

The NDIS and young children with developmental disabilities: Basic principles and major challenges

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OUTLINE

- How children learn and develop
- How children with disabilities develop and learn
- Families of children with disabilities
- Role and rationale of early childhood intervention
- Evidence of efficacy of early childhood intervention
- Implications for NDIS
- Major challenges
- Conclusions

There is also a Postscript containing reflections on all the presentations at the Forum.

HOW CHILDREN LEARN AND DEVELOP

- Children's development is shaped by the social and physical environments in which they spend their time
- Initially, children's main learning environment is the family, with early childhood programs and community settings playing an increasingly important role as they grow older.
- Relationships are the primary medium through which young children learn the skills that enable them to become fully participating members of society.
- The quality of the relationships and the range of experiences provided in each of these settings are what shape children's development and determine their well-being
- Children learn through 'massed practice' – having multiple opportunities to practice functional skills in everyday environments.
- Children also learn through participation in everyday activities and environments participation is vital to the health, development and quality of life of all children.
- Participation in these environments is the context in which children form friendships, develop skills and competencies, build mental and physical health, and determine meaning and purpose in life.

- Participation enables children to understand societal expectations and gain the physical and social competencies needed to function and flourish in their homes and communities.
- ***Meaningful participation is the engine of development and the key to attaining a true sense of belonging and a satisfactory quality of life***

HOW CHILDREN WITH DISABILITIES DEVELOP AND LEARN

Do children with disabilities learn in the same ways?

- Children with developmental disabilities have the same needs as all children – needs for attachment, nurturance, emotional responsiveness, care, safety and security etc.
- These crucial relationships qualities have the same impact on their development as they do on other children
- However, children with disabilities may have difficulty having these needs realised because of the nature of their disabilities – they may initiate interactions less frequently and give cues that are more subtle and difficult to read
- Children with disabilities may also have reduced access to the range of environments and experiences that other children have, and fewer opportunities to participate

FAMILIES OF CHILDREN WITH DISABILITIES

Do families of children with disabilities have the same needs as other families?

- Families of young children with disabilities have the same core needs as families of children who do not have disabilities – needs for social support, sufficient basic resources, access to information and services etc.
- However, families of children with disabilities can have difficulties in having these needs met
- Some of these difficulties are systemic: delays in having the child's developmental problems recognised, delays in receiving help, limited choices of services etc.

Some of the difficulties are at the personal level

- Personal challenges faced by families:
- Likely to be experiencing some distress and confusion
- Not knowing the system – what services exist, what the choices (if any) are
- Not knowing what the services provide – what to expect
- Not knowing what their role is – passive recipient of expert advice or active participant as equal partner
- Not necessarily being sure what their needs are - what they should be focusing on first

- Lacking the information they need to make fully informed decisions
- Lacking confidence in their own abilities to meet their child's needs

While professional help can be very helpful to families, it can also create problems for them. This can occur in several ways:

- when it is delivered in ways that make parents feel disempowered,
- when services do not consider the demands they are making on families, and
- when services are hard to access or poorly coordinated.

ROLE AND RATIONALE OF EARLY CHILDHOOD INTERVENTION

- While ECI providers can play an important role in supporting children with disabilities and their families, they have a limited role to play in the everyday lives of these children
- ECI providers have limited direct time with children with disabilities and their parents and therefore are not one of the main providers of early learning environments.
- The bulk of the child's learning occurs between home visits or other sessions with professionals, not during them.
- Therefore, individual therapy cannot be a major driver of development – what drives development is children's meaningful participation in everyday activities and environments

The overall aim of early childhood intervention is ***to ensure that the parents or other key caregivers are able to provide young children who have developmental disabilities with experiences and opportunities that help the children gain and use the functional skills they need to participate meaningfully in the key environments in their lives.***

EVIDENCE OF EFFICACY OF EARLY CHILDHOOD INTERVENTION

What services are provided

The evidence indicates that families benefit when ECI services provide a range of supports and services, including

- emotional support from family, friends, and professionals
- information about their children's disability and about relevant services
- help in learning their role in relation to ECI services
- strength-building and empowerment strategies to help parents develop the capacity to meet the children's needs
- practical support to help families meet the additional demands and resources associated with having a child with a disability
- timely diagnosis, assessment, monitoring and feedback

How services are provided

The evidence also indicates that the manner in which services are delivered matters. Key features of how services are delivered include:

- Above all, effective services are relationship-based – that is, based on a relationship between services providers and parents that is genuinely respectful and partnership between parents and service providers
- Effective services are based on the family's most salient needs and take account to the family circumstances
- Families make the final decisions about what issues to work on what strategies to use
- Services must be flexible, adapting to changing family needs and circumstances
- Effective services acknowledge and build on existing family strengths and resources

IMPLICATIONS FOR NDIS

What NDIS funds and the way in which the funding is distributed must serve the overall purpose of early childhood intervention: ***to ensure that the parents or other key caregivers are able to help the children gain and use the functional skills they need to participate meaningfully in the key environments in their lives.***

- *What* services are delivered must be proven to be effective in achieving this aim
- *How* services are delivered must also be based on what is known about effective ways of delivering support

The way in which the NDIS distributes funds must also serve the aims of ECI services.

Most importantly, the system of distribution must do no harm, eg. it should avoid adding to family stress.

Instead, funds should be distributed in ways that ensure that

- families are provided with all the information and support they need to make informed choices
- families are provided with options to meet their personal circumstances and preferences
- families are helped to become competent and confident managers of funds and services over time

MAJOR CHALLENGES

There are a number of practical challenges to be faced in implementing the NDIS – eg. integrating NDIS funding with existing state-funded services. These will be addressed by others at this forum.

Three other challenges: evidence-based practice, parents managing funds, and teamwork.

Evidence-based practice

- In reviewing the evidence for effective interventions, we need to consider both what is delivered and the way it is delivered – most analyses of evidence-based practice focus only on the former
- Evidence-based practices are not value-neutral – they are a means to an end, and the end or outcome always involves value judgments
- It is possible for an evidence-based intervention to be effective in achieving an outcome that is not desirable or that achieves its effects in a way that is undesirable
- This is a debate that the ECI field has yet to have

Managing funds

- A feature of the NDIS is that people with disabilities and their carers should have control of the funding
- However, when parents start out on their journey, they are not well placed to be able to make sound decisions about their own needs or those of the child, or about what forms of service would best meet these needs
- It is unreasonable and potentially harmful to expect them to be able do so from the outset – gradually phasing in responsibility for funding would be preferable
- An important role of ECI services is to progressively build the parents' knowledge and skills to the point where they are able to manage the funding effectively

Teamwork

- Families of children with disabilities often have to deal with multiple professionals and services, and can find this an additional source of stress and confusion
- Evidence indicates that parents prefer working with a primary service provider and that transdisciplinary or key worker service models result in better outcomes
- However, many professionals find the idea of such arrangements challenging and contradictory to the models of service in which they were trained
- The ECI field needs to resolve this issue, clarifying what these different models of service involve and under what circumstances they should be used

CONCLUSIONS

Conclusions for families

- The environmental experiences that you provide your children, not those provided by ECI professionals, are what shape their development
- However, ECI professionals can be enormously helpful to you in designing and providing such environments

- Best practice models of early childhood intervention are based on partnerships between professionals and parents through which parents become increasingly proficient at articulating their needs and negotiating the services to meet them

Conclusions for early childhood intervention practitioners

- ECI services should seek to progressively build parental confidence and competence in knowing what works best for them, what services they need to achieve their preferred goals, and how to manage the funds for such services
- The ECI field needs to clarify its understanding of evidence-based practices and how these relate to parental values and outcomes
- The ECI field also needs to build its understanding and ability to use different models of teamwork to suit different family needs and circumstances

Conclusions for NDIS and other policy makers

- What the NDIS funds matters – funding services that do not achieve the overall aim of early intervention services or that do not do so effectively is at best a waste of money and at worst counterproductive
- How the NDIS distributes its funds also matters – this needs to be done in ways that do not add unintentionally to family stress
- The NDIS should explore ways in which to progressively build parent capacity to manage NDIS funds to best effect

POSTSCRIPT

The following suggestions have been added after hearing all the presentations at the Forum.

Recommended actions for the ECI sector

In the light of the challenges identified by those involved in the NDIS pilot sites, there are some steps that the ECI field should consider in order to ensure that the integrity of ECI services is preserved.

- ***We need to monitor the effects the roll-out of the NDIS on families of young children with disabilities and on ECI services.*** To do this, we should specify what the experience of ECI should be for families and check to see if what is being provided has these effects. We might also conduct a series of short-term field experiments to explore the impact of different service models.
- ***We need to articulate and agree upon best practice model(s) of ECI service.*** At present, there is no agreement about what constitutes best practice, or practices are best suited to different family circumstances and preferences. We need to translate ECI principles into set of key general criteria, then rate the various forms of service being funded by the NDIS against these.

- ***We also need to articulate and agree upon a service framework that best achieves the goals of ECI.*** This should describe the journey that families make, from diagnosis to transition, and what forms of service they might receive at each stage. This can be used to rate the various forms of service funded by the NDIS.
- ***Finally, we need to articulate and agree upon what outcomes ECI services are seeking to achieve.*** This is necessary if we are to demonstrate that ECI services make a difference (eg. that they help children be more ready for school, or that they enable families to meet their children's needs more effectively).

Key features of NDIS-funded interventions

At the very least, the interventions or services funded by NDIS should be able to demonstrate the following characteristics:

ECI services or interventions should

- offer support to whole family, not just child;
- work with all children's key environments, not just the home environment;
- focus on changing key environments rather than directly changing children through therapy;
- provide families with choices (of agencies, models of service etc.);
- promote family competencies;
- avoid doing harm (eg. by adding to family stress);
- use practices known to be effective in building the capacity of caregivers to promote children's meaningful participation in everyday environments
- be staffed by practitioners who are trained in relationship and strength-based skills

RELEVANT LITERATURE

This paper draws upon the following papers:

Centre for Community Child Health (2011). **DEECD Early Childhood Intervention Reform Project: Revised Literature Review.** Melbourne, Victoria: Department of Education and Early Childhood Development.

<http://www.eduweb.vic.gov.au/edulibrary/public/earlychildhood/intervention/ecislitreview.pdf>

Moore, T.G. (2012). **Rethinking early childhood intervention services: Implications for policy and practice.** *Pauline McGregor Memorial Address* to the 10th Biennial National Early Childhood Intervention Australia (ECIA) Conference and 1st Asia-Pacific Early Childhood Intervention Conference 2012, 9th August, Perth, Western Australia.

http://www.rch.org.au/uploadedFiles/Main/Content/ccch/profdev/ECIA_National_Conference_2012.pdf

Moore, T.G. (2013). **Teamwork in early childhood intervention services: Recommended practices.** Briefing paper prepared for Early Childhood Intervention Australia (Victorian Chapter). Parkville, Victoria: Centre for Community Child Health, Murdoch Childrens Research Institute, The Royal Children's Hospital.

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Workgroup on Principles and Practices in Natural Environments (2008). **Agreed upon mission and key principles for providing early intervention services in natural environments.** Chapel Hill, North Carolina: National Early Childhood Technical Assistance Centre, Office of Special Education Programs, US Department of Education.
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http://www.nectac.org/~pdfs/topics/families/AgreedUponPractices_FinalDraft2_01_08.pdf

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