



ECIA Response to the Long-term Disability Care and Support Scheme

Productivity Commission Inquiry

April 2011

General

Early Childhood Intervention Australia (ECIA) welcomes the opportunity to submit its views on the current issues facing infants and young children who have disabilities or developmental delays and their families. As identified in the Terms of Reference, the NDIS is proposed to include infants and young children with disabilities and developmental delays.

About ECIA

ECIA is the peak body of professionals that promotes the interests of infants and young children with developmental delays and disabilities and their families. Our members are based in urban, rural and regional areas throughout Australia. The association has State and Territory chapters as well as the National body (ECIA Inc). Our central focus is to advocate for the provision of quality, comprehensive early childhood intervention (ECI) services that are accessible on an equitable basis and which offer responsive support to young children with disabilities and developmental delays and their families.

General observations

The provision of early childhood intervention services is a fundamental human right. Intervening early when a concern is identified to support children's development, is not only humane and ethical, but in the interests of the community generally. ECI is evidence based as effective in promoting children's functioning, well-being and learning, their quality of life and sustainable outcomes for children and families. ECIA advocates that governments promote the optimal development of all young children through well-funded initiatives that

effectively support the foundations of learning, family resilience and social inclusion. In relation to the NDIS Inquiry ECIA suggests that:

The applicability of the overall approach of the NDIS to infants and young children with disabilities and developmental delays should be considered separately to, and by a specifically directed inquiry, rather than being treated as if it is essentially the same as for teenagers and adults with disabilities.

1. Creating a system, such as NDIS, which caters for people with all levels of support needs, which is flexible according to individual circumstances, which is a right mostly paid for by automatic community contributions, which removes uncertainty for people with disabilities in need and which is available as soon as needed, is very welcome. The concept of consistent eligibility across the Nation, the ability to move across borders and take funding with them and the no fault insurance would be of benefit.

However, there are some significant ECIA concerns about what is proposed. This is especially true as it is quite unclear how the NDIS might impact on children and families - which children would be eligible for the NDIS and which would not. In turn it is unclear how this would impact the broader availability of early childhood intervention. Without such information, making comment about the NDIS readily descends into an if-then series of propositions. ECIA has endeavored to avoid such pointless speculation and make high level comments only. However, these concerns highlight why a separate inquiry into the issues for infants and young children with additional needs and their families is so important; unintended negative consequences could have such profound effects on the lives of children and families.

2. There is non-alignment with the National Disability Agreement (NDA) Strategic Direction 1 that was signed by Ministers in Dec 2010. In relation to ECI the NDIS does not appear at this point to be in accordance with the NDA commitment to Federal and State Governments working together to coordinate their efforts in the interest of people with disabilities. It is quite unclear how the NDIS would complement the efforts of States in relation to early childhood intervention. Rather than building on state government services, it appears that there may be an idea that early childhood intervention in the States and Territories is a blank slate. There is concern that initiatives such as Local Area Coordination in WA (for example) will be ceased if the recommendation is that services are based on the NDIS model.

There is concern that the State governments may not have any control over funding and administration and therefore may be unable to respond to the specific needs of their State, as well as concern about unintended consequences on the hard won evidence based developments of local early childhood intervention ? services and whether in fact there will be a reduction in State funding and initiatives.

Not all States have services as broken as the ones described in the NDIS document. There appear to be assumptions in the document that are not necessarily based on evidence about the condition of services in all states. ECIA contends that one solution does not fit all across all age groups.

3. In addition, the functioning of infants and young children are best supported when they are optimal in early childhood education and care environments (ECEC), which are generic early learning environments for all young children. It is disabling to these children to separate their therapies from their early education. However, there is a lack of connection between this initiative and COAG's Early Years Reform Agenda, the Early Years Learning Framework and a non-alignment with the National Early Childhood Quality Agenda. Families are being offered choice, but within a narrow range of options. True choice would include all evidence based options (Moore, 2010).
4. Placing families in control of the funds associated with their children has many benefits such as promoting self-control and self-determination, and prioritisation based on the most informed consideration possible of the consequences of decisions for families and the children for whom they are responsible. However, it also creates a number of problems that need to be considered in developing the system.
 - 4.1. When parents first find out that their children have additional needs, most families are not well placed to make informed choices about what will be most helpful. For a start they are generally in shock, and wanting a cure. But in addition they generally lack an appropriate knowledge base. Information about early intervention is new and not in the community generally. So families know about therapies and a medical model, but not about the recent developments in, and evidence informed knowledge base about, early childhood intervention.
 - 4.2. Parents require a considerable period of educational time and opportunities to learn about interventions, including education about the implications of their children's additional needs and careful discussion of their particular family circumstances, to determine what their best choices are for their children's and families' circumstances.
 - 4.2.1. Extensive education about intervention, often experience of types of interventions, as well as increased understanding of early childhood development, disability and the particular needs of their children and their family, are necessary, before most families are ready to make informed choices. This often takes years to achieve. Without this support, families can be left feeling guilty or regretting that they did not make the best use of opportunities potentially available whilst the children were young.

5. Placing families in the position of purchaser tends to create a “purchaser” mentality. That is, the NDIS model could lead families to believe that the Commonwealth was inviting them to buy in expertise external to the family. Early intervention for children relies on parents and carers developing an understanding of the impact of their behaviours and of what they can do as part of everyday interactions with children throughout family and community life, which will have the greatest benefit for children’s and families’ outcomes including on their quality of life. (Dunst, Trivette and Hamby, 2006) The NDIS or any disability scheme needs to build its supports on the current levels of informal care and support, rather than creating an expectation that 'external' services will provide the answers.
6. ECIA requests that the Commission clarify how the special case of infants and young children and the early intervention population in general, fits with the NDIS. For example,
 - 6.1. Which children, is it proposed, will be eligible for NDIS? Will it only be children with the most severe disabilities who get access to NDIS intervention funding (Tier 3)?
 - 6.2. What happens to children with emerging disabilities such as Autism Spectrum Disorder and mild-moderate intellectual disability, which may be described as global developmental delay, early in life? At what point are they eligible for Tier 3 support?
 - 6.3. How does this interface with State/ Territory early childhood intervention systems and funding?
 - 6.4. What is planned to happen to the Helping the Children with Autism (HCWA) and Better Start Initiative (BSI) funding? How will that funding fit with the NDIS or will it replace these initiatives?
7. Early childhood intervention is based on a social-educational model and many current Commonwealth disability initiatives are based on a medical model. A social-educational framework is backed by evidence that environmental interventions and supports (everyday learning experiences and opportunities in inclusive community and generic service settings) are very effective in promoting outcomes. See the Victorian State Early Childhood Intervention Services Reform Stage 2 Revised Literature Review, which was published (Moore, 2010). For infants and young children, the evidence is very strong that supporting their families, their carer-child interactions, and their local neighbourhood services, are crucial to their outcomes and that proactive, preventative interventions are more effective than waiting for delays to emerge. How is this evidence and approach reconciled with the NDIS?
8. As an individual focused, medical-model based initiative, how does the NDIS align with population level initiatives and community support opportunities? It is important that in investigation of the establishment of this initiative it is clear how related approaches will

be affected. It is important that gaps and unintended consequences are avoided or at least minimised, in the establishment of the NDIS initiative. For example,

- 8.1. In the name of providing equity, families of children with more severe disabilities may not receive the amount of support required, or families with complex social needs may not receive the support they need. How will changes in family and child circumstances be managed efficiently?
- 8.2. Children with disabilities and developmental delays are in different circumstances than adults with disabilities, by virtue of their age and developmental circumstances. For infants and young children, even with the most expert assessment, except in the most extreme cases it is frequently not evident exactly how their disability will emerge. Apart from the impacts of genetics and injury, the families' responses to their children's development will shape their experiences, needs and opportunities and therefore how their brains will develop (Schiller, 2010). To that extent how they will develop and function in the face of impairments and disabilities is unknown. The quality of relationships and the way they are engaged profoundly influences the outcomes for and sustainability of development of children (Dunst, Trivette and Hamby, 2007).
- 8.3. ECIA is unclear, and has concerns about, how the proposed NDIS relates to the following important approaches:
 - 8.3.1. preventative interventions especially with at risk populations
 - 8.3.2. evidence-based early childhood intervention
 - 8.3.3. palliative care
 - 8.3.4. family and community support
9. It appears that in the NDIS documents the concept of "early intervention" is used as if it has one set of applications, when in fact it is used in a number of different contexts and with different types of service provision intended/ inferred. The document refers to "early intervention" in several very different contexts, including for:
 - 9.1. Infants and young children and their families getting started in understanding their needs individually and collectively
 - 9.2. People with established disabling conditions requiring additional preventative therapies, equipment and supports
 - 9.3. People who have had accidents or newly established disabilities and who require rehabilitative therapies and/or starting out assistance and support
 - 9.4. The need for ECI is very different from the other contexts and it has different implications for support needs. A unifying national terminology (i.e. ECI) within the framework of NDIS is proposed, so different jurisdictions know what is meant for a set of services for young children with developmental disabilities or delays.

10. What assurances are there that the benefits families will receive under the NDIS will not shrink over time? As with the Medicare funding, when it started the government said there would be no gap in funding. Gradually over time the gap has increased.
11. Some special issues for the interface between NDIS and ECI include:
 - 11.1. ECI needs to be available to those without diagnosis:
 - 11.1.1. Children in a known risk category starting to show developmental delay
 - 11.1.2. Children needing preventative interventions, such as premature infants who have had a brain hemorrhage during or shortly after birth
 - 11.1.3. Children in families who are unable (or unwilling) to obtain a diagnosis quickly
 - 11.2. The rationale for this is preventative. These known risks lead in the vast majority of cases to disabilities or developmental delays. So to wait until greater problems have emerged is inhumane, unethical and ineffective, leaving children and families at significant risk of poorer outcomes than might otherwise be achieved. (Shonkoff and Phillips, 2000)
 - 11.3. ECI needs to be available to children whose families don't seek it out actively, so that the children's individual rights are preserved when at all possible. Some families including those avoiding acknowledgement of their children's disabilities and families in which the disability has been accommodated to an extreme extent, do not seek out supports. Hence, they are unlikely to seek out opportunities for their children if they are not organised for them. How will this be managed within the context of ECIS and NDIS? How can the children's disadvantages be minimised with the new systems?
 - 11.4. The socio-economic and parental educational backgrounds of families of children with disabilities and developmental delays are disproportionately low in relation to the population as a whole (Hemmeter et al., 2004). People with low socio-economic backgrounds, educational disadvantage and disability in themselves are least able to advocate on behalf of their children. These families are likely to be the least clear about their children's and families' needs and especially vulnerable to exploitation through commercial arrangements since they may be least educated about how to evaluate and most subject to emotion based decisions.

It has been suggested that Case Managers will help this process. However, this puts undue influence into the hands of Case Managers, who are of great assistance, but much better informed about disability services than early childhood intervention at this stage. To preserve the rights of children and their families and to avoid undue influence of individual case managers, significant education of parents and carers is required in order for them to be able to make informed choices. However, this would need to be a condition of services, as few families in such circumstances would seek out and choose education and information for themselves as part of a

package of support services. In addition, there would need to be provision for Case Managers to be kept up to date with the ECI literature and all available supports (which are quite separate from disability literature) to be able to support families to make fully informed choices.

12. The circumstances of children with additional needs are usually unclear at first, so what is required is often highly variable. In addition, families can change their minds frequently about their priorities and needs. So without highly adaptable support funding families may be less committed to goals than is desirable. This is evidenced in the case of the HCWA funding as reported in the reviews currently being undertaken. These reports to the HCWA inquiry should be considered when seeking to understand the possible potential intended and unintended impacts of the NDIS on what is available in early childhood intervention supports for infants and young children with additional needs and their families.
13. The provision of ECI is of a complex set of interrelated services depending on needs of children, families and circumstances. Services are best provided through providers working together collaboratively. Competing for funds does not make for the openness in collaboration most likely to be of assistance to families, and can lead to “cartels” of commercial providers and other arrangements which actually reduce family choice.
 - 13.1. How will such problems/ practices be minimised through the NDIS scheme?
 - 13.2. What will happen to small service providers who are likely to be especially vulnerable to the uncertainties of the market?
14. EC Interventions include but are not limited to interventions directed to promote the children’s functioning in home and community settings, resources such as equipment, family support services, parent-child interaction support services, counselling and consultation to generic services to promote their supports. These are most efficiently delivered through professional staff working very closely together.
 - 14.1. So there are a number of important services typically required in ECI that are not listed under the NDIS. How would they be provided if not under the scheme?
15. Early intervention services are relatively underdeveloped, being recently established, and evidence of what are the most effective intervention practices is being developed rather than having been well established for many years. Having access to funds does not mean access to services in ECI. Especially in rural and remote areas funding does not mean being able to access quality services. What initiatives are proposed to ensure coordinated practice and professional development is available?

At present early childhood intervention practices and processes in support of children and families are rather scarce, evolving and needing further development. The pre-

service training is often not at best practice level and in-service training needs to be made available systemically and in a planned fashion. In-service training available to professionals needs to be updated very regularly through a variety of techniques to be most effective in achieving practice developments and change. The varied techniques include lectures, mentoring and supervision coordinated to promote current best practice. (Dunst, 2010)

16. The confusing nature of the service system is the product of a combination of circumstances. Children and families using early childhood intervention have had very restricted available funding, and governments wanting to re-badge initiatives each time federal or state governments change or when budget initiatives are announced.

16.1. It is unclear that the NDIS will address making a comprehensive service system. In fact, it is highly likely that the limited supply of high quality practitioners will most likely follow the high incidence areas of need for service and those with the greatest return on investment for practitioners. Families with children with some disabilities may end up being under-resourced by a private practitioner system, thus defeating the purpose of the scheme, unless this eventuality is specifically planned for.

16.2. Is it intended that the States' systems will make up the gaps? If so, why would they? What agreements are proposed to ensure that this could eventuate?

17. There are concerns about the International Classification of Function for Children and Youth (ICF-CY), which is suggested in the NDIS. It appears that the focus in the NDIS is on medical diagnosis and not the well established WHO disability domains of function, activity and participation. It is therefore unclear how it is proposed to use the ICF-CY. In addition, whilst at this moment the ICF-CY is an extremely promising tool in development, in our opinion, it is not yet at a stage to be utilised effectively for the classification purpose with infants and young children, in contrast to its development with adults and teenagers.

Conclusion

There are many issues associated with including children currently eligible for ECI under the NDIS. These need specific investigation. Waiting lists for ECI are unacceptable and yet very frequent, so additional funding would be of great benefit. However there are many questions to be asked and possible drawbacks to the additional funding potentially available through the NDIS. The unintended consequences of including infants and young children and their families under the NDIS may effectively undermine already under-resourced and fragile supports, and have a large number of unintended negative consequences.

ECIA National and States/Territories proposes that the NDIS undertake an investigation with families and professionals of the unique characteristics and circumstances of the ECI population and system prior to planning and implementing specific NDIS and/ or ongoing ECI arrangements for the ECI population.

References

- Dunst, C J (2010) "Professional Development in Early Childhood Intervention – Factors Affective Effectiveness – Participatory Adult Learning Strategy (PALS)" Presentation at the Convention and Exhibition Centre, South Wharf in Melbourne, Victoria, 11th August
- Dunst CJ, Trivette CM, Hamby DW, (2007) "Meta-analysis of family-centred helping practices research", *Mental Retardation and Developmental Disabilities Research Reviews*, 13(4):370-378.
- Dunst CJ, Trivette CM, Hamby DW (2006) "Family support program quality and parent, family and child benefits", Asheville, NC: Winterberry Press; Winterberry Monograph Series.
- Hebbeler, K et al (2004) "National Early Intervention Longitudinal Study - Demographic Characteristics of Children and Families Entering Early Intervention – Executive Summary" <http://www.sri.com/neils/reports.html>
- Hebbeler, K, Spiker, D, Bailey, D, Scarborough, A, Mallik, S, Simeonsson, R, Singer M, Nelson L (2007) "Early Intervention for Infants and Toddlers with Disabilities and their Families: Participants, Services and Outcomes - Final Report of the National Early Intervention Longitudinal Study (NEILS)" <http://www.sri.com/neils/reports.html>
- Moore, TG (2010) "The Victorian Early Childhood Intervention Stage 2 Literature Review Revised" <http://www.eduweb.vic.gov.au/edulibrary/public/earlychildhood/intervention/ecislitreview.pdf>
- Schiller, P (2010) "Early brain development research review and update" http://www.ecementor.org/articles-on-teaching/Early_Brain_Development_Research_Review.pdf
- Shonkoff, J and Phillips, D (2000) "From Neurons to Neighbourhoods: The Science of Early Childhood Development" published by the USA National Institute of Science in 2011 at <http://www.nap.edu/openbook.php?isbn=0309069882>
- Trivette, C and Dunst, CJ (2009) Community Based Parent Support Programs at <http://www.child-encyclopedia.com/en-ca/parenting-skills/according-to-experts/trivette-dunst.html>