CHILD + FAMILY DISABILITY ALLIANCE

Child and Family Disability Alliance submission on:

- Foundational Supports for children with developmental concerns, delay and/or disability and their families, carers and kin.
- General Supports

DECEMBER 2024

kiind.

Association for Children with a Disability

Belongside Families

CHILD+FAMILY
DISABILITY
ALLIANCE

The Child and Family Disability Alliance

We have 80 years of combined experience, supporting 30,000 families raising children with disability across Australia.

The Child and Family Disability Alliance (CAFDA) is a national partnership between three long-established, independent family-led, not-for-profit-organisations.

Our shared vision is to build the capacity and wellbeing of parents and carers of children with developmental concerns, delay and or disability through our well established, robust and proven peer support and capacity building model.

We are well established, well connected, and trusted anchor organisations helping families to connect with one another, find place-based supports and grow their confidence to self-advocate.

Our aim is to empower parents and caregivers with the knowledge and connections they need to manage the complexities of parenting a child with disability or developmental concern/delay so families and children can thrive.

kiind.

Western Australia

With 36 years of operation, Kiind supports 6,500-plus families in WA, with 10-15 new families joining Kiind each week. Based at Perth Children's Hospital, their experienced team all have lived experience and assists families to build capacity, connect with one another and learn through a range of helpful information resources. They also do systemic advocacy to help decision-makers understand the lived experience of families. All services are free.

www.kiind.com.au

Association for Children with a Disability

Victoria

ACD is the leading advocacy service for children with disability and their families in Victoria. Their vision is an inclusive community where children with disability and their families thrive. They're a not-for-profit organisation that for more than 40 years has been led by families of children with disability. ACD provides information, capacity building and advocacy support to families raising children with any disability, from birth to 18, supporting more than 15,000 families a year.

www.acd.org.au

Belongside Families

New South Wales

Belongside Families is a peer support organisation for families of children with disability and helps families to navigate complex disability systems and services to build the skills, knowledge and confidence that will see their children and family thrive. Peer groups and programs, trusted resources and a supportive community are provided free-of-charge and are available online. Belongside Families is passionate to see all children and families live their best lives.

www.belongsidefamilies.org.au

Contents

Child and Family Disability Alliance acknowledges and pays respect to the past, present and future Traditional Custodians and Elders of this nation and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples.

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

4. Underpin the delivery of a 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

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 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 safe 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 is comprised of 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 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 wants to see the Foundational Support Strategy (the Strategy) drive marked stepped 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 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.

Systems outcomes are needed

Systems-related outcomes are noticeably absent in the DSS consultation papers. CAFDA would like to see outcomes related to: adherence to best practice in ECI; shared assessments; interface with education inclusion supports and seamless transitions between the NDIS and Targeted Foundational Supports.

Enablers of effective reform implementation should be tracked

Key enablers of effectively delivering this major national reform should be identified as part of the outcomes framework. Implementation science points to elements such as effective local-state-national co-governance; use of data and evidence to drive improvements; adequate and sustainable funding.

Align outcomes for Foundational Supports with related frameworks and strategies

Outcomes for Foundational Supports aimed at children and their families and carers should strongly interrelate with the upcoming ECI Best Practice Framework.

Outcomes should also be correlated, as far as practicable, with the Early Years Strategy and the National Aboriginal and Torres Strait Islander Early Years Strategy, the upcoming National Carers Strategy, the NDIS and the Supporting Autistic Children Guideline.

Changes families hope for:

I'd like to experience more peace of mind knowing my son is thriving and that the supports are making a positive impact.
Parent, ACD consultation, Sep 2024

The health and wellbeing of the child and the entire family can be impacted when children have delays/disabilities so early supports are so important in maintaining family units, reducing stress as well as skill development etc. are really important.
Parent, Kiind roundtable, May 2024

General Supports

Recommendation: 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
4. Underpin the delivery of a 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
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 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.

> *Families are doing much of the heavy lifting to coordinate different supports.*
>
> ***Parent, Kiind, Oct 2024***

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 experts 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 a 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 by 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

Warm referrals

Deeply connected with access across the disability, medical, health and education sectors.

Capacity Building Courses

Help and education to build parents' knowledge and skills to access and navigate systems and services.

Peer Worker Advice and Guidance

Timely support from a trained peer worker with help to connect to peers and navigate systems and services.

Empowering families

- Children's **development**
- Early **intervention** supports
- **Contemporary** models of disability
- **Positive vision** for their child
- Connecting to mainstream **supports**
- Setting up their child for success at early learning and **school**
- Helping their child grow **independence**

Facilitated Peer support groups

Delivered online and in-person plus connection to external peer support networks.

Volunteer Family mentors

Matching a parent with an experienced and reliable 'ally' to provide practical guidance, information and support.

Self-advocacy support

Empowering parents with the skills and confidence to advocate successfully for their child and their family.

> *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.

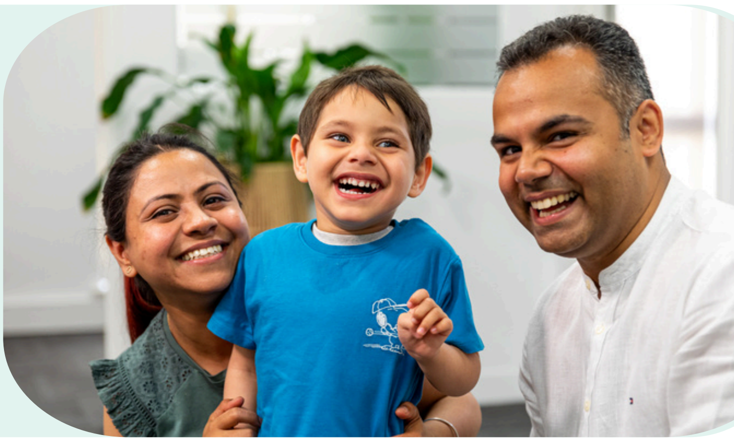
Autism Connect: a national information and advice service delivered via local partners (led by Amaze) for Autistic people of all ages and presentations, their families, carers and supporters.

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/carer 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, Belongside Families

Apr 2024

7. Provide 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 heath 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 are 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 with 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.

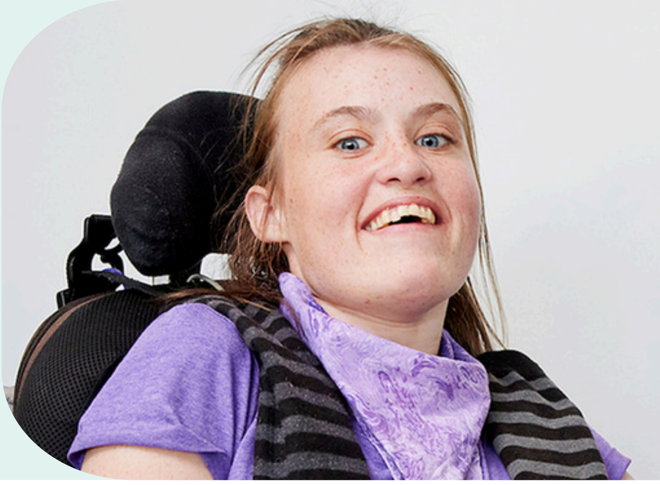
15. Allow for assessments to be cross-purposed and operate as a child's "passport" for access to various supports.

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 Torrest 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 Torrest 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 be 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
Shaping the future for Autism.

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 inc

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.
Dr Shannon Schedlich, CEO, Siblings Australia

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