EARLY CHILDHOOD INTERVENTION – International Perspectives and Parent Thoughts

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“The changing pattern of childhood disability” professional practice and research

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Activity

Why Early Childhood Intervention?
‘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)
'At the time of diagnosis of their child’s disability, parents ... can find their expectations of becoming a parent shattered.' (p.144)

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

Conliffe (2000)
Activity

What is our definition of Early Childhood Intervention?
'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)
‘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*
‘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.’

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

Guralnick (2001)
Activity

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

Wolfendale (2000)
Activity

What is the ‘how’ of Early Childhood Intervention – our practices?
Key reciprocal functions of Early Childhood Intervention

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

Carpenter (2004)
Key tenets of the Early Childhood Intervention Programme, Champion Centre, New Zealand

- Remediation
- Redefinition
- Re-education

(Champion, 2004)
‘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
What could have helped families?
(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 other 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

http://www.cafamily.org.uk/relationships.html; 27.04.2004)
Activity

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

(Feedback from a West Midlands SEN Regional Partnership seminar group, ‘Defining Early Intervention’, Birmingham, 13 May 2004)

- Co-ordination
- ‘Labelling’ issues
- Changing family dynamics, e.g. working mothers
- Pooling budgets
- Sharing of information across disciplines
- Shared criteria for referral, shared protocols
- Who should be involved in Early Childhood Intervention
- Work towards deeper and shared understanding / culture between agencies
- Strategic planning
Challenges to Early Childhood Intervention

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

*Carpenter (2004)*
‘Inclusivity is key to the self-defining family.’

Carpenter (2003)
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)_
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
'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)*
European Association on Early Intervention

www.eurlyaid.net

International Society on Early Intervention

http://depts.washington.edu/isei
The purpose of Early Childhood Intervention is to “ensure and enhance the child’s personal development, strengthen the family, self-competencies, and promote their social inclusion”

_Pretis (2005)_
He continues…

“These services are to be provided in the child’s natural setting, preferably at a local level, with a family-oriented and multi-dimensional teamwork approach”

from the Early Childhood Intervention project
European Agency for Development in Special Needs Education – March 2005
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

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?’

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.’
‘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)
‘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.’

‘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 21st 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.’

Mencap (2001)
Family-focussed evaluation of Early Childhood Intervention…

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

Early Childhood Intervention
Coventry, Great Britain; West Midlands SEN Regional Partnership
Activity

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

Factors for Successful Early Intervention for Children with ASD

- Core Principles
- Process
- Specific provision
- Strategic Management
- Operational Management

What are the key features?
What evidence is there (in practice)?
What are the benchmarks for evaluation?

Framework for Key Features for Success of Early Interventions for Children with ASD and their Families
Coventry: West Midlands SEN Regional Partnership

www.westmidlandssrcp.org.uk
‘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)
‘Recognising Fathers’ Research project

A few early findings:

• Fathers are keen to talk about their experiences – little previous opportunity

• Services and organisations are wanting to involve fathers

• A number of fathers’ groups exist around the country – run by men/fathers (e.g. SunDads)

• www.learningdisabilities.co.uk
‘Through Early Intervention, there is a unique window of opportunity to influence the developmental trajectory of children (e.g. plasticity, environmental factors, etc.).’

Guralnick (2004)
Engagement

‘It is important to do something and do it with a degree of intensity.’

Mesibov (2001)
‘We need a whole community to develop a child. We are that community, and these are our children.’

_Nigerian saying_