INQUIRY INTO FOUNDATIONAL AND DISABILITY SUPPORTS AVAILABLE FOR CHILDREN AND YOUNG PEOPLE IN NEW SOUTH WALES

Organisation: Belongside Families

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About Us

Empowering parents of children with disability

Belongside Families (formerly known as Kindred) is an independent family-led organisation that supports parents and carers raising children with developmental delay, disability and autism across NSW. Our staff, board, and volunteers have lived family experience of disability parenting, meaning Belongside Families has deep understanding of the challenges families face, and can provide support that is relevant and meaningful.

Through free online and in-person programs and peer groups, trusted resources and supportive community, we empower over 5,000 parents and carers each year to build the skills, knowledge and confidence to help their child and family to thrive.

Belongside Familie's work has a positive impact across NSW

Belongside Families fills a vital gap as the only family-led organisation in NSW providing comprehensive peer support, capacity building and connection to parents and carers of children with disabilities and developmental concerns during the crucial early years. We guide families through every stage of their child's journey – from diagnosis and early intervention to childcare, school transitions and across healthcare – regardless of their location, background or circumstances.

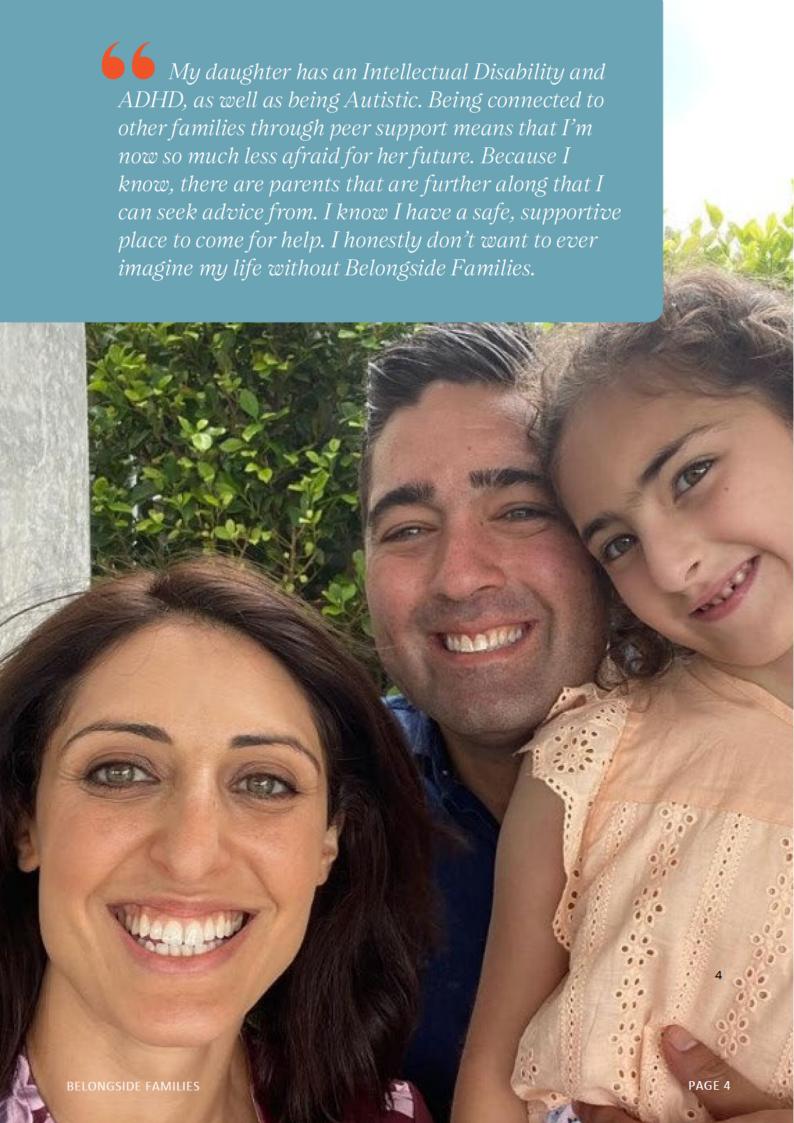
Drawing from our lived experience, we create welcoming, supportive and educational spaces that reduce isolation and prevent burnout. Our community connects parents with peers who truly understand their challenges and can offer practical, meaningful support when it matters most.

Through evidence-based, innovative and scalable programs, we empower families to become effective advocates for their children. Our approach fosters inclusivity, strengthens family resilience and creates pathways for children to lead thriving lives.

Belongside Families is a valued partner in the NSW community sector

We work collaboratively across the early childhood, disability, child and family sectors through partnerships including:

- the Child and Family Supports Alliance (CaFSA) NSW as Co-Chair and as a member of the Australian Child and Family Supports Alliance (ACaFSA)
- as a founding member of the Child and Family Disability Alliance (CaFDA), a formal partnership with family-led organisations in Western Australia and Victoria with national reach
- with Monash University, Australian Catholic University and Parenting Research Centre to deliver evidence-based parenting programs and peer groups to families of children with disability in NSW
- acting as a referral pathway for partners such as health practictioners and allied health professionals



Executive Summary

The time has come to fundamentally shift how the NSW Government supports families raising children with developmental concerns and disability by creating a connected, inclusive and family-centred system.

We are in the midst of the most significant reform opportunity in recent history. People with disability, families and the sector are not only ready—they have led the way with clear, practical solutions. What's needed now is commitment and sustained action.

Recommendations

This submission focuses on a critical layer of early intervention, foundational and disability support: peer support, capacity building, information and navigation for parents and carers of children with developmental concerns, delay and disability.

These supports lay the groundwork for long term outcomes by empowering families, reducing emotional distress, strengthening inclusion and easing pressure on more intensive and costly parts of the system.

We recommend strengthening NSW's early intervention, foundational and disability support system by:

- Guaranteeing early access to support: Ensure families can access emotional and developmental supports based on identified concerns, not formal diagnoses, to act early and prevent crises before they occur.
- **Embedding peer support and navigation:** Recognise these supports are essential infrastructure that empower families, build trust and improve system access.
- **Building a qualified peer workforce:** Develop and fund structured pathways for peer workers with training, supervision and fair employment conditions.
- **Embed family voice in governance:** Ensure families help to shape and evaluate the policies, programs and service delivery that affect them.
- **Co-designing major reforms:** Work with families and the sector to design and implement the next phase of foundational and disability support reforms.

Families are ready for change

We can transform the experience of families raising children with developmental concerns, delay and disability by:

- creating a system that puts children and families' needs first
- funding supports that start early and respond to what families actually need at different ages and stages of their children's development
- building a system that is simple for families to navigate, prioritising prevention and early intervention.

Peer support, capacity-building, and navigation are not optional extras - they are the systemic glue that makes everything else work. Without them, families fall through the gaps. With them, families thrive. And when families thrive, children thrive.

The Case For Reform Now

Building a system that includes every family

We know what isn't working for children with disabilities and their families

- Support comes too late, often only after a formal diagnosis, funding approval or service entry.
- Families are expected to coordinate their own care, despite being emotionally overwhelmed and systemically unsupported.
- Systems operate in silos early childhood, health, and disability rarely communicate, forcing families to navigate disconnected pathways.
- The emotional cost to families is invisible in policy, yet it directly impacts their ability to support their child.

This means we are missing opportunities to:

- set children up for a life of potential and possibility
- · create thriving resilient families
- maximise the impact of the NSW Government's investment in families and communities.

We also know what's working and what's missing

Families have raised the same themes are across multiple reviews - the NDIS Review, Disability Royal Commission and countless consultations:

- Families need support as early as possible, before their child is diagnosed with a developmental delay or disability, or eligible for supports.
- Relational community-based supports build parents' trust and supports deeper engagement.
- Peer support and family education help families act earlier and stay connected.

Government systems should:

- recognise parents and carers as partners in their child's development
- support families at all stages of their journey
- be designed to support tangible positive outcomes for children and families, not just deliver services.

The cost of inaction is high

Over 95% of families in the NDIS report needing help to feel supported, yet most wait years to get it (National Disability Insurance Agency, 2024). Despite this overwhelming need, timely foundational supports like peer connection and navigation are not embedded in NSW systems.

A child's development, wellbeing, and long-term outcomes are deeply influenced by the capacity of their parent or carer, including their mental health, access to support, knowledge of services, and confidence to actively guide their child's development (Australian Institute of Family Studies, 2021).

National data shows that carers of children with disability experience significantly poorer outcomes than the general population: only 64.2% rate their health as good or better, and just 33.7% have someone they can ask for practical help (National Disability Insurance Agency, 2024). Mothers caring for a child with disability also report lower emotional support and higher rates of psychological distress and poor physical health than their peers (Wrigley et al., 2023).

Despite these known challenges, most families still face long delays in accessing support. A recent Belongside Families survey found that most families went over two years without support, with some waiting up to six years to access peer support. Among families connected to the NDIS, only around 50% feel confident about how to support their child's learning and development (National Disability Insurance Agency, 2024).

In the absence of early intervention and foundational supports like peer support, navigation and early guidance, families must rely on:

- emergency or intensive services
- · systems designed for crisis, not prevention
- · repeated assessments and referrals

through Belongside Families' workshops and programs. It's given me so much confidence when facing difficult situations at the hospital, doctor's appointments, daycare or even out in the community. Through Belongside, I have a better understanding of my son and the tools to help him navigate the world. I feel so empowered as a parent.



What NSW families are telling us

As part our of our mission, Belongside Families creates opportunities for thousands of parents and carers across NSW to share what matters to them. Their stories are diverse - but the themes are strikingly consistent.

"I didn't know where to start."

Most families first notice a developmental difference long before formal diagnosis. But the system provides few entry points for early concerns. Families are left to:

- search the internet
- · wait for a GP referral
- ask friends who've 'been through it'
- bounce between ECEC services, maternal child health, and NDIS Local Area Coordinators.

"I needed help for me too."

Almost all support systems focus on the child - but families consistently tell us: supporting the parent is supporting the child. Emotional overwhelm, social isolation, and system stress are common in the first year after parents and carers notice concerns with their child.

"Before I joined a peer group, I thought I was the only one feeling this way. I thought I was doing something wrong."

Parent of a 5-year-old, south west Sydney

"Everyone told me something different."

Families report receiving conflicting advice about what support to secure for their child. One professional recommends a private Occupational Therapist. Another says to apply for the NDIS. A third says to "wait and see". The result is families shut down, delay decisions or burn out from trying to chase every recommended option.

"The biggest support I got was from another parent. She just calmly explained how things worked. I cried. It was the first time I didn't feel lost."

- Parent of a 3-year-old, NSW Central Coast

"I found help – because someone told me."

Time and again, families say they only found Belongside Families through word-of-mouth. Access is based on luck, not design. That's not how an early intervention or foundational system should function.

"No one referred me. It wasn't on a government website. My LAC or therapist didn't tell me about you or about peer support. It was just by luck that I saw a post on Facebook about your school workshops. I wish I had known about Belongside Families earlier."

Parent of a 8-year old, inner west Sydney

What families need

Families are saying So they must... Provide clear welcoming entry points where no diagnosis "I don't know where to begin." is required "I'm overwhelmed and alone." Offer early emotional support and peer connection "I just need someone to explain Fund peer-led navigation that makes support systems things." understandable to parents and carers "I'm trying to figure this out Invest in family education and decision-making support alone." Embed and scale up peer support as a core part of early "I only found help through intervention and foundational systems; another parent." Create formal referral pathways for peer support

Families don't want sympathy. They want a system that works: one that understands the emotional load of parenting a child with disability and invests in families as part of the solution.

During those first two years, I had no one, no other parents, who I could ask for advice or for support.

And that's a long time, especially at the beginning when you feel so overwhelmed and alone. When I first decided to sign up to a Belongside Families program, I had no idea just how much the decision would change my life.



Our Vision: Early Intervention & Foundational Supports

Families need a system where:

- they don't have to fight to be seen, heard or helped
- they don't have to wait for a diagnosis, a funding plan or a crisis before someone steps in
- they don't have to find the 'right' service every door leads to help, connection, and the next step.

Families tell us the same things, over and over:

"I didn't know where to start."

"I thought I was the only one feeling this way."

"I just needed someone to explain it all."

This is what early intervention and foundational supports are for.

Families aren't seeking another system. They are seeking a system that simply works. One that puts families at the centre - because when families are confident, supported and connected, children thrive.

Our vision isn't about creating new services in isolation. It's about prioritising:

- support for families' that starts early in their journey
- · connections to avoid crises
- navigation that is supportive and builds families' capacity
- a system that listens to parents and carers as experts in their child and family.

Let's build a system where the first thing a parent hears is "We're here, and we'll walk with you". This is the future that NSW families are asking for. With the right commitment, it's one we can build together.

Belongside Families programs are helping families now

Our programs are evidence-informed, practical, inclusive and delivered in accessible ways for all types of families. We design these programs in partnership with families.

When parents understand how things work, they are more engaged, less overwhelmed, and more likely to get the support their child needs.

Belongside Families' programs help parents to:

- learn the language of support systems
- · understand early learning, school, inclusion and NDIS processes
- create a positive proactive vision for their child's future
- understand their role in supporting their child and family.

Parents and carers who participated in our programs reported significant gains in confidence, connection and capability:

- 95% felt less alone
- · 94% felt more confident in making informed decisions
- 95% said they were better able to navigate systems and services
- · 91% felt more confident advocating for their child
- 95% reported improved knowledge and skills

Belongside Families is currently delivering these programs across NSW with government and philanthropic support. We now need the investment and policy commitment to scale what works.

Families have become part of my family and community. As a single parent I don't have much help and support, so this means a lot for me and my boys.

And now I work for Belongside Families. I get to share my experiences to help support other families.





Recommendations

This section outlines recommendations for addressing the Select Committee's Terms of Reference through the lens of family voice, system experience and Belongside Families' practical insights as a family-led organisation.

1(a): The role of such services and supports on a child's overall development, health and wellbeing

Current issues

Families are often the first to notice developmental differences in their children. They are expected to manage care, coordinate services and advocate for their child without the right information, emotional support or recognition of their role.

This lack of support impacts:

- child development outcomes
- · parent and carer wellbeing
- families' engagement with early learning, health and community services.

Foundational and disability supports should not only foster child development - they must also support the people who support the child.

Recommendations

- Ensure early intervention and foundational supports are available for families before their child's diagnosis including peer support, family education and navigation.
- These supports should:
 - be accessible to all families, not only those whose child has a formal diagnosis or access to the NDIS
 - prioritise families' access to early emotional support, developmental information and service literacy
 - be embedded in trusted settings like early childhood education and care, child and family centres, community hubs and children's hospitals
 - be delivered in ways that meet families' particular needs (e.g. delivered online by trusted familyled organisations).

- ·This approach can maximise the value of existing NSW Government funded supports and bridge current gaps in families' information and awareness.
- When families can access support early in their journey:
 - it creates the strong foundations necessary for children with disability to reach their full potential
 - they have reduced feelings of isolation, improved coping skills and confidence to access mainstream and community supports.
- The online peer-led model allows accessible timely support to be delivered at scale.
 - By eliminating the need for travel, childcare or diagnosis-based entry points, these programs meet families where they are.
 - These programs offer connection, information and emotional support when parents and carers need it most.
 - This approach helps families act earlier, feel less alone and build confidence long before they reach crisis point.

Case Study: Belongside Families' Virtual MyTime Peer Groups

Belongside Families delivers weekly virtual peer support groups to connect parents and carers of children with disability, developmental delay and autism across NSW. These groups are run by trained parent facilitators with lived experience and are open to families regardless of location, diagnosis or stage in their journey.

This includes:

- regular online peer group sessions
- safe welcoming spaces for parents to share experiences, receive emotional support and exchange practical strategies
- flexible participation options that accommodate caregiving responsibilities and reduce common barriers such as travel, cost and capacity.

This model demonstrates how peer-led virtual supports can deliver accessible high impact connections that complement formal systems, while meeting families where they are.



It was recommended that I join the local mother's group. I didn't think about it too much then; it was just what you're supposed to do. But I couldn't get the words out. I burst into tears when I was asked to share my birth story. None of the other women could relate. It's awful feeling like you don't belong in a space, and your child doesn't belong.

Which is why Belongside Families peer support is so crucial. Otherwise, who do I connect with? It's not like I can have these conversations with other parents I meet at the park. Having a safe and supportive space to connect with other parents raising children with disability is important. I've learnt so much through the perspectives of others.

1(b): The types of services and supports available and measures to improve effectiveness, availability and access of such services and supports in metropolitan, regional, rural and remote New South Wales, including medical, community-nursing, allied health services, NDIS services and other service delivery models

Current issues

Families' access to early intervention, foundational and disability supports in NSW is highly inconsistent, varying significantly by postcode, region and service model.

Families in regional, rural, and remote communities often:

- · rely on travel or telehealth to access even basic services
- fall between gaps between community, health and disability systems
- miss out on peer-led and non-clinical supports.

Even in metropolitan areas, navigation is a major barrier. Parents describe finding help 'accidentally,' often through word-of-mouth rather than via coordinated referrals or system design.

Peer-led, place-based and online programs are working now - but they are not funded as part of the NSW service system. They remain undervalued and inconsistently supported, meaning we are missing opportunities to set children and families up for success.

Recommendations

- Fund family-led peer supports with:
 - clear, visible access points for families, regardless of their child's diagnosis or funding status
 - flexibility to adapt delivery methods (e.g. in-person, online, outreach) based on local context and family needs.
- Recognise and resource family-led organisations as an essential part of the child and family sector.
- Establish ongoing foundational supports to deliver peer support and capacity building for families of children with disabilities, delivered by family-led organisations.
- Expand support for foundational support outreach and referral pathway programs to enable:
 - training for key health and education professionals who see families with children with disabilities e.g. allied health workers, GPs, early educators and teachers
 - support for parents and carers to connect with information, referral pathways, peer support and capacity building.

- Peer support can provide the connections and support for families to create thriving lives for their children
- It maximises the impact of government investment by improving coordination across health, disability and community support systems, minimising duplication and improving families' access to referral pathways.
- · This proven model helps families to:
 - o navigate the early stages of their child's diagnosis with acceptance and empowerment
 - access timely support in ways that suit their needs, reducing reliance on the NDIS and intensive services as the default entry point.

Case Study: Belongside Families' Western Sydney Peer Support Networks

In 2025, Belongside Families launched a program to create community-based peer support networks for families of children with disability in Western Sydney and the Hills District, supported by Stockland's CARE Foundation.

This includes:

- a mix of inclusive family fun days, parent and carer-only events, information sessions with local services and casual catch-ups designed to foster connection, reduce isolation and build community
- peer-led facilitation at all events, offering emotional support, shared lived experience and practical guidance
- capacity building workshops to help families navigate services and strengthen their advocacy skills
- ongoing peer communication and resource sharing through online channels
- multi-channel outreach and collaboration with Stockland volunteers and local organisations to reach families who are not yet connected to support.

It is a scalable, flexible model of community-based peer support that meets families where they are, whether online, in the park or around a table.



1(d): Gaps and barriers to accessing early childhood intervention and their impact on a child's overall development, health and wellbeing, as well as on their family or carers and other government services and systems

Current issues

Access to early childhood intervention in NSW is still largely tied to a child's formal diagnosis, NDIS eligibility or specific service pathways. This leaves thousands of families in limbo without access to timely or appropriate support.

Our research shows:

- families endure delays of 6 to 24 months between identifying their first concern about their child and receiving formal help
- families without NDIS access often receive little to no support
- the current NSW system places a significant emphasis on specialist assessments before families can access even basic developmental guidance
- current early intervention supports are framed around 'gateways' and eligibility, rather than prevention and inclusion.

"By the time we got help, we were already in crisis." - Parent, Sutherland Shire

Families tell us they need support early - before diagnosis, and before issues escalate to crisis level. Without early intervention, children miss critical developmental windows, and families fall into cycles of stress, escalation and fragmented care.

These delays also create significant financial strain, particularly for families who must self-fund private assessments or therapy while waiting for public pathways, exacerbating existing inequities and placing the greatest burden on those with the least capacity to pay.

Recommendations

- Guarantee families' access to early childhood intervention supports that do not require diagnosis or NDIS eligibility including:
 - peer support and emotional wellbeing programs
 - developmental and inclusion-focused workshops for parents
 - navigation and information support delivered early and often
 - connections to inclusive community settings from the start of a families' journey (e.g. early childhood education and care).

- When governments put children and families' needs at the heart of early childhood support systems, we can:
 - create more equitable systems for families, where access is based on need, not a child's diagnosis or funding status
 - o improve developmental outcomes for children
 - o reduce the demand for specialist or intensive services
 - o improve family wellbeing and resilience by reducing stress, confusion and burnout.

Case Study: Empowering Families to Navigate Early Education & School

With funding from Perpetual Philanthropic Giving, Belongside Families is currently helping parents of children with disability and developmental delay to build the confidence, skills and knowledge needed to navigate early childhood education and school systems. This includes:

- interactive peer-led online workshops in Supporting Your Child in Early Learning and Everyday Advocacy at Primary School
- plain language parent resources including advice on navigating education systems and tools to work in partnership with educators
- real life examples of inclusive practice and family experiences.

The program is currently helping thousands of families across NSW, including many who had never previously accessed formal disability supports. Families have reported they are more confident to speak up for their child's needs and have a greater understanding of how to work with early learning and school systems.



1(e): Opportunities to increase engagement across sectors and improved collaboration across both government and non-government services, including Aboriginal Community Controlled Organisations, early learning services, educational settings and health services

Current issues

NSW families consistently describe their experiences in accessing support as fragmented and siloed. Each service - whether in health, education, disability or early childhood education and care - often operates in isolation. Parents are expected to coordinate between systems, retell their story repeatedly and fill the gaps created by poor service integration.

Common challenges include:

- conflicting advice from professionals across different sectors
- · duplication of intake and assessment processes
- no shared pathways between universal and targeted services
- a lack of clear supported entry points that bridge related systems.

This is exhausting for families.

It results in:

- · wasted time and resources
- · missed opportunities for early intervention with children and families
- delayed developmental outcomes for children.

Recommendations

- Fund and embed peer and professional navigation roles in trusted settings such as children's hospitals, family-led organisations, early childhood intervention services and child and family hubs.
- These navigation roles should:
 - provide relational support and practical guidance to families
 - help to bridge services across sectors, rather than operating in isolation
 - be guided by family-centred culturally safe practices.
- This model has shown early success in Belongside Families' pilots and is ready to be scaled up across NSW.

- · Peer and professional navigation roles can:
 - improve service coordination by reducing families' confusion and disengagement with complex systems
 - ensure existing resources are used more efficiently by linking families to the right support sooner
 - increase families' trust and engagement with support systems, particularly in marginalised or under-served communities
 - reduce the pressure on intensive services by supporting families through coordinated early intervention pathways.

Case Study: Belongside Connect – Individual Peer Support for Families

Belongside Connect is an individual peer support and navigation service that offers personalised emotional and practical support to parents and carers of children with disability, developmental delay or developmental concerns.

With support from the Australian Government, our current pilot is being extended to reach more families across NSW. This includes:

- one-on-one support sessions delivered via phone or video by trained and qualified peer workers with lived experience
- a family-led approach tailored to each parent's immediate needs, whether that is emotional support, help navigating systems or understanding next steps
- follow-up with trusted resources, information or referrals
- easy access for families, with no referral, diagnosis or plan required.

This model is an effective early intervention strategy. It helps parents and carers to feel less alone, more confident and better equipped to engage with supports and advocate for their child.

Case Study: Family-led peer support at Perth Children's Hospital

Family-led organisation Kiind has delivered peer support for parents and carers of children with disabilities at Perth Children's Hospital for over 35 years. Their on-site peer worker team offers immediate compassionate support to families, especially those undergoing assessment, receiving a new diagnosis or travelling from regional areas for care.

Being embedded in the hospital allows families to connect with peer support early and often during their first interactions with the system. The model has also improved integration between health, disability and family supports, demonstrating how peer work can complement and strengthen clinical care.

Belongside Families is working closely with Kiind to bring this program to NSW.

1(g): Workforce issues in the child development and early childhood intervention sectors, including workforce demand and the availability, quality and capacity of existing workers

Current issues

NSW is facing significant workforce shortages in early childhood intervention, allied health and family support services, particularly in rural and regional areas. These gaps affect the quality, accessibility and continuity of services available to families.

At the same time, there is an underutilised, willing and highly skilled informal workforce: parents and carers with lived experience. Many are already providing informal peer support in their communities but without recognition, training pathways, or sustainable employment options.

Current workforce challenges include:

- high demand and long wait times for professional services
- · lack of cultural, regional and linguistic diversity
- a heavy reliance on professionals to provide supports that peers could deliver more effectively at lower cost.

"This is work that matters. It gave me identity, income and the chance to use what I've learned to help someone else."

— Belongside Families Peer Worker

Recommendations

- Develop and fund a structured peer workforce strategy as part of NSW's early childhood and disability support systems.
- This should include:
 - clear training, mentoring and credentialing pathways for peer workers
 - integration of peer roles into early intervention support teams alongside clinicians
 - recognition of peer work as a legitimate valued career path, not volunteer labour
 - standards for quality, supervision and ongoing support.
- This model is well established in the mental health sector and should be extended to the disability and early childhood sectors (reference).

- A valued skilled peer support workforce would:
 - o create new opportunities for early intervention supports, especially in under-served regions
 - o reduce the current burden on clinical professionals, allowing them to focus on complex care
 - improve the trust and cultural responsiveness of peer led services, especially in communities where peer support is highly valued
 - create new employment pathways for carers, improving women's economic participation and workforce inclusion.
- The disability and early childhood systems can learn from existing peer support models in the mental health sector.

Case Study: Strengthening the sector with a skilled peer workforce

Belongside Families currently employs 20 paid trained peer workers and engages over 60 peer volunteers across our programs. This is one of the largest dedicated peer workforces supporting parents and carers of children with disability in NSW. This includes:

- paid peer workers facilitating online groups, delivering 1:1 support, co-designing resources and contributing to sector consultations
- peer volunteers supporting group sessions, developing content, participating in reference groups and speaking at events
- a tailored training, supervision and support model
- flexible work arrangements that create meaningful roles for parents and carers.

Our peer workforce reflects the communities we serve: parents from metropolitan, regional and rural NSW with diverse backgrounds, and at different stages of their journeys.

This model supports career pathways for caregivers, who are primarily women, while expanding the capacity of the early childhood and disability sectors with skilled, trusted relational support.

Conclusion

NSW families are not asking for more systems - they are asking for a system that works.

Families want a system where:

- · help is easy to find
- · support can be accessed at the right time, not just after their child's diagnosis
- families are included and supported, not overwhelmed
- peer support, navigation and family education are recognised for what they are: essential infrastructure to set children and families up for success.

This submission draws on what families have told us, what we have seen on the ground, and what the evidence confirms. We don't need more inquiries. We need action.

Our recommendations provide a clear and actionable pathway to:

- create strong foundations through family-led early intervention and foundational supports that set children and families up for success from the early years
- maximise existing NSW Government investments through proven peer support and capacity building programs that empower parents and prevent burnout
- ensure major reforms deliver their intended benefits by amplifying family voices and supporting smooth implementation.
- early intervention and foundational supports are not just cost-effective they are transformational for children and families.

With proven solutions and extensive community connections, we are ready to partner with the NSW Government to turn this vision into reality.

For more information contact:

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When families thrive, children thrive



