SUPPORT FOR NEW PARENTS AND BABIES IN NEW SOUTH WALES

Organisation: Early Childhood Intervention Australia NSW/ACT

Name: Mrs Margie O'Tarpey

Position: CEO

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Inquiry into support for new parents and babies in New South Wales ECIA NSW/ACT SUBMISSION

ABOUT ECIA NSW/ACT

Early Childhood Intervention Australia (ECIA) NSW/ACT is the NSW/ACT Professional Association that promotes and supports the interests of young children with a developmental delay and/or disability, and their families. Its members are Early Childhood Intervention (ECI) professionals and service providers, including private practitioners, mainstream and early childhood sector organisations. ECI Services are based in metropolitan, rural and remote centres throughout NSW and the ACT and include small community organisations, large disability and children's services agencies and various government departments, reflecting the diverse ways in which services are provided nationally to young children with developmental delays and disabilities and their families. For further detail about ECIA NSW/ACT please see <u>Appendix 1</u>.

RECOMMENDATIONS

Recommendation 1 - We recommend establishing a Taskforce headed up by NSW Government on the most effective way to identify families with complex needs that require a joint multi-agency response, especially children at risk of significant harm.

Recommendation 2 - We recommend additional funding for Child & Maternal Health Services as well as Child Development Services and Community Health Services that provide physical health and mental health services for all children including those children that do not meet NDIS access requirements as well as those that have an NDIS plan.

Recommendation 3 - We recommend that premature babies be tracked and monitored for delays in development in order to put into effect a joint multi-agency response which includes ECEI Providers.

1. The adequacy of current services and structures for new parents, especially those who need extra support, to provide a safe and nurturing environment for their babies We support the principle of universal early identification of delays in development and/or disabilities and access to timely, comprehensive services for new parents and babies. The Early Childhood Intervention sector is reliant on universal early identification and screening services for babies within NSW Health as well as follow-up in home visits with new parents. For a description of ECI Services under the NDIS please see <u>Appendix 2</u>.

We note that ECI services' purview is the child's development, working in a multidisciplinary model to achieve functional outcomes around the following areas of major life activity:

- self-care;
- receptive and expressive language;
- cognitive development; and
- motor development.



ECI Services are not able to directly address a child's physical health, mental health and child protection needs. Where these concerns are present ECI services work together with Community Health, Mental Health and Child Protection services but are not able to provide funded services that are outside the child's NDIS plan.

Following identification we emphasise the need for a rapid coordinated response from an ECEI Provider, heath services, and community services particularly family support services. Coordinated joint service delivery is particularly important when supporting families in complex situations such as domestic violence and homelessness as well as families that have children with delays in development and disabilities.

ECI service providers report that there is great variability in knowledge about the NDIS within each Health District, particularly around the NDIS Early Childhood Early Intervention pathway during the transition to full Scheme NDIS as a means of accessing ECI services under the NDIS. ECI specialist service providers have been funded under the ECEI Approach to support families with children with delays and disability in the community and mainstream and if required to progress on to an individualised funding plan under the NDIS. As such the appropriate referral pathway is to connect the family with an ECEI Provider. Please see <u>Appendix 1</u> for an explanation of the NDIS ECEI Approach and the NDIS Transition.

Please see below comments from ECIA NSW/ACT members about access to Child & Maternal Health, Child Development and Community Health Services:

- In the Sydney metro region there are long waiting lists for diagnosis and therapeutic appointments with Child Development Services and Community Health with referrals to these services often coming back to the originating ECI service.
- ECI Services embedded in rural and remote communities advised us at the ECIA NSW/ACT Managers' Forum attended by 80 ECI services in NSW in October 2017, of limited availability of Community Health services for children age 0-6.
- Across NSW members report long waiting lists for diagnostic appointments with paediatricians and psychologists in metro areas and very limited service capacity in regional/rural/remote areas.
- ECI Services in the Mid North Coast reported earlier this month that the local Community Health service supports children with delays in development and disabilities for 12 months under the SAFE Start Programme before referring out to ECI services.

2. Changes to current services and structures that could improve physical health, mental health and child protection outcomes

Members in the Hunter New England regions have spoken with us about babies that are effectively being relinquished to the Care of the Minister due to family break-down. We believe that it is possible to support the child and family through a coordinated multiagency approach which works across traditional silos between health services, family



support/child protection services, community services and early childhood intervention services.

As each of the four key service systems have undergone significant reforms in terms of their scope, funding mechanism and service delivery modality in the last two years alone; we recommend establishing a Taskforce headed up by NSW Government on the most effective way to identify families with complex needs that require a joint multi-agency response, especially children at risk of significant harm. This approach is preventative of future needs as families with additional needs are identified and supported early, leveraging from the child's early brain growth, before risk of family breakdown.

We recommend additional funding for Child & Maternal Health Services as well as Child Development Services and Community Health Services that provide physical health and mental health services for all children including those children that do not meet NDIS access requirements as well as those that have an NDIS plan.

3. Specific areas of disadvantage or challenge in relation to health outcomes for babies

Universal early identification and screening is especially important for children with hearing and/or vision loss where interventions need to be put into place as a matter of urgency. We note that the Joint Standing Committee on the NDIS published a report in September 2017 on the *Provision of hearing services under the National Disability Insurance Scheme* recommending that children age 0-6 with hearing loss require immediate support and such need to be prioritised for access to the NDIS.

We would like to specifically note premature babies that in our members' experience are often picked up late. We recommend that premature babies be tracked and monitored for delays in development in order to put into effect a joint multi-agency response which includes ECEI Providers.

We note the following groups:

- Young parents that may require additional support to fulfil their parenting responsibilities especially if the child has delays or disabilities;
- Newly arrived migrants specifically around eligibility for access to the NDIS due to the NDIS residency requirements;
- In addition to language barriers, new parents from Culturally and Linguistically Diverse backgrounds may not be aware of early childhood services in Australia;
- Aboriginal &Torres Strait Islander community have a different cultural understanding of disability and childhood development and as a result require tailored response, at an individual family level and the community level;
- Families that have with multiple children with developmental delays and disabilities;
- Families living in remote NSW with poor access to public amenities in ample supply in metro regions;



- Children born into families where there are significant issues centring on intergenerational disadvantage and parental capacity to support child development;
- Parents that require additional support to effectively parent their child due to intellectual or psychosocial disability.

We note that Early Childhood Intervention services provide limited parent support through the child's NDIS plan as part of early childhood supports where the ECI practitioner provides guidance and advice to parents about their child's delay or disability and what to do at home to promote development. If the child 0-6 is not eligible for an NDIS plan, the ECEI Providers, as a first contact agency for families 0-6 interfacing with the NDIS, would refer the child and family to appropriate community and mainstream services including parenting supports through health and community services.

4. Models of support provided in other jurisdictions to support new parents and promote the health of babies

We recommend the drop-in centre model funded by the Australian Capital Territory Government, called the Child Development Service which provides wrap around services for children and parents including allied health, paediatrics and social work. For more information please visit

http://www.communityservices.act.gov.au/childdevelopmentservice/about-us

We also note that it is necessary to complement centre based services with outreach supports that meet the new parents and their baby in the community or in the home; in order to encourage inclusion and opportunity for natural learning from community members.

Under the Stronger Together block funded model many ECI services ran supported playgroups which are delivered by early childhood practitioners and structured around specific lesson goals for the families involved. ECI services also deliver parenting groups and classes for new parents and parents of children with developmental delays and disabilities. However, it is proving difficult to fund such groups with NDIS plan funded supports.

5. Opportunities for new and emerging technology to enhance support for new parents and babies

Some of our members, most notably the Royal Institute for Deaf and Blind Children have been running telehealth services for children age 0-6 and their parents since 2009. Teleschool provides education and therapy services to children with hearing or vision loss in regional and remote Australia, using high quality videoconferencing technology in the family home or other local facilities. For further information please go to https://www.ridbc.org.au/teleschool

Many other ECI services are trailing telehealth approaches to delivering services. In particular, LifeStart have won the 2017 NSW Disability Industry Innovation Award for Excellence in regional innovation for their Online Therapy Program.ⁱ



We note that the applicability of current telehealth programs for babies is yet to be determined and emphasise the need to meet with the child and family in the home environment in order to make a complete assessment of the child's developmental needs. Telehealth is a powerful tool for connecting with families; however we note that it needs to be used on case by case basis as an accompaniment to, and not a replacement of face-to-face appointments.

Given the rapid nature of development in the telehealth space, there is a need for further clinical evidencing of outcomes for children and families using telehealth services compared with face-to-face support. We recommend interfacing with the various Allied Health professional associations around the applicability of telehealth services in their particular field.

6. Any other related matters.

We would like to take this opportunity to thank the Legislative Assembly Committee on Community Services for the opportunity to provide input to this important inquiry and to register our interest to appear at a public hearing. To arrange an appointment please contact Margie O'Tarpey, CEO of Early Childhood Intervention Australia NSW/ACT on 9873 2593 or email motarpey@ecia-nsw.org.au.



APPENDIX 1 - ABOUT ECIA NSW/ACT

What we do

ECIA NSW/ACT leads and strengthens the sector by influencing policy, promoting quality services and building shared understanding of best practice to ensure that ECI practitioners and service providers are able to best support young children with developmental delay and/or disability and their families.

We support practitioners and service providers in their work with families to ensure that families are engaged and gain the skills and confidence in caring for their child and all members of the family.

We promote providing support to children and their families while they are waiting for services to ensure children and their families get support right from the start. We promote best practice principles and provide resources and materials to our members that assist them to provide quality services when working with children and families.

What we support

ECIA endorses a framework of evidence-based practices that promote, encourage and support principles that drive positive outcomes for children and families.

These practices lay the foundation for each individual's successful participation as a valued member within our diverse community. This has been articulated in our National Guidelines: Best Practice in Early Childhood Intervention.

These practices include:

- Family-centred and culturally responsive practice, which creates culturally inclusive environments for families from all backgrounds, and recognises the central role of families in children's lives.
- Inclusive and participatory practice, which recognises that, children regardless of their needs have the right to participate fully in their family and community life.
- Engaging the child in natural environments, to promote inclusion through participation in daily routines, at home, in the community, and in early childhood settings.
- Collaborative teamwork and capacity building practice, where the family and professionals work together as a collaborative and integrated team around the child, to build the capacity of the child, family, professionals and community.
- Evidence base, standards, accountability, to ensure ECI services comprise practitioners with appropriate expertise and qualifications who use intervention strategies that are grounded in research and sound clinical reasoning.
- Outcome based approach, which focuses on outcomes that parents want for their child and family, and on identifying the skills needed to achieve these outcomes.



What is early childhood intervention?

Early Childhood Intervention (ECI) is the process of providing specialised support and services for children age 0 to 6 with developmental delays or disabilities and their families in order to promote development, well-being and community participation.

ECI Services provide parents and families with the knowledge, skills and support to meet the needs of their child and to optimise the child's development and ability to participate in family and community life.

ECI Services provide individually tailored supports to the child including therapy, education, counselling, service planning and coordination, warm referrals to community and mainstream services.

Services are focused on supporting the child in their natural environments and in their everyday experiences and activities.



APPENDIX 2 - EARLY CHILDHOOD INTERVENTION UNDER THE NDIS

The Early Childhood Intervention Pathway for Children age 0-6 under the NDIS The pathway to supports for children age 0-6 is called the Early Childhood Early Intervention (ECEI) Approach which was developed by National Disability Insurance Agency in 2016.

What makes the ECEI Approach unique is that it does not have eligibility requirements other than a concern that a child age 0 - 6 years is not meeting their developmental milestones. The ECEI Provider would use tools such as the 'Ages and Stages', to assess the child's functional developmental needs and work with the family to:

- Explain the nature of the delay and how to support the child at home and in the community
- Refer to relevant community and mainstream supports such as Community Health and Child Care
- Provide interim therapeutic support services and monitor the child's development; these supports are provided in a best practice approach of working with and through the key people in the child's life and in the places where the family/child spend time.

If the ECEI Provider determines that the child requires longer term funded supports and the child meets the eligibility requirements for Developmental Delay under the *NDIS Act 2013*, then the ECEI Provider would start the NDIS access process. Once a child's plan has been approved the family would come back to the ECEI Provider for assistance with implementing the plan.

NDIS Transition for the ECI Sector in NSW

In late 2016 and early 2017, the NDIA established Early Childhood Partners (EC Partners) across some jurisdictions in Australia, contracted by the Agency to provide Early Childhood Early Intervention Services. The NSW transition was different due to the large number of children accessing services funded by the NSW government which needed to transition to the NDIS under the ECEI Approach.

The NSW Government and the NDIA agreed to put in place transitional arrangements through the current ECI service system in NSW. Fifty-four of the 100 ECI Service Providers were selected as ECEI Transition Providers. In line with the Bilateral Agreement between the Commonwealth and New South Wales; Transition to a National Disability Insurance Scheme (Bilateral Agreement), ECEI services were required to prioritise children currently accessing NSW Government ECI services by way of a list of children deemed eligible to access the Scheme, the defined children list. NSW Transition Providers provide ECEI services in a local government area for which they are funded. For the full list of Transition Providers see <u>https://www.ndis.gov.au/ecei/NSWeceiproviders.html</u>

ⁱ Showcasing Innovation NSW Disability Industry Innovation Awards 2017, winners & finalists, National Disability Services, Page 10, <u>https://www.nds.org.au/images/news/NSWDIIA Winners Finalists Booklet digital.pdf</u>