

**Noah's Ark Inc**  
**Submission to**  
**National Disability Insurance Agency**  
**Annual Price Review Consultation**



**May 2019**

## **Submission to the National Disability Insurance Agency (NDIA)**

### **Annual Price Review Consultations**

Noah's Ark welcomes the opportunity to provide comment to the NDIA regarding their annual review of pricing.

Noah's Ark has been involved in the National Disability Insurance Scheme (NDIS) from its commencement, through our services for children in the Barwon and ACT trials. Currently we are involved in the roll out throughout Victoria.

Noah's Ark is a non-government organisation providing early childhood intervention (ECI) services to children with disabilities and other additional needs and their families and carers. Noah's Ark operates from 20 centres across metropolitan and regional Victoria, as well as one centre in the ACT and another in Albury NSW. Last year these programs reached over 2,200 families. Noah's Ark currently receives funding from the Victorian Government (Department of Education and Training) for the delivery of ECI services, and has regional involvement in the Kindergarten Inclusion Support, Pre-School Field Officer and Parent to Parent Programs. In addition, Noah's Ark provides training and resources nationally.

Noah's Ark employs over 300 staff. Since the introduction of the NDIS, Noah's Ark has increasingly supported children in primary school in addition to its previous roles in the early years.

Noah's Ark has been active in the development of services for young children with a disability both in Victoria and nationally and has strong links to the early childhood intervention field internationally.

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## 1. Introduction

Early intervention for children with a disability supports the aim of the National Disability Insurance Scheme (NDIS) to enhance the independence and social and economic participation of people with a disability. Early childhood intervention also fits with the insurance approach of the NDIS as it creates the foundation of a sustainable scheme. Investing wisely in the early years of development has been clearly demonstrated to reduce long-term costs<sup>1</sup>. Early intervention can be powerfully instrumental in giving children and families a strong foundation for later development and participation.

Best practice in early intervention for children has a dual focus – promoting the development and well-being of each child, as well as building the capacity and supporting the wellbeing of their family<sup>2</sup>.

For children, the aim is to promote the child's development of functional skills that will enable them to participate meaningfully in family and community life. Not providing such support effectively can incur costs in several ways:

- In some instances, early intervention can address an emerging developmental problem so effectively that the problem is resolved, and the child no longer needs more intensive levels of support. Without such support, problems will escalate and become increasingly difficult (and costly) to manage, thereby incurring ongoing financial claims upon the NDIS.
- In most instances, children's developmental disabilities are not transient and are sufficiently severe to require ongoing support. Early intervention can ameliorate the impact of the developmental disabilities on children's development and ability to participate meaningfully, thereby reducing the demands on the family and other services, and their associated costs.
- Children with developmental disabilities are at their most vulnerable when they are very young and their relationship with their caregivers is just developing and most at risk of being compromised. The failure of children to develop strong relationships with the key adults in their life has lifelong negative implications.

Overall, the failure to provide effective early intervention for children with disabilities will have long term negative consequences for their development and capacity to participate in the family, education and community. It will result in them needing more costly forms of care and support across the life span.

For families, best practice in early intervention supports family functioning and builds parent capabilities during the difficult period starting from the identification of the child's developmental disability, seeking diagnosis and the realisation of the potential implications of the condition for the first time. The full implications of the child's developmental disability may only become evident over time. Families experience a range of additional stressors,

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<sup>1</sup> Institute of Medicine. (2000). Executive Summary. In J. Shonkoff & D. Phillips (Eds.), *From neurons to neighbourhoods: The science of early childhood development*. Washington DC: National Academics Press.

<sup>2</sup> Early Childhood Intervention Australia. (2016). National Guidelines: Best Practice in Early Childhood Intervention. Retrieved from <https://www.ecia.org.au/documents/item/186> (See Page 10 of this report for excerpt)

including: the need to for more information about their child and what to do; interpersonal and family distress; the need for additional resources and threats to their confidence in parenting the child<sup>3</sup>. The impact of these stressors varies according to the experiences of parents, the size of family networks and the resources available to families.

The stressors experienced by the parents or carers of young children with a disability are on top of the significant demands of raising any young child. They can reduce the ability of families to provide the essential developmental experiences needed by young children to grow and learn successfully<sup>3</sup>. When effective support is not provided, there are likely to be worse outcomes for the family and the wider society. These can take several forms:

- The demands of parenting a child with developmental disabilities often prevent one of the parents (usually the mother) from working, thereby reducing both the family income and the contribution that the family makes to social productivity as workers and taxpayers<sup>4</sup>
- Having a child with developmental disabilities increases the level of stress on parents, leading to a higher incidence of depression and other stress-related conditions, all of which have additional treatment costs to society<sup>5</sup>
- Children with developmental disabilities are more likely to be neglected or abused<sup>6</sup>, with adverse effects upon their development and well-being and higher societal costs in the form of child protection and other services<sup>7</sup>
- In some instances, families find the experience of having a child with a disability so burdensome that they relinquish the child into state care, which has a very high cost.

Overall, the failure to provide appropriate and effective support to families will lead to poorer outcomes for parents and families and additional costs will be borne by the family and the wider society.

Early intervention for young children with disabilities is a unique service because it commences with the identification of a developmental disability, it is the primary support for the child's learning and development, and it provides linkages to a complex set of children's services.

When families experience having a child with a disability for the first time, they need to build an understanding of how best to meet the needs of their child and family. Families must also

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<sup>3</sup> Guralnick, M. (2005). An overview of the developmental systems model for early intervention In *The developmental systems approach to Early Intervention*: H. Brookes Publishing Co.

<sup>4</sup> Australian Bureau of Statistics. (2012). Australian Social Trends. Retrieved from <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features30Jun+2012>

<sup>5</sup> Totsika, V., Hastings, R., Emerson, E., Lancaster, G., & Berridge, D. (2011). A Population-Based Investigation of Behavioural and Emotional Problems and Maternal Mental Health: Associations with Autism Spectrum Disorder and Intellectual Disability. *Journal of Child Psychology and Psychiatry*, 52(1), 91-99. doi:10.1111/j.1469-7610.2010.02295.x

<sup>6</sup> Sullivan, P., & Knutson, J. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, 24(10), 1257-1273.

<sup>7</sup> Moore, S., Scott, J. G., Ferrari, A. J., Mills, R., Dunne, M. P., Erskine, H. E., . . . Norman, R. E. (2015). Burden attributable to child maltreatment in Australia. *Child Abuse & Neglect*, 48, 208-220. doi:10.1016/j.chiabu.2015.05.006

learn how to work with service providers to ensure that these needs are met. When this is done effectively, by the time families leave early intervention, their personal circumstances and skills will have altered dramatically. Most parents should be familiar with the service system, confident in their ability to help their children, able to articulate their needs. They will be able to work with professionals as partners. Early intervention services for young children are effective when they support families gain the skills and confidence they need, over time, to manage their child and family needs.

The principal place young children spend time, and the principal place in which they learn and develop is in the family home. A key role of early intervention services is to support parents and carers to provide the child with appropriate learning opportunities. The time a young child spends with a therapist or educationalist is tiny compared to the time they spend with their family or carers<sup>8</sup>. The important role of families in supporting the development of young children underpins all early childhood policy<sup>9</sup>.

Many young children with a disability will transition quickly through several children's services, including childcare, preschool and school. Staff in children's services may have no knowledge or experience with a specific child's disability. Early intervention plays an important role in supporting different services to understand a child's disability and make adaptations. Importantly it supports continuity in how the child is supported across different settings which is critical to the successful implementation of strategies to support a child's development.

The NDIS has acknowledged that the early years is a specific developmental period with the introduction of the Early Childhood Early Intervention (ECEI) pathway. It is important that the NDIA Pricing Guidelines supports best practice in these services, for example through adequate funding for travel so services can be provided in children's homes or where they spend substantial time. A one size fits all approach for participants aged from birth to age 65 years will inevitably reinforce an adult centric approach. This will conflict with best practice in early intervention for children. It may also undermine family choice.

This submission addresses the following:

- the price control arrangements for Therapy Assistants.
- provider travel
- cancellations
- group and centre-based supports.

## **Therapy Assistants**

The discussion of pricing for therapy assistants invites the question of what types of ECEI and school aged services should be provided under NDIS and why. The lack of publicly available policy articulating why the NDIS is implementing early intervention for children is creating confusion and inconsistency.

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<sup>8</sup> Dunst, C. (2007). Early Intervention for infants and toddlers with developmental disabilities. In S. Odom, R. Horner, M. Snell, & J. Blacher (Eds.), *Handbook of Developmental Disabilities*. New York: The Guilford Press.

<sup>9</sup> Australian Government. (2009). *BELONGING, BEING & BECOMING - The Early Years Learning Framework for Australia*. Canberra: Australian Government

It is our view that the case for the use of therapy assistants has not been established. There is a real risk that price will lead to practices that are not in the best interest of the child.

If therapy assistants are to be introduced, then this should not occur until it can be demonstrated that it is in the best interests of the child. The NDIS needs to have a systematic process for determining how to proceed in this type of situation. A reasonable process would include:

- A review of the research, to determine when the use of therapy assistants is justified
- The development of supervision and delegation framework which identifies how therapy assistants are to be supervised by therapist in order to be effective and what tasks it is appropriate for them to undertake
- Identification of the training needed to work as a therapy assistant, who provides it and how it is funded
- A risk analysis of the consequences of the use of untrained staff, inadequate supervision, poor understanding of the role of the therapy assistants, liability if there are inappropriate actions, the specific risks for young children, the specific risks in the home environment and the capacity of the NDIA market funding and employment structures to limit the employment of inappropriate people
- The development of easy to understand information for parents about if, and when, it is appropriate to use therapy assistants and the risks involved

The therapy assistant role was developed many years ago to support the provision of centre-based group services for children with a disability or developmental delay. Since that time the understanding of how children learn best has developed considerably through both research and practice. It is now understood that children learn through their everyday activities with the people who have significant relationships them, primarily their parents, carers, families, educators and peers<sup>8</sup>. Consequently, the focus of providers of high-quality services has shifted to working in the family home, early education and community settings. The focus of these high quality ECEI providers has also shifted from being directed at groups of children to taking an individualised coaching approach with the key people in children's lives, building their skills and confidence to enhance the child's learning opportunities throughout their daily routines<sup>8</sup>.

The Victorian State Government has developed a supervision and delegation framework for allied health assistants and disability support workers in the context of the move to NDIS funding<sup>10</sup>. This extensive framework provides many case examples and resources to assist individuals and organisations understand their responsibilities regarding these support staff, however many questions remain:

- Part of the rationale put forward for using these support staff is to enable the limited resource of allied health professionals to be stretched further "particularly in rural and regional areas" (p10)<sup>10</sup>. This raises a concern that a lower quality service delivery model may develop to address the issue of thin markets and that country people will end up with a second-rate service.
- Case examples are used to illustrate the use of these assistants but there are no examples of their use in early childhood intervention, just a reference to suggest their role may be "limited to more complex situations" (p12)<sup>10</sup>. Just what tasks might be

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<sup>10</sup> Victorian State Government. (2018). *Amplify: Empowering students through voice, agency and leadership (Draft for consultation)*. Victoria: State of Victoria.

undertaken by staff with limited or even no qualifications with families of children with a disability remains unclear.

- There are a range of responsibilities outlined for the allied health professional who is delegating tasks to an assistant. These responsibilities include but are not limited to running training sessions; providing supervision, support and monitoring; undertaking risk assessments; and documenting plans, programs and evaluations. Some of these tasks are currently unfunded by NDIS, leaving a risk that while the NDIS is saving money on employing cheaper, less qualified staff to undertake tasks that may previously have been undertaken by allied health professionals, those allied health professionals may be taking on a higher burden of unfunded tasks to enable this to happen.
- These new responsibilities for Key Workers such as training and supervision are skilled and responsible undertakings for which organisations are advised that they “should ensure all staff with roles in therapeutic supervision have completed appropriate training” (p79)<sup>10</sup>. Under previous state government block funding arrangements, service provider organisations would set aside a percentage of their budget to provide training for staff. The state government in Victoria as well as many other states and territories often also provided financial support to ensure a highly trained workforce. Funding staff training under the NDIS is far more challenging as a) organisations are experiencing financial strain due to a range of issues including transition costs, inconsistency of income, increased competition, unfunded essential activities, delays in payment etc b) staff do not earn any money while they are being trained so the loss of income in addition to the expense of the training is borne by the organisation and c) state and territory governments have ceased to subsidise training. Training Key Workers to be able to appropriately supervise staff is yet another unfunded training expense. There is risk that in other training needs may be sacrificed in order to meet these new responsibilities thus further eroding the standard of service available when families are provided with professionally qualified staff.
- The assistants themselves have the responsibility for informing professionals when they have insufficient “skills to do a task being delegated to them” (p38)<sup>10</sup>. In a system fostering an increasingly casual workforce it may be challenging for person with limited qualifications or job security to be upfront regarding concerns they may have about their own ability to take on a task being requested of them.
- The support that is being offered to assistants also remains unclear as while the legal responsibility of those delegating tasks and the need for supervision, support and risk assessment is emphasised, examples are provided of supervision occurring “through a 5-10 minute office conversation” (p43)<sup>10</sup> or being provided “via email contact” (p50)<sup>10</sup>.
- The underlying principle of the Key Worker role is to provide one main professional to be the primary provider of services to a family<sup>11</sup>. This is for multiple reasons including to enable the development of a strong, trusting relationship between the family and professional which has been demonstrated to have flow on effects for family relationships<sup>12</sup>. Communication is simplified and the risk of the family receiving

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<sup>11</sup> Alexander, S., & Forster, J. (2012). *The Key Worker: Resources for Early Childhood Intervention professionals*. Malvern, VIC: ECII.

<sup>12</sup> Popp, T. K., & Wilcox, M. (2012). Capturing the complexity of parent-provider relationships in early intervention: The association with maternal responsiveness and children's social-emotional development. *Infants & Young Children*, 25(3), 213-231. doi:<http://dx.doi.org/10.1097/IYC.0b013e318258c63a>

multiple and conflicting messages is reduced<sup>13</sup>. The intrusion into family life is reduced as is the possibility that service provision becomes an additional family stress rather than reducing family stress<sup>13</sup>. This suggested change in service provision to introduce more people into service delivery goes against these aims.

- There is much research indicating that children with a disability have an increased risk of abuse, neglect and exploitation<sup>14</sup>. Any time further people are introduced into the family home, especially to undertake what may be intimate tasks involving dressing or bathing, the risk for the child increases. With research estimating that children with a disability have three to four times the likelihood of experiencing maltreatment than children without a disability<sup>6</sup>, making any policy or practice changes that may enhance that risk need to be treated with great caution.
- Finally, there is the question of control versus accountability. In the current NDIS planning system, decisions regarding what will be funded are made by the planner who may or may not have qualifications and experience in relation to young children with a disability. It is clear from the framework suggested by the Victorian State Government that the allied health professional needs to make decisions as to what tasks may be safe and appropriate to delegate and that they are accountable for this decision. The case examples provided in the framework all refer to block funding for goals. The allied health professional then decides within the scope of that funding as to whether or what tasks may be delegated. They would also need to clearly plan for the related expenses of delegating those tasks such as writing up the program, supervision, monitoring and evaluation and to charge NDIS accordingly. Otherwise we would simply be moving into a system of NDIS planners opting for cheaper, less qualified staff and shifting both the legal responsibility and the surrounding expenses onto financially struggling service providers. How the family retains choice and control also requires careful consideration.

This is not to say that there is no role for therapy assistants in the provision of high-quality adult services, but rather that the scope of that role needs to be carefully determined for children.

## Provider Travel

There is a disconnection between business rules for travel and the implementation of best practice services. For example, best practice in ECEI supports services working with children in their home and in the other places they attend, like preschool and childcare<sup>2</sup>. During the trial phase, there was a recognition that reasonable and necessary travel to the child's home was appropriate and an allocation of up to \$3000 for travel was included in packages. Subsequently, the NDIA introduced standardised business rules across all participants for travel which make assumptions that:

- it is possible to drive at 60 kms an hour throughout metropolitan and regional centres
- it is appropriate to have annual limits, regardless of where a family lives

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<sup>13</sup> Moore, T. (2012). *Rethinking early childhood intervention services: Implications for policy and practice*. Paper presented at the 10th Biennial National Conference of Early Childhood Intervention Australia, 1st Asia-Pacific Early Childhood Intervention Conference, Perth, Western Australia. [www.rch.org.au/uploadedFiles/Main/Content/ccch/profdev/ECIA\\_National\\_Conference\\_2012.pdf](http://www.rch.org.au/uploadedFiles/Main/Content/ccch/profdev/ECIA_National_Conference_2012.pdf)

<sup>14</sup> Jones, L., Bellis, M. A., Wood, S., Hughes, K., McCoy, E., Eckley, L., . . . Officer, A. (2012). Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. *The Lancet*, 380(9845), 899-907. doi:10.1016/S0140-6736(12)60692-8

The limit for children under 7 years was \$3000 and for children aged over 7 years it was \$1000. These rules added costs to the provision of services because they did not reflect actual travel time.

The third iteration of travel pricing was based on journeys in the metro areas taking a maximum of 20 minutes and in rural areas 40 minutes. This assumes that there are multiple services that specialise in working with children within this time frame if parents are to have choice. This is not realistic. Specialist children's services are thinly spread, particularly in relation to specific areas of expertise and outside metropolitan Melbourne. Most families Noah's Ark works with are previous clients under the state system and do not fit within the limits of these time frames. Families choose to continue the relationship they have developed with therapists in our organisation. Unrealistic travel limits considerably reduce family choice.

The latest travel arrangements are also inherently inequitable. It is based on each client paying for the trip from the previous appointment to their premises, except the last client who also pays additionally for the trip back to the office. As therapist often travel a distance to visit three families, then first trip is much more expensive than the second trip. Under this system, the cost of travel for a client in a similar location varies according to whether they are the first, second or third visit. As this sequence may change clients are frequently clarifying why their travel cost has changed. A more equitable approach needs to be developed to share the costs of travel to a particular area. An arrangement needs to be developed so that there are consistent charges for travel to families.

The introduction of the most recent travel arrangements has had serious implications for practice. The changes were introduced with considerably ambiguity about whether a specific allocation for travel should be put in children's plans. This led to some planners stopping putting in travel and reducing plans by up to \$3000. Anecdotally, families have been pressured to travel to centre based services to reduce their travel costs. The NDIA has failed to either clarify this situation or argue the case for change. Family choice has been undermined.

The inadequacy of travel reimbursement has had other serious consequences on practice. Some providers have decided to provide clinic-based services, to which the family travels, in order to be profitable.

Currently, Noah's Ark is unable to claim on average 30% of its staff travel time. This equates to \$21,112 dollars of service delivery time per week or an annual organisational cost of \$1,097,824 for the approximately 1,200 NDIS families it serves.

## **Cancellations**

The current business rules for cancellations is better than the initial rule that service providers could not charge for any cancellations by participants. The new rule allows for the charging for up to 90% of the agreed price for cancellations made after 3pm the day before service delivery and up to 6 hours per year. Noah's Ark appreciates this more generous arrangement and takes its responsibilities to minimise cancellations costs. However, young children, as is generally understood in the community, become ill more quickly and more frequently than older children and adults. As a result, the cancellations policy has a more adverse effect on service providers supporting young children.

The real costs of cancellations for community-based services is the impact of cancellations in relation to travelling to see families. Most days are planned around three visits. If one visit

is cancelled the travel still needs to occur to the location for the other visits and there are limited opportunities to visit other clients. Earlier notice of cancellations would improve the opportunity to address this situation.

The issue of cancellations raises a policy issue for the NDIA. From a financial perspective, a client that cancels frequently becomes a cost and services may be discontinued. However, the NDIS also has an obligation to operate in the best interest of the child. In the interests of the child, it is important to seek out and engage with all families, including families who do not work with services easily. Pricing needs to recognise accommodate the additional time spent with some families engaging them in the use of services for their child.

Many of these families come from low socioeconomic backgrounds and have limited educational backgrounds. Children from such a family will benefit most from early intervention, both in a general sense and specifically in relation to their disability. These families do not fit into a market model very easily, they are not good customers. On the other hand, if these families are not engaged, then the costs associated with the child's disability may escalate through the school years and require other forms of family intervention.

### **Group and Centre-Based Supports**

As discussed in the section regarding therapy assistants, greater clarity is needed in the provision of group-based services. The process suggested in that section is also relevant:

- A review of the evidence
- Identification of any training required to undertake the activities
- A risk analysis
- The development of easy to understand information for parents about if, and when, it is appropriate to use group programs

There are many evidence-based services which can be provided in a group at a centre such as parent education programs. Without a clear explanation, it may be understood that NDIA will fund out-dated practices that are not supported by research.

The current pricing guidelines for group and centre-based supports encourages flexibility. It is not clear how the current price guide supports this. Families and providers need greater opportunity to agree on the cost of a group program.

The most significant change to this area would be if families/ children could be charged for the whole a group program. Most programs run over multiple weeks and as discussed in the section regarding cancellations, there are many reasons why it is very unlikely that a family will make it to every session in a program. Previous federal government funding such as Helping Children with Autism, allowed services to charge for a program rather than just for the number of minutes the family attends. The current situation means there is uncertainty about whether there will be enough attendance to pay for the program. This is a disincentive to running these programs. If it was possible to charge for the program this would create enough certainty for a wide range of evidence-based programs to be offered.

### **Conclusion**

The provision of timely and effective ECEI and school aged services to children has the capacity to make a substantial contribution to the financial sustainability of the NDIS. It is essential that NDIA Pricing supports the best outcomes for children and the high quality, best practice services that will deliver them.

## BEST PRACTICES IN EARLY CHILDHOOD INTERVENTION

### Quality Area 1: Family

**Family-Centred and Strengths-Based Practice:** is a set of values, skills, behaviours and knowledge that recognises the central role of families in children's lives. Family-centred practice is a way of thinking and acting that ensures that professionals and families work in partnership and that family life, and family priorities and choices, drive what happens in planning and intervention. Family-centred practice builds on family strengths and assists families to develop their own networks of resources – both informal and formal.

**Culturally Responsive Practice:** creates welcoming and culturally inclusive environments where all families are encouraged to participate in and contribute to children's learning and development. Practitioners are knowledgeable and respectful of diversity and provide services and supports in flexible ways that are responsive to each family's cultural, ethnic, racial, language and socioeconomic characteristics.

### Quality Area 2: Inclusion

3. **Inclusive and Participatory Practice:** recognises that every child regardless of their needs has the right to participate fully in their family and community life and to have the same choices, opportunities and experiences as other children. All children need to feel accepted and to have a real sense of belonging. Children with disability and/or developmental delay may require additional support to enable them to participate meaningfully in their families, community and early childhood settings.

4. **Engaging the Child in Natural Environments:** promotes children's inclusion through participation in daily routines, at home, in the community, and in early childhood settings. These natural learning environments contain many opportunities for all children to engage, participate, learn and practise skills, thus strengthening their sense of belonging.

### Quality Area 3: Teamwork

5. **Collaborative Teamwork Practice:** is where the family and professionals work together as a collaborative and integrated team around the child, communicating and sharing information, knowledge and skills, with one team member nominated as a key worker and main person working with the family.

6. **Capacity-Building Practice:** encompasses building the capacity of the child, family, professionals and community through coaching and collaborative teamwork. The goal is to build the knowledge, skills and abilities of the individuals who will spend the most time with the child in order to have as great an impact as possible on the child's learning and development.

### Quality Area 4: Universal Principles

7. **Evidence Base, Standards, Accountability and Practice:** ECI services comprise practitioners with appropriate expertise and qualifications who use intervention strategies that are grounded in research and sound clinical reasoning. Standards based on these ECI key best practices will ensure ECI practitioners and services are accountable to continuous improvement and high-quality services.

8. **Outcome Based Approach:** focuses on outcomes that parents want for their child and family, and on identifying the skills needed to achieve these outcomes. ECI practitioners share their professional expertise and knowledge to enable families to make informed decisions. Outcomes focus on participation in meaningful activities in the home and community with outcomes measured and evaluated by ECI services from a child, family and community perspective.

***Early Childhood Intervention Australia***