

# Kindred



Federal Pre-Budget *Submission*

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# About Us

## Empowering parents of children with disability

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 Kindred 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.

## Kindred's work has a positive impact across NSW

Kindred 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 disability 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.

## Kindred 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 the 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 Kindred.





# Executive Summary

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

Kindred's 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 disability 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 Kindred 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 Kindred 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 disability 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.
  - Kindred 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 disability 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 disability, 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 Kindred 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 Kindred. 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 disability delivered by family-led organisations.
  - - See Proposed Projects – Peer Support & Capacity Building for examples of evidence-based support that Kindred is designing (p. 13).
- Change the funding criteria of the ILC Program to include support for 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 disability.
  - Kindred's 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: *Kindred's Western Sydney partnership with Stocklands*

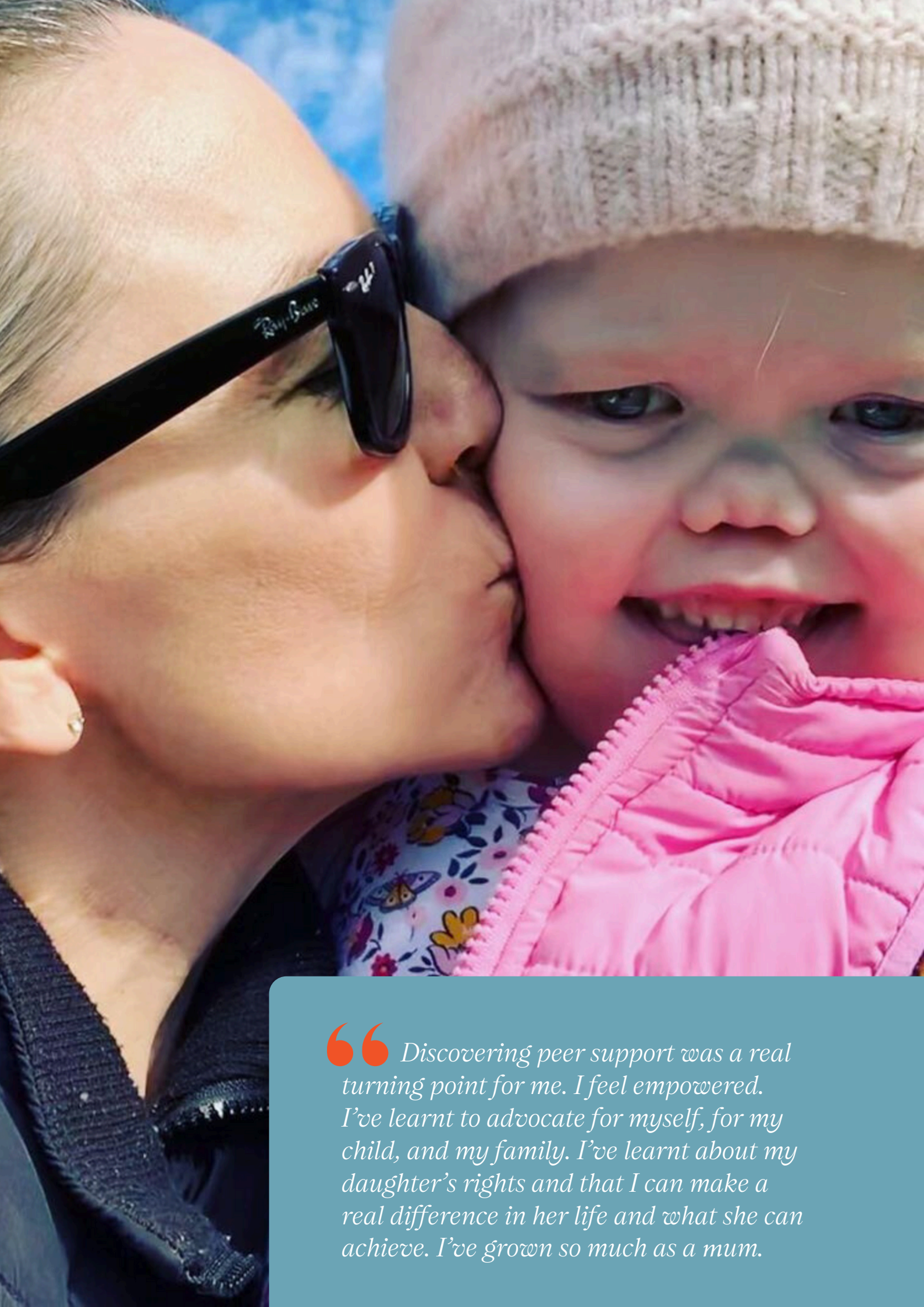
From early 2025, Kindred will launch an innovative six month program to create sustainable community based peer support networks for families of children with disability in Western Sydney.

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 Kindred's 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.

Kindred 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, Kindred 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

Kindred's research shows parents and carers want practical 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 Kindred’s 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.
  - The difference between parenting and caring can be indistinguishable for parents, meaning they do not advocate for themselves as carers to make the critical changes to paid work and health service interactions or seek access to carer focused support.
  - 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 interactions and mastery of multiple complex systems (for example disability, education, health, social services) to ensure their child's access to essential care and support.
- 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 disability 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 disability, 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.
- Kindred's 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*

Kindred 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 packages 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! Kindred 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

- Kindred was established to fill the gap of peer support for families of young children with disability 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, 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.
- Kindred has worked hard to raise the voices of families of children with disability 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 Kindred 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 Kindred’s 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 Kindred, 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 disability.

Kindred's 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, Kindred is ready to partner with the Australian Government to turn this vision into reality.

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When families thrive, *children thrive*



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