

## EARLY CHILDHOOD INTERVENTION – International Perspectives & Parent Thoughts

*Professor Barry Carpenter OBE*

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## Activity

### Why Early Childhood Intervention?

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**‘The news that a child has, or is at risk from, a developmental disability is often among the most frightening and confusing pieces of information that parents will ever receive.’**

*Beckman & Beckman-Boyes (1993)*

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**‘At the time of diagnosis of their child’s disability, parents ... can find their expectations of becoming a parent shattered.’  
(p.144)**

*Russell, F. (2003)*  
*‘The expectations of parents of disabled children’*  
*British Journal of Special Education, 30 (3), 144-149.*

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**‘For most parents the birth of their child is a joyous time. However, nearly 4% of parents receive distressing news about their child’s health. In fact, about every 3.5 minutes a parent is told that their child has a serious medical illness, health defect, disability or sensory impairment.’**

*Barrett et al. (2003)*

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**‘At birth Society makes a social contract with its families.’**

*Conliffe (2000)*

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## Activity

### What is our definition of Early Childhood Intervention?

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**'Early Intervention can be defined in all forms of child-oriented training activities and parent-oriented guidance activities which are implemented in direct and immediate consequence of the identification of the developmental condition. Early Intervention pertains to the child as well as to the parents, the family and the broader network.'**

*Heinen (1997, p.6)*

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**'Providing effective Early Intervention programmes for vulnerable children and their families constitutes one of the most important challenges for contemporary societies. State-of-the-art intervention requires the contributions of specialists from many disciplines, the construction of programmes that are firmly rooted in bio-medical and behavioural research, a programme development component that is capable of incorporating emerging research findings, and advocates and administrators to ensure that funding, personnel and related resources policies are available and consistent with the knowledge base and goals of Early Intervention.'**

*International Society for Early Intervention*

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**Early Intervention – the cornerstone of Government strategy in ensuring that 'every child matters'**

- ***'Early intervention is the cornerstone of our strategy. 'Every Child Matters' recognised the lasting benefits of early intervention – providing a sound foundation for future learning and development ... it should mean that help is available as early as possible, reducing the risk of long-term under-achievement and dissatisfaction'***

*'Removing Barriers to Achievement', 2004*

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## The Government proposes....

**'A modern family policy for the 21st century, which starts from what helps family life to flourish'**

The Children's Plan (2008)

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**'Early Intervention means professionals working in partnership with parents of children with special needs to help their children develop their knowledge and skills to reach their potential. It builds upon the strengths found in all children and families. Research and practice have proven that Early Intervention produces immediate and long term benefits for children with disabilities, their families, and society.'**

*Carpenter (2001)*

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**‘Early Intervention is best conceptualised as a system designed to support family patterns of interaction that best promote children’s development.’**

*Guralnick (2001)*

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**‘Early Childhood Intervention is a dialogue between the different actors – parents, child, professionals, financing bodies and research’**

*Pretis, M. (2006)*

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## **Activity**

**What is the purpose of Early Childhood Intervention – its goals?**

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## **Key goals of Early Childhood Intervention: a review**

1. **To support families in supporting their children’s development**
2. **To promote children’s development in key domains (cognitive, social, physical, emotional, linguistic) via early years curriculum and learning opportunities**
3. **To promote children’s coping confidence**
4. **To prevent the emergence of future problems**

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*Woffendale (2000)*

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## **Activity**

**What is the ‘how’ of Early Childhood Intervention – our practices?**

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## **Key reciprocal functions of Early Childhood Intervention**

- Support
- Education
- Liaison
- Communication
- The provision of information
- Collaboration
- Resources
- Advice

*Carpenter (2004)*

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## **‘Fragmented services create vulnerable families.’**

*Christine Lenehan  
February 2004*

‘The Children’s National Service Framework’  
Paper to the DFES Conference  
‘Removing Barriers to Achievement’  
25 February 2004

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## **What could have helped?**

(Ranked for importance)

1. A break or more breaks, or more flexible breaks
2. Emotional support / counselling
3. Support and information around diagnosis
4. Fewer financial worries
5. Help and support from families
6. Professional support
7. Support for the father
8. Recognition of the needs of the whole family
9. Practical help at home
10. Information about services and entitlement

*from a survey of over 2000 parents in the UK  
who have a disabled child*

(Contact a Family (2004) ‘Relationships – No time for us’.  
<http://www.cafamily.org.uk/relationships.html>; 27.04.2004)

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## **Activity**

**What are some of the future  
challenges for Early Childhood  
Intervention – the children...?**

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In New Zealand,  
recently reported figures suggest  
a 90% survival rate for pre-term  
infants less than 1,500 grams,  
with a 63% disability factor.

(Woodward et al., 2003)

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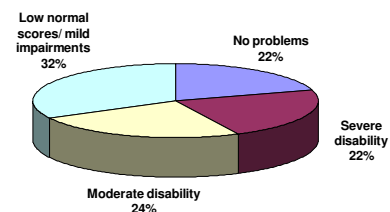
## **EPICure UK Study**

- Established 1995
- 80% survival of children born at less than 26 weeks
- Longitudinal study
- <http://www.nottingham.ac.uk/human-development/EPICure/>

(Marlow et al., 2005)

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**Proportion of children with disability out of  
241 children seen at 6 years  
by comparison with their classmates (Marlow et al., 2005)**

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So, for many, life begins like this...



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or like this...



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‘The first year of life gives you the organisational pattern of how you cope with external stimuli.’

*Patricia Champion (New Zealand) (2005)  
In B. Carpenter and J. Egerton  
Early Childhood Intervention  
Worcs: Sunfield Publications*

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### Challenges of prematurity: For the mother

- Birth period coloured by fear and distress
- The ‘unexpected’
- Illness
- Attention on the baby and its survival
- Her experience goes unprocessed
- She is not rehabilitated following the birth
- Normal social mores ignored – suspended visiting, celebrations, congratulation cards
- Significant interruptions to biological wiring
- Transition from pregnant person to new mother is delayed (and may never happen)
- Suspended grief
- Greater than usual risk of post-natal depression

NECIC 2012, SibU, Malaysia (After Patricia Champion, 1998)

### WARNING

FROM THE LIQUOR CONTROL BOARD



**Avoid alcohol during pregnancy.**

Alcohol use during pregnancy may cause birth defects such as Fetal Alcohol Syndrome.

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### The Perils of Alcohol in Pregnancy

“.... Even moderate consumption of alcohol had a serious effect on the formation of the body’s central nervous system. This indicates that the nerve pathways in the brain have been damaged”.

*Lecture given by Professor Peter Hepper, University of Belfast,  
Foetal Behaviour Research Unit to the Royal Society of Medicine  
16 November 2005*

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**Hepper's study appears to corroborate US research, conducted after birth, which shows that drinking during pregnancy lowers a child's IQ and increases hyperactivity.**

*Hepper, P. G., Dornan, J. C. & Little, J. F. (2005)*

**Maternal alcohol consumption during pregnancy may delay the development of spontaneous foetal startle behaviour**

*Physiology & Behaviour, 83, 711-714*

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## Foetal Alcohol Syndrome How is it caused?

- Alcohol is a teratogen.
- It crosses the placenta within 10–15 minutes of an alcoholic drink being consumed. Umbilicus goes white and flaccid.
- One unit of alcohol remains in the mother's system for approx. 1 hour (longer in a baby's).
- Results in reduction of brain cells and migration of cells to the wrong place.

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## Foetal Alcohol Spectrum Disorder (FASD)

- FASD is the single biggest cause of non-genetic learning disability.
- 1 in 300 children are affected (1 in 666 children with Down's syndrome).
- In the UK, this amounts to 600–1,200 occurrences per annum.
- England has the biggest binge-drinking, female population in the world. A quarter of women aged 16–24 years drink more than 21 units of alcohol per week. (14 units is the recommended maximum.) (*Health Survey for England, 2003*)

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*Continued...*

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- Excess drinking lowers babies' birth weights – more than 20 units of alcohol causes intellectual impairment. Babies with FASD have substantially smaller brains than average.
- In France, legislation demands that health warnings are displayed on alcohol bottles.
- In the US, the warning on alcohol bottles states:
- 'Drinking while pregnant is overly risky for the foetus: it is the major cause of mental retardation.'

Sources:

*Dr Moira Plant, Alcohol Research Group, Tommy's Charity, London*  
*Dr Raja Mukherjee, St George's Medical School, London*

**FURTHER INFORMATION:** [www.fasaware.co.uk](http://www.fasaware.co.uk) / [www.nofas.org](http://www.nofas.org)

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## Prevalence of autism

60 per 10,000 (1 in 166) children under 8 years <i>Medical Research Council, 2001</i>	91 per 10,000 in the total population (1 in every 110 people) <i>National Autistic Society, 2002</i>	1 in 800 school children (previously 1 in 1,000) <i>Department of Health, 2002</i>
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**Professor Baird, whose work is published in *The Lancet*, said: 'Prevalence of autism and related ASD's is substantially higher than previously recognised' She added: 'Services in health, education and social care will need to recognise the needs of children with some form of ASD, who constitute 1% of the child population'**

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. and Charman, T. (2006) 'Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)', *The Lancet*, 368 (9531), 210-215

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**‘Over recent years there has been a major rise in the rate of diagnosed autism. The main explanation for this is to be found in better ascertainment and a broadening of the diagnostic concept’**

(Rutter, 2005, p. 231)

Rutter, M. (2005) Invited Review: ‘Aetiology of autism: findings and questions’. *Journal of Intellectual Disability Research*, 49 (4), 231-238

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In 2005 there were 77 cases of measles: by June 2006 there had been 449 cases

(Health Protection Agency, 2006)

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## FAS and ADHD

- “We believe that a proportion of children who have ADHD may have developed it as a result of their mother’s drinking during pregnancy”
- “The startle movement (in the womb) is clearly not normal and would seem to indicate the child has the traits of fidgeting which we see in ADHD”

Margaret Barrow (2005)

*Clinical Geneticist, Leicester Royal Infirmary, UK*  
quoted in

Carr-Brown, J. and Halle, M. (2005) ‘Twitches that indicate alcohol may hurt babies’, *The Sunday Times*, November 20  
(<http://www.acbr.com/fas/AlcoholFetusUltrasound.htm>)

Also, Royal Society of Medicine Conference (2005)

“Alcohol in the Womb”: The link to FASD  
<http://www.fasconnections.ca/d108.htm>

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## The mental health problems of young children

- Emotional disorders, e.g. anxiety states, phobias, and depression
- Conduct disorders, e.g. aggression, defiance, anti-social behaviour
- Hyperkinetic disorders, e.g. disturbance of activity and attention
- Developmental disorders, e.g. delay in acquiring certain skills such as speech, social ability or bladder control
- Attachment disorders, e.g. children who are markedly distressed or socially impaired as a result of an extremely abnormal pattern of attachment to parents or major caregivers
- Eating disorders, e.g. pre-school eating problems
- Habit disorders, e.g. sleeping problems, soiling, spontaneous urination.

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‘4 in 10 young people with learning disabilities [in the age range 13–25 years old] will develop a mental health problem.’

From *Count Us In: The National Inquiry into the Mental Health Needs of Young People with Learning Disabilities*

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‘One in five children have SEN, but children with SEN are three times more likely to have mental problems.’

(Office of National Statistics, 2000)

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**'Poverty can increase the risk of a child having an impairment... Having a disabled child can also mean that parents find it harder to maintain full-time employment, their housing can be inadequate for their child's needs, and expenditure on basic needs is increased.'**

*(Prime Minister's Strategy Unit, 2005, p. 86)*

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**55% of families with a disabled child are living in poverty or on the margins of poverty.**

*(General Household Survey, 2002)*

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***'Families of children with severe disabilities are less likely to be car or telephone owners, even though they are more dependent on these services.'***

*(Family Fund Data, 1998)*

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***Housing – three quarters of families with a disabled child live in an unsuitable home.***

*Oldman & Beresford (2002) Housing Matters The Policy Press,  
Oldman & Beresford (1998) Homes Unfit for Children York: JRF*

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**'The challenge to our society is to loosen and break the stranglehold of poverty on the development of our children.'**

*Mittler (2000)*

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## **Activity**

**So what do you feel are some of the future challenges for Early Childhood Intervention?**

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## Challenges to Early Childhood Intervention

- Inclusion
- Practice models
- Styles of partnership
- Family-based intervention

*Carpenter (2004)*

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**‘Inclusivity is key to the self-defining family.’**

*Carpenter (2003)*

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## A is for ...

- **Availability** – presence of appropriate services
- **Accessibility** – services readily available
- **Accommodation** – responsiveness to individual needs
- **Affordability** – minimal time, money, energy costs
- **Acceptability** – individuality respected

*Simeonsson (1998)*

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## Features of transdisciplinary practice

- Lowering of disciplinary boundaries
- Empathetic human beings
- Empowerment approach
- Recognition of the systemic nature of the family
- Choice of services and level of engagement
- Negotiation
- Joint decision-making
- Shared perspectives
- Mediation
- **Multi-level partnership**

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## The Champion Centre, N.Z.



- The programme started with just a physio and an SLT (and the family, of course).

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**‘In a transdisciplinary team the roles are not fixed. Decisions are made by professionals collaborating at a primary level (rather than at a secondary level as in a multi-disciplinary team). The boundaries between disciplines are deliberately blurred to employ a “targeted eclectic flexibility”.’**

*Pagliano (1999, p.120)*

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**‘Holistic, family-oriented approaches require close collaboration between the range of professionals in the fields of pedagogy, psychology, social sciences and medicine.’**

*Peterander (1995, p.162)*

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#### **Four key features of the Developmental Systems Model**

- To guide Early Childhood Intervention programmes for vulnerable children and their families
- To maximise family patterns of interaction
- To address potential stressors related to risk and disability conditions
- To advocate community-based services

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*Guralnick (2001)*

**‘By redirecting our focus, we may enable partnership to become a reality once more. Do we have the will, the commitment, for the sake of our families, to shift the focus?’**

*Carpenter (2003)*

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*Fialka and Mikus (1999)* speak of the  
**‘dance towards partnership’**

and remind us that

**‘the only magic to forming partnerships is to slowly, tenderly and persistently share our dreams with each other, for it is our children who give us the reason and opportunity to strengthen our partnerships with others.’**

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**‘The professionalism on which you stand is not a different road to the one on which we tread... It’s also the road that’s cushioned and softened by the laughter and the smiles of love, and tears of our children. That road is the same road, and, when we relate to each other, we have the partnership that dreams are made of. From the educational psychologist who sits with you and tries to translate the vision you have for your child in the way his or her report is written, to the occupational therapist who’ll make a separate attachment to your child’s wheelchair so the cat can curl up next to your child, to the midwife who finds a lovely position you can feed your child in even though it’s completely against her textbook knowledge... These are professionals who are working in the spirit of the term “partnership”.’**

*Preethi Manuel (1996)*

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**‘It is difficult in a society that does not value disabled children to find help that is non-judgemental. Admitting that one’s child might be harder work than many does not come easily if you are trying to challenge outdated attitudes. Asking for support does not mean that you do not love your child, or that you are wishing them away.’**

*Wilson (2003)*

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'We believe that it should not be regarded as an exotic idea for disabled children and those close to them to aspire to a quality of life comparable to that enjoyed by others who do not live with a disability. In our view it is unacceptable at the beginning of the 21<sup>st</sup> century for the lives and experiences of disabled children and their families to be bereft of those features that many of us take for granted; features which make for an ordinary and reasonable quality of life. Families are our greatest resource and if they are not seen as a resource they become problems.'

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*Mencap (2001)*

## Family-focussed evaluation of Early Childhood Intervention...

- Endorses collaborative working
- Mutually values parents and professionals
- Works to shared agenda and shared goals.

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## Activity

**So, in the new phase of development for Early Childhood Intervention, what do you see as the 'Agenda for Development' ?**

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## The Agenda for Development in Early Childhood Intervention

Principle 2: Integration and co-ordination at all levels of the Early Childhood Intervention system is essential

Guralnick (2005)

[www.sunfield.org.uk](http://www.sunfield.org.uk)

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## Agenda:

- Training on team process
  - evolving transdisciplinary models based on respect for, and contributions of various disciplines.
- Develop new models for collaboration
  - collaborative consultation
  - Team-around-the-child (Limbrick, 2005)
  - Coaching (Espe-Schwindt, 2005)
- Establish leadership groups at every service level to promote co-ordination and integration

Guralnick 2005 : Carpenter & Egerton 2005

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## Early Childhood Intervention: an agenda for development

- Criteria for programme entry
- Outcome measures for successful interventions
- Roles and responsibilities of professionals
- Delivery of services within a changing society
- Sustainability of intervention programmes for children with complex needs
- Long-term outcomes for whom?
- A first step towards inclusion

*Carpenter, B. and Russell, P. (2005)*

'Early Intervention in the UK: current policy and practice'.  
In: M Guralnick (ed.) *A Developmental Systems Approach to Early Intervention: National and International Perspectives*. Baltimore: Paul H. Brookes.

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**'The severity of the child's disorder, at any level, can leave parents exhausted to a degree that is dependent on their stress tolerance. Many of them experience chronic pessimism and risk breakdowns in their functioning. Early intervention should seek to divert this bleak outcome. It should seek it vigorously and with great endeavour.'**

***Randall and Parker (1999)***

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## Engagement

**'It is important to do something and do it with a degree of intensity.'**

***Mesibov (2001)***

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## Major Accomplishments of Early Intervention

- Parent – child transactions
- Centrality of family centred approaches
- Family Orchestrated child experiences
- Effectiveness : Evidence from Model Programmes
- Principles of Early Intervention
  - Developmental framework
  - Integration and co-ordination
  - Inclusion
  - Early detection and identification
  - Surveillance & monitoring
  - Evaluation and feedback
  - Cultural competence
  - Evidence-based practices
  - Systems perspective

Guralnick (2007)  
 Paper to: Second Conference of the International Society on Early Intervention  
 Held in conjunction with the University of Zagreb's 7th Annual Scientific conference  
 Research in Education and Rehabilitation Science  
 Zagreb, Croatia – 14-16 June 2007

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**Look what effective Early  
 Childhood Intervention can  
 achieve....**

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**'We need a whole community to develop a child. We are that community, and these are our children.'**

*Nigerian Proverb*

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