

Finding *Your Way*

A practical guide for the early days of your child's disability, delay or autism diagnosis



Kindred



About This Guide

Finding Your Way has been created to help you navigate the early stages of your child's disability, developmental delay or autism diagnosis. It's designed to be both practical and flexible. Whether you prefer to read from start to finish or jump to specific sections based on the information or support you need at the moment, the choice is yours.

You'll find a wealth of useful information, personal stories, and tips from other families within these pages. We cover a wide range of topics, from funding and early intervention to understanding disability concepts. This guide is designed as a starting point based on what families told us they wanted to know at the beginning of their journey. Throughout the guide, we provide links to more information if you want to delve deeper.

Take the time to absorb the information that resonates with you and leave behind anything that doesn't. As your journey unfolds, you may find that certain sections become more relevant, so revisit the guide whenever you need.

While we use the term 'disability' throughout this guide, the content applies whether your child has a developmental delay, autism, a rare condition, another diagnosis, or no diagnosis at all. We use 'disability' for consistency, but recognise the diverse and individual experiences within our community.

Similarly, we often use the word 'parent', but this guide is for you whether you are a parent, family member, friend, foster carer, or anyone else caring for a child with disability.

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Welcome

If you are reading this guide, we can only assume that you have received some heavy news. Life-changing information that could potentially influence the life you had envisioned for your child and your family.

We want to acknowledge the range of emotions that come with receiving news that your child's life will be different, sometimes difficult, and now comes with a level of uncertainty. Whether you are feeling relieved or shocked, angry or empowered, please know that every emotion you feel, thought you have and tear you may shed is real, valid, justified and perfectly normal.

Many of these intense emotions aren't just about a report or diagnosis. They come from the heart-break of hearing your child being described in terms of delays and deficits instead of their unique talents, strengths, and character. And from the understanding that society doesn't always appreciate and celebrate differences for their beauty and strength as it should.

“

If you have young children who are different, understand that different isn't less, different is powerful and beautiful and so incredibly important.

CHLOE HAYDEN

”

Your child is not less. In the words of Chloe Hayden - “different is powerful and beautiful and so incredibly important”. This news may be a huge part of who they are, but it doesn't need to define them. Your child will still have interests and dislikes, things they are good at and things they are not so good at. You will still get to witness an incredibly strong and resilient human being grow in front of



you, at their own pace, in their own way. Celebrate the wins, both big and small, because each and every one marks another step forward in your child's journey.

This life will give you a front-row seat to your child's strength, determination, and bravery. Their presence in your life will open your eyes to a world of diversity, inclusion, and variety. You will find your heart full of a love fiercer than you could have imagined.

This love will always and forever be enough. There will be moments when you second guess yourself, and at times feel guilty. Acknowledge these feelings, give them their moment and when you are ready, show them the door, making way for the self-love and kindness that you deserve. More than any therapist or specialist, it's your support, and involvement that will make the greatest difference in your child's development. Your connection with them will shape their growth and help them thrive in ways no one else can.

Within the pages of this guide, you will be introduced to resources and information that will leave you with the knowledge, confidence, and strength to face the challenges that this journey will throw at you.

Know that you are not alone in this. There is a community of families who have been where you are. They are ready and willing to share all kinds of tips, tricks, words of advice, encouragement and support, a shoulder to cry on, an ear to listen and a large warm welcome that (we hope) allows you to feel seen, heard and validated.

We are here to support you every step of the way.

From,

*A community of parents
walking alongside you*





About Kindred

Kindred is an independent, not-for-profit, peer support organisation for parents and carers of children with disability, developmental delays and autism. As a community of parents, we understand the joys and the challenges of raising a child with disability.

Which means we've been where you are now. Whether you're just starting out on your journey, or you're at a point of transition in your child's life, know that we get it. And we've got you.

There will be struggles and challenges but with helpful guidance and support from a community of families who have travelled a similar path, your family will discover a future full of possibility.

Through our free online programs, trusted resources and supportive community, we help families just like yours to build the skills, knowledge and confidence that will see your child and family thrive.

No journey needs to be travelled alone.



Photo of some of Team Kindred.

As a family-led virtual organisation with team members spread across NSW & ACT, face-to-face meetups are rare, making this celebration extra special!

Free Online Support

- Peer groups
- Workshops
- Parenting programs
- Private Facebook group for families
- Resources created by families and professionals
- Stories from parents and people with disability



Beginning the Journey

Whether you've just received a diagnosis for your child, are exploring one, or waiting for the right diagnosis, you are welcome here. The information and perspectives shared within this guide are relevant to you, no matter what stage you are at in the process.

While every family's journey is unique, you're on a path that many families have walked before you, and it's important to realise that you don't have to navigate it alone. This section is designed to help you as you take the first steps and begin your journey.

Give Yourself Time and Space

Processing this kind of news is significant. Be kind to yourself and allow room for grace as you and your family adapt. This isn't something that happens overnight, so it's important to take the time you need. Be gentle with yourself, your child, and your loved ones as you move through this new reality together.

There's No Rush to Act

It's very common to feel a pressing need to quickly wrap your head around all the information you've just received and urgently begin the journey of finding therapists and applying for funding for your child. Before diving straight into action, we recommend taking a moment. While these logistical first steps are important, it's equally valuable to give yourself and your family the space to process and adjust.

It's okay to take things slowly. Remember that even small steps forward matter, and there's no need to rush through this period of transition. Prioritising your family's wellbeing during this time can make all the difference as you move forward.

Processing How You're Feeling

It's natural to feel a wide range of emotions. You may feel these all at once, or in stages. Whether you experience disbelief, anger, relief, or anything else, the most important thing is to give yourself permission to feel whatever comes up.

Sharing how you are feeling with someone you trust—a supportive friend, family member, or professional—can offer valuable support and perspective. Open, honest conversations can help you process your feelings and lighten the emotional load.

Sharing the News

When you're ready, you may want to share the diagnosis with others. There's no 'right' way to do this—every family is different. Some families choose to keep the news private for a while, while others feel more comfortable sharing right away. Trust yourself to know what feels right for your child and family.

Your approach might involve telling your inner circle first, then slowly expanding to a wider group, or you may choose to share it with everyone at once. Follow your instincts and proceed in a way that feels natural and supportive to your family's needs.

Depending on your child's age, you may want to include them in the process. It can be empowering for your child to know what's happening and to have a say in how the information is shared with others. Including them in these conversations can help them feel supported, heard, and involved.

To learn how other families approached sharing the news with family and friends, read [this story](#) from three parents in the Kindred Community.



“ *My mother has given me endless amounts of love and affection. And she was always the one who stood up for me. But as I grew, she gave me space to develop my own independence and resilience, which are some of her greatest gifts.*

I am non-verbal and she was my voice when I literally didn't have one. But she helped develop my skills and now I can sure as hell speak for myself. I am a wheelchair user but can sure as hell stand on my own two feet.

MARLENA



The Power of Peer Support

As you move through this experience, finding a community of people who truly understand what you're going through is vital. Support—offered by families who are walking a similar path—can provide both emotional and practical guidance. This is what's known as peer support.

Peer support comes in many forms such as—facilitated groups, one-on-one support, or access to resources and information developed by other parents. It's often by learning from other families and feeling connected through shared experiences that parents find not only understanding but also the tools they need to make informed decisions.

We encourage you to seek out peer support groups, whether through [Kindred](#), a diagnosis-specific group, or something local to your community. These networks are full of shared wisdom, insights, and genuine empathy that can be incredibly helpful.

Being in the company of families who truly 'get it' can provide comfort, perspective, and hope during this time. From practical tips to emotional reassurance, these communities can help you navigate challenges that may feel overwhelming when faced alone.

A Community Walking Alongside You

Here, you'll find messages from other families from our community who have walked this path before you. Their insights and experiences offer a window into what this journey can look like, and we hope you find comfort and strength in their words.

Let these reflections serve as an important reminder that you're not alone. There is a community walking alongside you.

- You are going to get through this one day and one decision at a time.
- It's ok to ask for help. No one needs to do this alone.
- Learn from the experience of other families.
- Ask questions. It's ok to get a second or third opinion if you aren't sure.

Messages From Parents in the *Kindred Community*

What We Wish We Knew in the Early Days

Your child doesn't need fixing.

- Your child is still your child. This piece of paper doesn't change who they are or your bond.
- Your child will have no greater asset in life than you. So it's important you take good care of yourself too.

- Take your time to go over any reports you receive. If there's anything you don't understand ask as many questions as you need.
- No diagnosis will change how incredible your child is.
- Life moving forward will be different but it certainly won't be a lesser life.
- Find your community. It's so important to connect with other parents who have children with disability. There's so much value having that support from other parents who understand your journey.
- Your mental health and well-being are important, too. Remember to take care of yourself.
- It gets easier.

Professionals may be experts in development but you are the expert in your child.

- Work together as a team with your partner.
- Look for your child's strengths and your own strengths. What you focus on will grow.
- Use your child's interests to engage them in your world but first meet them in theirs.
- Let your family know what's going on. Give them a chance to support you.
- Take care of yourself. With more energy and clarity, you can better meet your child's needs.

- This journey is a marathon, not a sprint pace yourself. Give yourself time - do what you can, when you can.
- Nothing is more important than your child's and your family's well-being.

Do not underestimate the power of a mother's intuition! Trust your gut! If something doesn't feel right- speak up. You know your child best.

A good life is possible!

- It's OK not to be ok.
- Help is available. Emergency respite and other supports exist.
- You have the right to ask questions and request more information from doctors.

Understanding Key Disability Concepts

If your child has recently been diagnosed with a developmental delay, disability or autism, you're likely hearing unfamiliar terms and phrases for the first time, especially if you have limited personal experience of disability. In this section we'll introduce you to some key concepts to help you understand disability in a way that can empower both you and your child as you navigate supports and systems.

Strengths-Based Approach

A strengths-based approach focuses on what your child can do, rather than what they can't. It emphasises building on your child's strengths, interests, and abilities to help their growth and development.

This approach fosters confidence, resilience, and a positive sense of self by recognising your child's unique talents. While addressing challenges is essential, focusing on strengths can create opportunities for your child to thrive.

For example:

- If your child learns visually, you might use pictures or visual aids to help them develop new skills.
- If your child loves animals, teach reading through animal-themed activities.
- If your child loves music, use songs or rhythms to teach counting, language, or following directions.
- If your child thrives on routine, use consistent schedules to help them learn new self-care skills.

Inclusion

Inclusion ensures that everyone can fully participate in all aspects of life, from education to social activities and employment. For children with developmental disabilities, inclusion means having the support they need to take part in the same activities and environments as other children—at home, in early childhood settings, and within the community.

Inclusive programs or environments allow all children to participate in activities suited to their interests and abilities. For families, inclusion means being actively involved in the same community experiences as other families.

Disability as Part of Identity

Disability is a part of who your child is, but it doesn't define them entirely. Many people with disability view it as a natural part of their identity, rather than something negative or limiting. It's important to approach your child's diagnosis with openness, seeing their disability as just one aspect of their identity, alongside their personality, talents, and interests. This perspective fosters self-acceptance and helps your child feel proud of who they are.





“When Dash was first identified as Autistic, the conversation with professionals became about all the things he couldn't do. Overtime, I learnt to advocate from a strengths-based approach and focus on how wonderful and unique my child is, exactly as he is.”

KRISTY



The Social vs. Medical Model of Disability

How you view disability itself can make a big difference in your child's life and the choices you make as a family. In this section, we'll explain two different approaches to disability - the social model and medical model - and how these can guide your decisions in areas such as healthcare, education, inclusion, and the overall well-being of your child.

 Medical Model	 Social Model
<p>Views disability as something within the person that needs to be 'fixed' or cured. It focuses on diagnosis, treatment, and intervention. In this view, a child with a developmental delay or disability might be seen primarily in terms of what they cannot do, with an emphasis on therapies to 'fix' those deficits.</p>	<p>Looks at disability as a result of barriers in society, not a problem within the individual. It emphasises that the environment and social attitudes can be disabling. In this view, the focus is on changing the environment, attitudes, and systems to better include and support your child.</p>

<i>Medical Model Examples</i>	<i>Social Model Examples</i>
Child uses a wheelchair and is unable to access the playground at recess.	With a wheelchair-accessible playground, the child can play with friends at school.
Child has severe expressive communication delays.	With access to a communication device, the child is able to communicate needs.
Child has poor social skills and is unable to play with others.	When engaging in preferred activities, child is able to share enjoyment with familiar peers.
Child is unable to sit still and concentrate for group time.	With regular movement breaks, and access to sensory supports child is able to engage in group time.
Child has poor executive functioning skills and lacks independence in daily tasks.	With visual schedules, child is able to unpack bag when arriving at preschool.
Child's writing is illegible and is unable to complete creative writing.	Child is able to express creative ideas verbally.

<i>When to Use Medical Model</i>	<i>When to Use Social Model</i>
When seeking medical treatment or applying for funding (like NDIS), focusing on your child's specific needs and challenges is often necessary to secure services.	To advocate for removing societal barriers and creating more accessible and supportive environments for your child, which promotes inclusion and empowerment.

You can find more information on other key disability concepts on page 46 of this guide.

Early Childhood Intervention

When your child's development doesn't meet expected milestones, you'll likely hear a lot about 'early intervention' and 'therapy.' It's natural to have questions about what these terms mean and how they can help your child.

In this section, we'll explore what early childhood intervention (ECI) is, the different types of therapy available, and how to make ECI work best for your child and family.

What is Early Childhood Intervention

Early Childhood Intervention (ECI) is a range of services and supports to help young children with developmental delays and disability get the best possible start in life. ECI is tailored to meet your child's unique needs and your family's priorities. It might include specialised therapies (like speech therapy or physiotherapy), educational programs, family support and supported playgroups.

The goal of ECI is to support your child's development during the crucial early years to reach their full potential. But it's not just about your child – ECI also aims to empower you as a parent. It provides you with strategies, knowledge, and confidence to support your child's growth and learning in everyday moments.

What is Therapy

Therapy is a type of ECI service which involves various activities and exercises to support your

child's development, improve their daily life, and help them reach their full potential.

Therapy is a partnership between your family and trained allied health professionals (therapists). It should focus on building on your child's strengths and overcoming challenges rather than trying to 'fix' your child.

In the early years, therapy might look different to what you imagine: it's often play-based and happens during everyday activities. For example, a speech therapist might show you how to encourage language during bath time.

To learn more about therapy, visit our [library of resources](#).

A note on language: In the guide, we use the term Early Childhood Intervention (ECI) because it is commonly used by medical professionals and familiar to many families. However, we recognise that the word 'intervention' may carry negative connotations for some families.



Understanding Therapy and Therapists

Therapists play a vital role in supporting your child's development. In this section, we cover the key therapists you might work with, some of the ways they can help your child and family, and how they often work across different skill areas to provide well-rounded support.

Speech Therapist

A speech therapist, also known as a speech pathologist, can help your child with things like:

- Speech development: Improving pronunciation, articulation, forming words and sentences.
- Language development: Understanding and using language both in speaking and listening.
- Alternative communication: Teaching sign language or introducing the use of communication devices when a child has difficulty communicating verbally.
- Social communication skills: Learning how to interact with others, take turns in conversation, and use body language.
- Feeding and swallowing: Addressing issues related to eating and drinking.
- Literacy: Supporting the development of reading and writing, including phonological awareness, reading comprehension and spelling.

Occupational Therapist (OT)

An occupational therapist helps children develop the skills they need for daily living and playing. They can assist with areas such as:

- Fine motor skills: Activities like holding a pencil, using scissors, and other activities that require hand-eye coordination.
- Self-care skills: Learning to dress, feed themselves, and manage other daily activities.
- Sensory processing: Processing and responding to sensory information (like sounds, textures, and lights) in a manageable way.
- Emotional regulation: Understanding and managing emotions.

Physiotherapist

A physiotherapist focuses on improving a child's physical skills, such as movement, balance, and coordination. For example, they can support with:

- Motor skills development: Improving gross motor skills like crawling, walking, running, and jumping.
- Strength and flexibility: Building muscle strength and improving flexibility.
- Posture and balance: Developing proper posture and balance, for physical activities.
- Mobility aids: Recommending and helping with mobility aids like walkers or wheelchairs.

Psychologist

A psychologist can support your child's emotional, social and behavioural development. They can assist with areas such as:

- Emotional regulation: Managing emotions and coping with feelings like anxiety, frustration, or sadness.
- Behavioural support: Understanding behaviour and identifying supportive strategies.
- Social skills: Improving social interactions, making friends, and understanding social cues.
- Family support: Offering guidance to families on supporting their child's emotional and psychological well-being.

Behaviour Therapist

Behavioural therapists focus on understanding and addressing behaviours that might be hindering a child's development and daily functioning. They can help with things like:

- Skill building: Teaching specific skills that help with daily activities, social interactions, and learning.
- Individualised plans: Creating personalised behaviour plans based on a child's unique needs and goals.
- Family training: Working with parents and caregivers to implement behaviour strategies at home and in other settings.

Best Practice in Early Childhood Intervention

Best practice in early childhood intervention refers to approaches and strategies proven through research and experience to be most effective in supporting children with disability and their families. These principles guide professionals in providing high-quality, family-centred care that promotes your child's development and well-being. When professionals use best practice approaches, your child receives tailored, evidence-based support that meets their needs. This gives your child the best chance to thrive, learn new skills, and overcome challenges.

Understanding the best practice principles helps you make informed decisions and work more effectively with your team, ensuring that your child and family receive the best possible support. Don't hesitate to ask your early intervention team how they're applying these principles in their work with your family.

Family Centred and Strengths Based

Families are the experts on their children and should be involved in decision-making. Supports should build on the child and family's existing strengths and capabilities. [Find out more.](#)

What It Can Look Like:

- Providing strategies that fit into your family's daily routines.
- Working closely with you to develop goals based on what is important to your family.
- Involving siblings in sessions and home activities.
- Focusing on your child's strengths when targeting new skills.



Engaging the Child in Natural Environments

Therapy and support should occur in familiar settings, like home, local community or childcare. [Find out more.](#)

What It Can Look Like:

- Physio session at your child's favourite park to help them use the equipment.
- OT observes your child during their morning routine and offers strategies to help with transitions.
- Speech therapist attends child care to observe your child at mealtime and shares strategies with the educator.



Inclusive and Participatory

Promotes a child's participation in family and community life. [Find out more.](#)

What It Can Look Like:

- Strategies are developed to help your child join in at playgroup.
- Support is provided to help your child participate in family outings.
- The physiotherapist goes to your child's sporting activity and provides strategies on how to support their participation.



Collaborative Teamwork

A team approach involves the important people in the child's life, including families, therapists and educators, communicating and collaborating to support a child's development. [Find out more.](#)

What It Can Look Like:

- Team meetings with you, your therapist and educator to set goals for your child at school and to discuss their progress.
- Sharing information and resources between team members.
- Speech therapist and occupational therapist working together on a feeding issue.



Evidence-Based and Accountable

Support should be based on the best available research and evidence, and outcomes should be measured. [Find out more.](#)

What It Can Look Like:

- The OT uses strategies that have been validated through research studies.
- Your therapists regularly evaluate the effectiveness of their support.
- Your child's therapist participates in professional development to stay up-to-date with the latest research and applies this knowledge in their work.



Outcomes-Based Approach

Focusing on achieving meaningful outcomes for the child and family. [Find out more.](#)

What It Can Look Like:

- Goals are set based on what's most important to your family.
- Progress towards goals is regularly reviewed and discussed with you.
- Strategies and supports are adjusted if goals aren't being met.



Capacity Building

Building the skills, knowledge and confidence of families and other caregivers to support their child's development. [Find out more.](#)

What It Can Look Like:

- You or a family member attends a workshop to learn about how you can support your child's transition to school.
- Parent only coaching sessions where the therapist teaches you specific therapy techniques.
- Your therapist provides you with information about new assistive technology you are preparing to trial.



Culturally Responsive

Respecting and responding to the cultural, linguistic, and social characteristics of the family. [Find out more.](#)

What It Can Look Like:

- Professionals ask about and respect your family's beliefs and values.
- Incorporating culturally significant activities into therapy sessions.
- Using interpreters when needed.



Where to Access Therapy

In New South Wales, there are different ways to access therapy services, and the options may vary depending on your location. Below is an overview:

Community Health Centres

Community health centres are located within local communities and offer therapies such as speech, OT, and physiotherapy, often at no cost if your child has a medicare card. These centres can also connect you with other local resources and support. Services will vary between centres, eligibility criteria may apply, and there are often long waitlists. Contact your local centre to learn what is offered and if a referral is required. Search 'community health centre + [your suburb or local area]'.

Not-for-Profit ECI Providers

In some areas of NSW, not-for-profit organisations offer comprehensive early childhood intervention services, including therapy sessions, supported playgroups, and family support. These providers usually have a team of different types of therapists who can collaborate to support your child. You can contact them directly to enquire about services. Payment options include NDIS funding or private payment. Search 'early childhood intervention + [your suburb or local area]' online to find providers in your area. A not-for-profit provider will generally have a .org.au web address.

Private Practices

Private therapy clinics may consist of solo therapists or a team of therapists. Some private clinics offer programs for both children and their families to learn new skills. You can find private therapists through recommendations from your GP, paediatrician, or by searching online directories. Payment for these services can be made using NDIS funding or privately.

Hospital Outpatient Clinics

Some children may be able to access therapy services through hospital outpatient clinics, particularly if they need specialised care. These clinics, often located in children's hospitals, are at



no cost (for medicare card holders), though waitlists can be long. A referral from your GP or paediatrician is typically required to access these services.

University Clinics

University clinics provide therapy services by students under professional supervision, offering a lower-cost option. To find these services, search online for universities offering programs in speech pathology, occupational therapy, or physiotherapy.

Early Childhood Education and Care Settings

Some early childhood education and care centres, such as preschools and childcare centres, provide integrated therapy services within the educational setting. These services may be delivered by visiting therapists or staff trained in early childhood intervention. Speak with your child's ECEC director or search online for centres offering these integrated services.

Telehealth Services

Telehealth has become a widely accessible option for families, especially those in regional or remote areas. Many therapists now offer online sessions for children and families, making therapy more convenient. You can search online for therapy services that provide telehealth options for children. Payment can typically be made using NDIS funding or privately.



Finding and Choosing the Right Therapist

A therapist can play a crucial role in your child's development. Choosing the right one can feel like a big decision. Here are tips from other families to help you find and select the best therapist for your child.

What to Look For

When searching for a therapist, it's essential to find someone who not only has the right qualifications but also aligns with your child's needs and your family's values. Here are key factors to consider:

- Experience: Does the therapist have experience working with children with similar needs?
- Approach: Does their approach align with your values and priorities for your child?
- Communication: Do they take the time to explain things in a way that helps you understand?
- Collaboration: Are they open to your input and questions and working in partnership?
- Location: Is their clinic convenient for you to get to? Or even better, can they come to your home or child's education setting?
- Cultural sensitivity: Does the therapist understand and respect your family's cultural background?

Questions to Ask

Asking the right questions can provide a clearer picture of a therapist's experience and approach. Here are some questions that can help you evaluate whether they're the best fit.

- About their experience: What experience do they have working with children who have your child's diagnosis or specific needs?
- About their approach: How do they involve parents and family members in the therapy process? How do they make therapy engaging and motivating for children?
- About best practice: Do they work in natural environments such as the home and education settings? Do they involve you in planning? Are they comfortable with siblings joining in? How do they measure and communicate progress?
- About communication and collaboration: How do they collaborate with other professionals

- involved in your child's care?
- About practical matters: What are their fees? What is their cancellation policy? Do they offer flexible scheduling options or telehealth?
- About their philosophy: How do they handle a situation where a child is resistant to therapy? How do they handle challenging behaviours during therapy?
- About their child safety practices: Will they work with your child alone? How do they screen their staff? Do they adopt the National Child Safe Standards? ([Find out](#) what to look for in an organisation or service to keep your child safe).
- About their approach: Do they offer a [key worker model](#)? How do they work collaboratively with professionals in their own organisation and externally to make sure everyone is on the same page to provide the best care?

Finding a Therapist

Finding the right therapist involves research, networking, and sometimes a bit of trial and error. Here are some steps to help you on your search:

- Contact local support groups: Reach out to local support groups for parents of children with disability. These could be local Facebook groups or parent groups that meet in your local area.
- Ask for recommendations: Ask your child's paediatrician, teachers, or other families for recommendations. They may know therapists who have successfully worked with children with similar needs.
- Research online: Many therapists have websites or are listed in online directories for finding therapists. Check if they have reviews on Google or Facebook.

Making Therapy Work for Your Family

Integrating therapy into family life is a great way to support your child's progress outside of therapy sessions. This section offers practical tips from experienced families on fitting therapy into your routine, understanding your role, and what to do

when changes are needed. The goal is to help make therapy an effective and positive part of your family's journey while supporting your child's development and maintaining balance in your daily life.

Fitting With Your Family's Needs

It's important to find ways to integrate therapy into your family's daily life. Here are some strategies that other families have found helpful.

- Flexible scheduling: Collaborate with your therapists to find suitable session times that accommodate your family's routines. This could involve scheduling sessions around your children's school times or arranging therapy during your child's most alert periods.
- Incorporating therapy into daily life: Look for opportunities to include therapy activities into your everyday routines. For instance, you can practice speech sounds during bath time or car rides, work on fine motor skills while cooking or doing chores together, or use playground time to address physical therapy goals.
- Exploring telehealth options: When in-person sessions are challenging, consider using telehealth as an alternative. Telehealth offers benefits such as reduced travel time, flexible scheduling, and the opportunity to practice skills in your home environment.
- Involving siblings: Getting siblings involved in therapy activities can be a way to work on your child's goals. This can promote understanding and bonding, make therapy feel more like family time, and provide natural opportunities for interaction and social development.

Your Role in Therapy

As a parent, you play a crucial role in your child's therapy by actively participating, sharing insights, and applying strategies at home. Families share what their involvement looks like.

- Active participation: Engage in therapy sessions to learn strategies directly from the therapist that you can apply at home. Don't hesitate to ask questions and seek clarification.
- Share your insights: You know your child best.

Share your observations, such as what motivates your child or what might be causing frustration. This information can help therapists tailor their approach to better suit your child's needs. Also, provide feedback on how strategies are working at home.

- Practice at home: Therapy doesn't end when the session does. Incorporate techniques into everyday activities to reinforce learning. Keep a log of progress and challenges to discuss with your therapist
- Set goals together: Partner with your therapist to establish meaningful, achievable goals. Ensure that these goals align with your family's priorities, and regularly review and adjust them as required.
- Be an advocate: Trust your instincts about what works for your child. Speak up if you have concerns or if something doesn't feel right. Collaborate with your child's entire support team.

When Therapy Isn't Working

Sometimes, despite everyone's best efforts, therapy may not be progressing as expected. Families share what you can do if things aren't working.

- Communicate concerns: Have an open, honest conversation with your therapist to discuss what isn't working and why you're concerned.

Research consistently shows that parent involvement has the most significant impact on development for children with disability.

Seek their perspective on the situation and explore possible changes.

- Review goals and expectations: Revisit the therapy goals and expectations. Are they still realistic and appropriate for your child? Adjusting goals can sometimes lead to better outcomes.
- Consider different approaches: If progress remains slower than expected or stress levels are high, explore different therapy methods or techniques. Different methods can resonate differently with each child, and finding the right fit can make a significant difference.
- Consider a change: If issues persist, consider finding a different therapist whose style and approach better match your family's needs. Remember, it's okay to make a change if it's in the best interest of your child and family.

Read our [resource](#) on what you can do when therapy isn't working for your child or family.



Beyond Therapy

When your child receives a disability diagnosis, therapy often becomes a primary focus. However, Early Childhood Intervention (ECI) offers a wide range of supports that can significantly benefit your child's development and contribute to your family's well-being. Below is an overview of additional services that can complement your child's therapy.

Every child and family is unique, so it's important to find the right combination of supports that work best for you. Speak with your ECI provider or therapist about how these services can benefit your child, and connect with other families to learn what has worked well for them.

Parent Education

Parenting programs equip you with practical strategies to support your child's development at home, boost your confidence, and connect you with other families in similar situations. Popular programs include: Hanen, Tuning into Kids and Circle of Security. Kindred also offers free [online workshops](#) led by parent peer facilitators, helping you learn to advocate for your child and navigate various services and systems. To find suitable programs, ask your early intervention provider, contact your local community health centre or council, search online, or connect with other families through [Kindred's community](#).

Peer Support Groups

Connecting with other parents who are raising children with developmental delays or disability can be incredibly beneficial. Peer groups, like [MyTime](#), offer a safe space for sharing experiences, receiving emotional support, and learning new ideas. You can join a local MyTime group or [Kindred's Online MyTime](#) groups - both options are free for families.

Supported Playgroups

Supported playgroups offer a nurturing environment where children can interact with other children with disability and develop important skills such as communication, sharing, and play. These groups also offer parents a chance to connect with other families. If you're not ready for mainstream playgroups, supported playgroups can be a stepping stone. Contact your local early intervention provider, council or [Playgroup NSW](#) to find a group near you.

Disability Specific Programs

These programs offer specialised support tailored to children with disability, focusing on skill development, social interaction, and targeted activities. They may include social skills groups or other programs designed to meet your child's unique needs. To find a program, contact your local early intervention provider or therapist, search online or ask other families.



One of the biggest benefits of going to the Magic Yellow Bus was community. A diagnosis can often shape your days around therapy and appointments, but for me, being a part of the community was just as important. It gave Elsdén a chance to build her skills without even realising it—whether through messy play or fine motor activities, she practised what we learned in therapy in a natural way. Yes, meeting goals was always at the back of my mind, but the best part was meeting other families, both with and without disabilities, and spending time together. As a Mum, there were no demands except to be present and have fun. We made special friends, and it helped me feel less lonely.



How We Made Therapy Work For Us

A Family's Story

When my son Alex was diagnosed with Williams Syndrome, everyone I spoke to stressed the importance of early intervention. So I thought that the more therapy sessions I could book in, the better. Our weeks were spent driving all over Sydney for multiple therapy appointments. I had 3 children under 3, who, out of necessity, came along to Alex's appointments. One day, our speech therapist asked that I stop bringing Sammy and Anneliese - she felt they were too distracting. I was at a loss about what to do.

Outside of therapy, things weren't working either. The homework we were given for Alex, an active 3-year-old, was to sit for 20 minutes and complete worksheets. It was just impossible.

Something Had to Change

Through a local Facebook group, I heard about an early intervention provider that offered not just therapy but parent education workshops and playgroups. We began to see a Key Worker. She was not only an occupational therapist but someone who could help with Alex's language goals and bring in other specialists when needed. Suddenly, our lives felt less like a revolving door of appointments and more like a team effort. We did therapy at home and in the community. The best part? Sammy and Anneliese were encouraged to join in.

I learned so much from the workshops and from the other parents I met. Therapy wasn't something that only happened in appointments — it became part of our family's life. Climbing monkey bars at the park was just as valuable as any hand-strengthening exercise and a lot more fun, too!

I Became Empowered

Over time, I went from feeling like a passive participant in Alex's therapy to realising I was key to making it work. I began to have a say in setting goals, and I found ways to incorporate therapy into our daily routines. The more empowered I felt, the more I saw Alex thrive.



Tips for Working with Therapists

1. Work with therapists you can learn from so you can build your own skills and knowledge.
2. Ask your therapist the reasons 'why' they are doing things, so it makes sense to you.
3. Think about what is going to make your life easier and ask therapist to help you solve problems.
4. Have clear goals to work towards, and don't try to do everything at once.
5. Believe in yourself; you are the one who can make the biggest difference in your child's life...you've got this!

Medical and Health

Whether your child has medical needs and requires regular medical care, or their sensory needs mean that appointments are overwhelming, accessing healthcare can be challenging for families of children with disability. In this section, we'll provide an overview of the healthcare system, how to navigate it effectively, and ways to advocate for your child and family's needs.

Accessing Paediatric and Specialist Care

General Practitioners (GPs)

Your GP is often the first point of contact when accessing healthcare services for your child. Building a long-term relationship with a GP who is familiar with your child's medical and developmental circumstances is valuable. They can help you navigate the healthcare system, provide referrals to specialists and simplify complex medical information to help you understand your child's health concerns. GPs also play a vital role in holistic care, not just for your child but for your entire family.

Paediatricians

A paediatrician specialises in managing children's healthcare, including developmental delays. Accessing a paediatrician usually starts with a referral from your GP. There are two main types of paediatricians: General Paediatricians focus on overall child health and general development, while Developmental Paediatricians specialise in developmental conditions and disability. Paediatricians work closely with specialists to ensure your child receives the care they need across all areas of development and health.

Specialists

When your child needs care beyond a GP or paediatrician, specialists such as neurologists, geneticists, and cardiologists may be required. Accessing specialists typically requires a referral from your GP or paediatrician. It's important to note that GP referrals are usually valid for 12 months, while paediatrician referrals typically last 3 months.

Private Practice vs Public System

In the public health system, there may be long wait times to see specialists, but services are often free or low-cost. On the other hand, private practices offer

faster access, though the costs can be significant. Many families, depending on their financial circumstances choose private care when time is a critical factor.

Outpatient Clinics

Outpatient clinics provide specialist care without hospital admission. These clinics may offer consultations with paediatricians, therapists, or other specialists, often with access to multidisciplinary teams. Because outpatient appointments can be infrequent and it's not as easy to speak with specialists between appointments, it's important to be well prepared. Write down your questions beforehand and bring any relevant medical records or test results.

Different Public Hospital Settings

Children's Hospital

NSW is home to several major children's hospitals, including the Children's Hospital at Westmead, Sydney Children's Hospital in Randwick and John Hunter in Newcastle. These hospitals offer specialised paediatric care and have a wide range of specialists and services, from routine care to complex surgeries. Your child's paediatrician and GP can often refer you to these hospitals when specialised care is needed.

Local Hospital

Your local hospital can handle less complex medical issues and help stabilise your child during emergencies. While some hospitals may offer specialised care, especially in larger areas, others - particularly in smaller locations - may not. If needed, they will coordinate with the children's hospitals or refer you for more specialised services.

Understanding Your Hospitals Facilities

If your child has a medical condition, it's helpful to familiarise yourself with the paediatric capabilities of

your local hospital. By understanding what services are available, you'll be better equipped to make informed decisions in an emergency. Speak with your GP or paediatrician to create a plan tailored to your child's needs. This preparation can help you act quickly and confidently in urgent situations.



Regional, Rural, and Remote Areas

Families in regional, rural, and remote areas often face challenges like fewer paediatricians and specialists and longer travel times for appointments. However, there are practical solutions to improve access. Many regional areas now host visiting specialists, bringing expert care closer to home. Telehealth services are also expanding, allowing families to consult with specialists remotely, reducing the need for travel. In emergencies, transport services can help get children to the care they need quickly.

Advocacy and Support

Advocating for your child's healthcare needs is an essential part of navigating the medical system. Ensuring your child receives the best possible care involves understanding your rights, asking questions, and seeking out the necessary support systems.

Healthcare Rights

Understanding your healthcare rights is crucial when accessing medical services for your child. These rights include the entitlement to safe and high-quality care, being informed about available services, treatment options, and associated costs, and being actively involved in decisions about your child's care.

Knowing your rights helps ensure that you and your child receive the respect and care you deserve throughout the medical process.

Advocating

Advocating for your child involves taking an active role in their care and speaking up on their behalf. Keep detailed records of all appointments, treatments, and medical interactions. This documentation can be invaluable when discussing your child's progress or concerns with healthcare providers. Don't hesitate to ask questions or seek clarification on any aspect of your child's care that you don't fully understand. Remember, you know your child best, and your insights are crucial to their care. If you're unsure about a diagnosis or treatment plan, it's perfectly acceptable to seek a second opinion.

In New South Wales hospitals, the [REACH](#) (Recognition, Engage, Act, Call, Help is on its way) system is available to escalate concerns about a patient's condition. This system empowers you to act if you notice a worrying change in your child's condition that you feel is not being adequately addressed. Familiarise yourself with how REACH works in your hospital so you can use it if necessary.

Read our [tips for advocating](#) for your child in the healthcare system.

Coordination of Care

Coordinating your child's care, especially when navigating multiple specialists and services, can be challenging. Ask at the hospital if there is anyone that can assist you to coordinate your child's care. Consider using a care diary or digital tool to track appointments and treatments and key updates.

Support Networks

Connecting with other parents and carers facing similar challenges can be a source of strength and guidance. Local support groups, online communities and peer groups like [Medical MyTime](#) can offer invaluable advice, shared experiences, and emotional support as you navigate the healthcare system. These networks can help you feel less isolated and provide practical insights on managing your child's care.

Cultural Considerations

It's essential that healthcare services are accessible, respectful, and culturally appropriate for all families. Understanding and advocating for your cultural needs is a key part of ensuring your child receives care that aligns with your family's values and traditions. Healthcare providers in New South Wales are required to provide culturally sensitive care, including access to interpreters. Speak to your GP or healthcare provider for more information.



Emotional Impact on Families

As a parent, it can be incredibly hard to watch your child go through medical procedures, hospital stays, or frequent specialist appointments. Seeing them face these challenges often brings feelings of helplessness, fear, and anxiety. When your child has developmental concerns or disability, the emotional weight is compounded by the stress of navigating a complex healthcare system, dealing with long wait times, and facing uncertain outcomes. To help manage these challenges, consider seeking support through counselling or joining a parent support group. You can access services such as hospital social workers, psychology services (via a Mental Health Care Plan from your GP), and parent support hotlines.



Preparing for Hospital Visits

- Explain the visit to your child using language they can understand.
- Bring along items that bring comfort, such as a favourite toy or blanket.
- Pack snacks and activities in case of potential long waits.
- Look into parking options, including any available disability rebates or discounts.
- Know where you are going by using hospital apps or websites for navigation assistance.
- Bring along documentation of your child's medical history, including diagnoses, medications, allergies, and past procedures.
- Be prepared for potential delays due to emergencies, and try to locate quiet spaces or sensory-friendly areas in the hospital.
- Many hospitals also provide child life therapy services to help children cope with the hospital experience - check with your hospital before your visit.

Families have shared more ways they helped to prepare their child for a hospital visit.

Education

While therapy often becomes the main focus after a disability diagnosis, education plays a crucial role in a child's development. It offers opportunities to develop social skills and independence, make friends and discover a sense of belonging. We'll explore the various options available, the supports you can access, and how you can be involved to ensure the best outcomes for your child.

Early Childhood Education and Care

What is Early Childhood Education and Care (ECEC)

Services like childcare, daycare and preschool, that provide care and educational experiences for children before they begin primary school. ECEC supports children in building foundational skills that prepare them for future learning and life experiences.

What are the Benefits

ECEC provides a strong foundation for children with disability to thrive. In inclusive, play-based settings, children can explore, learn, and develop essential skills. Some of [the benefits](#) include:

- The opportunity to learn from other children.
- Make choices and grow their independence.
- Take the skills they have learnt in therapy and apply them in the real world.
- Make friends and be part of the preschool and their local community.
- Prepare for the transition to school.

Choosing an ECEC

Start by considering what best suits your child's needs and your family's priorities. For instance, how does the physical environment align with your child's mobility and sensory needs? Have you considered the staff's experience in supporting children with disabilities, or their openness to training on medical aids or communication devices? While prior experience with disability is valuable, many families have found that a welcoming culture, a 'can-do' attitude, and a willingness to collaborate with your family and your child's support team are the most important factors. Use the [Starting Blocks ECEC finder tool](#) to locate quality ECEC services in NSW.

Available Supports

The NSW government provides [inclusion support funding](#) to help early childhood services accommodate children with a developmental delay or disability. Your therapists can also work with educators to provide guidance, resources, and training, ensuring your child receives the support they need. You can learn more about how this works in the 'Early Childhood Intervention' section.

Reasonable Adjustments

Children with disability have the [right](#) to participate in ECEC on an equal basis with other children. ECEC providers can make [reasonable adjustments](#) to include your child. This can look like changes to the routine to reduce transitions, changing a game from a standing to seated version so everyone can participate or creating a quiet space for sensory breaks. These adjustments can be easy and inexpensive to make.

Primary School

Starting school is an exciting milestone. When your child has a disability, this transition can also bring a mix of emotions and questions. With careful planning and preparation, you can help your child feel confident and excited about this new chapter.

Educational Settings in NSW

You have several options for your child's primary school education in New South Wales, including Public, Independent, Catholic, and disability specific schools, like Aspect. Each setting offers different resources and approaches to support your child's learning and development.

“

When we walk in the door every morning the kids yell 'Miller's here!'. Being in a supportive, inclusive environment, Miller participates in all the same activities. His educators adapt things to meet his needs so he doesn't miss out. I receive photos at the end of each day and Miller's always right there, taking part and playing with his friends.

We've been open about Miller's disabilities from the very first day and his classmates have just embraced him. He's invited to birthday parties and playdates.

Miller is non-speaking, and often, the other kids will ask me questions like, "Why does Miller wear hearing aids?". It's a great opportunity to help them understand Miller's needs and learn more about disability.

NATASHA

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Types of Settings

NSW Public Schools have different options available:

- **Mainstream classrooms:** Inclusive settings where children with disability learn alongside their peers. Every child, regardless of their disability, has the right to attend their local mainstream school.
- **Support classes:** Smaller classes with additional support staff for students with specific needs located within a mainstream school.
- **Schools for Specific Purpose:** Provide specialist and intensive support in a dedicated setting for students with moderate to high learning and support needs.

When to Start Planning

Children must be in school by their 6th birthday. It's suggested you contact the school in Term 1 in the year before your child starts school to submit their enrolment. Planning conversations will usually start in late Term 2 or 3. However, if the school may need modifications, such as a wheelchair ramp or accessible bathroom, it's recommended you contact the school two years before your child is due to start.

Supporting Your Child's Transition

Supporting your child's transition to school involves ongoing communication with the school, preparing your child for the new environment, and ensuring the necessary supports are in place. Visits to the school, social stories, and transition programs can help prepare your child. Hear from other families how they [supported their child's transition](#).

Available Supports

Children with disability in NSW schools may have access to a range of [supports](#), including SLSO's (teacher's aide), adjustments to the curriculum, sensory environment and routine, as well as building modifications. These supports are designed to help your child fully participate in their education. Public schools have funding available to support all children. Depending on your child's disability and needs, the school may be able to apply for [integration support funding](#).

Your Child's Rights

Students with disability are entitled to enrol in their local public catchment school and to be treated the same as other students without disability without discrimination. They should be welcomed as valued members of the school community and empowered to participate fully in school life. To support their individual needs, schools must provide reasonable adjustments and personalised support. Learn about your [child's rights](#).

Working Together

As a parent of a child with delay or disability, you play a central role in shaping your child's learning experiences, advocating for their needs, and ensuring they receive the support necessary to thrive.

How You Can Support Your Child

Your participation can help to set your child up for success. This can look like attending meetings,

“ We'd worked on throwing a ball in therapy for ages, but my son just wasn't interested. During a preschool visit, his therapist saw other kids playing with balls and invited him to join in. For the first time, he threw the ball! Seeing other kids having fun motivated him in ways therapy in a clinic never could.

LEILA



understanding your child's goals and contributing your insights to decision-making. Your involvement not only supports your child's learning but also builds a strong partnership with educators.

Speaking Up for Your Child

As a parent, every time you speak up for your child, you are advocating for them. By communicating your child's needs and preferences and addressing any concerns with ECEC providers or school staff you are ensuring that your child receives the appropriate support and accommodations they need. It can feel overwhelming, especially at the beginning, but remember you are your child's strongest advocate.

Working in Partnership

Educators, therapists, and other professionals bring expertise and resources, but you bring a deep understanding of your child's unique needs. By discussing your child's strengths and challenges, and working together as a team you can create strategies that will work for your child. Regular communication helps ensure that everyone is on the same page and working towards the same goals.

Sharing Information

Sharing information with educators can help them get to know your child. Start with an 'All About Me' that highlights your child's strengths, interests and strategies that work for them. This creates a positive introduction and helps educators see your child as a whole person. While reports and assessments can be

helpful when seeking funding or support, remember that your child is more than these documents. The goal is to provide educators with a well-rounded understanding of who your child is as a person alongside their support needs. Read our resource about how to create an All About Me for your child.

Your Support Networks

No one should navigate this journey alone. Connecting with other parents and support groups can offer invaluable advice, and emotional support. These networks provide a sense of community and understanding, helping you to navigate challenges and celebrate successes. Join the Kindred Community to be connected to other parents and caregivers.

Top Tips

1. Trust your instincts: If something feels off or isn't working for your child, don't hesitate to ask questions or seek clarification.
2. See it for yourself: Visit potential settings and observe the atmosphere, educator interactions with children, and whether the environment feels supportive and aligned with your child's needs.
3. Embrace play-based learning: Through play, children develop creativity, problem-solving, and social skills. It's more than fun—it's key to their growth.
4. Give it time: Be patient, celebrate small wins, and give your child the space to settle into new educational settings and routines.
5. Be solution focused: Collaborate with the school to find solutions. This approach ensures positive communication and that everyone is working together to support your child to thrive.



NDIS and Other Funding

Accessing therapy and specialised services can be essential for your child's development and well-being. Fortunately, there are several funding options available to help families cover the costs of these services. In this section we'll explore the National Disability Insurance Scheme (NDIS) and other supports, including Medicare.

What is the NDIS?

The NDIS (National Disability Insurance Scheme) provides funding to eligible people with disability, including children. The goal of the NDIS is to help your child achieve their goals, participate more fully in their community, and lead a more independent life. The NDIS can help fund:

- Therapies: Such as speech therapy, occupational therapy, and more, tailored to your child's needs.
- Specialised equipment: Including mobility aids, communication devices, or sensory tools that can help your child in their daily life.
- Family capacity building: Programs and resources that help you to support your child's development.

Early Childhood Approach

For children under the age of 6 with developmental delays, or under 9 with disability, the NDIS provides support through the Early Childhood Approach.

The Early Childhood Approach is designed to give young children and their families access to support

early, which can make a significant difference in a child's development. Importantly, children under 6 do not need a formal diagnosis to begin receiving support if there are concerns about their development.

If your child is under 9, you'll meet with an Early Childhood Partner. For children over 9, they are supported by a Local Area Coordinator.

Accessing the NDIS

Although NDIS processes may change over time, here's what you can generally expect when applying for support:

- Eligibility check: Use the NDIS online checklist to see if your child qualifies for support.
- Applying: Your local Early Childhood Partner can guide you through the application process and help you connect with the right services.
- Gather documentation: You may need to provide reports from doctors or therapists detailing your child's condition and how it affects their daily life. It's a good idea to ask your Early



Childhood Partner what documentation is required before obtaining expensive reports.

What To Expect from the NDIS Process

- **Submit an Access Request:** Complete your access request form with the required documentation.
- **Planning meeting:** If your child is eligible, you'll meet with an Early Childhood Partner or Local Area Coordinator LAC partner to discuss your child's needs and create a personalised support plan.
- **Receive your NDIS plan:** Once approved, you'll receive an NDIS plan detailing the funding allocated for your child's needs.
- **Using your funding:** You can start using the funding to access therapy and other supports outlined in the plan.

For more information, you can access video guides on the ins and outs of the NDIS in the [Kindred Community](#).

Please note: NDIS processes and systems may change over time; the information provided in this guide is accurate as of the time of publication (Oct 2024). At the time of creating this guide, there are significant changes being made to the way that children and families access and are supported through the NDIS, therefore we have kept information about the NDIS brief and have linked you to pages on the NDIA website to guide you through the process.



Advocating For Your Child

As a parent, you are the strongest advocate for your child's needs. Your input during NDIS planning meetings is not only valuable but essential. It's important to know that the NDIS process often requires a deficit-based approach - you'll need to focus on your child's challenges rather than their strengths. This can be difficult, but it's a necessary step to ensure your child gets the right level of support.

Navigating the NDIS can feel overwhelming, especially in the early stages, but gaining an understanding of the process will empower you to advocate with confidence. Kindred offers resources informed by the lived experiences of families, covering everything from preparing for a planning meeting and effective NDIS record-keeping, to managing your child's plan. Visit our [resource library](#).



Financial and Practical Supports

Caring for a child with disability comes with added responsibilities and costs. However, there are many supports to help ease the financial burden and services that can help both you and your child thrive. We've included some of the key [financial](#) and [practical supports](#) and services available, visit the Kindred website to learn more.

Medicare Rebates

- **Chronic Disease Management Plan (CDMP):** This plan allows children with chronic conditions, such as autism or developmental delays, to access rebates for up to five therapy sessions per year, including speech, occupational, or psychological therapy.
- **Better Access to Mental Health Care:** This provides rebates for up to 10 mental health services per year, including counselling and psychological support, through a referral from your GP. You can use this for your child or yourself.
- **Support for Complex Neurodevelopmental Disorders and Eligible Disabilities:** Medicare offers up to 20 lifetime sessions for children with complex neurodevelopmental disorders or eligible disabilities to access therapy and support.

Financial Supports

- **Carer Allowance (Services Australia):** A fortnightly payment for carers who provide additional daily care for a person with disability, medical condition, or frailty. There is no asset test for this allowance, but an income test applies. You may be eligible to receive both the Carer Allowance and other payments, depending on your circumstances.
- **Carer Payment (Services Australia):** An income support payment for people who provide constant care to someone with a severe disability or medical condition. Eligibility depends on your personal financial situation, including your and

your partner's income and assets.

- **Carer's Registration Refund (Service NSW):** If you receive the Carer Allowance, you may be eligible for a refund on vehicle registration fees through Service NSW.
- **No Interest Loan Scheme (Service NSW):** This program provides safe, affordable access to credit for people on low incomes. It can be used for essential goods and services, such as medical equipment or household items.
- **Essential Medical Equipment Payment (Services Australia):** An annual payment to assist with the energy costs of running essential medical equipment or heating/cooling for medical needs in the home.
- **Continence Aids Payment Scheme (CAPS) (Department of Health and Aged Care):** An annual payment to assist families with the cost of continence products for children with severe and permanent incontinence who are not eligible for NDIS support.
- **Health Care Card (Services Australia):** A concession card providing access to cheaper medicines and certain discounts if you receive specific payments from Services Australia.
- **Salvation Army Crisis Support:** The Salvation Army offers financial counselling, coaching services, and no-interest loans to assist families experiencing financial hardship.
- **Charitable Grants:** Several non-profit organisations and charities offer grants or subsidies to families in need of assistance for therapy, specialised equipment, or other services. These grants can be used to cover costs that are not fully funded by the NDIS or other programs.
- **Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) (Service NSW):** IPTAAS offers financial assistance for travel and accommodation costs for families who need to travel long distances for specialist medical treatment.

Practical Supports

- **MyTime:** Peer support groups run by a trained facilitator both in person and online for parents and carers raising children with disability. Preschool-aged children are welcome to attend in-person groups where a play leader will be on hand to engage in play.
- **Tailored Support Packages (Carer Gateway):** These packages provide services and supports based on your needs as a carer. This could include help with household tasks, planned respite, or equipment to assist with education and training.
- **Parent Line:** A free, confidential telephone counselling service for parents and carers in NSW. Qualified counsellors provide support on a range of parenting issues, from child development to managing challenging behaviours.
- **Relationships Australia:** Offering counselling, mediation, and group workshops, Relationships Australia provides support tailored to carers. Fees are based on income, but no one is turned away due to financial difficulties.
- **National Debt Helpline:** This not-for-profit service offers free, independent financial counselling to help families manage debt. They can also connect you with other services, such as legal advice or crisis support.
- **Mobility Parking Scheme (Service NSW):** This scheme provides parking concessions for people with medical conditions or disabilities that affect mobility or vision. With a Mobility Parking Permit, you can park in disability parking spaces and can be eligible for extended time limits or free parking in some locations.
- **Master Locksmiths Access Key (MLAK):** This initiative grants people with disabilities access to locked public facilities, such as accessible bathrooms, Changing Places facilities, and some National Parks.



Supporting the Whole Family

Amid the medical appointments, therapies, and new terminology, it's easy to lose sight of the fact that this journey involves not just your child but your entire family. Every family member is impacted and supporting them is essential for maintaining balance and emotional well-being. In this section, we will explore how you can support yourself and other members of your family to navigate this new chapter together.

While we wish we could tell you it's smooth sailing from here, the reality is that with a disability diagnosis comes lots of additional things to plan, co-ordinate and factor into your family's routine. However, there are many things you can do to ease the mental load, support all members of the family unit, and ensure you are looking after yourself. The good news is that with the right supports and services, knowledge and guidance, you can alleviate some of the overwhelm and allow yourself to find joy in everyday moments.

Your Role as a Carer

When your child is diagnosed with a disability, your role expands with the added responsibilities. First and foremost, you will always be a parent, but with this shift and growing demands, you also take on the role of a carer for your child.

Why Identifying as a Carer Matters

Carer is a term that some parents embrace, while for others it takes time to feel comfortable with; and that is ok. As a parent of a child with disability

you have a whole new set of additional responsibilities from managing therapies and navigating disability supports and healthcare systems to advocating for your child. These extra responsibilities can be demanding. Even if you don't use the term 'carer' to describe your caring role when speaking to friends and family, it can be helpful to know that when you identify as a carer when engaging with systems and services this opens doors to essential support.

Available Carer Supports

Many carer support services exist to offer you assistance - both practical and emotional. When you identify as a carer there are a range of supports from financial assistance to mental health supports that you are eligible for and may not otherwise have access to.

There are also services designed specifically for carers, including [Carer Gateway](#). These services can offer financial assistance, respite care, and emotional support, helping you manage your new responsibilities while prioritising your well-being. Find out what supports are available in the 'NDIS and Other Funding' section of the guide.

Supporting Yourself

The Importance of Self-Care

At this early stage, the thought of spending time doing anything other than caring for your child and ensuring they are accessing all the right supports can feel overwhelming or not a priority. You're not alone, self-care is all too often at the bottom of a parent's ever-growing to-do list.

Who is a Carer?

Anyone who provides unpaid care to a family member or friend with a disability, illness, or condition. This includes parents, foster carers, grandparents, and other family members who provide significant caregiving responsibilities.

Research has shown that self-care has a strong influence on child development. Parents who are kind to themselves and take time to recharge have better health and well-being, confidence in their parenting and more positive interactions with their children.

Wellbeing Resources

Your role in your child's life is essential, which makes prioritising your own wellbeing equally important. There are a number of resources and supports available to help you:

- Care Plan: This allows you to access Medicare rebates for mental health support and allied health services, such as physiotherapy.
- Healthy Mothers Healthy Families (HMHF) program: An evidence-based health and wellbeing program specifically for mothers caring for children with disability. Created by Professor Helen Bourke-Taylor, you can complete the online HMHF modules or [join a facilitated workshop](#).
- Get Healthy NSW: A free service offering personalised health coaching and support for maintaining a balanced lifestyle.
- Local Council Programs: Many councils offer free or low-cost wellness programs. Check what's available in your area on your local council website.

Professional Mental Health Support

The weight of the worry we carry for our children can take its toll, and our mental health is especially important. While self-care practices are valuable, support from a professional can provide you with tools to manage stress, anxiety, or depression effectively. Speak to your GP about a [mental health care plan](#) which can help with reducing the cost of seeing a mental health professional.

Tips from Families

When you hear 'self-care', you might think of facials and massages. But with a busy family schedule, self-care often needs to look different. Here are tips from families in the Kindred Community on how they fit easy, cost-effective self-care into their daily routines.

Quick and Easy Self Care Tips

- Drink your first coffee in the morning sun.
- When packing lunch for your children, prepare something for yourself, that way you always have healthy snacks and water to help you stay nourished.
- Schedule in small moments of time to yourself in your daily routine. This could be as simple as a quiet cup of tea before school pick-up.
- Try to find small windows of time to move your body. It can be as easy as parking slightly further away so you can take a short stroll to and from your destination.
- Practice deep breathing exercises.
- Write down or say 3 things you're grateful for to shift your mindset to positivity.
- Use any idle time (in the car, while doing chores) to listen to music or podcasts.
- Stretch or move for 5 minutes to release tension, even while waiting in a parked car.
- Call a friend for a catch-up chat.
- Hold your boundaries when booking appointments or planning social outings.

Listen to Professor Helen Bourke-Taylor, founder of [Healthy Mothers Healthy Families](#), discuss how to find practical ways to fit self-care into daily routines.



Focusing on the Whole Family Unit

Every family is different. Whether you're a single parent, part of a larger household, or have children at various stages of life, balancing the needs of the entire family is important.

Acknowledging Emotions

Each member of your family may react differently to the news of your child's diagnosis, processing the information at different speeds and experiencing a range of emotions. It's important to acknowledge these feelings as a natural part of the process. Open and honest communication is vital to ensure everyone feels included, heard, and validated.

Balancing Family Needs

Identify what's most important to your family—whether it's maintaining traditions, ensuring one-on-one time with each child, or preserving couple time. Knowing your non-negotiables can guide your decisions and keep the family grounded.

Couple Relationships

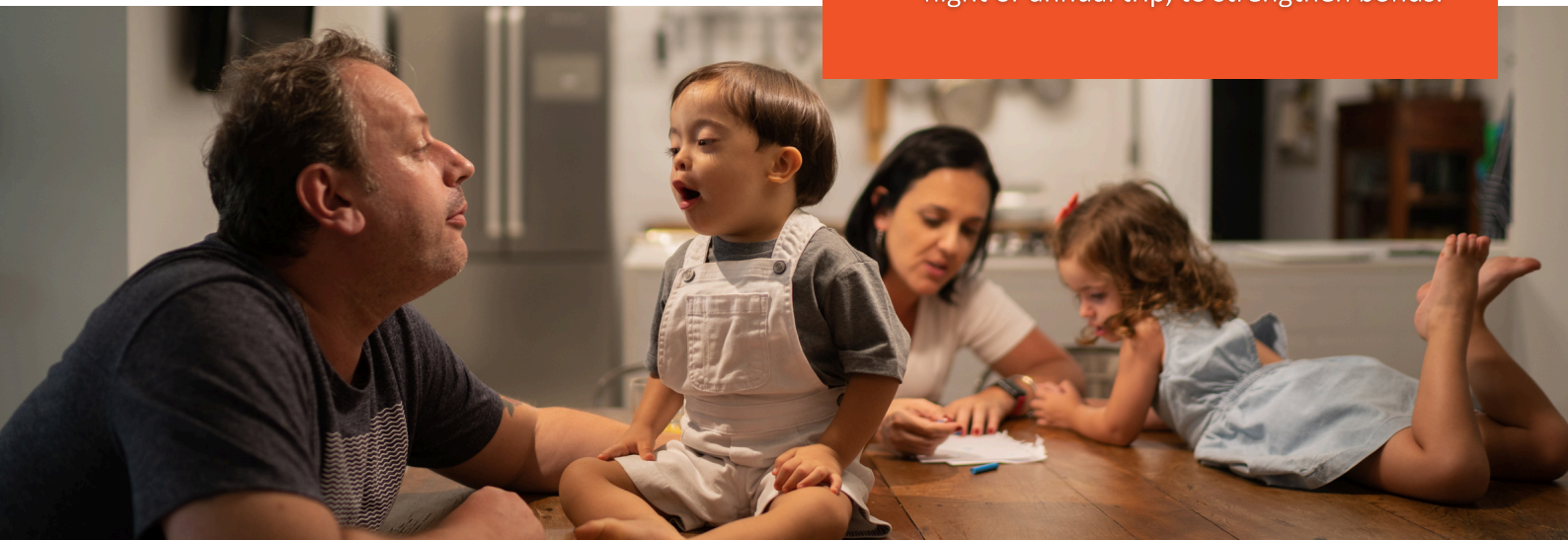
The extra responsibilities that come with your child's diagnosis can add extra pressure to the relationship with your significant other. It's important to nurture your relationships by talking openly and supporting each other. Try to carve out time for regular check-ins or a quiet evening together, even if it's just at home. If needed, consider [couples counselling](#) to navigate this challenging period together.

Working Together as a Team

Every family relies on teamwork, however when your family schedule becomes even more packed, working together as a team and good communication becomes even more imperative. Here are some tips from families.

Tips for Working Together as a Team

- Use a family calendar: A visible calendar displaying everything from therapy appointments to social outings helps everyone know what's happening.
- Schedule regular check-ins: Weekly or fortnightly check-ins with your partner can help you process what's happening and plan next steps.
- Encourage family dinner conversations: Use mealtime to check in with your kids. Asking, "What was the best part of your day?" fosters connection and gratitude.
- Foster safe spaces: Create a judgement-free space to discuss strengths, weaknesses, needs, and feelings. This helps in planning and leveraging each other's strengths during stressful times.
- Agree on non-negotiable family activities: Establish a regular family activity that everyone participates in, like a movie night or annual trip, to strengthen bonds.





Single Parents and Diverse Family Structures

Single parents or non-traditional families may face different and more complex challenges. Acknowledge these dynamics and prioritise reaching out for support tailored to your situation. Support groups for single parents or [resources](#) can provide additional assistance.

Extended Family and Friends

Grandparents and extended family members are part of your support system. Provide them with information about your child's condition and involve them in caregiving tasks when it feels right. Keeping communication open can help them understand how to best support you and your child effectively.

Supporting Siblings

Understanding Sibling Experiences

Siblings have unique relationships with each other. As parents and carers, it can be hard to truly understand the complex layers of connection and emotion between your children and how the news of a diagnosis may affect them. They may experience jealousy, confusion, worry, or even guilt. They might feel overlooked or burdened by additional responsibilities. Amidst the chaos of appointments and daily life, it's easy to forget that they are also experiencing this journey—just in a different way. It's crucial to create a safe space for them to express their feelings openly.

Kindred has [resources](#) to help you understand how you can support your other children.

Strategies for Supporting Siblings

- Ensuring you get one-on-one time with each of your children is vital to building up their sense of self-worth, countering any resentment towards each other, while also maintaining a strong foundation of trust and connection.
- As children grow, they often choose to confide in others. Ensure there are trusted adults in their lives who are invested and care about them who are available to reach out to. Whether they chat at family dinner on a Sunday or via facetime on a Wednesday, these trusted adults need to be a safe place your children can turn to freely share their thoughts, dreams, feelings and ideas without fear of judgement or consequence.
- Encourage all of your children to support one another equally. Disability or not, they will thrive knowing that their sibling has their back and is there when they kick a winning goal, splashes in the hydro pool or dances at the end of year recital.

Support for Siblings

There are services and supports offering specialised programs for siblings. Just as peer support is invaluable for you, connecting with others who share similar experiences is helpful for your children:

- [Siblings Australia](#)
- [Little Dreamers](#)
- [Young Carers NSW](#)



Asking for Help

Building a strong support network can make a significant difference in how your family copes, both emotionally and practically. The journey you're on can be challenging at times, and having people to lean on can help ease some of the pressure. You do not need to do this alone.

Identify Your Support Network

Take time to reflect on your support networks. Identify who is in your close circle and who you could ask for assistance. People often want to help but don't know how.

How to Ask for Help

- Start small: Practice by asking for small requests at first. This can help you become more comfortable with seeking help. For example, asking a parent at school if your other child can go to their house for a playdate as your child has a medical appointment.
- Be specific: Instead of saying "I need help," try to be clear about what you need. For example, "If you're heading to the shops today, could you pick up some groceries for us?" or "Would you be able to watch the kids for two hours on Thursday when we have a therapy appointment?"
- Match the task to the person: Consider the skills, availability, and willingness of each person in your support network. If you have a friend who loves cooking, ask them to prepare a meal. If someone is great with kids, ask them to look after your child for a few hours.
- Provide options: Give people choices when asking for help. This allows them to contribute in ways they're most comfortable with.
- Be honest about your needs: Open up about what you need, even if it feels vulnerable. Whether you need emotional support or practical help, let people know what would genuinely make a difference. Sometimes, just being there to listen can be the most valuable support.

- Don't feel guilty: Asking for help doesn't mean you're not capable—it means you're human. Everyone needs help sometimes, and asking for it shows strength and self-awareness. Letting go of guilt allows others to contribute, which can ease your burden and make things more manageable.

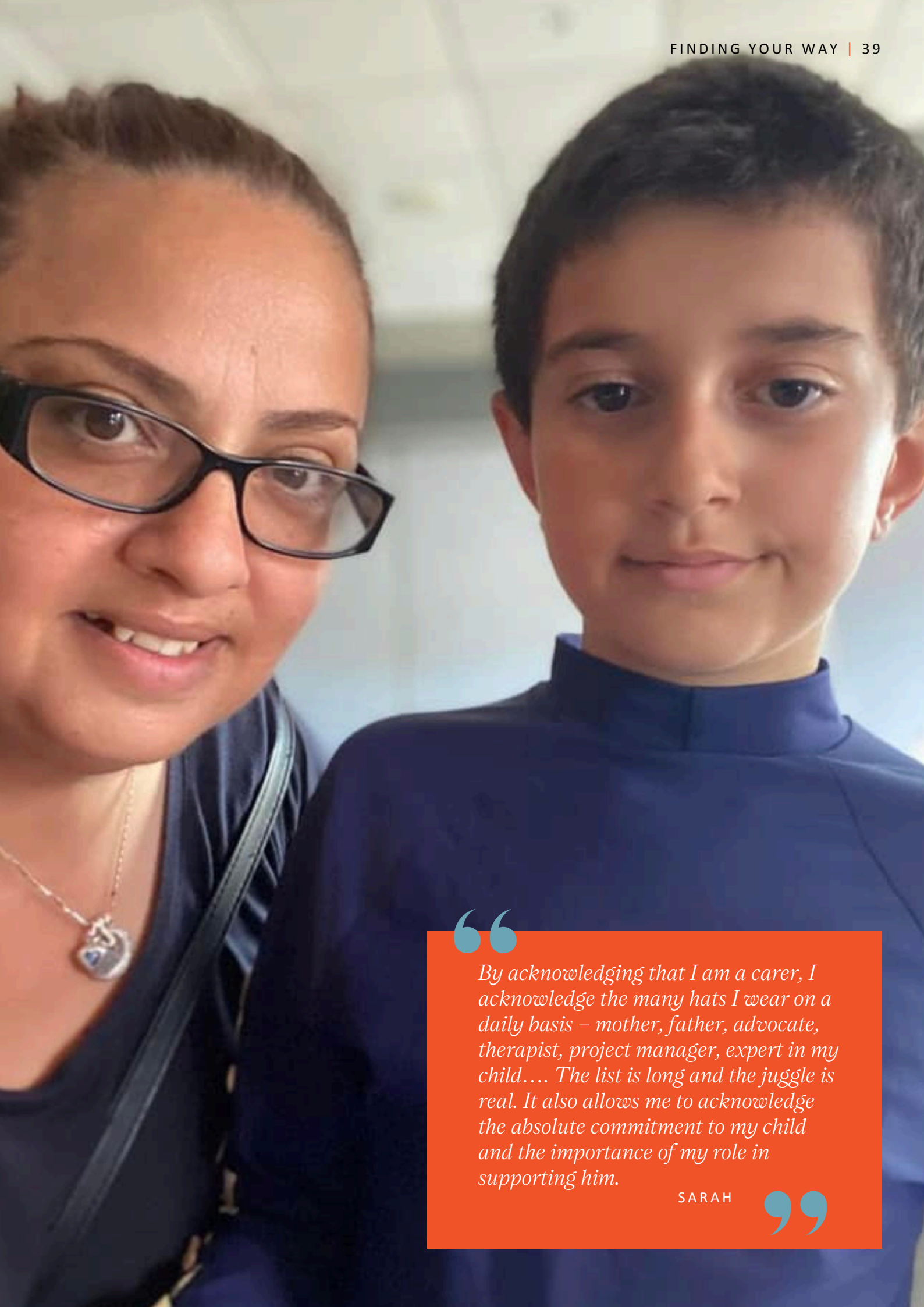
People may often say things like- "Is there anything I can do?" or "If you need any help, let me know". Having these tips in the forefront of your mind can help you think of practical ways your friends and family can step in to support you.

Remember, be gracious and kind to yourself, and them, let them help you.



Things You Could Ask For Help For

- Meal preparation or grocery shopping.
- Childcare for your other children during appointments.
- Respite care to give you a short break.
- Help with household chores or yard work.
- Emotional support through regular check-ins or coffee dates.
- Assistance with research or paperwork related to your child's care.
- Transportation to appointments.
- Attending an important meeting or appointment with you.



“

By acknowledging that I am a carer, I acknowledge the many hats I wear on a daily basis – mother, father, advocate, therapist, project manager, expert in my child.... The list is long and the juggle is real. It also allows me to acknowledge the absolute commitment to my child and the importance of my role in supporting him.

SARAH

”

Everyday Life

It's easy to fill your child's day with therapy and specialised services, but it's important to recognise the value of everyday experiences. From grocery shopping, to visiting the local park, these activities, which are part of everyday life, are just as crucial for your child's development and well-being, and connection to the world around them. We also recognise that getting out in the community can be really difficult, so we've included tips from parents on how they made it work.

The Value of Everyday Experiences

Engaging your child in daily life experiences offers a wide range of benefits that go beyond the therapy room:

- Everyday outings provide opportunities for your child to interact with others, develop social skills, and feel part of their community. Regular exposure to different people and environments helps build your child's confidence and sense of belonging.
- Without regular engagement in community life, it's easy for both you and your child to feel isolated. Getting out into the world helps you connect with others and reduces feelings of loneliness.
- Everyday activities introduce new challenges, helping your child develop a wider range of skills that complement what they learn in therapy.
- Being part of daily life teaches children how to manage change, deal with unpredictability, and adapt to new situations—all important life skills.

Everyday Places to Visit

There are many community spaces where your child can participate and feel included.

- Playgrounds offer opportunities for physical activity, social interaction, motor development and sensory play. Many communities have accessible playgrounds designed to be inclusive for all children. Gated playgrounds can also offer a safer and secure space for your child to play and explore.
- Swimming is a great way for your child to develop physical strength, coordination, and confidence. Many pools have adapted swim programs or quiet times for children with sensory needs.
- Libraries provide a calm environment where your child can explore books, attend storytime sessions, and engage in quiet, focused activities.
- Going to shopping centres helps your child become familiar with public spaces, practice communication, and engage in daily life activities like making small purchases or helping you with



shopping tasks. Many shopping centres have quiet periods where dimmed lighting and lowered music can help cater to your child's sensory needs.

When deciding where to start, consider your child's preferences and the environments they enjoy. For example, if they prefer quiet play, a visit to the local library could be ideal. If they enjoy sensory play and the outdoors, a nature walk may be fun. Focus on easy wins and places which are more manageable for your child and family, and over time you can expand the list of places in the community that you regularly visit.

Getting Out into the Community

While there are many benefits to being part of the community, some common barriers can make it challenging:

- If your child experiences behavioural challenges, public outings can feel overwhelming. You might worry about how others will react or whether the environment is suited to your child's needs.
- Children with high medical needs may require specialised equipment, making outings more complicated to manage.
- Bringing equipment like wheelchairs, communication devices, or medical supplies can feel logistically challenging.
- Unfortunately, some community members may not fully understand your child's needs, leading to unwelcome reactions or feelings of being judged.



Tips From Families

- Plan ahead for outings by bringing everything your child might need, such as sensory toys, communication aids, or medical equipment. Preparing your child for what to expect can ease transitions. Social stories and visuals can be helpful.
- Make the environment work for your child by visiting playgrounds with adaptive equipment or choosing quieter times to visit community spaces like libraries or shopping centres.
- Communicate with people around you if your child needs extra support or understanding. Educating others can foster a more inclusive environment.
- Work with your child's therapist to come up with strategies for handling specific challenges. They may even be able to accompany you on outings to support your child and come up with approaches which work for your family.
- Accessing the community can be challenging, especially for children with sensory overload or visual impairment. Celebrate the small gains and always have an exit plan in place.
- Choose activities aligned with your child's interests. Focus on activities your child enjoys to make outings more engaging and successful.
- Keep plans simple and local, and have a well-stocked nappy bag or tub in the car.
- Where possible, ask people to accommodate your schedule. If 9am works best, let your friends and family know. A relaxed and happy child makes for a better time for everyone.
- For special events, do a 'dry run' to the venue to check parking, access, ramps, and toilets. Disabled parking can be critical for children with mobility issues.
- Celebrate the small wins and build on them. Some days will be hard, and that's okay. Retreat, regroup, refocus, and try again.
- When packing medicine, buy oral syringes with caps to draw up medications before leaving, rather than taking all the bottles. They travel well in a Tupperware container.



Community Attitudes

When raising a child with disability, you may encounter judgement or misunderstanding from others. While no one should have to deal with such attitudes, they can sometimes happen, often due to an individual's lack of awareness or understanding about disability.

While it's not our job to educate everyone, how we respond in those moments can influence not only the situation but also how others begin to understand and embrace differences. It's not about excusing or tolerating unkind or unfair behaviour—it's about protecting your family's peace and helping foster a more inclusive, understanding community when you feel it's right for you.



Tips From Families

- Use opportunities to explain your child's behaviour in a way that helps others understand, even if it's directed at your child. For example, "Oh, that was loud! You must feel excited, but let's try to be quiet on the bus."
- It's important to know when to educate and when to walk away from judgement. Save your energy for situations where you can make a positive impact, and let go of unimportant interactions with strangers.
- If your child is having a hard time, focus on supporting them. If others don't understand, respond politely but avoid wasting energy on those who aren't receptive. "Thanks for checking in, we have wonderful supports and strategies, no need for concern."
- Show others how to interact with your child in a respectful and inclusive way. Siblings can be powerful role models in demonstrating how to treat your child with kindness and understanding.
- Over time, take the opportunity to explain your child's behaviours and needs to close family and friends. This can help them bond with your child in ways that respect their needs.
- When in public, I explain my daughter's behaviour in a way that strangers can overhear, showing that we're working on things and she is trying her best. Hoping they'll have some grace.
- Have a few ready answers for common questions or comments to help you feel more confident. But remember, not every interaction needs a response. Sometimes it's best to ignore and move on.
- It's natural to feel hurt or frustrated in the moment, but taking a breath before responding can help you approach the situation with calmness and clarity.



I've learned to block out any stares from strangers, but it's taken me years of work. I thought to myself I'll never be able to enjoy being in public with my girl if I'm always worried about people's reactions. I reminded myself a lot of the judgement comes from complete ignorance.

I remember how hard it was in the beginning—feeling constantly nervous about how others saw her. But over time, you learn to let it go. In general, no matter where I am or what situation we're in I'm always trying to lead by example.

MELISSA

Diversity, Representation and Language

Throughout this guide, you may come across concepts about disability that might be unfamiliar or even challenging at first. That's completely normal and okay. We're sharing these with you not to overwhelm or judge, but to inform and empower you. It's okay if you don't immediately connect with or understand everything – learning and embracing these ideas is a journey, not a destination.

These concepts are important to the disability community – a community that your child is now a part of. By familiarising yourself with these, you're taking a significant step in supporting your child and connecting with a broader community that can offer understanding and valuable perspectives.

Language Matters

Using the word 'disability' can feel confronting and even uncomfortable. You might feel that by saying your child has a disability, you're being negative or placing limits on them. However, it's important to know that the term 'disability' is widely used and embraced by the disability community as a way of asserting identity and advocating for rights. In this [article](#), read about the preferred language preferences for disabled people.

Disabled people encourage people to confidently use 'disability' instead of euphemisms like 'differently-abled' or 'special needs,' which are often used with good intentions but can feel dismissive. It's okay if it takes time to feel comfortable—what matters is your journey toward understanding. Read a [parent's perspective](#) on language.

Person-First vs. Identity-First Language

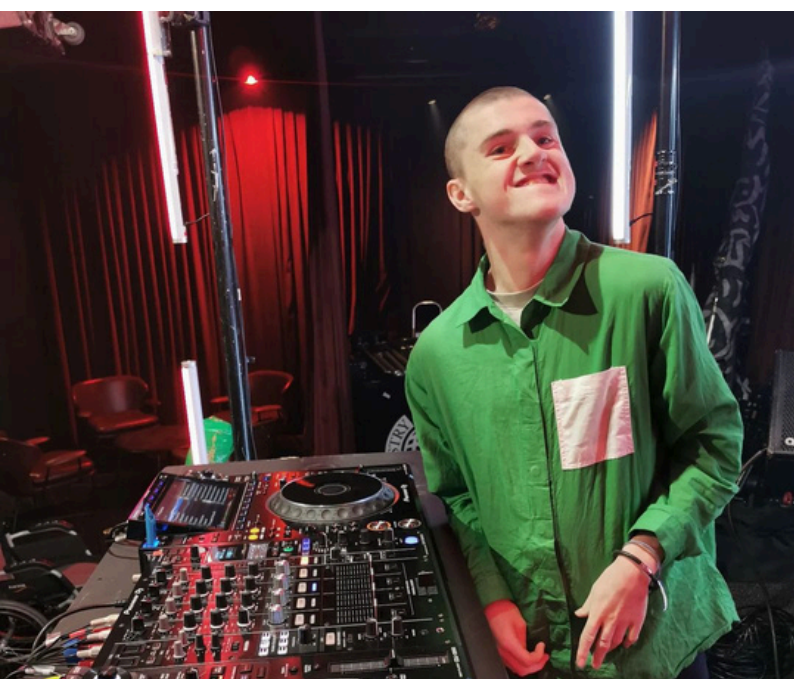
You may hear different ways of talking about disability:

- Person-first language: 'a child with autism'
- Identity-first language: 'an Autistic child'

Both approaches are valid, and preferences vary. Some individuals, particularly in the Autistic and Deaf communities, prefer identity-first language, embracing their disability as part of who they are. Above all, it's important to respect individual preferences.

Diversity

Every child is unique, with their own strengths and challenges, contributing to the rich diversity of our world. Embracing and celebrating these differences



“ Growing up, when I looked at magazines or the TV, I never saw anyone with a disability like me who used a walker and a wheelchair. It is really important for disability to be represented as it normalises it. I want to be that person that little kids see being amazing and having a disability.

DJ COOPER SMITH



fosters a more inclusive society, where everyone is valued for who they are. By recognising and appreciating each child's individuality, we create a culture that promotes acceptance and understanding. This celebration of diversity in all its forms promotes a more compassionate, connected community where every person's contribution is seen as valuable.

Neurodiversity

Neurodiversity is the idea that neurological differences, such as Autism or ADHD, are natural variations in how the human brain functions. Rather than viewing these differences as disorders that need to be 'fixed' or 'cured,' neurodiversity embraces them as part of the rich diversity of human thinking and behaviour. This perspective encourages understanding and acceptance, recognising that people with neurological differences contribute unique strengths and insights to society.

Representation

Positive representation of disability in media, books, and everyday life is essential in shaping how your child sees themselves and how others perceive them. When children are exposed to stories of people with disability living fulfilling, empowered lives, it challenges stereotypes and encourages a more inclusive view of disability.

Here are some ways to promote positive representation:

- Expose your child to books that celebrate diversity and feature characters with disability portrayed in a positive light.
- Explore TV shows and movies with disabled characters, such as Daniel Tiger, Sesame Street, Pablo and Loop, to provide diverse portrayals of disability.
- Create opportunities for your child to interact with people with disability, helping them build meaningful connections and a more inclusive perspective.
- Support and encourage your child to ask questions and discuss disability in a respectful and open-minded way.

What We've Learnt from the Disability Community

- Embrace diversity: Disability is a natural part of life, and it brings unique strengths and perspectives. Your child's differences are valuable.
- Supported decision-making: Listen to people with disability about decisions which affect their lives. This can start when your child is young by finding out what is important to them and offering them choices to include them in decisions.
- Presume competence: Always believe in your child's abilities. By assuming they are capable of more than what may be immediately obvious, you provide the opportunity for them to reach their potential.
- Focus on strengths: Build on what your child can do. Their abilities are just as important as their challenges.
- Advocate for inclusion: Push for environments that include everyone, rather than expecting your child to adapt to spaces that aren't accommodating.
- Support independence: Encourage your child to make choices and support them in becoming as independent as possible, at their own pace.
- Celebrate identity: Disability is a part of who your child is. Many disabled people see their disability as something to embrace, not something to hide or 'fix'.
- Trust their expertise: As your child grows, remember that they are the expert on their own experiences and needs. Listen to and trust their insights.

I envisioned Bridget living and working independently, and that vision helped shape our journey. Along the way, we focused on the small steps. 'Bit by bit' became my motto, and those steps have taken her to places we never imagined.

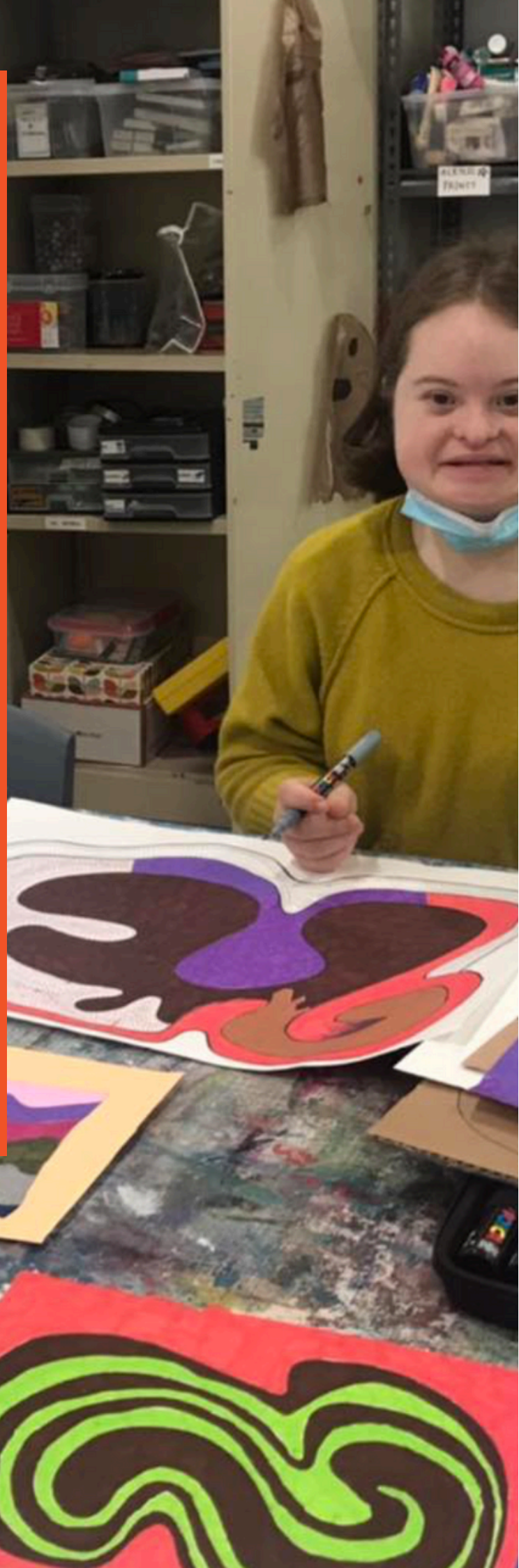
It all started with a love of colouring. At first Bridget would fill the entire page with the same colour. The next step was introducing colour-by-number books, where she's learned to use a variety of colours.

By Year 9, Bridget had chosen art as her focus, and after leaving school, her passion continued to grow. We hired an art tutor, and she began attending a weekly group-based art program.

Now, at 27, Bridget is an accomplished artist. She's won an emerging art prize, graduated from an arts program at Sydney University, and held multiple solo exhibitions.

It all started with following Bridget's interests, being guided by a vision, and taking small steps—each one leading her further than we ever thought possible.

BRIDGET'S MUM, KATE





Acknowledgements

This resource has been developed by Kindred in partnership with families of children with disability.

We are deeply grateful to the parents and caregivers in the Kindred Community who have generously shared their journeys, insights, and practical advice. Your contributions form the heart of this book, providing authentic guidance and support to others walking similar paths.

We would also like to extend our heartfelt thanks to the people with disability who shared their stories and experiences, enriching this resource with your invaluable perspectives.

We extend our sincere thanks to our funding partner, Stockland CARE Foundation, for their invaluable support, which has made the development of this book possible.

Kindred

Kindred is an independent family-led organisation, for parents and caregivers raising children with disability, developmental delays and autism. Through peer groups, workshops, educational resources and stories, we empower families to grow their skills, knowledge and confidence to support their children and family to thrive.



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