help advance inclusion.

- **Clearly articulate what best practice ECI looks like in education settings**

*The education department need to be consulted on what they believe is best practice and how this can be achieved and compare this to the recommendations of the health professionals and community expectations. there is a large gap... it rare for complex kids to thrive in a mainstream environment.*

- **Universal screening for developmental delays in education settings**

*We had several child nurse visits during his early years and nothing (disability, health or otherwise) was picked up... His [prep] teacher noticed some quirks and arranged for a speech pathologist to meet with him.*

- **Drive integration of ECI and education supports through the ECI Best Practice Framework**

*I would love to see more mainstream schools integrate our kids without a fight to have them enrolled...I'd love to have a best practice who can help to do this.*

*I've found frustrating communication with childcare. We asked for special food but they didn't do it, provided Doctor letter and still nothing. Sent dietitian. Still no change.*

*School didn't know how to work with us, it's been a very bumpy start. It would be helpful for teachers and principals to have a mentor ...who can show them how to support them best practice to engage and include the child.*

*It would be great to link therapy activities more to the classroom and curriculum where appropriate and relevant.*

*Better access granted by schools.*

- **Situate educators as part of the ECI eco-system**

*Your therapy is how they integrate into function and how they are and how they exist constantly, and even the Inclusion Support program did not understand that they actually said to me, the educators aren't supposed to do therapy for your daughter*

*Educators need to be skilled up with the knowledge and also the capacity to implement strategies.*

*Inclusion aids and integration staff are often lacking training in communication, behaviour management and are poorly equipped to help with learning*

*Thinking about day-to-day routines and how they could be more inclusive.*

*Viewing the educational environment as a whole, providing advice and strategies that support everyone.*

- **Make everyday settings as the default option for delivery of ECI supports.**

*Families recognise that this may require changes to funding and service agreements.*

*Availability of more, and more diverse, social groups.*

*Provide ECI therapies at kinder and schools.*

## **Family-centred approaches generate widespread benefits**

As to be expected, families and carers are heavily invested in the importance of family-centred approaches to ECI. Positive examples showcased the benefits experienced.

- **A partnership approach that respects parent/carer experience and voice**

*Collaborative goal setting, clear and open communication, encouragement and support, sharing of resources and the use of personalised strategies.*

*Treating families/individuals as equal in decision-making, allowing them to lead and be listened to rather than following a prescribed process.*

*I particularly appreciate that our speech therapist follows up after each session by emailing a summary of the recommendations made. It can be overwhelming trying to retain a lot of new information.*

*Our OT uses "Seesaw" app to share what she teaches each session and what my daughter enjoyed most. It helps us use the learnings at home.*

*Including my parents who also co-parent with me has made a huge difference. As we are all on the same page.*

*Our daughter's key worker empowers us to incorporate "therapy" into everyday activities. Each session can swap from daughter's goals to helping a parent cope with issues and incorporates actions for both parents to take between sessions.*

*Our provider understands that we are an asset to the therapy as well, as our kids tend to engage better when we as parents are better equipped to support their participation and growth.*

- **Promoting family wellbeing – including supporting and involving siblings**

*The health and wellbeing of the child and the entire family can be impacted when children have delays/disabilities so early supports to assist are so important in maintaining family units/reducing stress as well as skill development etc. are really important.*

*One of [our OT's] things is seeing the family as a whole system and how we're interacting and affecting each other and gently teaching me through modelling and the kids as well, like about co regulation and sort of being unflappable or when things the wheels fall off, that the wheels can get put back on.*

*Our occupational therapist takes the time each week to understand the challenges we face at home and customises each session to address our changing needs*

*Meeting us where we were at. Being flexible and adaptable at times when required (e.g. acknowledging when things have been a bit stressful/other things going on in the background).*



Many families spoke about the impacts on other children in the household when they have a sibling with disability and the benefits ECI supports have delivered.

*[when] the other kids are there, that what's worked really well ... because then it doesn't segregate us ... because everybody's part of it and we're all modelling it ... it becomes just a way of working together. And this is how we're going to respond when we're, you know, feeling overwhelmed.*

*In school holidays the therapists include my older children in the sessions and give them ideas of how to play with her.*

*Invited sibling to sessions to help with sibling rivalry/develop relationships between them. I was so thankful for the skills they both gained just in that one session - how to communicate with each other and take turns.*

*Our play therapist gave me a little handbook for my 3-year-old on having an Autistic sibling, like a social story type thing.*

*Guidance about how to talk to siblings of child with additional needs and manage sibling behaviour.*

Some families reported reluctance from therapists to involve siblings, and this was underscored across multiple consultation sessions as an area that needs deliberate attention in the review.

*When I asked if my autistic daughters twin could attend a speech session so the therapist could see their interaction. Was a blanket no with no discussion as to why.*

*I would like to see more help around the siblings and the communication between all our supports maybe a little more home supports being a single mum trying to give my children the best progress.*

- **Strengthening family and carer capability**

Families and carers shared many examples of when ECI professionals have built their skills and confidence, which has in turn meant they can better support and nurture their child's development.

*In this early age group, a lot of it is about us as parents - building our understanding of our children, their neurology, what their needs are, their sensory profile, all those sorts of things that make a difference to how we work as a family.*

*My child's therapists taught us not just the how of the activities/exercises we need to do with our son, but also the why, such as the targets/goals that we want to achieve.*

*All of our different professional supports have offered parent only sessions.*

*What has been really important to me (unexpectedly) was when our OT and Speech called myself outside of my daughters' sessions to let me know I was doing an amazing job.*

## **There are opportunities to strengthen family-centred approaches**

- **Support the family to better cope with and affirm their child's diagnosis and situation**

Some participants reported feeling grief, despair or helplessness regarding the situation for their child and them, and the importance of ECI in helping them work through this.

*Affirm that parents do not have to push their kids into square holes.*

*Celebrate the child that they see.*

- Address **family stress and burnout**

Additional stressors on families and carers was raised by many in the consultations, as was the important role ECI can play in helping to support and mitigate this.

*I found carer burnout is the worst and there is no help.*

*Therapists could support children and families through burnout even if the child cannot attend therapy for a while.*

*More support for parental mental health is needed.*

*Therapists need to understand how difficult it is to do homework...need more options for support worker to deliver the homework.*

*Don't pressure parents to do at home therapy that can jeopardise the parent relationship/connection.*

*Understand that I have other priorities that I have to juggle and so any therapies need to be easy and simple.*

- Be alert and responsive to **family complexity, including family violence**

We heard of instances where the child's delay or disability is used as a form of coercive control, with one parent denying there is anything wrong and refusing to implement routines or approaches suggested by ECI provider. We also heard that where a child with disability uses violence, safety of family members and carers is a live issue.

*My experience has been that therapists (due to the limitations of their expertise and who they see as their 'client') have focused so narrowly on my son's need to release energy that they have ignored my need to feel safe, resulting in a DFV situation. This is clearly not their intent but as part of a best practice guide, it would be good to ensure they are aware and considering whether the strategies they are recommending are inadvertently putting parents/carers at risk.*

*You need to parent differently to break the cycle of trauma.*

- Strengthen **accessibility, safety and responsiveness for diverse families**

Cultural responsiveness was not addressed in detail during consultations, however there were a number of culturally and linguistically diverse attendees that expressed interest in applying a cultural lens to the next phase of this project.

SNAICC are leading engagements with First Nations communities.

- Have **dedicated child free sessions** aimed at **strengthening family capabilities**

*Sessions to support family and carer learning and enable discussions without the child present are important.*

- Foster opportunities for **families and carers to learn with and from other families**

Connecting families through ECI supports was identified as an effective approach, but rarely experienced outside of supported playgroups and a handful of early intervention education initiatives.

*One of the public psychologists ran family sessions. So parents and child and modelled circle of security in a room set up like a play therapy room. It was really effective. I haven't seen anywhere else.*

Families and carers attending consultations for the review, expressed the value in coming together and sharing.

*I'm stealing some of these ideas.*

## **Families and carers like it when ECI professionals are child-centred**

Families and carers shared many positive examples where ECI professionals strongly engaged and respected their child while supporting their development and wellbeing.

- Being **affirming of each child and their condition**

*We had a really neuro affirming speech therapist ... Her methods were definitely different to what I was used to ... this made our child really accepting of her own condition, and therefore we just had to come on board. So our child had no qualms around being told about her condition...and we realized it wasn't the end of the world. So that was probably the most life-changing experience for us.*

*Our psych now gives up her spinning chair at the beginning of every appointment so she can move how she needs to.*

We heard that ECI professionals need to be alert to the way they speak about the child in front of them and avoid creating additional self-consciousness about their disability.

- Understanding and **respecting each child as an individual**

*Should consistently tailor activities to the child's unique likes and dislikes.*

*Get to know child, their interests, motivations, understand what to look out for before child becomes too dysregulated, can pre-empt and distract/redirect child back to task.*

*My child's swimming teacher has just been amazing at finding the way past my child's anxiety in a way that absolutely supports the individual way she experiences the world. Constantly adjusting her techniques, adjusting expectations, changing approach. All of this while holding my child with the upmost respect and putting her voice first.*

*Actively listening to my son's preferences and incorporating him into his learning experiences.*

*Professionals in a child's life should take time to understand the child's personal interests and emotional needs better...to tailor interventions that truly resonate with the child's individual experiences and aspirations.*

- Being led by the **interests and preferences of the child**

ECI professionals that make sessions fun and enjoyable for children to take part in are highly regarded by families and carers. The value of play based learning is increasingly well understood by families.

*Our current physio is great at using my child's interest (there's usually one strong interest at a time) to motivate her in doing exercises. She loves sheep - he pretends to be a sheep!*

*Our beautiful speechy did a whole entire speech session in a pool going down a water slide and in a whirlpool.*

*It was really important that the dog could be included in a lot of the sessions.*

*She bought one toy [each visit] ... and then they were actually solving or building or drawing or creating crafting together. That's how she made him engage throughout the whole session, and through solving or playing ...she implemented her strategy like using his language or asking for manners.*

*After 15 min his concentration is not there anymore and he's just trying to get out of the room. And his therapist is like, so maybe we can use the whole environment. I couldn't believe when she just opened the door for him, and we just followed him around the centre. And he's learning much more like that. And it's you know, it's a lot of work for us going up and down and running, but that's the way he learned.*

*Our therapists use my son's strengths and interests - he loves music, particularly Arctic Monkeys and Green Day and has used these to help with reading (lyrics) writing (song titles), initiating speech etc.*

In contrast, the following example of what not to do was shared.

*Therapist had a really strict plan of what she wanted to do in each session, and how she wanted it done and where she needed my child to sit in what direction and gonna do this in this order, and she was very rigid about it. It didn't suit my child at all. And kind of was made to feel as though my child was a problem.*

Families and carers ideas about how ECI supports could be more child-centred, affirming and responsive to child voice included:

- Embed expectations of **neuro-affirming practice** in the upcoming Framework

Neuro-affirming practice was a strong theme across consultations, with autism being the most highly represented condition among the children of attendees. Ensuring the recent Best Practice Guidelines for Supporting Autistic Children correlate with the upcoming ECI Best Practice Framework will be important.

*Ensure the neuro affirming lens in the recent guidelines for Autistic kids is not lost.*

*Essential training for all therapists - neuroscience, trauma etc - shouldn't be able to provide ECI without this background!*

*Therapists that understand neurodivergent issues.*

*Double empathy problem.*

*Awareness of PDA profile is SO important (and doesn't seem super common).*

- **Avoid presumptions about the child's competencies**

*I wish they did not assume that her lack of spoken communication means a lack of comprehension.*

*My child was the opposite in that she was very verbal but not good comprehension. Therapists and school aides often presumed she understood.*

## **Accessing the right mix and dosage of supports is a real challenge**

There was concern that the NDIS has created a therapy frenzy, with families and carers unsure about the best mix, intensity and layering of therapies and supports, and receiving competing information from different sources.

Families and carers shared stories of going straight from diagnosis into therapies. Some felt pressure to enlist their child in as many therapies as possible, all at the same time. This was driven by fear that the window of opportunity was rapidly closing to make developmental gains.

Families and carers further along the journey reflected that they wish they had drawn pause, been discerning about options, not rushed to do everything at once, and understood that supports can be staged and layered.

*So the paediatrician goes, oh you'll want psychology and OY and speech etc and bye, bye, you're done.*

*And then you go into a Facebook group and you're like, Oh my God, I've got to get them on a waiting list for speech and OT and psych and social skills.*

*And you're just completely overloaded by wanting to do the right thing that there's no or little pause for learning critical assessment, making actual choices about therapies.*

*And a lot of people have that journey, they do everything and the kids get burnt out, family get burnt out.*

A parent that is also working as an ECI professional reflected

*Often, I will be working with parents, and they will say, my child goes to daycare 5 days a week, and then we've got to do 20 h of therapy, because that what they've been told the evidence recommends.*

*It needs to be about making sure that a child has access to the right therapies in the right mix and protecting the importance of the right amount of downtime.*

It is hoped that outputs from the ECI Best Practice Review, together with NDIS Reforms and Foundational Supports will ensure families and carers have strong and independent guidance to help navigate this.

## Significant equity of access challenges continue

We heard that some families are experiencing significant barriers to accessing ECI supports: location, cost, long waitlists (and common for ECI professionals to have closed their lists) and service rationing.

*I would like that for my child to have the opportunity for the best outcomes without it, relying on my competence. In terms of being able to navigate that for her. Families are doing much of the heavy lifting to coordinate different supports*

Families and carers overwhelmingly reported being involved with a range of ECI professionals, often scattered across different providers and settings. Those with experience of ECI supports pre-NDIS reflected that things were now more complicated and inefficient, with families having to do much of the heavy lifting to access and join the dots between supports.

*We haven't had a lot of coordination outside of us sending separate updates to all the different therapists/people involved. I spend a lot of time as the go-between getting reports/letters from one professional to give to another.*

*High turnover of therapists and a lack of coordination between therapists feels like a lot of work for us.*

*Over reliance on parents to forward information and educate early childhood educators.*

*Our therapists are from different companies. We send out an email asking them to each share one thing that's progressing well, and one thing they've noticed is a barrier ... and just reply to each other.*

*We all share an app to communicate together so we all know how my child is doing through the day and what supports she needs.*

*We keep a list of things currently working on that can be shared with others.*

## There are some good examples of ECI supports being well coordinated and planned

We heard positive accounts of coordination between ECI professionals.

- **The key worker model is working well**

*Having one go-to person, who knows your child and family, and can tap-into the skills and knowledge of a multidisciplinary team is invaluable.*

*Our daughter's key worker has always visited her kindergarten to help the early childhood workers ... especially around behaviour management and behaviours of concern.*

But cautions were sounded that a transdisciplinary approach cannot replace specialist expertise where needed.

- **Cross-disciplinary and cross-setting collaboration makes a difference**

*OT & physio who specialise in my child's condition work in the same clinic. Physio communicates on the phone with the local physio who conducts hydro*

*to align strategies, every quarter or so. OT & physio similarly provide advice via email to rehab clinician every 6 or so months.*

*Our allied health team all communicate really well, and all meet every semester to discuss and ensure all on the same page, using the same language and also meeting with the teacher.*

*Our psych, speechie and OT have been collaborating on behavioural issues and have all visited school to upskill teachers and support staff.*

*The continence specialist visited childcare, school and home. Then created a plan and an app to record progress. And checks in with us all individually to help problem solve.*

*Interdisciplinary allied health assessment as an infant at Royal Children's Hospital. Senior Physiotherapist, OT and Speech Pathologist in the same room at the same time. Coordinated efficient, clear plan.*

*Our Student Support Group meetings are very helpful.*

- **Good transition planning is important**

*The early intervention preschool teacher who is doing a lot of the transition work with the school we are going to next year which is really great.*

*But families and carers have mixed experiences of it.*

*Transition to primary school was challenging as the school did not take the recommendations from his early intervention teacher at pre-school.*

## **A systematic approach to planning and coordination ECI supports is needed**

- **Standards and systems to drive communication and collaboration**

*Requirements for regular meetings and shared communication tools.*

*A collaborative platform where professionals can track progress and update each other on strategies to ensure consistency in support.*

*Professionals had a clearer understanding of each other's roles and interventions. This way, they can better integrate their efforts and tailor their approaches to complement each other, creating a more cohesive support system for my child.*

- **Shared assessments that can be used for multiple purposes**

*When my daughter was 'verified' for school, it was very frustrating we had to continue to fill this form out every year, causing extra appointments and then updated reports for every year when its again costing extra from our funding and extra paed appointments outside of what we needed.*

- **Easy transitions and connections between different systems and supports**

*Transition from the Children's Hospital early intervention to NDIS. You are left to work it out on your own.*

*Close collaboration between stakeholders and not getting to the argument who is funding what and it's just one consistent approach.*

## **Quality and consistency amongst ECI Professionals is variable**

Using the Review of Best Practice in ECI to promote development and quality across the sector was identified as an opportunity.

*Introduction of the NDIS has meant the numbers of therapists who have gone quite quickly into private practice with limited or no experience in some cases has really ballooned, and that means that there is now a very significant variability in the experience and quality and expertise... Therapists are working in very isolated ways in private practice compared to other sort of workforce models that we may have had in the past.*

### **2.4.4 Outcomes that matter to families and carers**

#### **How families and carers know their ECI supports are working**

Families and carers appreciated the importance of setting goals and tracking progress against these with ECI professionals.

*When you need to write new goals because the current goals have been surpassed! that's exciting.*

They also nominated some tell-tale indicators that things are heading in a good direction.

- **Child trusts and is happy to engage with therapist**

*The better the engagement the better the change*

*Seeing the child gain confidence in building relationships and trust with therapists and supports.*

- **A happier, more confident child**

*If she is happy, wanting to participate in life.*

*I see my child's confidence increasing, improved family connections, happier child.*

*... he is happy and can self-identify improvement as he feels better that he's improving...*

- **Noticeable improvements in their child's skills and functioning**

*Improved speech less echolalia. Can now have a two-way conversation.*

*More ability for imaginative play.*

*Can now dress herself.*

*Watching my daughter take a deep breath to calm herself down when being nervous and then voicing that she is nervous.*

*Can stand now and walk with help.*



*Her showing us her independence - this is a sure sign that she is achieving her goals!*

*Last year at kindy- we were lucky to get 2-3 hours there. This year she is attending school full time, is so happy to go and be there everyday*

- **Parent/carer is feeling more skilled and confident**

*As a parent you are not so stressed and feel like you are building your own skills to help. Progress can be very slow, so measurements need to take these subtle improvements into account.*

## **Changes families and carers are hoping to see for their child**

- Self-esteem, self-understanding, self-acceptance

*My daughter embracing herself in a neurodiversity affirming and celebratory way*

*Less (or no) masking.*

*Confidence and a strong sense of self in the family/classroom/world she is in.*

*Joy and fun rather than struggling.*

- Better self-regulation

*Managing emotions and knowing what to do when he has meltdowns.*

*Progress in my child's skills with his emotional regulation, and safety awareness.*

- Greater independence

*Independence is a great goal, with benefits for everyone.*

*I hope to see increased confidence and improved skills in areas he's working on, like communication or social interactions.*

*They are thriving i.e. developing, making friendships/being included, trying new things, having great experiences.*

*For my daughter to be able to navigate transitions.*

- Closer relations with peers, family and community

*Being a valued member of the community and make genuine friendships*

*growing the child's support team beyond therapists e.g. family, friends, teachers*

## **Changes families and carers are hoping to see for themselves**

- **Being welcome and supported in the community**

*Able to take my daughter into the community without fear.*

*That I wouldn't have to advocate... for everything.*

- **Improved wellbeing**

*Less stress.*

*To feel there is always hope.*

*Less fear of the future and about how supports will work when she is older/we are older.*

- **Skills and confidence**

*Feel like I am somewhat in control and that I am doing what is required.*

*Confidence / evidence knowing that I've done the best I can to support them.*

*I'd like to experience more peace of mind knowing my son is thriving and that the supports are making a positive impact.*

## **Changes families and carers are hoping to see in their household**

- **Better experience for siblings**

*Her siblings not feeling like they are compromising ALL the time.*

*My daughter to consider feelings of her siblings.*

- **Calmer, easier household**

*Better mental health for myself and kiddos, more rest and understanding*

*Being able to enjoy each other as a family*

- **Family as a team**

*Working positively as a team to support our child with a disability and each other.*

## **Changes families and carers are hoping to see in the community**

Across all consultations, families and carers highlighted their hopes for positive community changes. Noting some aspects may be outside the scope of the ECI Review, the sentiments expressed provide critical context.

*Visibility in the community.*

*Accommodations without judgement.*

*A world where mothers don't have to give up work due to the lack of inclusiveness.*

*Knowing that my kids won't try to crack their heads open to try and fix their brains because the world around them is telling them that they're the issue.*

*Not have to feel guilty for asking support, because our disabilities aren't visible.*

*Being confident that my child can truly belong in the mainstream and not having to justify their right to access mainstream schools, community, sporting classes etc*

*That more public housing is wheelchair accessible, and more businesses are wheelchair accessible as well.*

## **Change is not always linear or improvement**

An important caution was that discussions of outcomes are often based on the assumption of linear progress and improved function, which may be not realistic for some disability types, or at some points in time.

*Autism is a dynamic disability, just because they can do something one day doesn't mean they can the next.*

*I find that a really tough question because I have had to let go of so many hopes in all those categories.*

*Learning 'leaps'- we tend to go awhile where nothing seems to change and then have a big jump of progress.*

## **2.5 Summary of key considerations**

### **In the upcoming draft ECI Best Practice Framework**

1. Embed real life family and carer voices, insights and examples throughout the draft Framework so that is a relevant, relatable and tangible for families
2. Address the interface between ECI supports and education (childcare, kinder, school) to help tackle the significant inclusion challenges that continue to impact many children with disability
3. Provide for everyday settings to be the default location for delivery of ECI supports
4. Position and equip families and carers as partners in ECI support to translate and embed effective approaches in day-to-day life
5. Ensure ECI services better support and nurture family wellbeing
6. Expect and equip the sector to deliver child-centred and affirming practices as the norm
7. Require ECI professional to align and coordinate efforts – including through a key worker model
8. Guide families and carers about the best mix, intensity and staging of supports for their child and circumstances
9. Consider outcomes that matter to families and carers
10. Make connections to the Best Practice Guidelines for Supporting Autistic Children

## 3. References

### 1. Introduction

Lundy, L. (2007). 'Voice' is not enough: conceptualising Article 12 of the United Nations Convention on the Rights of the Child. *British Educational Research Journal*, 33(6), 927-942. <https://doi.org/10.1080/01411920701657033>

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