GETTING EARLY CHILDHOOD EARLY INTERVENTION RIGHT

Timely approval of NDIS plans to access essential early childhood intervention and therapy is critical to ensuring the best possible developmental, educational and social outcomes.

Adopting proactive methods to ensure the delivery of more responsive assistive technology, building enhanced capacity of parents/carers to make informed decisions and enabling better integration of NDIS with health and education systems to support children with complex conditions, are issues that require immediate resolution.

The time is now to get early childhood intervention right in Australia.

BACKGROUND

Early childhood is a period of prominent brain development where a child's learning and development is most rapid. Learning and development during these early years has significant impact on the child's future intellectual and functional development. Over the span of the last few decades the sphere of Early Childhood Early Intervention has developed into an effective, research and evidence-based set of practices which, provided at the right time can support the development and well-being of children with disability or developmental delay. There is extensive evidence proving that investment in the early years of children's health, development and wellbeing is the most cost-effective means of managing long-term health conditions and health inequity.

While the NDIA has already undertaken necessary measures to enhance and promote positive ECEI practices, Alliance20 believes that greater learning and collaboration between the disability service sector and the agency can help to mature the ECEI program to its full potential.

CURRENT ISSUES

The NDIS Early Childhood Early Intervention (ECEI) operating model must get the right package of supports to the right children at the right time to maximise their developmental outcomes. At present there are a number of issues with the model:

- **TIME DELAYS** – There are severe time-delay concerns pertaining to the initial steps of the ECEI process. Most significantly, many plans take extended periods of time to be approved. It appears that the more 'complex' the plan (and as such needing higher funding), the longer it takes. Time frames range from 1 day to 6 weeks. The time that a client may stay within the ECEI "gateway" from referral until they get a plan is unclear. In addition, key ECEI service providers in the sector have confirmed that the waiting times to receive confirmed access to the scheme and then the child's first plan is severely high.
  Example: There are 7300+ children who have made access and are currently waiting for their first plan. About 2865 children have been waiting for more than 50

days since their access was confirmed. Alliance20 is aware that the end-to-end process for many families on average is 6 months[1].

- **INFORMATION** - In the face of lack of easily accessible, evidence based, reliable, up to date, comprehensive information on ECEI pathway, the majority of parents/guardians undergo relentless stress and struggles to make information-based decisions on what is best for their child.

- **EQUIPMENT** - Securing adequate funding for equipment for young children or children with very complex physical needs is a challenge prevalent among many participants. This is compounded by lack of information on where the equipment request is in the approval process and delays in outcomes of requests. The timely provision of equipment is essential to supporting children to optimise their opportunities to achieve their goals for mobility, communication and participation.

- **PERSONAL CARE SUPPORT** - There is often inadequate recognition and appropriate funding for young children with complex personal care needs to provide support for parents in the home. Families need to be at crisis point to get these types of supports.

- **MARKET GAPS** – Recent data indicates that the number of children from Aboriginal/Torres Strait and CALD backgrounds who might be at risk of a developmental delay, who may or may not access or get the support of an ECEI partner or any other service to be significantly high. Thus, focus should be given to provide timely, accessible and equitable services to every child in every corner of Australia.

- **QUALITY MEASUREMENTS** - Absence of an overarching quality measurement framework to assess the standard of individual outcomes of children who undergo Early Childhood Early Intervention process remains problematic.

IMPACT STATEMENT

IMPACT FOR PARTICIPANTS

- Limited or no access to specialist planning and support services for more complex conditions

- NDIS plans that do not adequately reflect support needs for both child and family

- Delays involved with determining eligibility, especially for young children under two

- Increased risk of not maximising the critical ‘time’ period in which EI supports need to be delivered, therefore impacting development outcomes

IMPACT FOR PROVIDERS

- Inability to remain viable under current funding model

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[1] Data provided by Project Officer for Waitlist Strategy in NDIS Partner Performance Team.

- Despite a large number of therapy providers registered to deliver services, a high percentage are sole traders with limited capacity

IMPACT FOR THE MARKET

- Specialist providers may exit the market due to funding constraints

- Increased costs to scheme over time if EI supports are not adequately provided

PROPOSED SOLUTIONS

Consideration could be given to:

- Service Design:
  Alliance20 supports the goal of a national approach in this area. ECEI should be timely, family-centred, comprehensive, well-integrated and lead to long term outcomes such as participation in mainstream settings. However, we also recognise the importance of ensuring that children with complex needs receiving both early learning supports along with specialist therapeutic supports as evidenced by best practice and individualised planning. To achieve these outcomes, we strongly recommend that ECEI programs include both Early Learning Supports and Diagnosis-specific Therapeutic Interventions:

    - Early Learning Supports: individual or group programs that support developmental milestone acquisition (that is, enriching and engaging environments and activities that support children and families to develop skills, relationships and resilience) for all children with developmental delay or disability

    - Diagnosis-specific Therapeutic Interventions: Individual or group programs that focus specifically on reducing the impacts of disability (that is specialist interventions that support motor training; spasticity management; AAC; behaviour support; dysphagia management; prescription of specialist equipment, hearing and vision specific services) for children with complex, lifelong disability

- Accessing right equipment at the right time:
  A streamlined process for managing equipment requests that includes a system to track the progress of the request and consider devising a loan pool of equipment to provide timely access to equipment that will meet the changing needs of children. This equipment is often not for long term use and needs to be reviewed and updated regularly.

- Parent support:
  Effective capacity building of parents/ carers and other relevant parties to enable families to access appropriate and timely supports and reliable information from a wide range of sources in order to enhance families' capacity to make more informed decisions and to gain more control over their lives.
  Example: *The agency can adopt to publish in the NDIS website a selected amount of timely research and evidence-based material on ECEI and an updated best practice guide comprising even the most complex conditions.*

- Recognising complexity levels of each disability:

Data indicates children with cerebral palsy require different and specialised interventions. Evidence-based research demonstrates that in other complex conditions, specialist early intervention, for example, using Applied Behaviour Analysis for children with autism leads to better outcomes. It is strongly recommended that children with early identification of life-long disability have access to specialist early intervention that optimises their outcomes.

- Quality measurements:

Assuring the delivery of outcome based, effective ECEI services is the responsibility of not only the NDIA but also the service providers. A20 believes that below mentioned suggestions to be a viable pathway in achieving this end but building a strong work/consultation relationship between the agency and the sector can further strengthen these efforts.

  - As the governing body overseeing systematic implementation of the services provided under the scheme, the agency can adopt to implement quarterly consultations with ECEI service providers to ensure best practise of ECEI, review standards and discuss challenges.

  - Compiling a compendium of resources that can be utilised as a guide to maintain quality and standards of ECEI with input from the sector experts and the agency.

- A mainstream interface:

Consideration must continue to be given to children with complex needs that require specialist supports that assist them to access and coordinate numerous interactions between disability, educational and health settings. Without this, ECEI services cannot be truly responsive or well-integrated and cannot achieve positive outcomes.
Example: *A child with complex health requirements like peg feeding or suctioning as a result of their disability finds it difficult to access basic early childhood education opportunities like pre-schools. To address such issues, the Department of Education, Department of Health and the NDIA have a common responsibility to partner in effective collaborations to make facilities like 'In home care' easily accessible and available without families having to undergo complex and unnecessary intricacies.*

- Integrated support:

Opportunity now with a Commonwealth scheme to ensure that children with lifelong disability can draw from Medicare and NDIS funding in the same plan to ensure seamless and integrated support for the child. This may reduce the need to continually review plans and confirm what will be funded by each scheme.

- A community-based solution for people from ATSI/CALD backgrounds:

Developing an alternative funding mechanism to enable ECEI partner functions to be embedded in Aboriginal and other community based medical services, as children from such backgrounds with development delays and/or disability are more likely to be identified early through these channels.