## **Early Childhood Intervention**

Your guide to choosing the right early childhood intervention (ECI) for your child



For babies and children with a range of physical and neurological conditions.

An initiative of Cerebral Palsy Alliance

Having the right support for each stage of your child's development is important. As your child develops, they may need different interventions, strategies or more experience in a particular area.



## So how do you ensure your child gets the supports and expertise they need?

With nearly 1500 early childhood intervention (ECI) providers available in NSW and ACT alone, ranging from generalist providers through to disability specialists, comparing providers based on cost or location can seem the simplest solution.

However, if the desired outcome is to ensure your child learns to move independently, communicate, or make friends, you may decide a provider's expertise and experience is more important than the distance from home or cost of services.

Recommendations from friends, family and trusted health professionals are a great way to shortlist a few providers for consideration. But even with a solid shortlist the final decision is yours.

That's why we have created this handy guide to help you compare what providers offer, so you can decide what matters most to you and your family.

The information included is based on:

- feedback from parents on what mattered to them most when choosing a provider; and
- insights and learnings from a number of experienced disability specialist therapists, clinicians and researchers.

So whether you're choosing your very first provider, or wondering if you should stay where you are, this guide will help you review provider websites and enable more informed conversations with providers or your Early Childhood Early Intervention (ECEI) Coordinator.

ECEI Coordinators are professionals who help children and their families access supports and services that are tailored to a child's needs. These supports can be through mainstream community services or funded through the National Disability Insurance Scheme (NDIS).













Other considerations

Neuroplasticity



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## Finding the right experience and expertise

In a recent research study, parents told us they find it hard to see where providers differ in their expertise and experience<sup>1</sup>.

Therapy providers range from generalists supporting people with common and routine conditions, through to those with specialist expertise in disability therapy and interventions for children with complex, rare, or multiple conditions. Understanding what areas of expertise a provider has, and how much experience they've had in treating children with disabilities, is a great way to give you confidence in your choice.

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#### Questions to ask a provider might include:

What experience and success have they had working with babies and children?

The first five years of a child's life are a time of rapid brain development. Finding a provider that has a deep understanding of optimising a child's neuroplasticity and how to make the most of your child's early years is key.

Working with younger clients will also require a different approach to working with adults. So it's worth finding someone who understands the need for thinking differently when it comes to babies and young children, as well as a clinician who can make the experience fun so your child enjoys the learning.

"People have the tendency to look at a glass as either half full or half empty but those people are missing the point when it comes to neuroplasticity - in a lot of cases the glass can be refilled. Anika is a shining example of refilling that glass!"

#### Kylie, mum of Anika

#### Are they a generalist or a specialist?

A generalist provider provides therapy support for common conditions affecting the general population, e.g. stuttering, rehabilitation after a sports injury, workers compensation injuries, and equipment to support ageing patients to live at home. But it's rare they will also have a deep understanding and experience of complex disabilities diagnosed at birth or in early childhood.

If your child has more complex needs like learning how to feed or swallow, independent mobility, or working with communication devices, a specialist disability provider will likely have the expertise to identify more targeted therapy that can result in better and faster outcomes. You may even want to ask about the level of experience a provider has working with your child's particular disability. For example:

- Do they provide specialist services for cerebral palsy such as casting, wheelchair prescription, robotics, or management of hips?
- Do they provide specialist services for autism spectrum disorder, such as prescription of customised communication boards or devices?
- Do they provide specialist services for Down syndrome, such as liaison with the hospital over the management of cardiac complications?

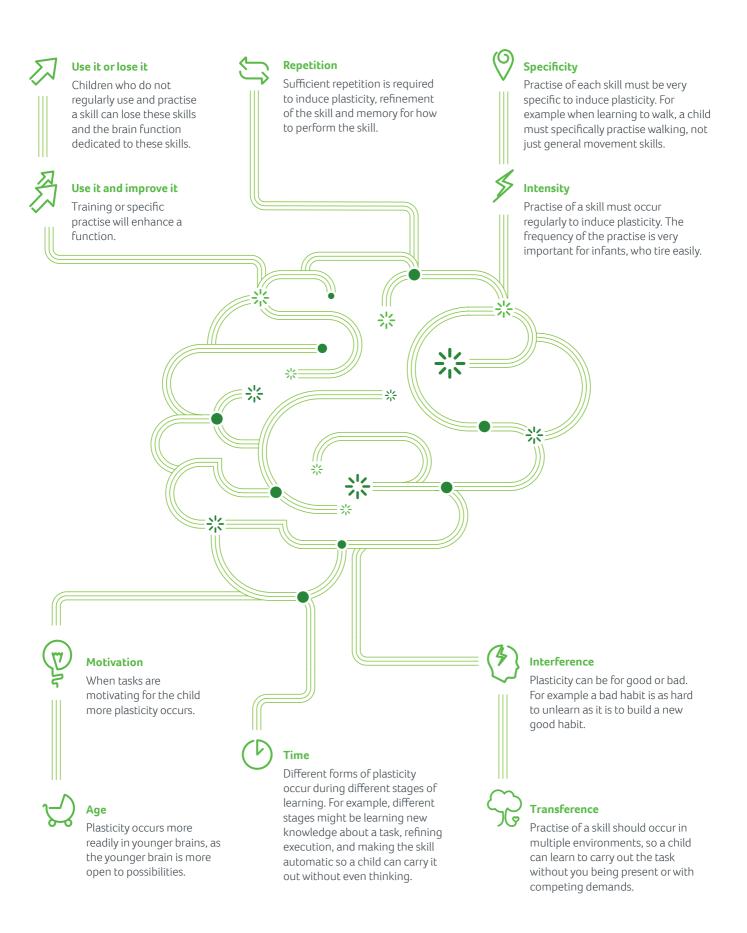
# What is neuroplasticity?

Put simply, neuroplasticity is the brain's ability to change – to rewire, relearn and strengthen important connections.

When the brain is injured or grows abnormally, neurons are damaged, altered or lost, causing disability. The good news is that the brain will attempt to create new pathways around an injury, by allowing a healthy area of the brain to take over, or relearning how to do things by strengthening an existing healthy connection.

The brain's neuroplasticity is most potent in children aged 0-6, which is why getting access to early intervention as soon as possible is vital.

### Interventions that have proven to provide positive outcomes include the following principles of neuroplasticity<sup>2</sup>:



#### <sup>2</sup>Kleim, I. A., Iones, T. A. (2008), Principles of Experience-Dependent Neural Plasticity: Implications for Rehabilitation After Brain Damage, Journal of Speech, Language, and Hearing Research. Vol. 51, S225–S239,

February 2008, D American Speech-Language-Hearing Association

## Evidence-based therapies and interventions

Advancements in early intervention therapies and treatments are being developed all the time. The more we learn about how the brain works and its ability to change and build new neural pathways, the more targeted therapy can become. Choosing a provider that's keeping up-to-date with the latest in research and proven interventions is a great way to be confident your NDIS plan is funding therapies that will deliver results.

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#### Questions to ask a provider might include:

## Do they predominantly provide active early interventions?

Research now shows that active early interventions deliver stronger and longer lasting neuroplasticity outcomes than passive "hands-on" early interventions.

In fact, passive early interventions (e.g. stretching or massage) have been proven not to improve a child's motor capacity. Passive early interventions also have a negative effect on cognitive development long-term (Morgan et al 2016).

So you may want to ask specific questions about a provider's interventions. For example:

- Do they predominantly provide passive massage, stretching, and positioning?
- Or do they provide active motor training, cognitive training, and attention training?

#### Are they using evidence-based interventions?

Not all interventions are created equal. Some interventions predict certain outcomes, but lack real evidence. Others are backed by robust clinical research, which is tried, tested, and proven to produce positive outcomes.

Before selecting a provider, ask about the different interventions they provide, and whether there is clinical research to support the promised outcomes.

It is wise to confirm whether they offer specific named evidence-based treatments that address your child's individual needs or do they offer the same therapy to all children.

For example:

- alternative and augmentative communication (AAC) for children with autism spectrum disorder
- treadmill training for children with cerebral palsy
- Triple P Positive Parenting Program for children with behavioural challenges.

It's also important to note that interventions that do not have a recognised evidence base may not be funded by the National Disability Insurance Scheme (NDIS). Do they offer therapy at the right intensity to reach the outcomes that you desire for your child?

Traditionally therapy is offered weekly,

However, some interventions work better at

higher intensities or in short focused bursts,

Ask how often they will see you and your

child, so you can understand whether they

offer the same frequency of appointments for

all conditions and treatments, or if they vary

treatment based on what your child needs.

This will help you understand whether or not they are in a position to provide evidencebased therapy at the right frequency to help

for example in a 2-week intensive therapy day

fortnightly, or even monthly.

your child make progress.

camp.



### Do they offer access to the latest equipment and technologies?

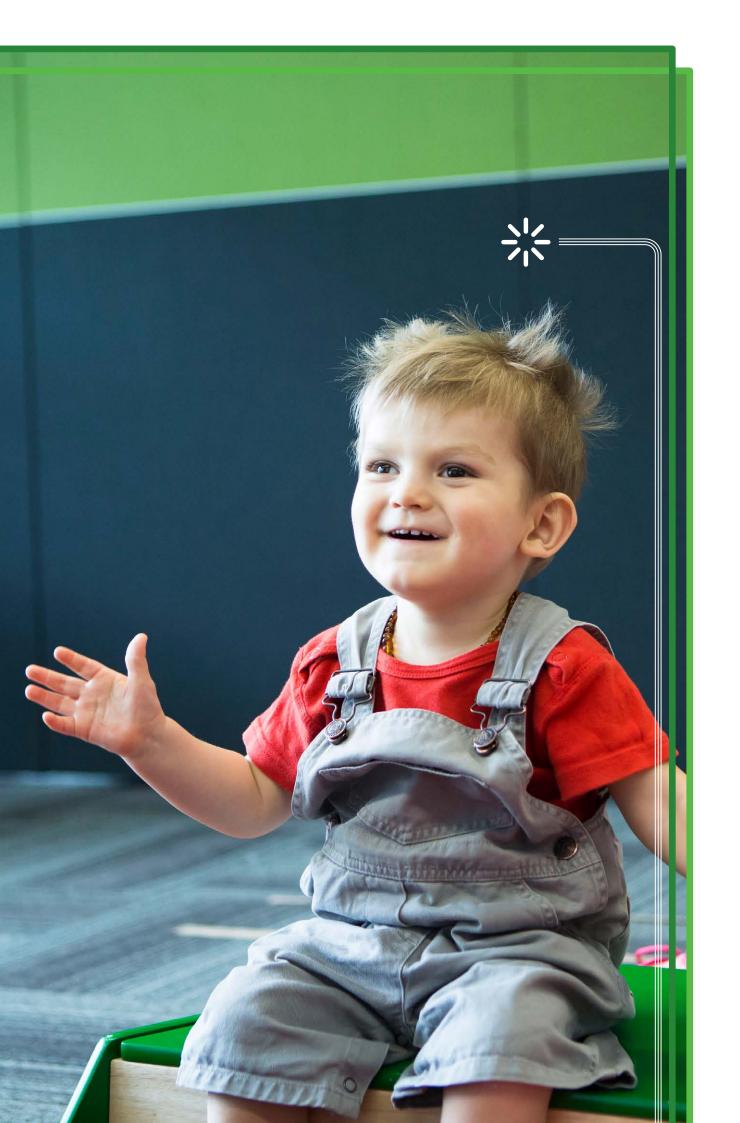
The rapidly accelerating rate of technological innovation has tremendous potential to improve the lives of those living with a disability. Think gamified rehabilitation, virtual reality, 3D printed orthotics, or state-of-the-art Teleservice.

For many, accessing these latest innovations isn't always easy, so it's worth considering the size of a provider, and whether they have the interest or capability to offer you access to new interventions that will meet the longer term needs of your child and family. Expertise

"Intensity is not a type of intervention, it is a dose (amount or frequency) of intervention. If an intervention is known to be 100% ineffective, it won't matter how much of it you do, you will never get a positive improvement. Therefore, what you do and how much you do are both important. Effective interventions have an optimal dose where meaningful progress is achieved. It is important for parents to understand the required dose to make progress, and whether this dose is affordable and feasible for the family."

Professor Iona Novak, Head of Research, CPA





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## The team around your child

As you search for the right provider, you may hear the terms keyworker, multidisciplinary, transdisciplinary, and interdisciplinary. These are different ways providers organise their staff to deliver services.

While each way has its advantages, the most important thing is to ensure your child has a team of people around them who work together and in partnership with you.

#### Questions to ask a provider might include:

Do they work in a team or as a sole practitioner? Do they co-ordinate care with others in your child's team or do you need to be the conduit between team members?

Choosing a provider that offers multiple therapy disciplines in one location has considerable benefits, such as increasing the ability of your child's therapy team to share information and work towards goals in a collaborative way. For example, if your child is working on a goal related to motor skills with their physiotherapist, they may also need support to adapt their environment through equipment and modifications, so having an occupational therapist available to work with the physio in the same location allows the child's needs to be managed more holistically and effectively.

A single provider that offers many services also reduces your need to drive to various locations to see different therapists.

#### How will they track and measure your child's progress?

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Changes in your child can be dramatic or incremental, which is why a good provider will constantly monitor your child's progress to see how they're tracking against their goals.

It's important to find a provider who will:

- collaborate with you on goal setting
- regularly review progress along the way
- keep you informed through informal regular feedback, or through a more formalised reporting model.

#### Does one practitioner address all your child's needs or is there a team of experts?

If your child needs help with specific areas of their development such as walking or swallowing food safely will your child see a specialist to support development in these specific areas, or will one practitioner address all of their needs?

#### Are reports and assessments presented in a shareable and easy to understand format?

It's likely you will need to share your child's reports and assessments with other people (your ECEI Coordinator, another provider, a medical professional, or even a teacher). Make sure you have access to all reports and assessments for your child, and ask whether reports are produced digitally or by hand – a comprehensive report won't be much help if it's illegible!

A good report will use clear and simple language to identify goals set, progress made and future recommendations. Clarity in these areas is particularly important when it comes to your National Disability Insurance Scheme (NDIS) plan review.

Your NDIS plan is a document that outlines the needs, goals, aspirations and disability supports you require (including any funding you might receive). It's reviewed each year by your ECEI Coordinator to ensure your child is getting the right supports.

## Other things to consider

While considering expertise, types of interventions, and different approaches is important, there are other things you may want to keep in mind.

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#### Questions to ask a provider might include:

#### What additional benefits do they offer? 🛛 🖵

Convenient appointment times, visits at home or in the community, and block appointments can make life so much easier for you and your family. Other things to consider might be free parking or somewhere safe for your child's siblings to play while a therapy session is taking place.

#### Will you be encouraged and supported to actively participate in your child's therapy?

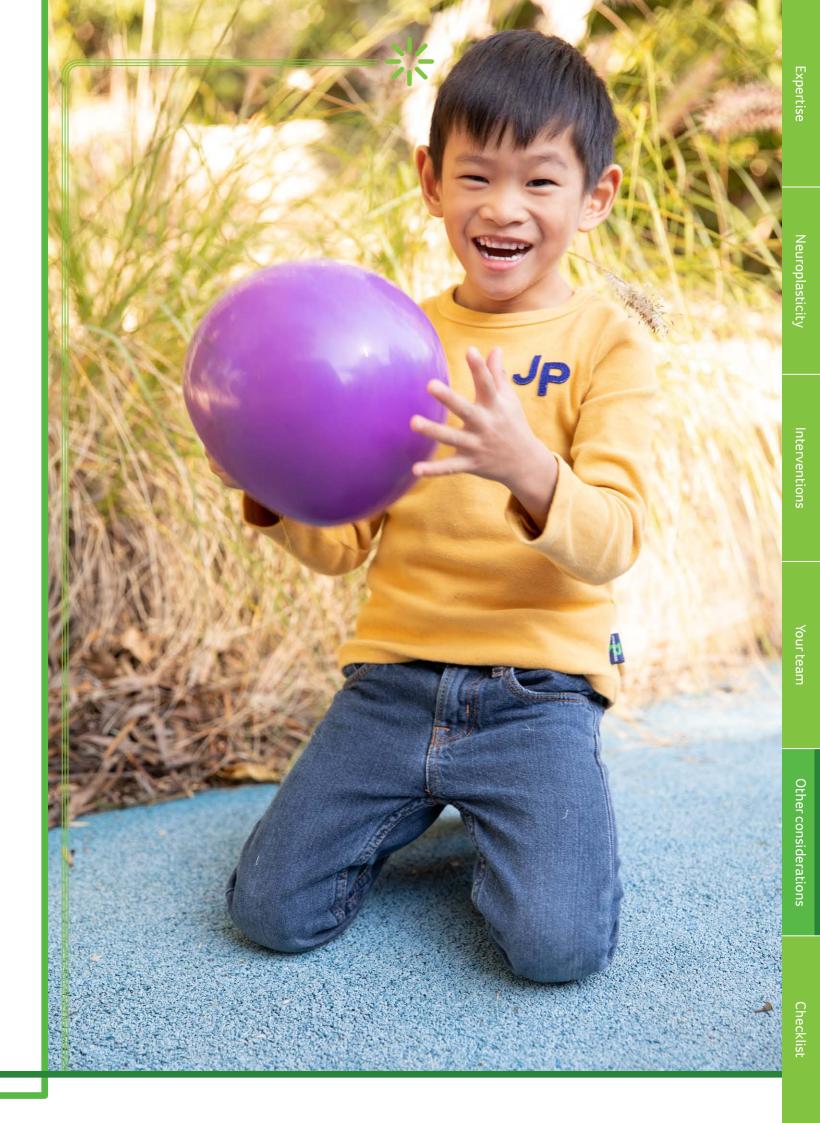
Earlier in this guide we discussed how active early intervention has been shown to have much better outcomes. The key to active early intervention is repetition and intensity, both of which can be carried out in the home environment. So choosing a provider who enables you to continue providing therapy at home can have enormous additional benefits on your child's ability to meet their goals.

## What services do they offer beyond the age of 6?

As your child grows and develops, they may need access to additional services such as specialised equipment, support transitioning to school or social skills development. Choosing a provider who can meet your child's changing needs as they grow has many benefits:

- Consistency of therapists
- Familiarity for your child
- No need to repeat the search for a new provider.

Families tell us that having all services under one roof not only provides better results, they also get the benefits of saved travel time, and more convenient appointment scheduling options.



When it comes to brain injury in babies and children, we know that to be successful, early intervention must address:

Individual needs

Be individualised to the child's specific needs to maximise a child's potential.



#### **Complication minimisation**

Minimise known complications that might interfere with learning.



#### Real-life skills

Focus on practising real-life skills (training in motor skills, cognitive skills, communication skills, reading skills, sleeping skills).



#### Learning opportunities

Maximise learning opportunities in the home, preschool/ school and other key environments.

#### **Parental support**

Include parental support to reduce anxiety, stress and depression in parents.



## Your checklist for choosing the right provider

Choosing the right provider for your child's early intervention needs can seem daunting. Here's a priority checklist you can print out to help you shortlist and compare providers.

When you speak to providers on your shortlist, ask if you can visit their centre and meet the team before agreeing to any service. This gives you the opportunity to explore their location and facilities, and will help you feel more comfortable with your choice.

#### **My shortlist**

Provider 1:

Provider 2:

Provider 3:

Do they have experience with disability?			P3
What experience and success have they had working with babies and children?			
Are they a generalist or a specialist?			
Do they provide specialist services for your child's particular condition?			
What interventions do they use?			
Do they predominately provide active early interventions?			
Are they using evidence-based interventions?			
Do they offer therapy at the right intensity to reach the outcomes that you desire for your child?			
Do they offer access to the latest equipment and technologies?			

What is their approach to ECI, and how do they communicate with other therapists?	P1	P2	P3
Do they work in a team or as a sole practitioner? Do they co-ordinate care with others in your child's team or do you need to be the conduit between team members?			
Does one practitioner address all your child's needs or is there a team of experts?			
How, and how often, will they track and measure your child's progress?			
Are reports and assessments presented in a shareable and easy to understand format?			
Other things to consider?			
What additional benefits do they offer?			
Will you be included in decision making or invited to actively participate in your child's therapy?			
What services do they offer beyond the age of 6?			

Notes			

Checklist


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## About CPA

Cerebral Palsy Alliance (CPA) is a leading provider of early childhood intervention services throughout NSW and ACT, supporting children aged 0-6 years, and beyond, with a range of physical and neurological disabilities to achieve their goals.

Conditions we support include cerebral palsy, autism, global developmental delay, acquired brain injury, muscular dystrophies, stroke and genetic syndromes.

We work closely with our families to create a personalised and family-centred approach to suit every child's individual developmental needs.

Start your journey with us today and let us help your child become the person they're really meant to be.

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