



Belongside *Families*

Federal Pre-Budget *Submission*

JANUARY 2025

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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 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 Families' 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 (0-8 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 Sydney Children's Hospital and large allied health not-for-profit organisations.

“ My daughter has an Intellectual Disability and ADHD, as well as being Autistic. Being connected to other families through peer support means that I’m now so much less afraid for her future. Because I know, there are parents that are further along that I can seek advice from. I know I have a safe, supportive place to come for help. I honestly don’t want to ever imagine my life without Belongside Families .



Executive Summary

The Australian Government can unlock the potential of community-based support for families of children with disability now by adopting Belongside Families' recommendations.

Our plan will improve outcomes for thousands of children with developmental delay and disability and their families across NSW and online.

Investing in families has never been more important

When a child is diagnosed with a disability or concerns are identified, they and their family begin a complex journey that requires support, guidance and connection with others who understand their experience.

Ninety per cent of a child's brain development occurs in the first five years of life, making early family support crucial for children with disability. Thriving parents are essential to support a child's development and create the strong foundations necessary for children with disabilities to reach their full potential.

When families are set up for success, the Australian Government maximises outcomes from its investment in children's early years by:

- reducing demand for avoidable acute and intensive supports
- setting parents up to improve the course of their family's life, based on increased resilience and wellbeing
- building sector capacity through prioritising evidence-based programs.

Our plan for the 2025-26 NSW budget

After decades of fragmented solutions, we are excited to see real appetite for change from government, families and across the community sector. However, we know that some of the most challenging decisions must be made in this Budget.

Belongside Families' evidence-informed approach to capacity building and empowerment provides a clear path forward for lasting change.

Our Pre-Budget Submission outlines recommendations for:

- setting families up for success with Foundational Supports
- maximising the value of Australian Government investments through peer support and capacity building for parents and carers
- supporting carers of children with disabilities through the National Carer Strategy
- creating systems that are designed by families for families.

With proven solutions and extensive community connections, we are ready to work with the Australian Government to turn this ambition into action.

Our Vision For *Children & Families*

No family should start their journey alone.

Families wait months and often years before they are connected to peer support. In a recent Belongside Families survey, the majority of families reported they went without support for over two years. It took up to six years before some families were connected to a peer support service.

Our vision is for:

- parents and carers to easily access peer support as soon as they have concerns about their child's development
- families to explore the full ecosystem of supports and find quality options which best fit their child and family's needs, with support to do so on their own terms
- parents to have access to uplifting, supportive and educational spaces, helping to reduce burnout and isolation
- parents to have access to low intensity peer-based supports that provide connection, emotional support, and problem-solving skills to boost their resilience, when they have to wait for access to particular services.

As a result:

- families are more resilient
- parents and carers have access to accessible local, community and mainstream options for connections and support
- children are better set up for a life of potential and possibility
- the Australian Government maximises benefits to families and communities from its investments.

“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 event, I had no idea just how much the decision would change my life.”



Budget Recommendations

1. Foundational Supports

Setting families up for success through peer support & capacity building

Current issues

- Families of children with disabilities face significant challenges that impact their wellbeing and ability to support their child and family.
- Children can thrive when families feel confident and supported in their role as caregivers.
 - If parents cannot access the right advice, support and connections, they experience increased stress and burnout, poor mental health, social isolation and decreased quality of life for themselves and their family.
 - This means parents are less able to advocate for their child's needs and can miss opportunities to secure appropriate support which can adversely impact their child's development and opportunity to be included where they live, learn and play.
- Families currently must navigate complex state and federal systems across different ages and stages of their child's development.
 - To access the right information, advice and supports, families need to know they exist, where to find them and have the right support to participate.
- The design of Foundational Supports must not entrench the current challenges for children and families.
 - Belongside Families has been working with the Department of Social Services to support consultation with families on Foundational Supports.
- Families have told us they need:
 - a whole family-centred approach to capacity building and support
 - peer groups to provide a trusted place for parents to share experiences, learn from each other and become connected in a safe and supported environment.
- As eligibility for children under the NDIS is tightened, families urgently need access to alternative supports now.
 - Children with disabilities and their families will bear the brunt of any delay to the implementation of Foundational Supports.

Recommendations

- Finalise intergovernmental negotiations on Foundational Supports as soon as possible.
- Establish ongoing funding under Foundational Supports to deliver peer support and capacity building for families of children with disabilities, led by not-for-profit family-led organisations.
- Provide support for outreach and referral pathway programs under Foundational Supports 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.
- Ensure Foundational Supports funding is new and additional to the Information, Linkages and Capacity Building (ILC) Program and Inclusion Support Program.
- Establish a national sector led portal for families to find programs and support in early years (0 – 8 years).

Benefits

- Foundational Supports can provide the connections and support for families to create thriving lives for their children if delivered by proven and trusted family-led organisations.
 - These organisations can help reframe the experience of families to acceptance and empowerment.
- Evidence-based quality peer support and capacity building programs and services help families to navigate:
 - the early stages of their child's diagnosis with acceptance and empowerment
 - complex systems so they can access the right support at the right time.

“ I feel like Belongside 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.



2. Peer Support & Capacity Building

Maximising the value of Australian Government funded supports

Current issues

- Families often struggle to access the right support at the right time due to fragmented, complex and confusing systems.
 - Navigating support systems like the NDIS, healthcare and education for their child is incredibly complex for parents.
 - Understanding and applying for available support is often complicated and time consuming, adding to the mental load of caring.
- Families with a child with developmental concerns or disability need support to understand how to meet their child's needs.
 - Families are falling through the gaps at the point of diagnosis and are prioritising extensive therapy and disability services.
 - Parents need to be connected with high quality peer support, grounded in strengths-based and evidence-based practice as early as possible.
- The Australian Government must ensure it has the ongoing sector capacity to deliver critical supports to children and families via proven and trusted community-based organisations.
 - Many community-based organisations are struggling to deliver enduring benefits to families due to piecemeal and fragmented funding.
 - Ad hoc and unsustainable funding threatens to undermine the successful implementation of Foundational Supports, NDIS reforms, the National Carer Strategy and the National Autism Strategy.

Recommendations

- Expand ongoing multi-year support for peer support and capacity building for parents of children of disabilities delivered by family-led organisations.
 - - See Proposed Projects – Peer Support & Capacity Building for examples of evidence-based support that Belongside Families is designing (p. 13).
- Change the funding criteria of the ILC Program Fund to support existing projects which demonstrate significant benefits to children and families.
- Draw on state and territory government expertise to assess proposals under the ILC Program.

Benefits

- Peer support is a highly effective way of meeting the additional needs of parents of children with disabilities.
 - Belongside Families' proposed approach would maximise the value of existing Australian Government funded supports and bridge current gaps in families' information and awareness.
- When families can access peer support, they have reduced feelings of isolation, improved coping skills, and confidence to access mainstream and community supports.

Case Study: *Belongside Families Western Sydney partnership with Stocklands*

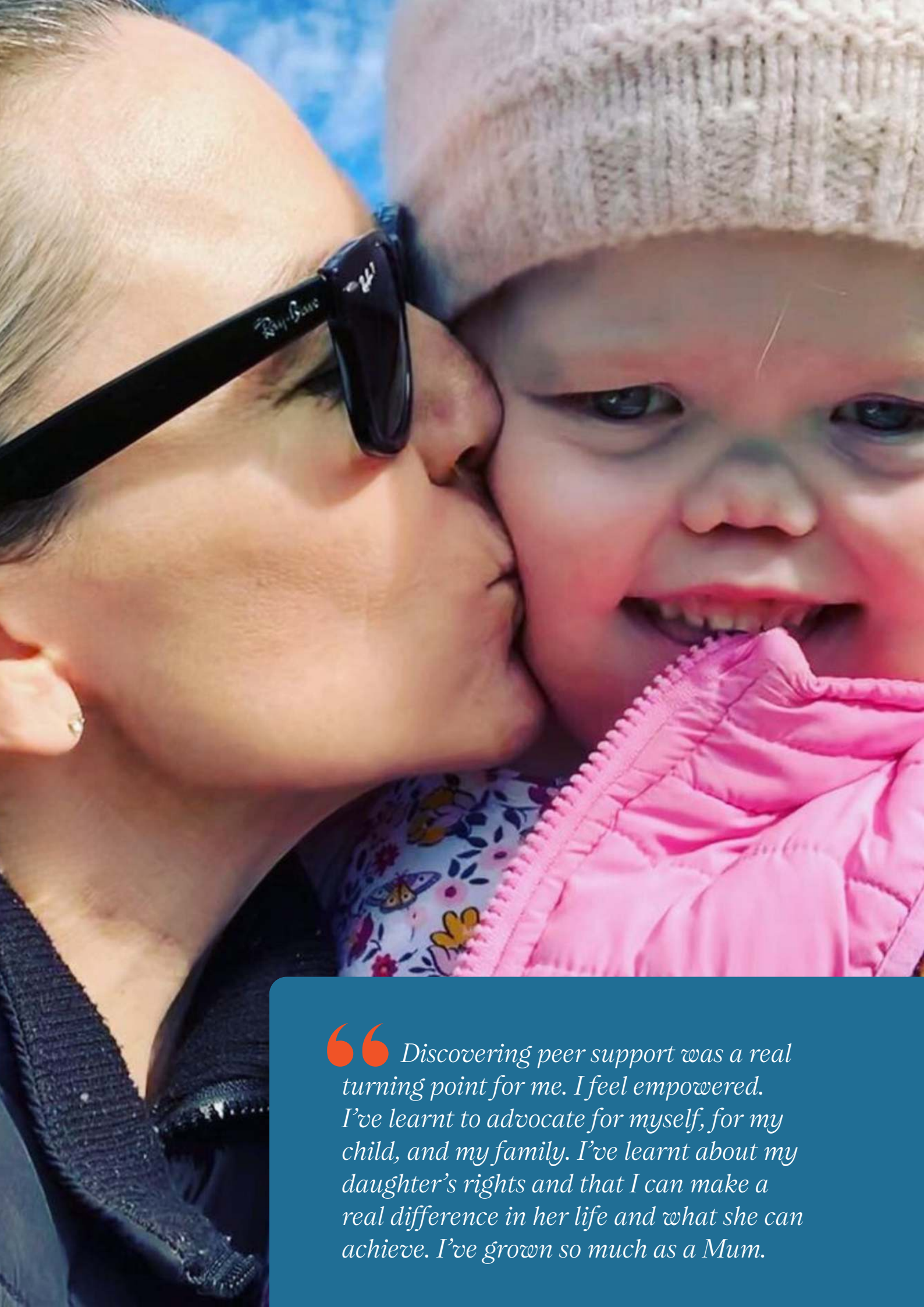
From early 2025, Belongside Families will launch an innovative six month program to create sustainable community based peer support networks for families of children with disability in Western Sydney.

This includes:

- in-person peer support events across three locations (Stockland Wetherill Park, Stockland's Merrylands Shopping Centre and Elara Inclusive Playground, Marsden Park) with guest speakers and facilitators providing practical advice and emotional support
- online capacity building workshops to help families navigate services and develop their advocacy skills
- online communications for ongoing peer support and resource sharing
- multi-channel outreach and collaboration with Stockland volunteers and local organisations to boost participation.

This pilot is a key component of Belongside Families' broader strategy to expand our physical presence into high need communities in partnership with community based organisations. We are developing scalable sustainable community based peer support to reduce families' loneliness and isolation.

Belongside Families will draw on lessons from this project to inform the expansion of community based peer support networks to the NSW Central Coast and South Coast in 2025.



“ Discovering peer support was a real turning point for me. I feel empowered. I’ve learnt to advocate for myself, for my child, and my family. I’ve learnt about my daughter’s rights and that I can make a real difference in her life and what she can achieve. I’ve grown so much as a Mum.

Proposed Projects - Peer Support & Capacity Building

NSW Children's Hospital – Family Support Pilot

Drawing on the successful Kiind WA/Perth Children's Hospital model, Belongside Families has identified a significant opportunity to establish family-led support services within Children's Hospital's in NSW.

Health professionals and families have expressed strong interest in expanding this proven approach.

Parents need to be able to connect with peers who understand the support they need for themselves and their family. Outreach in children's hospitals can be a highly effective means of connecting families with peer support, when they need it most.

An on-site peer support team will provide a warm connection for families, identifying services available to meet their needs. Co-location within the hospital ensures seamless integration with health and disability support services, creating clear pathways for families when they need support the most.

Collaborate with Carers of Children with Disability

Belongside Families' research shows parents and carers want practical carer support and advice at the very first contact point when seeking help. In response, we are designing interactive training for allied health workers working with children from birth to eight years old with disability or developmental delay.

This project will help allied health workers to better identify and support carers early in their journey. This includes interactive training on family-centered practice, online modules focused on practical skills, guided action plans for real world application and reflection prompts to reinforce ongoing learning.

Allied health workers will gain confidence and skills to identify new carers and link them to appropriate supports early in their carer journey. This will help to reduce reliance on more intensive supports when children are older.



“ 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.

3. National Carer Strategy 2024 – 2034

Supporting the unique and complex challenges faced by carers of children with disability

Current issues

- Carers of children with disability play an invaluable role in our society, providing round-the-clock care and support that is often unrecognised and undervalued.
- Parent carers face distinct challenges compared to other carer groups.
 - Parenting and caring can be indistinguishable for parents and they do not advocate for themselves in terms of recognition and accommodates in paid work, health service interactions, education and training etc.
 - Their caring role often extends throughout their child's life, requiring constant adaptation to changing needs and long-term planning.
 - Caring across their child's developmental stages requires time consuming interaction and mastery of multi-system (i.e. disability, education, health, social services) access and participation for their child's health, development and education. This is time consuming and stressful.
- Carers do not exist in isolation from the children they care for.
 - When children cannot access the support they need, it directly impacts the carer's wellbeing, often leading to burnout, exhaustion, health disparity and financial strain.
 - When children do not have the support required from parents/guardians to access the services that they need, children fail to thrive.

Recommendations

- Prioritise measures that support carers of children with disabilities in the 2024 – 2027 Action Plan including:
 - creating a Carer Gateway that supports different family circumstances, recognising that caregiving roles vary significantly in intensity and complexity
 - expanding flexible respite care options tailored to the unique needs of families caring for children with disability
 - increasing the Carer Payment/Allowance to better reflect the true cost of caregiving
 - increasing carers' access to mental health support including subsidised counselling services and mental health services that are additional and specifically targeted for parents compared to those available to the general public
 - funding free, or low cost-highly effective, and accessible education programs tailored to carers of children with disability to learn how they can support their own health and enhance their caregiving skills
 - developing a national outreach campaign to parent carers of children with disability to increase awareness and utilisation of existing government platforms and support services for carers.

Benefits

- By targeting carers of children with disabilities, the Australian Government can identify new carers and link them to appropriate supports early in their carer journey.
 - This preventative strategy will maximise the value of the Australian Government's investment in carers and decrease the need for more costly and complex support later in the family's journey.
- Belongside Families' recommendations support the following Priority outcome areas in the National Carer Strategy:
 - Carers can access supports, services and programs at the right time, right place and in the right way
 - Ensure carers are able to develop knowledge and skills when needed to fulfil their caring role
 - Carers can access, and participate in employment and education or training, including to improve their financial wellbeing
 - Carers have access to supports that safeguard their psychological, physical and social wellbeing.

Healthy Mothers Healthy Families

A low cost and accessible evidence based health education program tailored to carers of children with disability

Belongside Families is the national delivery partner for Healthy Mothers Healthy Families, with current support from the Australian Government's ILC Program. This is an evidence based mental health and wellbeing program developed by Prof Helen Bourke-Taylor (Monash University). It targets mothers who disproportionately shoulder caring responsibilities, experience greater health impacts within families and face a wide range of barriers to access services for themselves. The program was developed through collaborations between health practitioners and mothers of children with disability, and designed for Australian mothers. Several scientific studies show the program to be highly effective.

This is the only Australian program targeting mothers who represent 95% of carers for children with disability. It is delivered online to increase its accessibility, using a proven e-health group model. Participants can access workshops with workbook delivered by health practitioners or mothers, health coaching delivered by an occupational therapist providing therapy for the child with disability, and self-directed e-learning package available in the website.

After attending Healthy Mothers Healthy Families:

- 95% of mothers reported an increase in health-promoting activities such as eating well, exercise and socialising
- 98% of mothers reported improvements in their personal well-being
- 92% reported depression symptoms within average limits after the workshop.



“ While therapies focus on my child, as the mother, I’m the one tasked with implementing and executing them—alongside a million other responsibilities! Belongside Families is the first service that has put me at the forefront. This not only impacted me but also my disabled children. I can now better care for them and I feel empowered to advocate for their needs.

4. Amplifying the voices of families in major reform

Creating a system that works for families

Current issues

- Belongside Families was established to fill the gap of peer support for families of young children with disabilities or developmental delays.
 - Over the past five years, we have become the primary source for families seeking guidance and support, based on the quality of our services and commitment to positive evidence-based practices
 - We are a trusted voice for families and have been engaged by the Australian Government to consult families on major reforms including the National Autism Strategy, National Carers' Strategy, NDIS Review and Foundational Supports.
- We have a 'once in a generation' opportunity to create a system that works for children with disabilities and their families.
 - Governments, the community sector and families are all ready for change
 - However, families and support services are uncertain about how key reforms like Foundational Supports will work.
- Belongside Families has worked hard to raise the voices of families of children with disabilities in major disability reform processes, on behalf of the families we represent and as part of CaFDA and CaFSA alliances.
 - We knew this was vital to deliver urgent and meaningful reform for families
- Our advocacy has significantly improved the results of policy and program design, ensuring decision makers heard directly from families with lived experience.
 - However, this level of effort is not sustainable for a family-led organisation.
- The Australian Government will need support from independent family-led organisations to ensure:
 - major reforms like Foundational Supports work as intended
 - families understand how they will be affected by these reforms
 - children and families can enjoy the full benefits of improvements to the accessibility, affordability and quality of services.

Recommendations

- Provide operational funding for family-led organisations to support:
 - implementation of major Australian Government reforms
 - the design, testing and establishment of Foundational Supports (similar to the NDIS rollout)
 - capacity building of families to be ready for these reforms.

Benefits

- Children and families can enjoy the benefits of major Australian Government reforms sooner if they understand its vision and are ready for change.
- Family-led organisations like Belongside Families' have the networks, expertise and track record to support this by:
 - being a trusted source of information and advice for families through periods of significant change
 - supporting the transition from current services to new systems across the disability, health and community sectors
 - providing timely advice, support and evidence to the Australian Government during the design and implementation of major reforms.

“I’ve built my knowledge through Belongside Families’ workshops and events. 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.”



Conclusion

Every child deserves the opportunity to reach their full potential, and every family deserves the support they need along their journey. The 2025-26 Budget presents a historic opportunity to transform how we support families raising children with developmental concerns, delay and disabilities.

Belongside Families' recommendations provide a clear and actionable pathway to:

1. Create strong foundations through family-led Foundational Supports that set children and families up for success from the start.
2. Maximise existing Australian Government investments through proven peer support and capacity building programs that empower parents and prevent burnout.
3. Ensure major reforms deliver their intended benefits by amplifying family voices and supporting smooth implementation.

By adopting these recommendations, the Australian Government can significantly improve outcomes for thousands of children with developmental delays and disability and their families across the state.

Our evidence-informed, family-led approach will:

- connect families with support when they need it most
- reduce isolation and prevent caregiver burnout
- build family resilience and advocacy skills
- create clear pathways for children to thrive and being included
- maximise returns on government investments.

The time for transformative change is now.

With proven solutions and extensive community connections, Belongside Families is ready to partner with the Australian Government to turn this vision into reality.

For more information contact:

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stacey@belongsidefamilies.org.au





When families thrive, *children thrive*



www.belongsidefamilies.org.au



END

Collaborate with carers of children with disability

Belongside Families' research shows parents and carers want practical carer support and advice at the very first contact point when seeking help.

In response to this finding, we are designing interactive training for allied health workers working with children from birth to eight years old with disability or developmental delay.

This project will help allied health workers to better identify and support carers early in their journey. This includes interactive training on family-centered practice, online modules focused on practical skills, guided action plans for real world application and reflection prompts to reinforce ongoing learning.

Allied health workers will gain confidence and skills to identify new carers and link them to appropriate supports early in their carer journey. This will help to reduce reliance on more intensive supports when children are older.



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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 vitally important. I've learnt so much through the perspectives of others.



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“

Kindred has provided invaluable support and assistance during some of the most challenging time of our lives and helped us be better parents to all our children, not just our little one with a disability.



“

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 Kindred event, I had no idea just how much the decision would change my life.



Discovering peer support was a real turning point for me. I feel empowered. I've learnt to advocate for myself, for my child, and my family. I've learnt about my daughter's rights and that I can make a real difference in her life and what she can achieve. I've grown so much as a Mum.



A close-up photograph of a smiling man, a smiling woman, and a young girl. The man is on the left, the woman is at the top right, and the girl is in the foreground. The girl has a pink heart sticker on her cheek and is wearing a blue denim jacket. The background is bright and out of focus.

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Empowering Parents of Children with Disability

Kindred is the family-led peak body supporting families raising children with developmental delay, disability and autism across NSW.

Our staff, board, and volunteers have lived family experience of disability, meaning Kindred has deep understanding of the challenges families face, and can provide support that's relevant and meaningful.

Through free online 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.

Kindred is a trusted resource for parents of children with disabilities

Ninety per cent of families attending Kindred's programs said they helped them to:

- improve their knowledge and skills
- navigate systems and services
- increase their confidence and ability to advocate
- feel less isolated and have a more positive outlook on life.

“

Families are doing much of the heavy lifting to coordinate different supports.



Summary of Recommendations

Scope and outcomes

1. Broaden the proposed outcomes for Foundational Supports to include:
 - for children: promote inclusion in early learning and education settings
 - for families: explicit reference to the wellbeing of families, including siblings
 - for community: measures relating to involvement in community life
 - for workforce: disability competence; culturally safe for Aboriginal and Torres Strait Islander communities; responsive for diverse communities and aligned with best practice service and systems levels measures: shared assessments; interface with education
 - service and systems levels measures: shared assessments; interface with education inclusion supports; seamless transitions between the NDIS and Targeted Foundational supports
 - reform enablers: effective local-state-national co-governance; use of evidence to inform change; accountability and funding

Align outcomes, where practicable, with related national frameworks and strategies.

General Supports

2. Scale up family-led, child-focused organisations as an anchor for families and carers to receive rapid, trusted, strengths-based support, early in their journey
3. Locate family-led information, advice and connection services in all children's hospitals across Australia and provide peer outreach in child and family hubs/centres

- Underpin the delivery of nationally coherent approach to family-led supports for families and carers of children and young people via a network of proven and trusted family-led anchor organisations
- 4.

5. Invest in a broad and rich eco-system of family and disability-led organisations to deliver diagnostic specific, culturally specific and local place-based initiatives
6. Create the enabling conditions for a diverse tapestry of safe and sustainable peer support options
7. Provide for bite sized family capacity building workshops delivered as part of an interconnected suite of supports
8. Improve and expand access to disability informed courses and programs aimed at strengthening parent/carer skills
9. Strengthen the Raising Children's Network and Starting Blocks, in preference to the Disability and Carers Gateway, as the key national platforms for housing information aimed at families raising children with disability.

Targeted Foundational Supports for Children

10. Provide demand-based funding so that every child who meets access thresholds can receive support. Guarantee a minimum level of support for each tier of Targeted Foundational Supports.
 -
11. Ensure that Targeted Foundational Support improve upon - and do not diminish what is currently available in some states and territories
12. Enshrine strong equity considerations into access criteria for Targeted Foundational supports
 - - Create streamlined access and referral pathways. Avoid creating administrative hurdles or making access complex.
 - Do not exclude children and families because of their visa or residency status.
 - Proactively design culturally safety approaches for Aboriginal and Torres Strait Islander families.
 - Consider level of family complexity, alongside a child's delay, when determining intensity of support requirements, with default one on one provision where:
 - there is involvement with child protection
 - more than one child in the family has development delay
 - a parent or carer has disability
 - the child is excluded from, or not attending ECEC/school.

- Allow sufficient time for families to develop trust and relationships with supports.
- Minimise non-attendance rules that result in families losing access to supports.

13. Require Targeted Foundational Supports to be delivered in accordance with the upcoming Best Practice Early Childhood Intervention Framework.

14. Allow for children and families to move between different tiers of Targeted Foundational Supports and have repeat periods of support if needed. Support easy movement between Targeted Foundational Supports and the NDIS. Ensure that commitments to defer changes to NDIS pathways for children until Targeted Foundational Supports have been tested, implemented and ramped up are honoured.

15. Allow for assessments to be cross-purposed and operate as a child's "passport" for access to various supports.

16. Urgently progress NDIS recommendations to support early identification of developmental concerns - including through upskilling maternal and child health nurses and introducing universal and consistent assessment processes, with Aboriginal and Torres Strait Islander adapted approaches.

17. Embed, where practicable, Targeted Foundational Supports into education settings

Workforce and community

18. Enable and mandate best practice in Targeted Foundational Supports through:

- commissioning approaches that provide the enabling environment
- performance, accountability and outcomes measures
- upskilling professionals and organisations
- showcasing and celebrating best practice

19. Recognise and invest in the development of the family peer workforce

20. Actively involve families, people with disability and their representative organisations in co-design and governance of Foundational Supports at a local, state and national level.

Overview

CAFDA comprise family-led organisations supporting over 30,000 families and carers

The Child and Family Disability Alliance (CAFDA) is a national partnership of not-for-profit family-led organisations. Established by families for families, our boards, management and front-line staff all have lived experience and understand the joys and the challenges of parenting a child with disability. We are currently supporting more than 30,000 families and carers raising children with all kinds of disability and developmental delay across Australia. CAFDA members have been providing Foundational Supports for decades and bring a broad and deep perspective that crosscuts different systems, services, jurisdictions and locations, diagnosis, ages and reform eras.

Sticking to our knitting, this submission focuses on design of General Foundational Supports for families and carers of children and young people and Targeted Foundational Support for children. We understand consultations on Targeted Foundational Supports for 9 to 21-year-olds will take place in 2025 and look forward to being involved in those. We have undertaken significant engagement across in the past 12 months with families, carers and key stakeholders including CYDA (who have led consults with young people), Early Childhood Intervention experts, sector peaks and governments to inform our position.

The Foundation Supports Strategy needs to be ambitious

CAFDA want to see the Foundational Support Strategy (the Strategy) drive marked step change. We call for Strategy outcomes to be expanded to reflect things that families and carers have identified as high priority. Explicit outcomes related to children being included and engaged in early learning, school and community life and for the wellbeing of families - including siblings – are needed. We also call for outcomes related to systems changes and reform implementation.

Strengthening family and carer capacity helps children have better lives

It is reassuring that both the NDIS Review and DSS Foundational support consultation materials clearly reflected the overwhelming evidence that children have better outcomes when families and carers feel confident, supported and included in their role as caregivers, first teachers and nurturers.

CAFDA welcomes the commitment to embedding information, advice, peer support and capacity building for families and carers as a central component of the forthcoming Strategy, both in the early years of a child's life and beyond. Significantly increased investment that redresses the disinvestment (post NDIS introduction) in family centred and family capacity building approaches is a must. Australia cannot afford to skimp on this critical enabler of better outcomes.

General Supports for families should be family and disability-led, with a nationally coherent approach anchored in family-led organisations

Strategic, connected and intentional design of general Foundational Supports aimed at families and carers is needed to break from the current haphazard approach. We call for this to be anchored via a network of proven and trusted family-led, child-focused, place-based organisations that facilitate a high quality, high-fidelity and coherent suite of coherent offerings across Australia, tailored for jurisdictional and locational differences. This would be augmented by a rich, connected eco-system of diagnostic specific, diverse population and local initiatives delivered by specialist disability and family led organisations.

There is significant scope to improve and expand training for families and carers

Our submission points to programs and courses used by families and carers that are ripe for improvement and expansion. Current reviews of adjacent programs that fund these courses such as the DSS Families and Children Activity, Review of Children, Youth and Parenting Programs, offer opportunity for rapid headway.

Raising Children's Network is a preferred platform

We caution against seeking to repurpose the Disability and Carer Gateways as the main national platform for families and carers of children with disability. The trusted and highly used Raising Children's Network provides a safe soft entry point to find reliable information about disability and developmental differences and what support is available.

Much is riding on the effective design and roll out of Targeted Foundational Supports for children. CAFDA welcomes the priority given to developing Targeted Foundational Supports for children. We are acutely aware of the significant groundwork that needs to occur to create a nationally coherent approach. Mindful of the negotiations currently underway between governments, our recommendations go to high-level design.

We call for a minimum support guarantee backed by demand-based funding and for Targeted Foundational supports to strengthen – not diminish – what already exists.

Strong and explicit equity considerations are needed to ensure that Aboriginal and Torres Strait Islander children, those on temporary visas and children involved in family protection do not miss out.

Consistent screening and referral processes from well-equipped universal services (particularly maternal and child health nurses and GPs) will be a key enabler of this.

To turn the vision of a unified and connected system of supports into reality we underscore the importance of easy movement between different tiers of Targeted Supports, access to repeat periods of support and simple transition into NDIS if needed.

Families, people with disability and representative organisations need to be involved and have voice throughout all stages of the journey and at different levels of design and implementation: local, state and national. Collectively, we cannot afford to get this critical reform piece wrong.

Designing Targeted Foundational Supports for children to align with the current review of Best Practice in Early Childhood Intervention (ECI) will also be imperative. This will mean moving away from the market-oriented, therapy-heavy and clinic-based approaches that families have experienced under the NDIS.

Families have told us they do not want another siloed program, but rather something that connects with and enhances what already exists in the places they already know and go to. We call for Targeted Foundational Supports to be integrated into education and everyday settings. We point to opportunities to leverage related national reform directions in Early Childhood Education and Care (ECEC), the Better and Fairer Schools reforms and child and family focussed place-based initiatives. Key State reform initiatives (such as improvements to WAs Child Development Service) also present opportunities.

A family peer workforce has a powerful role to play

Peer workers play a vital role in equipping families and carers to address the challenges and joys of having a child with disability or developmental concerns, navigating systems and advocating for their needs. At this time of significant change and uncertainty, a capable and connected family peer workforce is needed now - more than ever - to walk alongside families and carers. CAFDA recommend investing in the coordination and development of family peer workers.

The introduction of Foundational Supports present both huge opportunities and huge risks. Families are being asked to make a huge leap of faith and trust to embrace the significant changes flowing from implementation of the NDIS Review. Foundational Supports, if done well, offer huge opportunity to deliver real improvements.

Careful design, sufficient funding, staged transition, coherent interfaces with the NDIS, strong governance and shared commitment across all types of politics and levels of government is needed. Honouring commitments made to defer changes to NDIS pathways until Targeted Foundational Supports have been tested, implemented and ramped up is critical. Ensuring that children do not fall through transition gaps when ageing out of the NDIS early childhood approach is particularly urgent.

Families, people with disability and representative organisations need to be involved and have voice throughout all stages of the journey and at different levels of design and implementation: local, state and national. Collectively, we cannot afford to get this critical reform piece wrong.

Scope and Outcomes of the Upcoming Foundational Supports Strategy

Recommendations: scope and outcomes

1. Broaden the proposed outcomes for Foundational Supports to include:
 - for children: promote inclusion in early learning and education settings
 - for families: explicit reference to the wellbeing of families, including siblings
 - for community: measures relating to involvement in community life
 - for workforce: disability competence; culturally safe for Aboriginal and Torres Strait Islander communities; responsive for diverse communities and aligned with best practice service and systems levels measures: shared assessments; interface with education
 - service and systems levels measures: shared assessments; interface with education inclusion supports; seamless transitions between the NDIS and Targeted Foundational supports
 - reform enablers: effective local-state-national co-governance; use of evidence to inform change; accountability and funding

Align outcomes, where practicable, with related national frameworks and strategies.

Broader, more ambitious outcomes are needed

We recommend substantial enhancements to the proposed outcomes associated with Foundational Supports.

Children being welcomed and included in education is the highest priority for families. While not wanting to diminish the responsibility of education systems, Foundational Supports need to work collaboratively with education settings to advance inclusion.

Fundamentally children do well if families are supported. Beyond supporting families to understand and feel confident in supporting their child's development, Foundational Supports should have family-related outcomes, including sibling wellbeing.

2. **Scale up family-led, child-focused organisations as an anchor for families and carers to receive rapid, trusted, strengths-based support, early in their journey**

Caring for a child with disability or developmental differences can be overwhelming

When a child begins to develop differently, it can be an all-encompassing experience for that family, impacting many aspects of life: health, disability, education and employment.

When parents and carers lack good advice, support and connections, they are more likely to experience increased stress and burnout, poor mental health, social isolation and decreased quality of life for themselves and their family.

They may also be less able to advocate for their child's needs and delay or miss opportunities to secure appropriate support which can adversely impact their child's development.

Collectively, we need to minimise the amount of time families spend in grief, loss and isolation and ensure they are on a positive trajectory. A strong system of high-quality Foundational Supports should make it easier for families to access timely and reliable information and advice from supportive, safe and trusted sources. This can help families to more rapidly access the most appropriate supports while also making sure they are ready and able to receive that support.

Family-led organisations help families get to where they need to be more quickly, more effectively and still intact. We are expert at breaking down the complexity of navigating multiple systems into small steps so families can access support at the right time and be in the best state to experience the benefits. Families repeatedly tell us it is reassuring to be guided by understanding peers who are in their corner, can help them to chart a course forward and who stay the distance as a trusted touchpoint.

The earlier families can connect with this support, the better. Enhancing the role and visibility of family-led, child focussed organisations as a landing place for families at the beginning of their journey ought to be prioritised when ramping up Foundational Supports. Access to rapid, trusted and strengths-based peer-support at this critical early point helps put families on a positive trajectory.

3. Locate family-led information, advice and connection services in all children's hospitals across Australia and provide peer outreach in child and family hubs/centres

To meet families and carers where they are at and make it easy for them to connect with timely support, CAFDA recommends peer outreach in places such as children's hospitals and child and family centres

Kiind has been providing family-led connection and support at Perth Children's Hospital for over 35 years. Kiind's on-site peer worker team provide a warm and ready connection for families – including those going through assessment and diagnostic processes and families from regional and remote areas travelling to Perth for treatment. Being on site at the hospital means families are rapidly connected with peer supports. It has also strengthened the interconnect between peer support and the broader health and disability services system. CAFDA recommends this approach be replicated across Australia, in all children's hospitals and potentially in major child and family hubs.

4. Underpin the delivery of nationally coherent approach to family-led supports for families and carers of children and young people via a network of proven and trusted family-led anchor organisations

The upcoming Foundational Support Strategy ought to drive rapid evolution away from the current experience of isolated and disconnected initiatives operating in a patchwork of locations. Instead, families and carers of children and young people - wherever they live in Australia – should be assured access to a high quality, high fidelity and coherent suite of peer-led supports.

CAFDA call for this nationally connected approach to be anchored by known and trusted family-led organisations that are committed to aligning efforts and working as part of a co-ordinated network to achieve outcomes and impact that are greater than the sum of its parts.

A networked approach (rather than a single national organisation) makes good sense given geographic considerations and the vast differences between key state and territory led systems (such as maternal and child health, early childhood intervention supports, pre-school and school, child and family services) that children and their families are navigating. The network anchors would comprise family-led organisations that are inclusive of all disabilities and developmental issues, have wide reach into community, deep understanding of service systems and a recognised state/territory-wide remit.

This network would foster a nationally coherent approach to the delivery of General Foundational Supports for families and carers of children and young people by:

- developing a shared practice framework
 - maintaining a shared contemporary, evidence-informed knowledge library
 - collaborating on content and curriculum for capacity building workshops
-
- operating national communities of practice to share learnings, scale up what is working well and foster innovations
 - providing a national lens on implementation of Foundational Supports across different state and territories and informing and supporting state and national systemic improvements
 - connecting to family focussed supports and resources that are diagnostic specific, culturally specific or place-based being delivered by Aboriginal Community Controlled Organisations, family and disability led organisations
 - fostering and developing a quality family peer workforce
 - monitoring and reporting against a shared performance framework.

The concept of anchor organisations

Anchor organisations are established, well known and trusted institutions with broad community reach that provide a safe, stable harbour to rely on and return to. They lead, foster and maintain strong connections with a rich eco-system of diverse and mutually reinforcing supports for the benefit of the community they serve.

Perth Children's Hospital staff and medical professionals literally walk families over to our peer support team so Kiind can play our distinct part in supporting and equipping families.

Carrie Clark, CEO, Kiind



Change the direction

Currently children who are identified as having developmental concerns, delays or disability are referred straight to the NDIS. To change this one-way direction and for families to be connected with peer based supports (alongside accessing Targeted Foundational Supports or the NDIS as needed) then place-based family-led anchor organisations are needed to provide a consistent point of referral.

Solid Foundations is a model ripe for national application

To address the aspirations and unmet needs of families and carers, CAFDA have developed the Solid Foundations model. Depicted in the graphic below, Solid Foundations reflects the culmination of many years of experience and expertise gained from delivering highly successful, co-designed programs and services that enhance the capacity and resilience of families and carers.

With potential for national application, this model combines six interconnected pillars of support:

1. Warm referrals
2. Peer Worker Advice and Guidance
3. Capacity Building Courses
4. Facilitated Peer Support Groups
5. Volunteer Peer Mentors
6. Self advocacy support

The Solid Foundations offer is aimed at parents and carers of children aged from birth to early adulthood with developmental concerns, delay and disability, regardless of whether they are receiving NDIS funded supports. It is designed to complement and enhance existing supports and importantly, to provide the connective tissue that stops families from falling through the gaps.

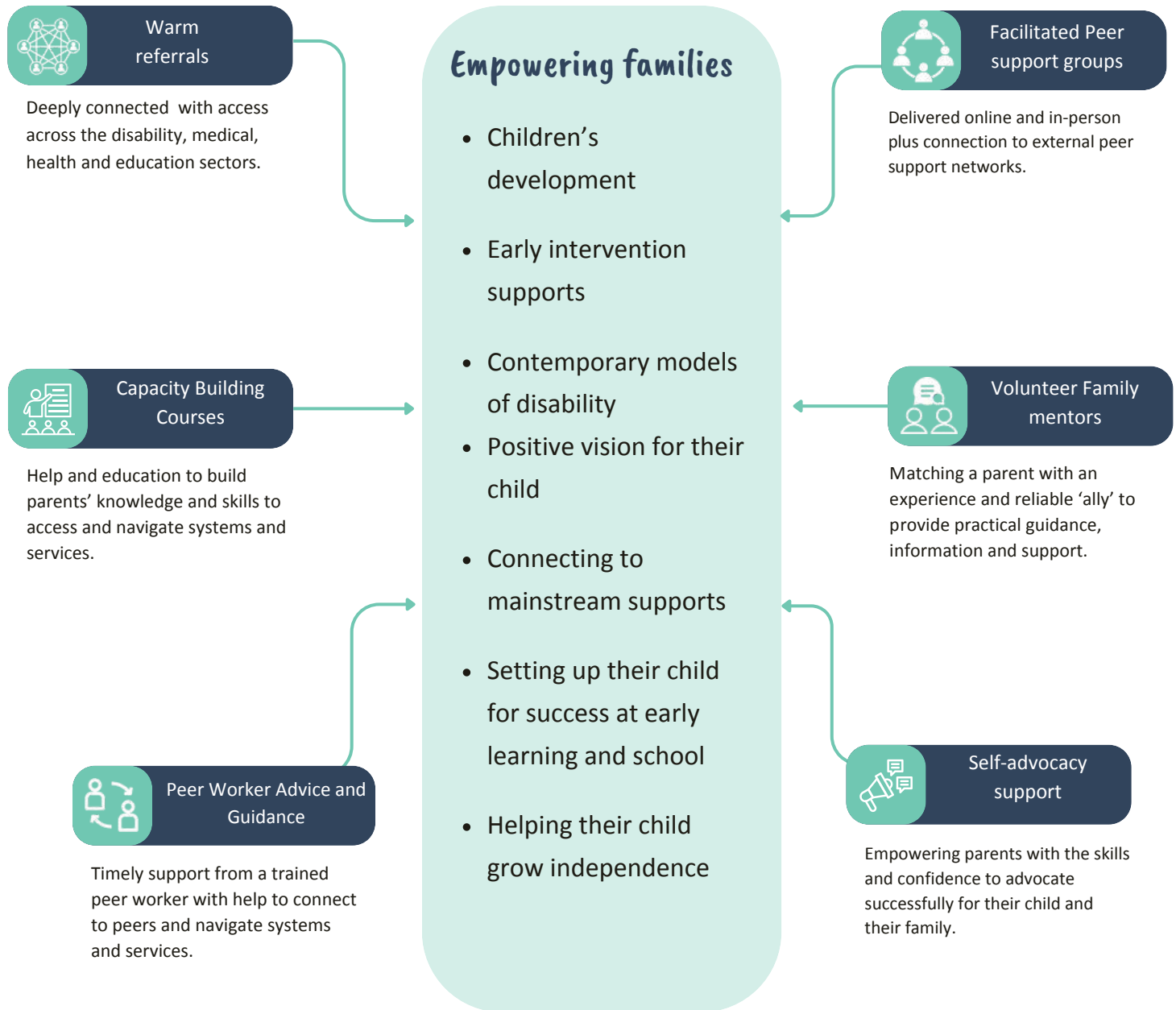
Support options can be undertaken in any mix and order and can be tapped into by families as and when needed.

Such clear advice. I have felt so overwhelmed for weeks and you gave me easy to follow directions for the next steps in our situation.

Parent who participated in self-advocacy coaching, 2024



The Solid Foundations Model



When you're a parent experiencing the greatest depths of grief and fear about your child's wellbeing and future, it means absolutely everything to have a caring organisation that metaphorically puts its arms around you – and sometimes actually.

Professor Andrew Whitehouse,
The Kids Institute



5. A broad, connected mix of family and disability-led organisations are needed to deliver initiatives that are diagnostic specific, focussed on diverse populations or local places

An assortment of tailored offerings that are disability-led, diagnostic specific, directed at a particular population group or particular to a distinct location need to be fostered and promoted. These would augment capacity building efforts facilitated via the proposed network of family-led anchor organisations.

We can point to a range of positive initiatives that need to be embedded as part of a connected and ongoing suite of supports. Below we name just a few of these and explain why.

Autism Connect: a national information and advice service delivered via local partners (led by Amaze) for Autistic people of all ages and presentations, their families, carers and supporters.

The Short Statured People of Australia: a national organisation providing information and peer support and importantly, connecting families to adults with lived experience.

The Roadmap to Healthy Kids: A guide for First Nations families who have a child with disability or developmental concerns created by Kiind and Communicare. This localised, accessible and practical resources has been co-created with First Nations families.

Syndromes Without A Name (SWAN) and Rare Voices – provide tailored information and support for rare and undiagnosed conditions.

Our son has a rare disease, finding and connecting with families like ours has been a gamechanger.

Parent, Kiind consultation, Jul 2024



6. Families need a diverse tapestry of safe and sustainable peer support options

CAFDA hope to see an array of peer support options flourish under the new model: family-led, disability-led, local, diagnostic specific and culturally specific, dads groups, grandparents groups and so on. A mix of delivery models are needed: group based, personalised mentoring, in person, online and social media groups (that are safety moderated).

Investing in key enablers is critical to supporting the safety and sustainability of peer models and the wellbeing of those that lead them. Key elements include:

Funding backbone organisations to assist grassroots groups with development and wellbeing of peer leaders, remuneration of peer leaders, support evidence-based inputs, provide funding and auspice grants, use their channels and networks for promotion and referrals.

Addressing participation barriers – such as the costs or logistics of childcare, for families in need.

Live mapping of available groups relevant to families and carers (could be done by network of family-led anchor organisations) to help families, maternal child health nurses, early learning services and schools and ECI practitioners to boost awareness and promote services.

MyTime. Funded by DSS (as a carers initiative) and delivered by community, family and disability led organisations, MyTime is well regarded. Suggested enhancements for future iterations include a broader range of delivery partners, embedding peer workers as facilitators and greater connection with anchor organisations for family/carers support. A range of more diverse options are sought including: different ages and stages; medically complex; dads; cultural groups and virtual options.

Some notable gaps in current offerings include disability-led peer support for families raising children with cerebral palsy or ADHD.

Peer support... taught me things that I didn't learn from our therapists.
Parent, Kindred, Apr 2024



7. Provide for bite sized family capacity building workshops delivered as part of an interconnected suite of supports

Many families like the flexibility of receiving topical information in easy to digest, bite size sessions, that they can dip in and out of, with no commitment to regularly turning up. In our experience, single sessions/workshops are best situated as part of an interconnected suite of supports facilitated by organisations that families already know and trust.

Key design elements include:

- codesign with families, including identifying topics responsive to family needs and interests
- peer facilitated for safety and relatability
- involving content experts (where relevant) in workshop development and delivery
- a regular schedule of repeat and new workshops that families can dip in and out of when able
- different delivery modes and timeslots to meet different household needs, recordings to allow flexible engagement
- designed to meet different accessibility needs
- built in follow-up with the potential to connect families to further information, advice or supports.

Families consistently identify three broad areas of capacity building they are seeking: understanding of their child's disability; how to support their child's development at home and skills and confidence to self-advocate for their child and family.

Self-advocacy skills workshops in high demand

CAFDA partners deliver more than 100 workshops a year for families, building knowledge, skills and confidence to self-advocate for children to improve education outcomes. These workshops are oversubscribed and highly recommended by families.

Top issues families are telling us they want workshops on:

- self-advocacy skills for education
- sibling wellbeing
- building children's agency
- avoiding family breakdown
- career and financial implications

8. Improve and expand access to disability informed courses and programs aimed at strengthening parent/carer skills

Multi-session structured courses and programs for parents and carers are highly valued, particularly when they are disability informed, targeted, practical and specific. We've received significant feedback on several programs – including some which DSS fund through adjacent programs that are currently under review.

Early Days. This autism specific program (previously funded via DSS) was identified as an important first step for family's understanding of autism.

Now and Next and Envisage – Helping families develop goals and a vision for their child and family.

Hanen Centre programs. The communication and literacy focussed allied health delivered programs have been commended by families across Australia. CAFDA recommends this is upscaled and made available at no cost.

Tuning into Kids and Tuning into Teens. Families suggested that disability informed versions ought to be considered. Current review of DSS Families and Children Activities (through which it is funded) creates a live opportunity for this.

Supported playgroups. Have been widely commended by families as providing real time, practical guidance – particularly where allied health support is embedded. Current review of DSS Families and Children Activities (through which it is funded) creates a live opportunity to expand these.

9. Strengthen the Raising Children's Network and Starting Blocks as the key national platforms for housing information aimed at families raising children with disability.

Families and carers raising children seek information from a wide range of sources. Platforms that families already trust and use provide an important soft entry point to access current and reliable information about developmental concerns and disability and learn where they can go to for further advice and support.

The Raising Children’s Network: This high traffic site has continued to expand and remain current. It incorporates written and video information and houses high quality resources that are generated by peers and professionals, including information on disability and developmental differences. CAFDA see this as the natural platform for housing and linking to information, tools and resources that are supported with government funding (including ILC programs past and future) including resources developed by and for families and people with disability.

Starting Blocks: Many families talked about the challenges and confusion of finding allied health supports, especially at the start of their child’s journey. The NDIS provider finder tool does not offer enough guidance or any information about availability or appropriate expertise.

The Starting Blocks platform is an online directory that helps families to find and assess all ECEC options in their local area, this could be expanded to include registered ECI providers and Targeted Foundational Supports services.

The Carer Gateway and Disability Gateway: Families reported mixed experiences and for some, low awareness of these platforms. Families caring for children often do not identify with the language of ‘carer’ or ‘disability.’ Others reported dissatisfaction with supports received via the Carer Gateway system, which can turn them off using the related platform. For these reasons, CAFDA recommends against repurposing Carer or Disability Gateway as the main platform for information, tools and resources aimed at families.

It shouldn’t be so hard and time consuming to get reliable and practical information and to find services that can help.

Parent, ACD consultation,
Nov 2024



Targeted Foundational Supports for Children

Recommendations: Targeted Foundational Supports for Children

10. Provide demand-based funding so that every child who meets access thresholds can receive support. Guarantee a minimum level of support for each tier of Targeted Foundational Supports.
 - .
11. Ensure that Targeted Foundational Supports improve upon - and do not diminish what is currently available in some states and territories
12. Enshrine strong equity considerations into access criteria for Targeted Foundational supports.
 - .
 - Create streamlined access and referral pathways. Avoid creating administrative hurdles or making access complex.
 - Do not exclude children and families because of their visa or residency status.
 - Proactively design culturally safety approaches for Aboriginal and Torres Strait Islander families.
 - Consider level of family complexity, alongside a child's delay, when determining intensity of support requirements, with default one on one provision where:
 - there is involvement with child protection
 - more than one child in the family has development delay
 - a parent or carer has disability
 - the child is excluded from, or not attending ECEC/school.
 - Allow sufficient time for families to develop trust and relationships with supports.
 - Minimise non-attendance rules that result in families losing access to supports.
13. Require Targeted Foundational Supports to be delivered in accordance with the upcoming Best Practice Early Childhood Intervention Framework.
 - .
14. Allow for children and families to move between different tiers of Targeted Foundational Supports and have repeat periods of support if needed. Support easy movement between Targeted Foundational Supports and the NDIS.
 - .

Ensure that commitments to defer changes to NDIS pathways for children until Targeted Foundational Supports have been tested, implemented and ramped up are honoured.

- 15 Allow for assessments to be cross-purposed and operate as a child's "passport" for access to various supports.
 - 16 Urgently progress NDIS recommendations to support early identification of developmental concerns - including through upskilling maternal and child health nurses and introducing universal and consistent assessment processes, with Aboriginal and Torres Strait Islander adapted approaches.
 17. Embed, where practicable, Targeted Foundational Supports into education settings
-
- 10 Provide demand-based funding so that every child who meets access thresholds can receive support. Guarantee a minimum level of support for each tier of Targeted Foundational Supports.

A support guarantee is needed

We acknowledge that governments are currently negotiating key issues with respect to Targeted Foundational supports for children such as delivery mechanisms; eligibility thresholds; assessment and referral pathways and the intensity and duration of various tiers of support.

It is essential that Targeted Foundational Supports are backed by demand-based funding so that support is available for every child who meets the threshold for access. If capped funding means support places get exhausted, this will rapidly undermine trust and confidence that “lifeboats” outside of the NDIS can be relied upon.

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

Parent, Kiind consultation,
Sep 2024



11. Ensure that Targeted Foundational Supports improve upon - and do not diminish what is currently available in some states and territories

While appreciating that delivery of support may look quite different in different locations, a minimum guaranteed level of support associated with each tier ought to be guaranteed as the basis for a transparent and consistent approach.

Targeted Foundational Supports need to build on and upscale what is already working in various states and territories and avoid reducing or diminishing effective initiatives that already exist outside of the NDIS. For example, WA's Child Development Service provides vital assessment and ECI supports.

12. Enshrine strong equity considerations into access criteria for Targeted Foundational supports

Learning from NDIS experiences, equitable considerations need to feature strongly in the design of Targeted Foundational Supports and be responsive to the many ways in which families may be marginalised, experience vulnerabilities and have difficulties in accessing help.

Learning from NDIS experiences, equitable considerations need to feature strongly in the design of Targeted Foundational supports and be responsive to the many ways in which families may be marginalised, experience vulnerabilities and have difficulties in accessing help. Some key considerations are listed below.

Temporary residents: children should not be excluded because of visa or residency status.

Culturally safe processes: protections for Aboriginal and Torres Strait Islander families that are cognisant of risks of engaging with support and the ongoing impacts of colonisation must be front and centre.

The level of family complexity, alongside a child's delay, should be considered when determining support, with default one on one provision where:

- there is involvement with child protection
- more than one child in the family has development delay
- a parent or carer has disability
- the child is excluded from, or not attending ECEC/school

Allowing sufficient time for families to develop trust and relationships with supports.

Minimise non-attendance rules that result in families losing access to supports.

13. Require Targeted Foundational Supports to be delivered in accordance with the upcoming Best Practice Early Childhood Intervention Framework.

All ECI supports should reflect best practice

Families and carers that we have consulted as part of the ECI Best Practice Review have told us loudly and clearly that they expect all ECI supports to reflect best practice.

It is imperative that the upcoming ECI Best Practice Framework is reflected in the design and delivery of Targeted Foundational Supports for children and the early childhood pathway in the NDIS.

We anticipate a shift to best practice ECI as the norm will deliver significant changes: key worker, transdisciplinary approaches, family and community centred approaches and embedding support in everyday environments. Most of the families we connect having only known the NDIS – with its market-oriented, clinic based and therapy heavy approach. Changes to the way ECI supports are delivered will need to be accompanied by clear and comprehensive information and family-led communication.

14. Allow for children and families to move between different tiers of Targeted Foundational Supports and have repeat periods of support if needed. Support easy movement between Targeted Foundational Supports and the NDIS.

A unified system of support requires easy movement between programs

Families embrace the vision in the NDIS Review for a unified system of support. However, this comes with the significant caveat that children will be able to move seamlessly between gradations of Targeted Foundational Supports and the NDIS, as and when needed.

The pathways between mainstream, foundational and NDIS supports need to be smooth and clear for the local community.

Who is eligible for Targeted Foundational Supports and at what level of intensity, who should go straight to the NDIS and the process to transition a child into the NDIS will be all important.

The NDIS Review recommended that any changes impacting children should not be introduced until iterative and co-designed projects to test reforms are run and Foundational Supports for children and their families are implemented and ramped-up. This absolutely needs to be adhered to.

Likewise, avoiding creating a new gap for children aged nine and over - before Targeted Foundational Supports are developed for this age group are developed - is imperative.

15. Allow for assessments to be cross-purposed and operate as a child's "passport" for access to various supports.

A “passport” to access various supports and reduce red tape would be welcome

A strong message from families and carers is that they are fed up with red tape, long wait lists, stress, trauma and costs of needing to engage in separate assessments - often covering the same content - for access to different programs and services. They are understandably perplexed by the inefficiencies for themselves and a workforce experiencing huge shortages. Of high concern is the impact on their children.

As part of transitioning to the new system, we urge that careful consideration be given to streamlining and cross-purposing assessments where practicable. Providing children with an effective “support passport” that can be used to access various programs would be helpful.

And really think about how and when you do assessments and reports. We need to remember that these are little children, not test subjects.

Young person with disability, Sep 2024



16. Urgently progress NDIS recommendations to support early identification of developmental concerns - including through upskilling maternal and child health nurses and introducing universal and consistent assessment processes, with Aboriginal and Torres Strait Islander adapted approaches.

Early identification of developmental concerns is a priority

The NDIS Review called for Targeted Foundational Supports for children to be closely linked with mainstream services, particularly early years education (playgroups, ECEC, schools) and early childhood services (child and maternal health).

While these interfacing systems are not directly addressed in the DSS consultation papers, there are significant implications for the design and enablement of effective Targeted Foundational supports.

Timely and consistent referrals to Targeted Foundational Supports will be heavily reliant on universal services to identify concerns and refer families for assessments and support. We need to drive a shift away from families feeling like they have to fight to get their concerns acted on and the “wait and see” approach to developmental issues that can be taken by health professionals.

NDIS Review recommendations for a universal and consistent national approach to developmental monitoring and screening, including assessing for developmental delay, need to be urgently acted on. Equipping GPs and child and maternal health nurses, so families are not on long wait lists to see specialists, will be key.

Child and maternal health services vary considerably across Australia. We consistently receive feedback from families about the need to upskill this vital front-line workforce to better detect and understand developmental concern and disability and connect families with information and support.

A way to advance this may be via establishing disability specialist roles (inspired by Disability Liaison Officers in Victoria’s health services system) to rapidly strengthen the capability of the maternal and child health workforce and to serve as a contact point for families.

Culturally safe and responsive approaches are needed to redress structural inequities and ensure they are not further entrenched. We welcome ASQ-TRAK: created in 2023 as a developmental screening tool for observing and monitoring the developmental progress of Aboriginal and Torres Strait Islander children across 21 age intervals from two months to 5.5 years.

17. Embed, where practicable, Targeted Foundational Supports into education settings

Inclusion and engagement in education is a burning issue

Always top of mind for families, driving inclusion in early learning, school and community life is an urgent priority that the Foundational Supports Strategy needs to address head on.

The interface between education funded inclusion initiatives and other disability programs is ambiguous and haphazard.

Families have told us they do not want another siloed program, but rather something that connects with and enhances what already exists in the places they know and go to.

There are good reasons to embed Targeted Foundational Supports into education settings

Embedding Targeted Foundational Supports into early learning and schools aligns with long running calls by families for coordination and collaboration between their child's allied health supports and the early learning environment.

Families have told us of their positive experiences where ECI supports work in partnership with education:

- more consistency for children
- shared strategies and coordinated goals
- educators having greater insight and understanding of child's needs and behaviours
- real-time support for educators from professionals who understand the context and child
- tailored strategies to support children, including identifying and implementing reasonable adjustments, room set-up and ways of addressing challenges before they escalate
- increased understanding between teachers, education support staff and allied health
- removing the need for families to take on the primary role of providing information and education to staff about disability and their child's support needs.

Recommendations of WA's Review of Child Development Services are broadly pulling in this direction. We note that the state government has accepted recommendations calling for extending delivery of Child Development Services in Child and Parent Centres and potentially in ECEC centres and has also accepted recommendations to expand school based allied health services, including mobile allied health services.

The surrounding reform environment can be leveraged

There are significant opportunities to leverage related reforms in the design and delivery of Targeted Foundational Supports for children.

ECEC inclusion: extending the Disability Standards for Education to ECEC and establishing an Inclusion Fund to provide targeted support for children with additional needs has been called for in the Productivity Commission's 2024 Report on the Future of Australia's ECEC system, A path to universal early childhood and care. The Australian Government's ECEC Inclusion Support Program is being reviewed by the Department of Education.

Better and Fairer Schools reforms: are set to deliver increased funding for public schools (to meet the Gonski base Student Resource Standard, including needs-based increments); expand full-service models (schools as community hubs models); increase funding transparency and accountability for disability related spending.

Children and families focussed place-based initiatives: The Investment Dialogue for Australia's Children is currently being established. This government/philanthropic partnership seeks to improve the wellbeing of children, young people and their families in 50 communities experiencing intergenerational disadvantage by 2030. A dedicated Early Years Working Group will collaborate on further establishing and embedding innovative early learning models and integrated approaches to improve early childhood development. This will include a focus on Aboriginal and Torres Strait Islander led approaches, holistic early learning models, integrated services, workforce uplift and full-service school models to support continuity of child development.

Child and Family Hubs are being expanded, including through various state government initiatives. These typically bring together supports across health, education and social care and provide families with opportunity to build social connections. Currently, there are around 450 hubs of various types and sizes providing a local and welcoming 'front door' for families within their community. Hubs are often situated with early years services, primary schools, Aboriginal Community Controlled Organisations and primary health care.

Communities for Children Program is currently being reviewed by DSS.

Community and Workforce

Recommendations: community and workforce

18. Enable and mandate best practice in Targeted Foundational Supports through:
 - commissioning approaches that provide the enabling environment
 - performance, accountability and outcomes measures
 - upskilling professionals and organisations
 - showcasing and celebrating best practice
19. Recognise and invest in the development of the family peer workforce
20. Actively involve families, people with disability and their representative organisations in co-design and governance of Foundational Supports at a local, state and national level.

18. Enable and mandate best practice in Targeted Foundational Supports

Concerted and mutually reinforcing efforts to drive the delivery of best practice ECI in Targeted Foundational Supports are required.

Commissioning arrangements that promote best practice: Service design implications of the commissioning model need to be carefully considered. Informed by lessons from the NDIS, commissioning can either create the enabling conditions for best practice or work against it. CAFDA hope the use of innovative and collaborative commissioning approaches could reverse some of the workforce and service system fragmentation that has followed introduction of the NDIS.

Performance, accountability and outcomes measures that are linked to best practice at multiple levels: professional registrations; individual service agreements; Foundational Support Strategy outcomes measures. We see this as a positive opportunity to deliver more consistent quality, improved coordination, transdisciplinary approaches and create efficiencies for professionals and families.

Upskilling: ECI professionals, the organisations that employ them and the broader community in best practice.

Showcasing and celebrating best practice to make it visible and tangible – so professionals, families and the community know it when they see it.

19. Recognise and invest in the development of the family peer workforce

The family peer workforce has a powerful role to play

Workforce shortages and pressures are widespread across different sectors and parts of Australia. Peer workers play a vital role in equipping families and carers to address the challenges and joys of having a child with disability or developmental concerns, navigating systems and advocating for their needs. At this time of significant change and uncertainty, a capable and connected family peer workforce is needed now - more than ever - to walk alongside families and carers. Pivotal to supporting a smooth transition, the family peer workforce can help identify and address implementation issues, in real time.

CAFDA recommend investing in the coordination and development of family peer workers, through measures such as micro credentials, quality standards and communities of practice that connect family peer workers employed across different settings.

20. Actively involve families, people with disability and their representative organisations in co-design and governance of Foundational Supports at a local, state and national level.

Families and people with disability need to active in co-design and governance

People with lived experience have enormous investment in this change process and have so much to offer through its development and implementation.

Families, people with disability and representative organisations need to be involved and have voice throughout all stages of the journey and at different levels of design and implementation of Foundational Supports: local, state and national.

Collectively, we cannot afford to get this critical reform piece wrong. To this end, CAFDA are prepared to work collaboratively to achieve strong outcomes and look forward to engaging on the next phases of design and implementation of Foundational Supports, including targeted supports for children aged over nine and navigators.

Endorsed by



Amaze is pleased to endorse the CAFDA submission to the Foundational Supports for children with developmental concern, delay and/or disability and their families, carers and kin consultation paper.

David Tonge, CEO, Amaze



Siblings Australia endorses this CAFDA submission and believes the recommendations can help guide the development of quality Foundational Supports for children with developmental concern, delay and/or disability and their families, including their siblings.

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