Benefits of Early Intervention for Children With Developmental Disabilities

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Early intervention programs are designed to enhance the developmental competence of participants and to prevent or minimize developmental delays. Children targeted for early intervention may either include environmentally or biologically vulnerable children, or those with established developmental deficits. There is growing consensus based on the best available evidence that early interventions can exert moderate positive effects. However, this literature is limited by substantial methodological weaknesses in most studies. Therefore further randomized clinical trials are needed to ascertain which programs best meet the needs of children with or at risk for developmental disability.

EARLY INTERVENTION provides a range of educational and therapeutic programs to families and their children with developmental delays. More specifically, these early programs target infants and toddlers from birth to 3 years of age, and in some interventions this has been extended up to 6 years. The age of onset of intervention is dependent on the type of disability but generally begins as soon as either the developmental delay or the risk for such deficits is clinically recognized. The intervention may include a wide array of services and programs that are aimed at maintaining or maximizing the child’s development. The primary objective of early intervention is to enhance the competence of participants in all developmental domains so as to prevent or minimize delays. Additionally, most interventions also assist families in coping effectively with daily challenges at home and in the community.

FOR WHOM?

Early intervention programs are directed at young children who have or are at risk for acquiring a developmental delay. Three risk groups have been identified and include (1) environmentally vulnerable children who are deemed disadvantaged as a result of a deprived physical and social environment that may limit growth and development, (2) children biologically at risk due to conditions that can result in developmental deficits (e.g., prematurity, fetal alcohol syndrome, asphyxia), and (3) children with established risk as they have been diagnosed with a medical condition that is known to adversely affect developmental progress (e.g., Down syndrome). These risk factors are described in detail in the articles by Aicardi and by Msall et al., elsewhere in this issue.

TYPE OF SERVICES

For environmentally disadvantaged children, psychoeducational programs that emphasize cognitive and social skills are generally used to address intellectual goals and improve parent-child interactions. Children with biological impairments or established developmental deficits represent a very heterogeneous population with varied needs. Services usually involve a multidisciplinary team, including occupational and physical therapists and speech/language pathologists. These professionals provide therapeutic interventions to eliminate or minimize the diverse impairments that may present across all developmental domains.

Services may be classified as providing prevention, remediation, or compensation. For prevention programs, early identification of those at high risk for developmental delay is essential, so as to initiate the intervention programs before deficits manifest. The primary focus of these programs is to facilitate the acquisition of developmental skills and to inhibit or minimize the long-term effects of specific risk factors on development. These programs often include infant stimulation or enrichment programs using developmentally appropriate activities. Services are given before the diagnosis of a developmental delay and are therefore referred to as primary prevention.

Remediation programs are intended to improve areas of difficulty and are therefore directed at children with an identified developmental delay. These services, referred to as secondary prevention, try to eliminate or diminish
delays, as well as attempt to prevent further disabilities. Services are also provided for children with developmental deficits that cannot be remediated. Compensation techniques are used for developmental deficits that cannot be changed substantially by available interventions, so as to minimize the effects of these difficulties on overall functioning and independence. For these services, technological approaches (aids and adaptations), and behavioral techniques (eg, cues or prompts) are used to maximize functioning in children with residual deficits. Early intervention programs support all these approaches.2,7

Early intervention services may be directed at the child and/or family. Child-focused programs are generally carried out at centers or schools and involve the participation of a group of children in a program designed to promote developmental acquisitions and school readiness. For example, these programs may begin soon after birth in the neonatal intensive care unit (NICU) or at preschool. Family-focused programs involve the family’s participation at the center or through home visits. These interventions are designed to improve parenting skills and relationships. By optimizing caregiving behaviors, parent-child interactions are facilitated and subsequent development of their children enhanced.8,10 Families are increasingly recognized as knowledgeable consumers and effective agents for maximizing the developmental performance of their children. Families are valued as active participants in early intervention services and are involved in prioritizing goals and identifying specific needs.11-13

HISTORICAL PERSPECTIVE

Infant stimulation programs have been available for many decades, but early intervention has evolved dramatically since the 1960s.14,15 The early programs were directed primarily to disadvantaged groups, with the underlying assumption that early interventions will improve the future development of these children. A huge investment was made to programs, such as Head Start for children of low socioeconomic status. This program provided education, health care, social services, and parental support to promote optimal development. Overall, efficacy studies have shown substantial cognitive and social benefits.1,6,10,16 As a result, the budget for Head Start has grown substantially from 404 million in 1974 to over 3 billion in 1994.10

More recently, programs have been developed and instituted for biologically vulnerable populations, such as preterm infants of very low birth weight (VLBW). Widening availability of early intervention programs to other high-risk populations was due, in part, to advances in our understanding of infant behavior and development, and in the fields of neonatology and pediatrics. Furthermore, societal and political pressures regarding the developmental outcomes of children at risk have also contributed to the expansion of early intervention services. Concomitantly, there were important changes in legislation that relate to early intervention in the United States.17 Education of the Handicapped Act Amendments of 1986 (Public Law 99-457) ensured federal incentives for programs that were already available to school age children (1975: PL 94-142). This earlier legislation mandated that all children with disabilities were entitled to education in the least restrictive environment (ie, integrated environments) with the right to all related services needed (eg, rehabilitation, transportation, medical) within the school environment. PL 99-457 was enacted to extend such services to infants and preschoolers (0 to 6 years) with disabilities. The Individuals with Disabilities Education Act Amendments of 1991, or IDEA (PL 102-119), strengthened early intervention service provision, by emphasizing family-focused programming, prevention strategies, and better coordination and transition of services. Eligibility criteria for early intervention programs are determined by each State, but generally include those diagnosed with a condition with an established or known risk for delay, children with a developmental delay determined by standardized instruments, and those at environmental or biological risk that are likely to develop disabilities without interventions.5,14,16,18

EARLY INTERVENTION: DOES IT MAKE A DIFFERENCE?

Justification

Two contrasting views predominate the early child development literature. The neuromaturational view theorizes that there is a gradual unfolding of a predictable sequence of developmental skills that is hard-wired into the central nervous system. This process is innate and genetically determined. This biological determinism is believed to be relatively uninfluenced by environmental experiences.19-21 Therefore this view places little

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weight on external interventions and learning opportunities as facilitators of developmental acquisitions. In contrast, the behaviorist or systems view emphasizes the importance of learning or training in shaping development. Environmental experiences enable young children to interact and problem solve, thereby stimulating new developmental skills. More recent theorists postulate that environmental "interventions" can modify biological insults and maximize developmental gains through enriched experiences. In disadvantaged groups, a poor social environment can exacerbate developmental difficulties, and therefore provision of enriched environments can be beneficial to this group of children as well.1,21-22

There is substantial empirical evidence to support the latter view that environmental experiences can exert effects on development. Several animal studies, such as the exemplary work by Short-Degraff in rats9 and Hubel and Weisel in kittens and monkeys,23-24 have demonstrated that environmental enrichment can evoke neural modifications and accelerate aspects of development. These studies clearly illustrate that sensory enhancement or deprivation conditions encountered early in life can alter the neuroanatomic circuitry of the nervous system. This rearrangement of connections typifies the plasticity of the immature nervous system.9,25 Accumulating evidence in infant behavior and development further support the view that environmental experiences profoundly influence the health and developmental competence of children. Experiences are recognized as necessary to achieve developmental potential. Furthermore, experiences must occur early to achieve maximal effects (concept of critical period). It is also increasingly appreciated that active, self-initiated interactions with the environment are necessary to produce developmental effects, supporting child-focused interventions that involve the active and ongoing participation of the child.1,9,17,22,26

Clinicians would agree that there is an interplay between intrinsic (maturational) and extrinsic (environmental) forces that shape motor development. Early intervention programs therefore furnish enriched environmental opportunities to stimulate and enhance developmental acquisitions in children at risk for developmental disabilities. The question remains as to which interventions are most effective in optimizing the future outcome of children who are at risk for developmental disabilities.25

**Treatment Efficacy**

There is growing consensus that based on the best available evidence, early intervention can have substantial benefits to children developmentally at risk.8,10,27 Overall, interventions improve scores on developmental outcome measures, strengthen parent-child interactions, and provide a supportive environment for the family. Programs also increase the collaboration between professionals. There are some elements of the intervention that appear to be important in exerting positive effects on development. Structured programs that continue throughout childhood appear to have long-lasting effects.6,28 Furthermore, programs that combine a child-focus and a parent-focus are likely to produce gains on a greater range of developmental outcomes,8 although the relative contribution of parent participation remains somewhat controversial.29

Whether interventions of earlier onset are better remains a point of disagreement. In one review of five studies, there was no significant effect of earlier versus later intervention; however, other studies on small samples of children with cerebral palsy or Down syndrome demonstrate a benefit of earlier entry into intervention programs.30,31 The age at referral and subsequent effect of an early intervention program for developmentally delayed children (with cerebral palsy primarily) was evaluated by Sharkey et al.31 Children admitted before 9 months (mean: 5.3 months) to the program showed a greater benefit from the intervention than those entering into the program after 9 months (mean: 13.4 months). Children were not randomized, therefore there may have been a bias in the population referred earlier. Shonkoff and Hauser-Cram16 also reported a benefit of earlier entry into intervention programs in their quantitative analysis of 31 studies, for the mildly disabled subgroup only (P = .008).

Long-term follow-up studies demonstrate enhancement in school achievement, better parenting skills, greater independence, lower criminal activity, and higher earnings in cohorts who have received early intervention programs.6,10,32 Greater availability of programs coupled with changing societal values regarding inclusion of the disabled have undoubtedly ameliorated parental coping skills...
and adaptive capacity of their disabled children at home and in the community.6

Environmentally Vulnerable Populations

The best evidence of the benefits of early intervention is with disadvantaged children and their families (low income, undereducated). This is, in part, due to being the first population targeted for early intervention and therefore a large number of short-term and long-term efficacy research studies have been conducted. For this population, early educational enrichment has been successful in enhancing the developmental outcome of these children.8,33 The best example of this intervention is the Head Start Program which began in the mid 1960s and has served several hundred thousand children per year. The earlier Head Start programs were child-focused, and primarily cognitive and social outcomes were measured. Studies have demonstrated gains in Intelligence Quotients (IQ) immediately after program completion compared to controls, although there was a “fade out” phenomenon as children approached school age, as the differences between groups diminished over time. If support systems are maintained through the school years, there are greater benefits for these children. Children who participated had less need for special education, were less likely to fail a grade, were more likely to graduate, and had less criminality and need for social services. In the 1980s and 1990s, family-focused interventions were added to this program; however, the data are preliminary and inconclusive regarding additional gains.6,10,26,34-35

Improved cognitive competence has also been demonstrated in other programs directed at environmentally at-risk children.1 In a review of studies by Bryant and Ramey,56 the magnitude of the effect was dependent on the intensity of the interventions and the combined involvement of parents and their children in the program. The objective of the Abecedarian Project was to determine if mental retardation caused by deprived environments could be prevented by an intensive, preschool program. This high-quality program included educational, medical and nutritional support. Results of this randomized intervention demonstrated improved intellectual and academic achievement in participants. Twelve-year follow-up of the cohort demonstrated a persistence of a 5- to 10-point advantage in IQ, as well as a reduction in grade failures of almost 50%, and a diminution in borderline IQ (IQ < 86; 13% of participants compared with 44% of controls).8,36 Project CARE was a home and center-based program that also showed greater intellectual achievements in participants compared with controls.28

Biologically At-Risk Populations

Infant stimulation programs have been instituted in recent decades on newborn populations determined to be at high risk for developmental sequelae. The predominant target group has been neonates born preterm. Overall, infant stimulation programs have been found to improve parenting skills and to facilitate short-term gains in growth and development. However, there is a paucity of long-term follow-up data.6,9,33 Furthermore, apart from infants born prematurely, studies on other biologically at-risk groups are lacking.

Infants that are VLBW are deemed to be doubly vulnerable as they are often environmentally disadvantaged as well as biologically at-risk for developmental delay.3 The efficacy of tactile stimulation programs in the NICU was reviewed by Ottenbacher.57 Quantitative analysis of 19 studies indicated that infants receiving such programs performed better on a variety of dependent measures. Furthermore, programs in the NICU that include individualized developmental care by caregivers and parental developmental education and reinforcement have also demonstrated medical improvements and higher developmental scores in infancy in participants.38,39

A number of randomized trials have been launched to evaluate the effects of longitudinal interventions over the first years of life in LBW infants. In one study, a multidisciplinary infant development program coupled with parent education and counselling in infants <1,800 g significantly lowered the incidence of developmental delay at 1 and 2 years.40 In another study, parents and their children were particularly responsive (i.e., better cognitive abilities and more optimal home environment) to a one year home intervention in the birthweight category <1,500 g when compared with heavier preterm peers.29 Similarly, the Vermont Intervention Program included parent education sessions at home and at the hospital for families of LBW infants. Divergence of cognitive scores favoring those who participated was evident at 3 years and persisted at 7-year reassessment.41
In summary, results reveal positive effects of a variety of early interventions for preterm infants; however, these randomized clinical trials were limited by small sample size. The strongest evidence for such benefits is the Infant Health and Development Program, which was an eight-site randomized controlled trial providing a comprehensive, structured curriculum for 985 LBW premature infants. This large clinical trial evaluated the efficacy of combining developmental and support services with pediatric follow-up to reduce cognitive, behavioral, and health problems in children of low birth weight. The intervention included a home-based program that provided ongoing parental support and education on health and development (0 to 3 years), as well as a center-based structured program for their children (1 to 3 years) concurrent with regular parent group meetings. The cohort was ≤2,500 g and ≤37 weeks' gestational age. One third of the sample received this intervention package, whereas two thirds received periodic developmental surveillance and referrals as needed, but no intervention. At 3 years, there were significant differences in IQ scores (9.4 point spread), in receptive vocabulary (6.4 points), and fewer behavior problems. This was especially significant in the heavier LBW group (2,001 to 2,500 g), and for children of mothers of low education. These benefits were already evident by 2 years. The program terminated at 3 years, but the cohort was followed longitudinally. At 5 years, there was a persistence of effect on cognitive measures in the heavier LBW group only. The lack of sustained effect on the lighter group was attributed to the greater complexity of problems and greater risk for neurological deficits, which may require ongoing developmental support. Similarly, at 8 years, the participants in the heavier LBW group continued to excel in cognitive and academic performance, although the differences attenuated somewhat. It should be noted that the curriculum offered in this program was largely adapted from programs for socially disadvantaged children of normal birth weight, but did not specifically address the individual needs arising from biological deficits such as neuromotor impairments (eg, abnormal muscle tone) or functional disabilities (eg, dependence in daily living skills). This is exemplified by the higher incidence of neurological abnormalities in the lighter LBW (<2,000 g) in both participants and controls.

Established Risk Populations

Within the rubric of early intervention, programs are available for children with conditions that are associated with developmental delay, such as cerebral palsy and Down syndrome. Relatively few efficacy studies have been conducted for these disabled populations. The evidence is conflicting, but overall, early interventions provide short-term gains in developmental achievement, particularly in less severely disabled children. There appear to be positive effects on family acceptance and caregiving abilities, such as feeding, handling, and play. Simeonsson et al reviewed 27 studies (1975 to 1982) evaluating treatment efficacy for children with disabilities. Although 93% reported positive effects, statistical data were presented in less than half. This body of literature is fraught with methodological flaws, such as small sample size and lack of a control group. A number of meta-analyses have been conducted, whereby data are aggregated from several studies and quantitative analyses are performed to establish patterns across studies. The advantage of this approach is that it affords a comprehensive synthesis of the findings over a large range of subjects, programs, and measures extracted from many small studies. However, the data extracted are limited by the quality of the studies themselves. The analysis includes determination of “effect size,” which exemplifies the magnitude of the effect attributed to the intervention, and is equal to the mean difference between the experimental and control groups divided by the standard deviation of the control group (or mean difference between post-test and pre-test if there is no control group). An effect of 0.5 is believed to be clinically significant. Casto and Mastroperri reviewed 74 efficacy studies (1937 to 1984, most >1970) of early intervention on children 0 to 5 years of age with disabling conditions (44% mentally retarded, 29% combination of disabilities). A meta-analysis revealed that these heterogeneous programs did accomplish moderately large immediate effects over a range of outcome variables. The mean effect size was 0.68 (0.68 standard deviation superiority in performance in children receiving the intervention compared with controls), with a lower effect of 0.43 for better designed studies (N = 20). Parent involvement could be effective but was not essential to ensure benefits. An earlier age of initiation of intervention did not prove to be advantageous in this analysis; however,
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it should be emphasized that the samples varied widely with respect to extent of disability. The intensity and duration appeared to be a key element of success of a program, with more dramatic benefits (effect size >0.8) for longer, more intense programs. Long-term benefits remain unclear.17

A second meta-analysis was carried out on the same data set, but excluded those with either major design flaws, two treatment groups, or those including samples with predominantly disadvantaged children, children enrolled after 3 years of age, or institutionalized children. A moderate positive effect of early intervention was determined to be 0.62 in 31 studies analyzed. Intelligence was the most ubiquitously studied outcome with an effect size of 0.62 for IQ. Language skills demonstrated the greatest effect (1.17), and motor performance had a lower positive effect (0.43). The age at entry had no overall advantage, except for children with mild disabilities, as entry <6 months was more beneficial in this subgroup of children. There were no significant advantages of home versus center-based programs. Structured programs were more effective overall (0.92) than unstructured ones (0.59). Extensive parent involvement was better (0.70) than little or no involvement (0.30), particularly if the parent participated with their child. Interestingly, children with developmental delay showed the most benefit, and those with orthopedic conditions made the least gains.16

Several early intervention studies have been directed at children with specific conditions. Several reviews of the effectiveness of such interventions for children with Down syndrome report positive gains in cognitive ability and adaptive functioning, with the greatest achievements in fine motor and self help skills.50-52 Positive effects of early intervention programs were often noted in areas not measured using standardized instruments, and statistical significance was not always achieved owing to small samples. A further limitation is that the majority of studies did not have a control group.48,50,53

In keeping with the relatively low effect size reported in meta-analyses for motor outcomes in disabled populations and for children with orthopedic conditions, there is a lack of evidence to support the efficacy of rehabilitation interventions in children with cerebral palsy. Individual studies as well as systematic reviews present conflicting results.30,54-57 In one review of 18 studies that evaluated occupational or physical therapy interventions, support for treatment efficacy decreased with increasing methodological rigor of studies. Only four studies in this review were believed to meet minimal design standards.58 An important limitation in existing studies is that outcome measures were primarily restricted to quantitative assessment of motor skills. Qualitative measures as well as outcome measures across other developmental domains may illustrate unrecognized benefits of interventions for children with cerebral palsy.1

There are a number of impediments to evaluating efficacy of early intervention in populations with established disability. These include the following: (1) unsuitability or lack of sensitivity of existing standardized measures, (2) ethical considerations which limit application of a control (no treatment) group, (3) heterogeneity of degree and type of disability in populations of interest, (4) small numbers of children available for study that meet selection criteria, and (5) use of a structured, standardized curriculum is less likely to meet the individual treatment needs of disabled children. These issues present a challenge in the design of future studies.51

CONCLUSIONS AND FUTURE DIRECTIONS

There is broad agreement in the literature that early interventions provide modest positive effects on the developmental achievements of children with or at risk for developmental disability. The best available evidence lies in studies of interventions for socioeconomically disadvantaged children.28 Overall, structured, long duration, intensive, child-centered programs appear to optimize benefits. There is increasing recognition of the importance of family participation in maximizing the developmental potential of their disabled children. Parents who are more skillful and knowledgeable can more efficiently facilitate the growth and development of their children.28,11,15-16

There are still many unanswered questions regarding the benefits of early interventions. How do we best identify those in need of early intervention? When should these programs begin and for how long? Which programs are most efficacious for specific target populations? Further large-scale randomized clinical trials using rigorous methods on homogeneous populations are needed to resolve these issues, particularly in children with established disabilities.25,28,47 The content of many pro-
grams are comprised of psychoeducational approaches to maximize cognitive, language, and behavioral skills. Children at-risk may have more global needs. For example, motor impairments restrict exploration and interaction with the environment, limiting development in other domains. Furthermore, dependence in daily living skills may influence self-esteem and other psychosocial domains. Therefore, programs may need to include stimulation of motor performance and facilitation of functional independence in all activities. Single-site interventions hinder generalizability, and statistical power is often weak owing to small sample size. Long-term studies have elucidated that positive effects gained immediately following interventions attenuate over time. McCarton et al8 suggest that periodic "injections" of additional interventions at appropriate intervals may be necessary to more effectively minimize developmental deficits that emerge as these children mature (eg, preacademic skills, peer relationships, motor coordination). The outcomes measured in studies to date have concentrated on intellectual and behavioral domains, with little evidence available of possible benefits in other facets of development. Therefore, future studies should use a wider range of outcome measures to more fully acknowledge the spectrum of benefit.4, 17 Measures of functional capabilities (eg, socialization, daily living skills), quality of life, and burden of care would be especially pertinent to ascertain the extent to which these costly interventions abate disability and improve life quality.3 Outcomes that relate to family functioning are also particularly relevant.

Ongoing critical appraisal of the efficacy of early interventions is unquestionably worthwhile, to ensure that programs selected will maximize the future health and well-being of children and families who are challenged daily by developmental disabilities. The pediatric neurologist has an invaluable role to play in targeting those who may benefit from early intervention programs, in monitoring progress, and in ensuring that services are provided as needs arise. 30 Health professionals need to keep abreast of the best evidence for efficacious programs, to inform families appropriately, and thus ensure that their children can achieve their functional potential.

REFERENCES

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