

Centre for Community Child Health



# Early intervention and inclusion for young children with developmental disabilities

Presentation at Hunter Area Early Childhood Intervention Coordination Program Forum on Early Childhood Intervention, Inclusion and the NDIS for Children 0-8 years  
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**Early intervention and inclusion for young children with developmental disabilities**

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## Introduction

Society has changed dramatically over the past few decades, with significant impacts upon, children, families, communities and services. At the same time as these changes have been occurring, our knowledge of child development and the significance of the early years has been growing, and our views about disability and difference have been changing. This confluence of social change and new knowledge has led governments and service systems to seek new ways of configuring and delivering services. At the societal level, this has taken the form of efforts to integrate service systems, place-based initiatives, and multilevel interventions. At the mainstream ECEC service level, we have seen the introduction of the national Early Years Learning Framework and the National Quality Framework. At the early childhood intervention level, there have been changes in our understanding of how best to promote the development of children with developmental disabilities, and in the nature of the relationship between parents and professionals. This paper explores the implications of these changes for mainstream and specialist early childhood services, and considers how we can create fully inclusive environments for all children.

## Outline

- The nature and significance of the early years
- Developments in disability services
- Developments in early childhood services
- Developments in early childhood intervention services
- Developments in inclusion
- Conclusions and reflections
- Resources and references

## What have we learned about how children learn and develop?

Our understanding of early childhood and the role it plays in life-course development continues to accumulate. Key messages from research are the following:

- What happens in the prenatal and early years has profound implications for later development – this is the time when developmental plasticity is at its greatest
- Adaptation and learning start in the womb and are continuous
- Learning and development are cumulative, with later development building upon earlier development.
- Relationships are the medium through which young children learn the skills that enable them to become fully participating members of society.
- Every environment in which young children spend their time provides opportunities and experiences that shape development – there is no such thing as a neutral or non-learning environment.

For a succinct summary of recent research on the early years and the implications see paper by Moore (2014). This paper concludes thus:

*This accumulation of new knowledge about the impact of prenatal and early childhood experiences on health, wellbeing and development in later childhood and over the life-course must change how we view the early years. It is no longer appropriate nor useful to view the first two or three years of life as a period to*

*simply keep children healthy and safe, while allowing development to take its course until they reach school age. Instead, we need to be taking steps to ensure that children are provided with early childhood environments and experiences that build attachments, competencies and skills from birth, and protect them from escalating chains of adverse experiences.*

### Developments in disability models and services

The way in which we view disability has changed significantly in recent decades. Key developments in conceptualisation include:

- The World Health Organisation's reframing of disability in terms of the restrictions that social environment places upon the person's capacity to participate in life activities (WHO, 2002)
- Thomas Armstrong (2010)'s notion of neurodiversity:

*Human beings and human brains exist along continuums of competence. People with disabilities do not exist as 'islands of incompetence' totally separated from 'normal' human beings. Rather they exist along continuums of competence, with 'normal' behaviour simply a stop along the way.*

*Human competence is defined by the values of the culture to which you belong - whether you are regarded as disabled or gifted depends largely upon when and where you live.*

- In his book *NeuroTribes: The legacy of autism and how to think smarter about people who think differently*, journalist Steve Silberman (2015) explores the tension between changing individuals with autism to fit the 'neurotypical' world and changing the world to be more autism-friendly.

*Instead of viewing [autism] as an error of nature – a puzzle to be solved and eliminated with techniques like prenatal testing and selective abortion – society should regard it as a valuable part of humanity's genetic legacy while ameliorating the aspects of autism that can be profoundly disabling without adequate forms of support.*

- Psychiatrist Jordan Smoller (2012) makes a similar case regarding mental health and behaviour:

*The more we learn about the architecture of the mind, the more we see that conditions we recognise as disorders are variations of the same biological and psychological systems that operate in all of us.*

*Normal and abnormal are like night and day: we recognise them as different, but there is no sharp line between them.*

We have also learned from research about how children with disabilities develop and learn, and whether the key features of child development outlined above apply to them. As summarised by Moore (2009), the key findings are:

- 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

We have also learned that disability does not necessarily mean disaster. On the basis of his monumental study of the impact of various forms of difference on parents and children, Soloman (2014) observes

*Almost any characteristic can be experienced as an identity or an illness, and it is our human limitation not to be able to hold both points of view in mind at once. If we strive to do so, however, we may discover that while individual differences are lonely, the fact of difference is common to most of humanity. The families I studied ended up grateful for lives they would have done anything to avoid.*

There have also been significant changes in services for children with disabilities: we have moved from segregated service models to integrated services, and then to inclusive services. The ultimate goal is a service system based on principles of universal design.

Another major change is the introduction of the **National Disability Insurance Scheme** which will have a profound effect on how services are provided to people with disabilities and their families. The NDIS is a new way of providing community linking and individualised support for people with permanent and significant disability, their families and carers. The National Disability Insurance Scheme Act 2013 received Royal Assent on 28 March 2013 and became fully operational on 1 July 2013. The objects of this Act are to:

- give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities 2006;
- provide for the National Disability Insurance Scheme in Australia;
- support the independence and social and economic participation of people with disability;
- provide reasonable and necessary supports, including early intervention supports, for participants in the NDIS;
- enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports;
- facilitate the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability;
- promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community; and
- raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability

### Developments in early childhood services

At the same time as these changes have been occurring in disability services, there have been major developments in 'mainstream' early childhood services. These have been driven by two key national frameworks:

- Council of Australian Governments (2009). **Belonging, Being and Becoming — The Early Years Learning Framework for Australia.**

This Framework is based on a view of children's lives as characterised by belonging, being and becoming:

- *Belonging* acknowledges children's interdependence with others and the crucial role of relationships
  - *Being* emphasises the significance of the here and now in children's lives
  - *Becoming* emphasises learning to participate fully and actively in society
- Australian Children's Education and Care Quality Authority (2011). **Guide to the National Quality Standard.**

The guiding principles of the National Quality Framework are:

- The rights and best interests of the child are paramount.
- Children are successful, competent and capable learners.
- Equity, inclusion and diversity underpin the framework.
- Australia's Aboriginal and Torres Strait Islander cultures are valued.
- The role of parents and families is respected and supported
- Best practice is expected in the provision of education and care services.

Both these key documents are based in models of full inclusion and on promoting participation, which means that they are intended to apply to children with developing disabilities as well as those without developmental problems.

## Developments in early childhood intervention services

Paralleling the changes in early childhood services have been changes in early childhood intervention practice. Key findings from recent reviews of research and practice (CCCH, 2011; Moore, 2012; Workgroup on Principles and Practices in Natural Environments, 2008) have led to the following conclusions:

- 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.***

*For full accounts of these changes, see Centre for Community Child Health (2011) and Moore (2012).*

These changes have profound implications for ECI services and practitioners:

- The key aim is to maximise children’s opportunities to practice functional skills in everyday environments – home, ECEC and community
- This implies significant changes in the role of ECI professionals – there is a much greater focus on working with parents as partners, on key skills such as coaching, and on key strategies such as routines-based approaches
- Another major implication is that every setting in which the child spends time becomes a setting for early childhood intervention – therefore ECEC settings are ECI settings
- To make this transformation, ECI professionals need to expand their scope: they need to work with ECEC setting in ways that parallel the way they work with families, engaging ECEC professionals as partners, using coaching techniques and routines-based approaches

## Developments in inclusion practices

- Inclusion is *the meaningful participation of children with developmental disabilities in the same range of home, early childhood and community environments, experiences and activities as other children.*
- An inclusive environment or program is one in which all children, regardless of ability or background, are able to participate in all activities of their choosing.
- From the family perspective, inclusion is defined as the active involvement of families of children with developmental disabilities in the same range of community environments, experiences and activities as other families.
- An inclusive community environment or program is one in which all families, regardless of their abilities or backgrounds, are able to participate in all activities of their choosing.

In the US, the Department of Health and Human Services and US Department of Education have recently issued a joint *Policy Statement on Inclusion of Children with Disabilities in Early Childhood Programs* (2015). It is their view that

‘all young children with disabilities should have access to inclusive high-quality early childhood programs, where they are provided with individualized and appropriate support in meeting high expectations.’

They see this inclusion agenda as not just applying to children with disabilities:

Though this policy statement focuses on including young children with disabilities in early childhood programs, it is our shared vision that all people be meaningfully included in all facets of society throughout the life course. This begins in early childhood programs and continues into schools, places of employment, and the broader community. Inclusion in early childhood programs can set a trajectory for inclusion across the life course, making it critical that we include individuals with disabilities in all facets of society from birth.

In both the US and Australia, the peak early childhood and early childhood intervention bodies have issued joint statements committing themselves to the provision of fully inclusive early childhood services. In the US, the CEC’s Division for Early Childhood and the National Association for the Education of Young Children issued a joint position statement on early childhood inclusion in 2009, while in Australia, Early Childhood Australia and



Early Childhood Intervention Australia issued a joint position statement on the inclusion of children with a disability in early childhood education and care in 2012.

As part of its *Focus on Inclusion Project*, Early Childhood Intervention Australia (NSW) commissioned a set of resources to help ECI practitioners deliver inclusive practice: *Focus on Inclusion Project resources* (ECIA – NSW, 2013-14) – available at <http://www.ecia-nsw.org.au/projects/inclusion-tool>

As described in the first of these resources – the Background Paper (Moore, Symes and Bull, 2013) – the key elements of inclusion are as follows:

- *Access*. The most fundamental element of inclusion is enabling children with disabilities access to a wide range of environments and experiences. This requires removing physical or structural barriers, and providing multiple ways to promote learning and development.
- *Participation*. Meaningful participation is the engine of development and the key to attaining a true sense of belonging and a satisfactory quality of life.

Why meaningful participation? Participation is more than being present in different environments – the person must be actively engaged and their involvement must be more than tokenistic. For participation to be meaningful, the person's role and contribution must be valued by all those involved in the activity, including the person themselves.

- *Functional skills*. In order to be able to participate meaningfully in everyday activities, children need functional skills – of communication, mobility, social skills, self-management etc.
- *Environmental adaptations*. One key way in which children's inclusion can be promoted is to modify the environment. This is in contrast to trying to modify the child, ie. trying to teach the child skills to manage the environment as it currently exists, even when that environment is designed for people without disabilities.

Environmental modifications can take many forms, including physical modifications of buildings, the use of technological aids, and changes in routines. The social environment can also be modified to create a more accepting and inclusive social interactions.

- *Use of natural environments and routines*. Another key way in which children's inclusion can be promoted is through the use of natural environments and daily routines.
- *Engaging and responsive caregiving*. Promoting responsive caregiving is an essential first step in ensuring that children build secure relationships with caregivers and early childhood service providers.
- *Building strengths and capacities*. Given that the primary role for ECI practitioners is to help family members and service providers build children's capacity to participate, it is essential that they use capacity-building and strength-based strategies.
- *Mobilising personal supports*. Positive social support is vital for families of children with disabilities, and is often more important in people's lives than professional support.
- *Attitudinal change*. Successful inclusion often depends upon changes in attitudes on the part of those who interact with the child. This includes parents themselves, as well as ECEC staff, other children, and community members.
- *Providing specialist support*. For children with disabilities to be able to participate meaningfully in home, early childhood, and community settings, it is essential that families, early childhood service providers and community services are provided with specialist support.

- *Engaging and responsive service delivery.* Relationships are just as important for parents and caregivers as they are for children. The efficacy of support services depends as much upon the manner in which services are delivered as on what is delivered.

Several promising strategies for delivering inclusive services based on these principles have been developed: *universal design*, *tiered models* of meeting children's needs, and *routines-based and natural learning opportunities approaches*.

- ***Universal design.*** The creation of inclusive early childhood programs does not depend upon adapting the mainstream curriculum for the benefit of those with developmental disabilities, but on creating a curriculum and environment that is designed from the start to cater for the individual needs of all children (Conn-Powers et al., 2006; Darragh, 2007; Hitchcock et al., 2002; Rose et al. 2002; Rose & Wasson, 2008; Rose & Gravel, 2011).
- ***Tiered models for meeting the need of children with particular challenges.*** Several version of tiered models have been developed, all based on the provision of a high quality core curriculum, supplemented by progressively more intensive supports for those children having difficulty mastering the key skills needed for meaningful participation in the ECEC service's activities. Tiered models include *Response to Intervention* (Buysse & Peisner-Feinberg, 2013), the *Pyramid Model* for Promoting Social-Emotional Competence and Addressing Challenging Behaviour (Hemmeter, Fox & Snyder, 2013), and *Building Blocks* for Teaching Preschoolers with Special Needs (Sandall & Schwartz, 2008).
- ***Routines-based and natural learning environments approaches.*** These involve understanding the normal routines in home and ECEC settings (McWilliam, 2010), and exploiting ways of building upon the natural learning opportunities these provide to give the child multiple opportunities to practice the functional skills they need (Noonan & McCormick, 2014).

## Conclusions and reflections

### Conclusions

- There is a slow but discernible shift in societal values regarding difference, diversity and disabilities that suggests the emergence of a more inclusive society
- There is also a convergence of values and practices between ECEC and ECI services that supports the development of more inclusive early childhood environments
- The overall aim of both ECI and ECEC services is to ensure that children's early learning environments – in family, ECEC and community settings – help children develop the functional skills they need to participate in those environments
- *Participation is the engine of development* – we must ensure that all children are able to participate meaningfully in their everyday environments
- All children stand to benefit from fully inclusive ECEC services

### Reflections

- There is a crucial difference between focusing on services and focusing on outcomes – services (such as ECI therapy services) are a means to an end, not an end in themselves
- Professionals cannot prescribe or know beforehand what form of service is needed by a family – they need to work with families first to find out what their priorities, capacities and resources are

- What matters first and foremost is that families are clear about what outcomes they want, with the choices about the form of service and the service provider depending upon these goals
- One of the key roles of ECI providers is to help families decide what outcomes they would like to achieve, choose what strategies for achieving these outcomes would work best for them, and build their capacity to implement these strategies
- The medium through which all this is achieved is the relationship between parents and professionals, and the collaborative partnership they establish

## Resources

### *Australian resources to support inclusion*

Early Childhood Intervention Australia (New South Wales) (2013-14): *Focus on Inclusion Project resources* - <http://www.ecia-nsw.org.au/projects/inclusion-tool>

- Moore, T.G., Symes, L. and Bull, K. (2013). **Strengthening Inclusive Practices in Early Childhood Intervention Services: Background Paper**. North Rocks, NSW: Early Childhood Intervention Australia (New South Wales). <http://www.ecia-nsw.org.au/documents/item/1062>
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Anne Stonehouse and Claire Boschetti (2012). **A Piece of Cake - Linking inclusive practice to the EYLF and VEYLDF**. Melbourne, Victoria: Yooralla.

Margaret Sims (2011). **Social Inclusion and the Early Years Learning Framework: A Way of Working**. Mt. Victoria, NSW: Pademelon Press.

### *Other resources to support inclusion*

Epstein, A.S. (2007). **The Intentional Teacher: Choosing the Best Strategies for Young Children's Learning**. Washington, DC: National Association for the Education of Young Children.

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McWilliam, R.A. and Casey, A.M. (2007). **Engagement of Every Child in the Preschool Classroom**. Baltimore, Maryland: Paul H. Brookes.

## *Universal design for learning*

Conn-Powers, M., Cross, A., Traub, E. and Hutter-Pishgahi, L. (2006). The universal design of early education: Moving forward for all children. **Beyond the Journal: *Young Children on the Web***, September 2006. <http://www.journal.naeyc.org/btj/200609/>.

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Hitchcock, C., Meyer, A., Rose, D. and Jackson, R. (2002). Providing new access to the general curriculum: Universal design for learning. **Teaching Exceptional Children**, 35 (2), 8-17.

Rose, D.H., Meyer, A., Strangman, N. and Rappolt, G. (2002). **Teaching Every Student in the Digital Age: Universal Design for Learning**. Alexandria, Virginia: Association for Supervision and Curriculum Development.

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Rose, D.H. and Gravel, J. (2011). **Universal Design for Learning Guidelines - Version 2.0**. Wakefield, Massachusetts: CAST (Centre for Applied Special Technology). <http://www.udlcenter.org/aboutudl/udlguidelines>

## *Tiered models*

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## *Routines-based and natural learning environments approaches*

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