

ECIA(VC) Consultative Forum -
Developing Outcomes in Early Childhood Intervention
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**OUTCOMES IN EARLY CHILDHOOD INTERVENTION:
THE HISTORICAL, POLICY AND RESEARCH CONTEXT**

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The importance of outcomes for children

Pollard and Rosenbaum (2002) argue that, in rearing children, we should have some idea about how we want our children to turn out:

‘Another way to put it would be to say that we need to begin with the end in mind. We don’t usually do this when it comes to rearing children. We pretty much rear them by the seat of our pants. We develop strategic plans for so many relatively unimportant things in our life, and we spend so much time working on these plans that never get used, that in the end strategic planning has given strategic planning a bad name. But we don’t take the time to make strategic plans for the most important things in our lives, our children. Part of the reason is that we don’t know what we want our children to be in the end. We may say we want them to be healthy, to be happy, to be content. But what does that really mean?’ (p. 14)

Issues in identifying outcomes in early childhood intervention

• ***Lack of clarity about aims***

For early childhood interventions services to be effective, it is essential that there is agreement about what they are trying to achieve, what the desired outcomes are. However, shifts in early intervention philosophy and practice have been accompanied by changes in how we conceptualise what outcomes we are seeking for children and families (Moore, 1996; Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker and Wagner, 1998). The result is that there may no longer be a clear consensus in the ECI field as to what the desired outcomes are. This is the view put by Butler (1996) who argues that, in the field of developmental disabilities as a whole, there is ‘a lack of consensus about what outcomes are desirable – and by whom’ (p. vii).

Historically, one of the key changes that has occurred in the theory and practice of early childhood intervention have been the progressive widening of the targets and goals of service delivery – from a predominantly child-focussed approach to one that encompasses family and community goals (see chart from Moore, 1996).

• ***How do we know what works?***

But if we are not clear about the outcomes we are aiming for, then

- we will be less likely to achieve desired outcomes,
- we will be unable to judge the efficacy of the service we provide,
- we will be less likely to choose a methodology that is known to be effective in achieving desirable outcomes, and
- we may persist with approaches and goals that are not achieving anything.

When services are not driven by outcomes, then they are driven by other factors such as

- habit / custom (this is how we have always done it),
- unproven assumptions (these particular children need this kind of program), or
- community expectations (assumptions regarding the nature of professional expertise and the consequent demand for ‘hands on’ therapies).

- ***Confusing means with ends***

In the context of business, Levitt (1975) has shown that industries that become product-oriented rather than consumer-oriented inevitably decline and lose their customers. They are under the illusion that continued growth is just a matter of continued product or service innovation and improvement. But the consumers don't care about the products or services in themselves, only in what they can do for them. Industries or services that lose sight of that are at risk of losing their customer base.

According to Levitt, industries that thrive *start* from the customers' needs and work backwards – they focus on what the customers want and need and then tailor what they produce or deliver to meet those needs. They spend less time on the producing or refining the product or service itself and more time on staying in touch with customer desires.

Human services, including early childhood intervention, sometimes focus more on the product (service) than the outcome, that is, they are primarily concerned to deliver high quality services and to improve the ways in which they deliver services. Another way of putting this is that they think that the aim of early childhood intervention is to provide all the wonderful early intervention services that we are trained to deliver.

But that is to confuse the means with the ends. All our technical expertise and various forms of service are only a means to an end – to make some kind of change in the child and family. The question is what kind of change are we seeking? And exactly how does the services we provide achieve that change? Thus, we need to be clear about what we are trying to achieve as well as have a clear evidence-based model of how those goals can be achieved.

- ***Funding early childhood intervention services – outputs or outcomes?***

In the face of this uncertainty, governments have funded early childhood intervention and other services on the basis of outputs (actual services provided) rather than outcomes (what these services achieved). However, outputs are not necessarily related to efficacy, ie. to achieving desired outcomes: providing families with a certain level of service does not guarantee that the service is the one best suited to meeting the child and family needs. Moreover, this way of funding services continues the confusion between means and ends by focussing on the service to be provided rather than what the ultimate aims are.

- **Who chooses the outcomes?**

Is it the job of government to determine what the outcomes of the services it funds should be? Should the professionals be the ones to decide? What say should parents have? The exercise that we are engaged in today suggests that we think that the choice of outcomes should be made collaboratively by government and professionals.

Does this mean that parents have no say? How does this sit with family-centred practice, particularly the principle that service should be based on the needs and priorities of parents?

Conclusions

The tasks that need to be tackled, therefore, are

- to agree what outcomes for children and families we are seeking,
- to decide how these outcomes are to be measured, and
- to determine what methods are best suited to achieving these outcomes

In thinking about outcomes, we will look briefly at changes in definitions of ECI, and formulations of outcomes for children, outcomes for parents and families, and the balance between the two.

Definitions of early childhood intervention

Some idea about what early childhood interventions think they are aiming can be gleaned from the definitions of what ECI is. Here

- ***From Shonkoff and Meisels (1990) – Handbook of Early Childhood Intervention (1st Ed.)***

Early childhood intervention consists of multidisciplinary services provided for developmentally vulnerable or disabled children from birth to age 3 years and their families. These programs are designed to enhance child development, minimize potential delays, remediate existing problems, prevent further deterioration, limit the acquisition of additional handicapping conditions, and/or promote adaptive family functioning. The goals of early intervention are accomplished by providing developmental and therapeutic services for children, and support and instruction for their families.

- ***From Meisels and Shonkoff (2000) – Handbook of Early Childhood Intervention (2nd Ed.)***

Early childhood intervention consists of multidisciplinary services provided to children from birth to 5 years of age to promote child health and well-being, enhance emerging competencies, minimize developmental delays, remediate existing or emerging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family functioning. These goals are accomplished by providing individualized developmental, educational, and therapeutic services for children in conjunction with mutually planned support for their families.

	1990	2000
Age range	Birth to 3 years	Birth to 5 years
Target group	Developmentally vulnerable or disabled children	All children
Aims	<ul style="list-style-type: none"> • To enhance child development • To minimize potential delays • To remediate existing problems • To prevent further deterioration • To limit the acquisition of additional handicapping conditions, and/or • To promote adaptive family functioning. 	<ul style="list-style-type: none"> • To promote child health and well-being • To enhance emerging competencies • To minimize developmental delays • To remediate existing or emerging disabilities • To prevent functional deterioration, and • To promote adaptive parenting and overall family functioning.
Methods	<p>These goals are accomplished by providing</p> <ul style="list-style-type: none"> • developmental and therapeutic services for children, and • support and instruction for their families. 	<p>These goals are accomplished by providing</p> <ul style="list-style-type: none"> • individualized developmental, educational, and therapeutic services for children in conjunction with • mutually planned support for their families.

- **From Moore (1996)**

Early intervention services aim to provide families of young children with developmental disabilities and delays with the support, knowledge and skills they need to promote their children's developmental and functional adaptation to the family and community in which they live.

- **From ECIA (VC) Policy Statement (1999)**

Early childhood intervention is the provision of a range of specialist educational, therapy and general support services to infants and young children (from birth to school age) who are developmentally vulnerable or disabled and their families.

The aims are

- for children, to maximise both their overall development and their functional adaptation to family and community environments.
- for families, to provide the support, knowledge and skills they require to meet the needs of the child and of the family as a whole.

- **From ECIA(VC) brochure (2003)**

Early childhood intervention services are services for young children with disabilities or developmental delays, and their families.

Early childhood intervention services aim to

- provide families with the support, knowledge and skills to meet the needs of their child and the family as a whole
- optimise children's development and their ability to function as well as possible in family and community life
- enable families and children to join in the life of their community to the fullest extent possible.

- ***DHS Community Care Division – Early Childhood Intervention Services vision and key priorities (2003)***

Vision: Families caring for a child with a disability or developmental delay are able to access flexible and responsive specialist supports within the universal platform of services, to support them in raising their child within the family and community and enabling them to achieve their developmental, social and emotional potential.

Goal 1: ECIS are part of a comprehensive and integrated continuum of child and family services (spanning government, non-government and private providers) that supports all children and families. ECIS provide additional supports for children with a disability or developmental delay, prior to school entry, whose support needs are additional to those usually available through universal services.

Goal 2: ECIS are linked to the development of collaborative relationships with universal services to build community capacity, foster participation of all children and families in local community life and enable the early identification of children and families in need of specialised support.

Goal 3: The principles of family centred practice underpin ECIS delivery. Services will focus on building parents' capacity to care for their child and promote independence and choice for families in navigating the service system, acknowledging the links between children's developmental outcomes and their immediate experiences within the family.

Goal 4: To ensure the delivery of high quality, responsive services to children and their families, there is a need to develop a highly skilled workforce and strong and sustainable service providers.

Outcomes for children

Some authors (eg. Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker and Wagner, 1998) suggest that there is likely to be little disagreement among researchers and practitioners about what outcomes we are seeking for children. However, the matter is by no means clear cut.

Issues which are still subject to debate include

- ***Should we be aiming at developmental goals or functional goals?***

Child outcomes have traditionally been measured through norm-referenced IQ tests or developmental scales. There are a number of problems with using conventional intelligence tests or developmental scales as outcome measures in the context of early childhood intervention. There is an increasing emphasis in the literature on functional rather than developmental goals and on the use of measures of functional ability as an alternative to traditional ability and norm-referenced measures.

Others have suggested greater focus on assessing the processes of social and emotional development, as well as the underlying functional capacities that lead to cognitive gains, rather than simply measuring the achievement of concrete milestones (Shonkoff and Meisels, 2000).

Closely linked to this emerging perspective is the call for an approach to evaluation and intervention that is embedded within the child's natural environment and conducted in an ongoing information-gathering manner rather than as a series of disconnected snapshots of competence. This reorientation is particularly important for the evaluation of children with significant motor and sensory impairments, whose progress is often not reflected in standardized test scores.

In the context of school reform, Sailor (1996) discusses *outcomes-based education*. This approach focuses on what students gain from learning and what they can accomplish with what they have learned, rather than simply what they learned. This leads to a more individualised approach to all students.

- ***Should we be aiming at short-term or long-term goals? Should the effectiveness of early childhood intervention be judged in terms of its short-term or long-term outcomes?***

Strictly speaking, ECI can only be held accountable for outcomes at the point at which the children leave service and move to school services (Guralnick, 1989; Meisels, Dichtelmiller and Liaw, 1993). The educational and environmental experiences they have subsequently may or may not build upon their ECI learning. Therefore, it must be recognized that the long-term outcomes of ECI are significantly dependent upon learning opportunities during the school years. Nevertheless, as Meisels et al. (1993) point out, whether or not ECI has long lasting effects is an empirical question that warrants investigation.

If it is true that successful early learning may be undermined or 'washed out' by poor subsequent experiences, then it is likely to be true of some children and families only – others will have received enough support from ECI to be able to manage during the school years with minimal support. (One of ECI's aims for parents is to 'equip them for the journey'.) Other families fail to become fully empowered and need ongoing support.

Another point to note is that not all children start service at birth – ECI outcomes will obviously differ for children starting service early compared with those who start much later.

The question of what outcomes we should be seeking for children was one of the topics considered at a workshop of leading US early childhood interventionists held in June 1999 under the auspices of the Committee for Integrating the Science of Early Childhood (Shonkoff, Phillips and Keilty, 2000) and subsequently discussed in the final report of this group (Shonkoff and Meisels, 2000). The consensus was that the focus should be on three key dimensions of child development and functioning:

- *Self-regulation*: emotional reactivity, attention and activity level, and other behavioral aspects of school readiness, such as taking turns and following directions
- *Interpersonal skills and relationships*: infant attachment, parent-child relationship, peer relationships
- *Knowledge acquisition skills and problem-solving abilities*: mastery motivation, problem-solving strategies, and the ability to generalize learning from one situation to another

Outcomes for parents and families

Regarding outcomes for parents and families, there is even less agreement. Bailey et al. (1998) are of the view that 'clearly the field has not reached consensus as to desired family outcomes' (p. 315).

A variety of definitions and models have been proposed (Allen and Petr, 1996; Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker and Wagner, 1998; Turnbull, Turbiville and Turnbull, 2000).

As part of the preliminary conceptual work done for the National Early Intervention Longitudinal Study (NEILS), Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker and Wagner (1998) proposed two broad types of family outcomes and eight questions which they believed were 'consistent with the current values, theories, and models of family functioning and relationships between families and professionals across the life span, and reflect the outcomes that early intervention could be expected to impact' (p. 316). Their framework is as follows:

- **Family perceptions of the early intervention experience**

1. Does the family see early intervention as appropriate in making a difference in their child's life?
2. Does the family see early intervention as appropriate in making a difference in their family's life?
3. Does the family have a positive view of professionals and the special services they provide?

- **Impact on the family**

1. Did early intervention enable the family to help the child grow, learn and develop?
2. Did early intervention enhance the family's perceived ability to work with professionals and advocate for service?
3. Did early intervention assist the family in building a strong support system?
4. Did early intervention help enhance an optimistic view of the future?
5. Did early intervention enhance the family's perceived quality of life?

Bailey et al. (1998) note that this framework has not been validated and offer it as vehicle for discussion. The framework was developed as background for the design of the NEILS, a major longitudinal study, and presumably is being used and tested in the study. Actual measurement of each of these questions is also still to be determined, although they suggest ways in which this could be done.

Turnbull, Turbiville and Turnbull (2000) classify family outcomes into two broad classes:

- **motivation outcomes** (self-efficacy, perceived control, hope, energy, and persistence)
- **knowledge / skill outcomes** (information, problem-solving, coping skills, and communication skills)

Another framework has been offered by Allen and Petr (1996), based on a reformulation of family-centred practice as being guided by two key principles:

- Facilitating **family choice** in the following areas
 - definition of the family (ie. who the family comprises)
 - who makes the decisions in the family (ultimately the parents or caregivers)
 - the unit of attention (ie. who the service is to be delivered to)
 - the nature of the parent-professional relationship
 - the sharing of information
 - the identification of concerns, goals, and intervention
- Building on family **strengths and capabilities**.

Re **family outcomes**, participants at the Committee for Integrating the Science of Early Childhood workshop (Shonkoff, Phillips and Keilty, 2000) agreed that early intervention services should be directed to three key aspects of family functioning:

- Parent-child relationships and interactive styles
- Family status and function
- Cultural values and beliefs

According to Bailey et al (1998), a common theme in discussions of **quality of life** is that 'a fundamental criterion for the effectiveness of any intervention endeavour ought to be the extent to which it improves the quality of life as perceived by persons with a disability or their families' (p. 43).

Another outcome to be considered is the quality of the relationship between families and professionals. This point is made by Blue-Banning, Summers, Frankland, Nelson and Beegle (2004) when considering the results of a study they conducted that identified indicators of professional behaviour that were facilitative of collaborative partnerships. In the course of the study, parents repeatedly emphasised that for them the quality of their partnerships with service providers was a critical element of their overall quality of life.

'Time and again, these participants referred to the stress and exhaustion caused by the perceived necessity to fight for services, cope with humiliating or disrespectful regulations or provider attitudes, or otherwise deal with breakdowns in their relationships with professionals. These results lead us to suggest that the quality of partnerships might be conceptualised as one additional outcome for which programs should be held accountable. At the very least, the quality of partnerships between families and professionals might be conceptualised as an intermediary outcome or one of several critical prerequisites for successful student and family outcomes.' (pp. 181-182)

Blue-Banning and colleagues see these results as having implications for service outcomes. For professionals in education and early childhood intervention, the outcomes they are seeking are likely to be improved academic achievement and functional life skills. For families, the desired outcomes are improved quality of life for their children with disabilities and for themselves. Blue-Banning and colleagues suggest that the quality of the parent-professional relationship be added as an outcome. They believe that developing a viable method of measuring the quality of relationships, based on the indicators identified in this study, will enable this type of outcome to be evaluated.

Finally, it could be argued that, both because each family is unique and because family-centred practice requires that parents should ultimately determine the goals to be sought, evaluations should be individually designed to assess the extent to which the parent's preferred outcomes are achieved. Techniques such as goal attainment scaling have been devised for this purpose (Kiresuk, Smith and Cardillo, 1994). Bailey et al. (1998) suggest that, 'This approach, while intuitively appealing and appropriate for an individual family, does not lend itself to the evaluation of outcomes for families as a class of recipients of a broad range of services' (p. 315).

Balance between child and family outcomes

Regarding the balance between child and family outcomes, the key issues are what is the balance of child and family outcomes being sought and how has this been determined. There is evidence that the natural tendency of practitioners is to focus primarily on child goals and pay too little attention to parent and family needs and goals.

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**FORMS OF EARLY CHILDHOOD INTERVENTION
FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES**

LEVEL	FOCUS	FORMS OF SERVICE	OUTCOMES
CHILD	<ul style="list-style-type: none"> • Child's disability • Other intrapersonal factors (eg. temperament) 	<ul style="list-style-type: none"> • Medical intervention • Direct therapy services to the child • Structured teaching programs 	<ul style="list-style-type: none"> • Maximize child's cognitive functioning • Maximize child's adaptive and social functioning
PARENTS	<ul style="list-style-type: none"> • Reactions to child's disability • Knowledge and skills in managing child's disability 	<ul style="list-style-type: none"> • Individual counselling • Marital counselling • Parent education programs • Parent-to-parent contact • Parent support and discussion groups. 	<ul style="list-style-type: none"> • Increased parental capacity to care for and educate child • Meet parents' personal needs • Prevent breakdowns in marital relationships
FAMILY	<ul style="list-style-type: none"> • Siblings' attitudes to disabled child • Attitudes of extended family members 	<ul style="list-style-type: none"> • Group programs for siblings, grandparents • Respite and special home help • Holiday camps • Financial and welfare assistance. 	<ul style="list-style-type: none"> • Increased family capacity to care for and educate child • Reduction in level of family stress
COMMUNITY	<ul style="list-style-type: none"> • Community attitudes to child with disability • Ability of local generic services to cater for child with disability 	<ul style="list-style-type: none"> • Integration of child into local community settings • In-service programs for generic early childhood staff • On-going specialist support for child in local community settings 	<ul style="list-style-type: none"> • Child able to attend local community services • Child has regular contact with non-disabled peers • Community develops greater understanding and tolerance for children with disabilities
SOCIETY	<ul style="list-style-type: none"> • Societal attitudes to disability • Adaptability of generic services 	<ul style="list-style-type: none"> • Advocacy • Public education • Government policy and funding 	<ul style="list-style-type: none"> • Children with disabilities able to live at home • Cost saving to society • Increase in human dignity

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