

GETTING EARLY CHILDHOOD EARLY INTERVENTION RIGHT

With the right interventions in early childhood, the life long future for children with disability will be open to greater opportunities and choices, often with lesser dependence on disability services. A determination to achieving this must be a key focus of the NDIS.

Alliance20 has identified a range of matters that need to be addressed and which it could provide assistance with shaping future approaches. These range from better integration of NDIS with health and education systems to more effective practices and systems.

BACKGROUND

Today, infants with disability do not need to follow the path of earlier generations. To achieve the long term benefits, NDIS interventions at the earliest possible opportunities must be made. We know that by doing so the life long future of children with disability can be full of possibilities and opportunities that have not been available before.

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:

- **NAME OF SERVICE** – the term early intervention is used widely across families, sectors and service providers, and can mean different things to different groups, renaming this program (with an outcomes perspective) may assist and also mitigate confusion and some of the risks/conflicts.
- **INTEGRATED CARE APPROACH** – children with complex needs benefit from integrated approaches to planning and funding services. The current boundaries, roles and responsibilities are unclear and cause stress for families and inefficiencies in services.
- **INFORMATION** - parents/guardians have been confused about the approach; particularly the role of the ECEI Access Partner. Families report frustration with waiting times for plans and confused about responsibilities with state government services.
- **TRAVEL** - best practice for ECEI and therapy includes services in participants' homes or community settings. Without adequate travel funds for a home-based service, quality and outcomes are limited, which have a longer term detrimental effect on children. This is unachievable with the current travel cap and 10 KM travel restrictions. There is also no consideration of travel time in urban versus rural settings. Current arrangements will lead to more centre based services which is not in keeping with NDIS principles and objectives or with evidence on the delivery of ECEI and therapy.
- **EQUIPMENT** - there have been a number of challenges in securing adequate funding for equipment for young children or children with very complex physical needs. 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.
- **PLAN APPROVAL TIME DELAYS** – Many plans take extended periods of time to be approved. It appears that the more ‘complex’ (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.
- 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.

IMPACT STATEMENT

IMPACT FOR PARTICIPANTS

- Limited or no access to specialist planning and support services
- NDIS plans that do not adequately reflect support needs for both child and family
- Delays in 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 model
- 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 should be given to:

- More detailed information and clarification is required on access requirements for infants and small children with neurological and physical impairments.
- 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
- Confirmation that the NDIS is not a diagnosis based scheme and children who would benefit from early intervention supports can receive them on the basis that they meet the early childhood intervention requirements.
 - A streamlined process for managing equipment requests that includes a system to track the progress of the request.
 - Consideration to be given to 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.
 - Consideration be given to providing adequate support to families. Appropriate and timely support for parents with young children can have a significant impact on long term well-being of family and outcomes for the child.
 - 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 child. This may reduce the need to continually review plans and confirm what will be funded by each scheme.
 - Consideration to be given to include state based education funding for disability within the planning.
 - It is essential that service providers ensure that services offered are evidence based and aligned with current research. This requires innovative service design, time and resources to develop and translate to the service delivery environment to ensure that services are sustainable in the current developing market.
 - Data indicates children with cerebral palsy require different and specialised interventions. Data in other diagnostic groups is also indicating specialist early intervention (not generic), 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.
 - Experience of working with parents after an early diagnosis is that in the “hope of a cure” they feel decisional conflict about which interventions to choose for their child. Given their primary source of information prior to visiting a “planner” is unfiltered internet sources, they are buying a mixture of care with their NDIS

funds, some of which is evidence based and some of which can be ineffective or harmful. This is a policy issue affecting the lives of children that we recommend is addressed by delimiting which interventions are allowable within the scheme funding, a system comparable to the Pharmaceutical Benefits Scheme (PBS)