

Foundational Supports for young children with developmental concerns, delays or disability, and their families

Discussion paper

1st August, 2024

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Preamble

This paper has been prepared by Professionals and Researchers in Early Childhood Intervention (PRECI), the peak body for practitioners and researchers working in the field of Early Childhood Intervention (ECI) in Australia. PRECI is an Australian research-to-practice organisation focused on outcomes for young children with developmental concerns, delays or disability, and their families.

This paper has been developed to assist in the discussions currently taking place within the States and Territories regarding foundational supports. As described below, *foundational supports* is the term being used to refer to supports and services for people who have some level of disability but do not have significant care and support needs that would warrant NDIS funding.

This discussion paper focuses on foundational supports for children aged up to 9 years of age with developmental concerns, delays or disability, and their families.

Background

As originally conceived by the Productivity Commission (2011), the NDIS was meant to be the third tier of a three-tiered system and would cater for those with significant disability. The three tiers were as follows:

- **Tier 1:** *Everyone*. The NDIS would provide all Australians with insurance against the costs of support in the event that they, or a family member, acquire a significant disability.
- Tier 2: *People with, or affected by, a disability*. All governments would continue to support a range of community and carer support services for people with lower level or shorter-term disability.
- Tier 3: Access to funded individualised supports. These would be targeted at the much smaller group of people with significant care and support needs.

Prior to the advent of the NDIS, the states and territories had prime responsibility for ECI services and provided both Tier 2 and Tier 3 ECI supports and services for young children with developmental concerns, delays or disability. When the federal government introduced the NDIS, the states and territories, to varying degrees, stopped providing these Tier 3 ECI services and withdrew much of the various forms of Tier 2 support they had been providing. This left a vacuum, with the NDIS becoming what Minister Shorten dubbed 'the only lifeboat in the ocean' and Bruce Bonyhady called 'an oasis in the desert' – two contrasting metaphors to describe the

fact that the NDIS had become the only meaningful source of support for children with developmental delay and/or disability. The lack of acceptable alternative forms of support for children with developmental concerns / developmental delay or mild/moderate disability led to an unexpectedly high influx of children into the NDIS. As there were few alternative services available, most families wanting support for their child/ren applied for NDIS access. A minority who could afford to do so paid for services themselves.

This is a budgetary problem for the federal government and both a budgetary and a service system problem for states and territories. The federal government's budgetary challenge is how to reduce the costs of the NDIS which have grown well beyond expectation. The budgetary problem for the states and territories is how to fund the foundational supports system. The service system challenge for states and territories is to determine what form foundational supports should take and where they should sit in their respective early childhood education and care (ECEC), health, education, and welfare systems.

Independent Review into the National Disability Insurance Scheme

The need for foundational supports was one of the many issues addressed by the Independent Review of the NDIS (Department of Prime Minister & Cabinet, 2023). In fact, the first of the NDIS review's 26 recommendations was for *the establishment of a separate tier of disability services, to be called 'foundational supports'*, sitting outside the NDIS and accessible to many more people with disability: This was to be part of a continuum of mainstream, foundational and specialist supports to address the needs of all children with disability or developmental concerns. Supports provided outside the NDIS should include:

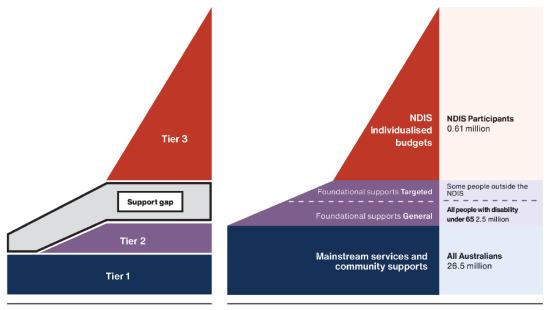
- *mainstream supports* (including early identification of children with developmental concerns, and inclusive education), and
- *foundational supports* (including expanded supports for children with emerging developmental concerns, delays or disability, and relevant programs and services).

Within the NDIS, children under the age of 9 with higher levels of need should receive specialist support through a reformed ECI pathway. This should include an agreed definition of 'likely to benefit', that is, who would be likely to benefit from the specialist support and whose needs could be appropriately met through the reformed foundational supports system. This new tier was to be funded jointly by federal and state governments.

Two levels of foundational supports are proposed:

- *general supports*, available to all children with disability and their families and carers. These supports include navigation support and information and capacity building for individuals, families and communities.
- *targeted supports*, primarily for those children and their families who are not eligible for an individualised budget through the NDIS and are in most need of additional support. These supports include home and community care-type supports, aids and equipment, and early childhood supports.

The relationship between these various forms of services is shown in the following figure which depicts the NDIS Review's vision for an integrated, graduated model of supports for all people with disability.



Current state - Disconnected system

Future vision - Connected, balanced and fair system

Another recommendation of the Review was that federal and state governments should jointly invest in a *capacity-building program for families and caregivers of children with developmental concerns, delays or disability*. This would take the form of universally available family programs which include information, peer support and creating and implementing a vision for their child for a valued and included life. This will mean families have access to timely support, be empowered with information and resources and connected with other families so they can build skills and confidence to support their child. This should be underpinned by building the capacity of mainstream services and practitioners to identify developmental concerns and disability, and providing greater support for families to navigate mainstream, foundational and NDIS service systems.

A further recommendation was that federal and state governments should jointly invest in *early supports for children with emerging development concerns, delays or disability.* This should include support from a skilled Lead Practitioner (and associated team) to help children who are not eligible for the NDIS to build their skills and participate in everyday activities. The Lead Practitioner should provide families with information about child development, building their confidence and knowledge to support their child in everyday routines. It should also include implementing and evaluating a range of other early support models. The delivery of these early supports should be closely linked to and integrated with mainstream services, particularly education and early childhood services.

The full Government response to the Review has yet to be released. However, following the release of the Independent Review, National Cabinet agreed that the design of the additional Foundational Supports would be jointly commissioned (and

paid for) by the Commonwealth and the states and territories. Since then, the government has made a start in addressing some of the Review recommendations, including foundational supports. An announcement from the Ministers Rishworth and Shorten in January stated:

Work will begin on an important Foundational Supports Strategy that will be critical to restoring the NDIS to its original vision of supporting those with significant and permanent disability, within a unified system of support. The Strategy will be considered by National Cabinet in the second half of this year. The Foundational Supports Strategy will be led by the Minister for Social Services Amanda Rishworth in consultation with Minister for the NDIS and Government Services Bill Shorten.

\$3.6 million was allocated to 'undertake design and consultation work on a system of best practice early childhood supports.' A consultation process is being planned and will be announced shortly.

Other relevant government policies and reviews

ECEC and disability services have been the focus of numerous government reviews in recent years. These reviews highlight the issues that Foundational Supports will need to address. They include:

• Review of Best Practice in Early Childhood Intervention (DSS, 2024-25)

This review is in fulfilment of Action 2.4 of the Early Childhood Targeted Action Plan, which is part of the implementation of Australia's Disability Strategy 2021-2031: *Review guidance for best practice in early childhood intervention, seek to review current guidance and prepare a framework for best practice in early childhood intervention that reflects current research and evidence.* The primary objective of this work is to co-produce an Australian Early Childhood Intervention Practice Framework that is founded on the best available evidence and can be implemented and evaluated for effectiveness and impact. The goal is that all children growing up in Australia live in thriving families and communities that support their health, development and wellbeing, and that children with developmental delay/concerns, or disability receive the support they need to participate fully in their families and community.

The review is being conducted by a consortium led by the University of Melbourne in partnership with Murdoch Children's Research Institute (MCRI), Professionals and Researchers in Early Childhood Intervention (PRECI), SNAICC - National Voice of our Children and Children and Young People with Disability Australia (CYDA).

• Australian Consumer and Competition Commission report (2023)

This report focused on the market for the supply of childcare services. The review found that childcare markets under current market settings are not delivering on accessibility and affordability for all children and households across Australia. The report notes that childcare services and government support and regulation (across different levels of government) are highly interconnected. A change to

one aspect of the system can have wide-ranging impacts across the sector. Issues and policy responses cannot be considered in isolation and must be assessed across the whole childcare sector.

Improving Outcomes for All: The Report of the Independent Expert Panel's Review to Inform a Better and Fairer Education System (Department of Education, 2023)

This Review outlines a roadmap to strengthening Australia's school education system, including both government and non-government sectors, to ensure it delivers excellence and equity for the whole Australian community. The Panel recommended seven reform directions to be considered by all parties to the next Agreement, including improving equity. Far too many students face barriers to participation and achievement, particularly those who come from priority equity cohorts, including First Nations students; students living in regional, rural and remote locations; students with disability; and students from educationally disadvantaged backgrounds.

Regarding students with disability, the Panel considered that more should be done to strengthen the quality of inclusive education, and that there is an urgent need to better support students with disability. Governments, school systems and approved authorities must commit to continuing to build the capability of schools and educators to embed inclusive education in their school culture and teaching practices. This would ensure every student with disability receives an education that values their strengths and capabilities. Accordingly, the Panel recommended that all governments, school systems and approved authorities jointly develop an implementation plan to deliver on their commitment under Australia's Disability Strategy 2021–2031 to build capability in delivery of inclusive education for students with disability.

The Panel also commented on the importance of all students coming to school ready and able to learn. To ensure that this happens, the Panel recommended that all governments take steps to embed and strengthen linkages between schools and other services, such as community, family, health (including speech and occupational therapists), and disability support services, by implementing full-service school models that better integrate these services within schools and improve partnerships between schools and external agencies, institutions and community members.

• Review of Inclusion Support Program (Department of Education, 2023)

This review by Deloitte Access Economics found that the Inclusion Support Program (ISP) was aligned with the broader government focus on inclusion and ECEC was not adequately connected or integrated with other Commonwealth and state inclusion and early intervention services or programs.

It found that, although the ISP is intended to develop workforce capabilities of educators, it is not optimised to do so. Instead, the supports provided tend to be interpreted and applied as relief or capacity measures. While ISP is intended to focus on a broad measure of inclusion, the program has a strong focus on

disability and prioritises funding based on diagnosis. Further, it does not effectively allocate resources to proactively invest in capability building, reflective practice and service improvement. Program monitoring has a strong focus on payment acquittal and short-term KPIs; it is not presently focused on outcomes or practice improvement.

• Productivity Commission Inquiry into the Early Childhood Education and Care Sector (2023-24)

Among other issues, the draft report from the Productivity Commission (2023) notes that ECEC services should be inclusive of all children, including those with disability and those from diverse cultural backgrounds. But current government supports fail to reach many children who require them. The report recommends that the Australian Government should significantly increase funding for the Inclusion Support Program and streamline the requirements of the program to expand its reach.

• Safe and Supported: National Framework for Protecting Australia's Children 2021 – 2031

Safe and Supported sets out how all governments, Aboriginal and Torres Strait Islander leaders and the non-government sector will work together to help children, young people and families in need of support. The focus areas are: a national approach to early intervention and targeted support for children and families experiencing vulnerability or disadvantage; addressing the overrepresentation of Aboriginal and Torres Strait Islander children in child protection systems; improving information sharing, data development and analysis; and strengthening the child and family sector and workforce capability. The first of six guiding principles is ensuring access to quality universal and targeted services designed to improve outcomes for children, young people and families.

• Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023)

The Royal Commission concluded that mainstream systems must be significantly reformed to remove substantial barriers to people with disability accessing quality education, employment and housing. The Commission identified a need for specific guidance around early detection of developmental difficulties in Aboriginal or Torres Strait Islander children, and a need to deliver disability-inclusive and culturally safe support services through a trained First Nations disability workforce.

In addition to these reviews, there are several policy frameworks relating to ECEC and disability services. These include:

• National Early Years Strategy (2024-2034)

This is the Australian Government's overarching framework to shape how the Government ensures that all children in Australia thrive in their early years. The aims are to reduce silos across government programs, integrate and coordinate

early childhood initiatives for greater impact, achieve better outcomes for children and their families, and meet Australia's commitments under human rights treaties.

National Disability Strategy 2021-2031 – Early Childhood Targeted Action Plan

The Early Childhood Targeted Action Plan (TAP) focuses on children from infancy to school age with disability or developmental concerns, their families and carers. Key objectives of this TAP are:

- Enable early identification of disability or developmental concerns and develop clearer pathways and timely access to appropriate supports.
- Strengthen the capability and capacity of key services and systems to support parents and carers to make informed choices about their child. (This includes reviewing guidance for best practice early intervention').
- Encourage a stronger sense of inclusion and provide opportunities for parents, carers and children to build peer networks, including for Aboriginal and Torres Strait Islander and culturally and linguistically diverse parents and carers.

• National Autism Strategy

This Strategy, still being developed, will be for all Autistic Australians. It will cover key reform areas including access to services, healthcare, education, and employment. It will help guide a more coordinated, national approach supporting autistic people at each stage of life. The draft National Autism Strategy was released by the Department of Social Services for public feedback in April and it is expected that the final Strategy will be considered by the Government by the end of 2024.

The very existence of these various policies and reviews illustrates a problem: as noted in the Productivity Commission report (p. 53), 'Meaningful coordination and collaboration between jurisdictions and levels of government is missing from the current ECEC policy landscape.' All of these reviews, including the Independent NDIS Review, need to be considered together and a new integrated vision for a truly inclusive ECEC sector developed, along with a new national agreement and mechanism to improve policy coordination and implementation. This is the stated aim of the National Early Years Strategy, but it is not yet clear how that will be achieved. *What is clear is that it would only add to the crowded policy space if foundational supports were developed without reference to these other proposals and plans.*

Considerations

In designing a system of foundational supports, the following issues need to be considered.

Who are they for? There are four groups of children and their families for whom foundational supports should be available:

- Children with developmental concerns
- Children with mild and moderate developmental delays and disability
- Children waiting for NDIS ECI services
- Children with more severe levels of disability

Children with more severe levels of disability should receive NDIS support. However, not all their needs can be met through NDIS funding. They will still need inclusive education opportunities and other supports that are available to children with mild and moderate disability, and their families, and they should still be able to access all mainstream and foundational support services.

The foundational support needs of children are different from those of adults. Half the recipients of the NDIS are under the age of 18 years and the solutions needed for these children and young people, particularly those below school age, are not the same as those for adult participants. What is rarely acknowledged is that the NDIS is essentially an adult service model, and that this model does not work well for young children and their families. Discussions about the NDIS typically focus on the needs of adults with disability, and assume that these recipients are clear about their needs and are able to exercise choice and control in selecting services, supports and providers. This adult model does not work so well with young children and their families who are much less likely to be clear about what their needs are, what their role is, what forms of service and supports are appropriate for their child and family, or how to choose a suitable service provider. This means that foundational supports for these families need to be conceptualised and implemented differently to those for adults with disability.

The importance of early identification. In the early years, the nature and extent of children's developmental problems are emerging and it may be unclear whether the child has a developmental problem or not. There is considerable variation in development during the early years. Some children who are delayed in some aspects of development will catch up with appropriate experiences and opportunities. The earlier such children are identified and supported, the better.

There are also some children who display delays or differences in development as the result of underlying neurological or other impairments. These children may not catch up but may have life-long conditions and support needs. These children need and benefit from services that are knowledgeable about child development and responsive to child and family needs over time. The function of such support is (a) to monitor the child's development, (b) to build the capacity of parents, caregivers and others (eg. ECEC services) to help the children develop the functional skills they need to be able to participate meaningfully in everyday home and community settings, and (c) to refer to appropriate services where required. Building functional skills needs to start as early as possible, so a foundational support system needs to be able to respond promptly to parental concerns and to children with emerging or identified developmental challenges. Again, the earlier such children are identified and supported, the more likely it is that the family and others will be able to provide the children with the conditions they need to participate and thrive. **Taking parental concerns seriously.** Parents are usually the first to raise concerns about their child's development, and these should be taken seriously and support provided at this point. A foundational support system could include various forms of augmented universal services such as a facilitated playgroup or other community-based support. The aim should be to provide parents and caregivers as promptly as possible with comprehensive developmental guidance and support. This support should be available without having to wait and should not be conditional upon receiving an eligibility determination or a designated diagnosis.

Taking professionals' concerns seriously. Parents are not the only ones who may have concerns about a child's development. Others, such as Maternal and Child Health nurses, GPs, childcare providers and early childhood and school educators may also raise concerns about a child, although not all are able to have these taken seriously and addressed. ECEC practitioners, who are the ones who spend most time with young children, sometimes find it hard to have their concerns followed up by other professionals in the system. It is important that all such providers are able to have their concerns addressed and acted on promptly to ensure comprehensive support for the child.

Creating clear pathways to support. The current service system does not provide consistent and reliable ways of responding to parents'/carers' developmental concerns and providing appropriate support. What is lacking is a clearly articulated pathway that describes how children with developmental concerns or disability are identified, how parents can gain access to appropriate developmental support services (foundational supports), and then how they can access the NDIS if needed. The problem lies in the early and middle parts of this pathway – what parents do when they have concerns about their child's development, how the child's development is monitored – rather than the final stages – referral to the NDIA (if needed). The form that these pathways take may vary according to local resources and conditions. There should be a *no wrong door* approach coupled with *soft entry* points to supports that do not require an eligibility determination.

Embedding foundational supports. Foundational supports should be embedded in mainstream settings and service systems and not provided in clinical settings. However, the current service system may not be fit for purpose. One problem is that there are no consistent places where mainstream services are located. There are lots of resources and services but they do not form a coherent service system that ensures that all families of young children get the support they need in a timely fashion. Services are funded and delivered in silos, not in an integrated way that enables them to respond to the needs of families in a holistic way. One way in which this challenge can be addressed is through the development of Integrated child and family centres and hubs. All states and territories have some form of communitybased child and family hubs, but these are not universally available, and vary considerably in what services they provide. These should be developed as standard features of every community that serve both as social hubs (to promote social connections between parents) and service hubs (to simplify access to services and to promote service integration). Such hubs can include mainstream, foundational supports, and tertiary services, and can facilitate the embedding of foundational supports and ECI services in mainstream programs.

Supporting children and families in rural and remote areas. Families living in rural and remote areas are poorly serviced under the NDIS. They may receive funding packages which they may be unable to use because of the lack of appropriate services. This problem is likely to continue unless new funding or commissioning arrangements are introduced to ensure that those living in rural and remote areas have access to both general and targeted foundational supports as well as NDIS services.

Supporting children and families from diverse backgrounds. As society has become more diverse, services have often struggled to meet the needs of families from diverse cultures and backgrounds. As a result, such families can find it hard to access services such as the NDIS, may receive services later and may receive smaller levels of support. Two groups for whom this is true are Aboriginal and Torres Strait Islander families and communities, and families from culturally and linguistically diverse backgrounds. In designing foundational supports, it will be important to consider what adaptations will be needed to ensure that families from these groups have equal access to the full range of supports in a timely manner and that the supports are provided in a way that is culturally acceptable to the families concerned.

Understanding the continuous nature of (dis)abilities. There are no absolute cutoff points for any disability: every disability is a continuum. This means that eligibility criteria are essentially arbitrary and are therefore likely to be contested. It also means that there will always be children who do not quite meet the eligibility criteria for the NDIS. We need a service system that can cater for every gradation of child functioning, not one that only caters for those who are at one end of the continuum and neglects the rest, some of whom will be only marginally less impaired than those deemed eligible for the NDIS. This would involve strengthening the capacity of mainstream ECEC and other services to support children with varying degrees of developmental delay and other developmental challenges.

Promoting the capacity of ECEC services to cater for all children. Several of the key ECEC strategies and reports outlined earlier stress the importance of mainstream ECEC being inclusive of all children, including those with developmental concerns, delays or disability. The capacity of mainstream ECEC services to cater for all children needs to be expanded. This could include use of universal design for learning and multi-tiered systems of support. In the design of a system of foundational supports, a major role for specialist ECI providers and inclusion support workers should be to promote the capacity of ECEC services to be able to meet the needs of all children effectively.

Building a capable workforce. Providing effective support to young children with developmental concerns, delays or disability, and their families, requires a workforce that is appropriately trained and supported. This includes training for mainstream practitioners in recognising children with developmental concerns and responding to parental concerns. Training is also needed for ECEC providers in catering for the full spectrum of abilities, backgrounds and needs. Specialist ECI providers also need training in how to design and provide foundational supports, and how to build the capacity of mainstream services to identify and meet the needs of children with developmental concerns.

Understanding child and family needs. Children with developmental concerns, delays or disability are children first of all and have the same general needs as all other children, including opportunities to participate in home and community settings. However, because of the nature of their developmental difference or disability, they may have difficulties having their needs met, and therefore need additional support or environmental adaptations. These additional supports will vary according to the needs of the child and family but will have a common aim: to enable the child to have the same range of experiences and opportunities as other children in home, community and ECEC settings, and to build the capability and capacity of these universal settings to meet the child's needs. If this is done effectively, there will be no need to channel the children into different service systems.

Similarly, families of children with developmental concerns, delays or disability are families first of all and have the same needs as other families. They need opportunities to be able to participate in community activities with other families, as well as employment. Depending on the nature of their child's disability, they may have difficulty getting these needs met. Again, the services and support they receive should be designed to ensure that these families have the opportunity to participate in community and work settings.

Providing opportunities for inclusion and participation. The NDIS Review noted that there is not enough support for children in everyday settings, where they live, play and learn. Better support is needed in maternal and child health centres, and in integrated child and family centres, so that developmental delay and developmental concerns are picked up as soon as possible and these children get support in these natural settings. Specialist early childhood intervention services should be embedded in these settings for maximum impact.

Number of children and families needing support services. Three-tiered service systems are often framed as universal, targeted and treatment services, with universal services available to the whole population, targeted services for those deemed to be at risk or with short-term needs, and treatment services for those requiring more intensive help. For children, the majority should have their needs met through universal support services, a minority through targeted or second tier (foundational support) services, and an even smaller number will need tertiary level (NDIS) support. There are no fixed proportions that determine the numbers of those in a particular population who need different levels of support. The NDIS Review estimates that 2.3% of the population under the age of 65 will need NDIS support, while 7.1% should receive foundational supports and the remaining 90.6% receive mainstream services. Whether these are appropriate proportions for children under the age of 9 remains to be determined.

Transitioning to a new service system. The transition to a service system that provides general and targeted foundational supports is a major undertaking and will take some time. Many service providers will need to refocus their services, retrain their staff and form new partnerships with other services. This will take time and a phased transition may be needed to avoid too much disruption.

Managing vested interests. Many service providers will have a vested interest in participating in a new stream of foundational support services and funding. Care needs to be taken to ensure that their legitimate needs for an income stream do not outweigh the need to create a system that works for children, their families and communities.

Key issues for discussion

Key decisions need to be made about what form foundational supports should take, who should provide these supports, who should fund them, and where they should be located.

• What form(s) should foundational supports take?

What is known about effective ways of supporting children and families in the early years?

Who should provide these supports?

Is the provision of foundational supports a joint responsibility shared between mainstream and specialist services?

What role is there for health, welfare, education and other services?

Do we need new dedicated providers of foundational supports or should we build upon the services that exist already?

Who should fund foundational supports?

National Cabinet has agreed that the new Foundational Supports would be jointly funded by the states and territories and the federal governments. What should this look like in practice?

• How many children and families will need foundational support services?

How many young children with developmental concerns, delays or disability should receive foundational supports? And how many will need NDIS packages?

• Where should foundational supports be located?

Should foundational supports be co-located with mainstream services? Should there be different locations or arrangements for general and targeted supports?

How can the needs of families in rural and remote areas best be met?

What form should foundational supports take in rural and remote areas? How might these be funded and managed?

• How can the needs of families from diverse backgrounds best be met?

What form should foundational supports for families from culturally and linguistically groups take?

What form should foundational supports for Aboriginal and Torres Strait Islander children and families take?

• How can foundational supports be embedded in mainstream ECEC and other services?

How will mainstream and specialist providers work together? What additional training or resources will be needed to ensure that mainstream ECEC and school services are able to meet the needs of children with developmental disability?

How should foundational supports be accessed?

How can we ensure that any parent with concerns about their child's development or a child with disability is able to access foundational supports in a straightforward fashion?

What skills are needed by those providing foundational supports?

What training is needed for those providing foundational supports?

The ECI sector already has many of the necessary skills. What additional training is needed?

How can the transition to a new service system best be managed?

Should there be a phased introduction of a new foundational supports system? What would this look like?

How can services prepare for the transition?

• How can vested interests be managed?

How can the legitimate needs of current NDIS service providers be managed in a way that does not compromise the development of a system that works for children, their families and communities?

Conclusion

When you build a system for children with disabilities, you build a system that works for all children. (Burchell, 2021)

Getting a comprehensive and effective foundational support system in place would be of benefit to all young children and their families, not just those with developmental concerns, delays or disability.

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