The Effect Of Early Referral And Intervention On The Developmentally Disabled Infant: Evaluation At 18 Months Of Age

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***Abstract*: This study examines the age of referral and the effect of early intervention for the physically handicapped child. Fifty children were referred before 9 months of age, and they were compared with 55 children referred after 9 months of age. At 18 months of age, the children in the earlier referred group showed greater developmental progress in acquisition of skills in all of the six areas tested: perceptual-fine motor ($P < 0.0003$), cognition ($P < 0.0001$), language ($P < 0.0004$), social-emotional ($P < 0.0001$), self-care ($P < 0.0001$), and gross motor ($P < 0.0002$). The results show that, at least in the short term, there is a critical age for onset of intervention to achieve the most benefit for the developmentally disabled child. Family physicians should be alert to early warning signs of neurological deficits in order to obtain early treatment for these children. (J Am Board Fam Pract 1990; 3:163-70.)**

Public law 99-457, a series of amendments to the Education of the Handicapped Act that were passed in 1986, has a number of features that will increase availability of early intervention programs for infants. First, the law gives strong incentives to states to begin serving children from birth to age 6 years. Second, it allows and encourages states to include in their services those children from birth through age 2 years who are "at risk" of developmental delay, in addition to those who have definite neuromuscular handicaps. Family physicians can implement the law by: (1) referring children to early intervention if they are "at risk" of developmental delay; (2) monitoring the progress of children referred; and (3) serving as advocates for the family, as well as the child, to see that intervention is consistent with the parent's goals and is without burden to the family unit.

Some primary caregivers might hesitate to refer infants with subtle neurological disabilities to early intervention for fear of alarming unnecessarily the parents of children who might "grow out" of their problems. Therapists believe that the earlier a child with a disability is referred for treatment, the more successful will be the intervention. However, the efficacy of early intervention is controversial.

There is little published research to resolve this conflict. Two recent reviews, using meta-analysis to synthesize data from numerous studies, have noted the scarcity of empirical studies addressing the age that children start intervention programs.[1,2] Investigators from the Utah State University Early Intervention Research Center reviewed 300 studies of early intervention efficacy, including environmentally disadvantaged and physically handicapped children.[3] They found only five studies that compared starting children at two different ages when all other variables were held constant. These studies showed a 0.04 standard deviation advantage for children who begin later. When other studies were examined, which took into account age at start-up but with other confounding variables, there was a 0.16 average effect size favoring children who began earlier.[3]

A more recent meta-analysis examined the impact of early intervention services on physically handicapped children aged < 3 years.[2] This report found that programs that focused on "mildly" impaired children had significantly higher out-

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comes when the children were enrolled before they were 6 months old ($t = 8.15$; $P = 0.008$). Because of small sample size, similar analyses could not be performed for programs aimed at "moderately" or "severely" impaired youngsters.

In reviewing studies of children aged < 1 year who were referred for developmental therapy (i.e., physical or occupational therapy), the reported effects of early intervention showed variable results. Scherzer and colleagues,[4] using a pretest and posttest design with random assignment, evaluated the effects of 6 months of treatment on a group of cerebral-palsied children. Fourteen received neurophysiologic physical therapy, and 8 received traditional range of motion. The researchers believed that the children who were treated at a younger age showed less evidence of motor and social changes than those who were treated later, although statistical analysis was not performed to substantiate the interpretation. In contrast, Kanda, et al.[5] compared the age of onset of walking in a group of 8 spastic diplegic children who began treatment before 9 months of age with 21 children who began treatment between age 9 months and 3 years. The average age to start walking was 8 months earlier in the younger-aged treatment group. Connolly and Russell[6] reported that children with Down syndrome who were treated before age 6 months made more progress in terms of developmental age than those treated after they were 6 months old. These studies investigated subgroups of developmentally delayed children, and the size of the samples were small, which is true of much research on the developmentally disabled within a limited age range.

A recent study by Palmer, et al.[7] evaluated a group of spastic diplegic children when they were aged 12 to 19 months. The motor outcome of the group receiving 12 months of physical therapy was no better than the group receiving 6 months of physical therapy following 6 months of infant stimulation treatment. Thus, the study did not support the tenet that physical therapy started earlier is more effective in the treatment of cerebral palsy. Bax stated in an editorial about this report:

> Many proponents of early physical therapy would have hoped that children would be identified and in a treatment programme very much earlier than that. The spastic diplegic form of cerebral palsy really ought to be identified within the first year.[8]

Thus, both groups enrolled in this study were treated later than one would want to test a hypothesis about age of onset of early intervention, and perhaps more importantly, both groups were receiving early intervention during the entire study. One was receiving physical therapy, and the other was receiving infant stimulation. What method of intervention works for which children is a controversial question that has not been adequately addressed in the literature.

The present study examines the age of referral and the effect of early intervention for the developmentally delayed child. We report the developmental outcomes at 18 months of age of two groups of children: those who entered the early intervention program before or during their 8th month of life and those that entered after they were 9 months old.

Methods

Sample

One hundred nine consecutively referred children treated for at least 6 months in the Early Intervention Program, Easter Seal Society of Volusia and Flagler Counties, were evaluated. They were referred by numerous physicians across two counties, although the majority were referred from Halifax hospital, which houses the major neonatal intensive care unit. Four children were excluded from the study because they normalized. Normalization was defined as the age-appropriate performance of at least four of the six developmental areas on the Early Intervention Developmental Profile (EIDP).[9] The children were divided into two groups. Fifty (25 girls, 25 boys) were referred before 9 months of age (the early group). The mean age of referral for this group was 5.26 months. The other 55 (23 girls, 32 boys) began treatment after 9 months of age (the late group). The mean age of referral for this group was 13.44 months.

Diagnosis of the children with cerebral palsy was ascertained by the therapists using the criteria outlined in the Appendix.

Tests

The EIDP was selected as the infant assessment tool for two reasons. First, it is one of the best-

designed and practical diagnostic-prescriptive curriculum systems with specific disability modifications.[10] Second, the six developmental areas could be matched to the personal expertise of the therapists participating in the study. The EIDP is made up of six scales that provide developmental milestones: perceptual-fine motor (PFM), cognition (C), language (L), social-emotional (SE), self-care (SC), and gross motor (GM). The self-care section for this study consisted of feeding skills only. The EIDP authors assigned items to specific age ranges based on standardizations or research from other instruments. Concurrent validity of the profile was examined by correlating each of the six profile scales with standardized evaluation instruments. The coefficients for all the scales were generally high, ranging from 0.33 between the gross motor scale on the EIDP and the Receptive Expressive Emergent Scale to 0.95 between the gross motor scale on the EIDP and the Bayley Motor Scale.[11]

The EIDP was implemented at the initial evaluation and after each 6 months of intervention. The PFM and C sections were given by an occupational therapist, the L and SC sections by a speech therapist, and the SE and GM sections by physical therapists.

Interobserver reliability was evaluated by estimating the indexes of agreement of two raters who independently scored the performance of 10 children on the developmental profile, EIDP. Reliability coefficients for accuracy were calculated for each profile area. With two observations on each test, the Pearson product-moment correlation (r) was chosen to estimate the magnitude of relations between paired scores. Agreement was excellent across all six scales ($r = 0.98–1.00$) and significant ($P < 0.00001$). Confidence intervals for the true mean difference between the raters had a confidence level as low as 80 percent and still covered 0.

Intervention

Each child visited the center once weekly for 90 minutes. The treatment model consisted of parent and child rotating approximately every 30 minutes from one therapist to the next in one large treatment room. The session consisted of hands-on treatment, which encompassed teaching the parent handling and positioning techniques to make activities of daily living easier at home and activities to facilitate normal movement and appropriate developmental milestones. Treatment techniques were based on neurodevelopmental principles developed by the Bobaths.[12-14]

Therapists (speech, occupational, and physical) were responsible for dealing with problems of the child and answering questions from the parents. The speech therapist focused on feeding skills and acquisition of receptive and expressive language. The physical therapist was responsible for gross motor activities; orthopedic problems; and arranging for necessary adaptive equipment, such as wheelchairs, prone standers, and walkers. The occupational therapist focused on fine motor skills and activities of daily living. Children functioning at an appropriate age in a specific area would not be seen by the relevant therapist. Nine children fell into this category and were seen for 40-minute sessions by individual therapists.

The program was dependent upon home follow through by parents. Parents' abilities to carry out the program were monitored by having them demonstrate instructed written handling and exercise techniques each 6 months, and proficiency was recorded by the therapist. Each child was reevaluated each 6 months, and a team conference was held that included the relevant therapists, a social worker, and the program director. Therapeutic goals were established at this conference, and these goals were then shared with the parent. Progress was checked and recorded during treatment sessions. The evaluation was sent to the referring physicians at these 6-month intervals, and a prescription to continue treatment was required on a yearly basis.

Payment for treatment was determined by a sliding fee scale, which was dependent upon the parents' income. Adaptive equipment was available on loan when needed. Thus, financial status was not a hindrance.

Data Analysis

T-tests and chi-square analysis of infants' and parents' characteristics were used to ascertain whether the two groups were clinically and statistically equal at the outset (Tables 1,2).

The child's score in each area was derived by taking the highest item number among four consecutively passed items. The score for each area was plotted on a profile graph (Figure 1) and the

Table 1. Characteristics of Infants (n = 105).

	Early Group (n = 50)	Late Group (n = 55)	*P*
Number of girls	25	23	
Number of boys	25	32	0.5193*
Mean birthweight (g)	2478.3	3041.6	0.3006
Mean gestational age (wk)	35.9	35.2	0.5538
Birth order			
First child	20	34	
Second child	15	11	
Third child	9	5	
Fourth child	3	2	
Other	1	0	
Not available	2	3	0.1687†
Diagnosis			
Down syndrome	3	7	
Cerebral palsy			
Spastic quadriplegia	4	5	
Spastic diplegia	6	5	
Spastic hemiplegia	3	5	
Athetoid quadriplegia	6	12	
Ataxic quadriplegia	2	1	
Hyptonic quadriplegia	15	11	
Hyptonic hemiplegia	1	1	
Myelomeningocele	6	2	
Mental retardation	1	1	
Other syndromes	3	5	0.6761‡
Mean developmental levels			
Perceptual-fine motor	1.620	2.727	0.0000
Cognition	1.700	2.873	0.0000
Language	2.240	3.352	0.0000
Social-emotional	2.120	3.491	0.0000
Self-care	1.837	3.241	0.0000
Gross motor	1.510	2.519	0.0000

* $X^2 = 0.4153$. † $X^2 = 6.4382$. ‡ $X^2 = 7.5297$.

connecting line was dated. The horizontal lines within which the points fall represent developmental levels. The profile graphs and developmental levels were determined by an outside researcher. Evaluations of developmental levels between the early and late groups at age 18 months were compared. Statistical analysis of the mean developmental levels between the two groups was determined by *t*-test analysis. Both separate and pooled variances were generated, and the larger of the two *P* values are reported.

Results

Tables 1 and 2 summarize the characteristics of the groups. The developmental levels of the late group at the onset of intervention were significantly higher than the early group in all areas. No significant differences were found in the early versus the late group for sex, birthweight, gestational age, birth order, or diagnosis. Thus, the distribution of baseline variables between the two infant groups appeared to be equal, except for developmental levels. There were no significant differences for parents' marital status, mothers' educational levels, or mean age of the father at the child's birth, but there were significant differences in the fathers' educational levels and the mean age of the mother at the child's birth.

When developmental testing was done at 18 months, the *t*-tests for differences in mean functional levels between the two groups showed that the early group had significantly higher levels in all six areas (Table 3): perceptual-fine motor ($P < 0.0003$), cognition ($P < 0.0001$), language ($P < 0.0004$), social-emotional ($P < 0.0001$), self-care ($P < 0.0001$), and gross motor ($P < 0.0002$).

Discussion

Our evaluation of developmental outcomes at 18 months of age shows an advantage for physically handicapped infants referred before 9 months for early intervention. This advantage included fine- and gross-motor development, cognition, language, and social-emotional skills. Our data suggest that a program that includes physical, occupational, and speech therapy, as well as a home program, can enhance the outcome of children who are referred before 9 months of age compared with later referral, at least in the short term. Follow-up studies will be able to ascertain whether the early group maintains their advantage.

Clinically, in all areas, the children referred before 9 months were more than one developmental level ahead of those referred later; moreover, they were approximately two developmental levels ahead of their counterparts in social and emotional skills.

One of the limitations of this study was that we did not randomly assign children to treatment at different ages, but this was not feasible in our setting because parents had the right to choose to have their child participate in early intervention. In fact, Bax noted that the use of control groups with handicapped children has proved to be one major stumbling block to evaluating methods of treatment.[15] He also stated that we might have to accept the fact that certain types of evaluation will have to be done on an uncontrolled basis. Thus, we attempted to establish the equality of

Table 2. Characteristics of Parents (n = 105).

	Early Group (n = 50)	Late Group (n = 55)	*P* Values
Marital status			
Married	40	39	
Divorced	1	6	
Single	4	7	
Foster	5	3	0.1972*
Mother's highest educational level			
Grade school	0	4	
High school	32	32	
Technical	1	1	
College	12	10	
Graduate school	2	1	
Not available	3	7	0.3419†
Father's highest educational level			
Grade school	4	5	
High school	18	31	
Technical	5	3	
College	13	6	
Graduate school	4	0	
Not available	6	10	0.0406‡
Mean age of mother at child's birth (years)	27.0	24.0	0.0208
Mean age of father at child's birth (years)	28.3	28.1	0.9066

* $X^2 = 4.6748$. † $X^2 = 4.5051$. ‡ $X^2 = 11.6003$.

our two groups by comparing the distribution of baseline variables in both the child and parents.

Our two groups of infants appeared to be equal, except in developmental levels, where the infants in the early group at the outset were significantly lower than the late group. This result was expected because of their lower chronological age. Thus, at the onset of intervention, the early group did not have higher test scores that could account for their significantly higher developmental levels at 18 months.

Comparison of parents' characteristics showed no significant difference between the two groups, except for fathers' educational levels and the mean age of the mother at the child's birth. The fathers of the early-treated group were more highly educated. Perhaps this influenced early referral because parents were more attuned to aberrant behavior and problems in their children. There is also the possibility that parent compliance with the home program was better in these families, because of greater comprehension. However, in most instances in both groups, it was the mother who was present at the sessions and instructed in the activities. The difference in the mother's age at the child's birth was statistically significant, but a maternal age of 27 years in the early group versus 24 years in the late group is not clinically significant. Missing data about parents' educational levels were due to single parent households, foster home placements, and infant adoptions.

There has been criticism that the positive results of early intervention in the very young child, the early group in this study, might be influenced by inaccurate early newborn assessment. Scrutton stated, ". . . there is probably a proportion of normal-but-different babies treated 'successfully' in the age group under 3 months."[16] We attempted to circumvent this problem of "normal but different" by disqualifying any child who "normalized" – defined as performing age-appropriately in at least four out of six developmental areas. All children were followed until at least 18 months of age to detect normalization before their scores were included in the study. Also, we realize that the prediction of neurological outcome in the premature infant is difficult, perhaps even after the 18-month follow-up.[17] We controlled effectively for this factor because there was no significant difference between gestational

Table 3. Values of *t*-Tests Comparing Mean Developmental Levels for the Early and Late Groups.

Areas	Early Group			Late Group			*t*	*P*
	n	$\bar{X}$	*s*	n	$\bar{X}$	*s*		
Perceptual-fine motor	50	4.74	1.86	55	3.47	1.55	3.77	0.0003
Cognition	50	5.1	1.89	55	3.69	1.63	4.07	0.0001
Language	48	5.19	1.55	52	4.1	1.42	3.66	0.0004
Social-emotional	48	7.04	2.32	55	5.13	2.31	4.19	0.0001
Self-care	48	5.17	1.6	52	3.98	1.29	4.05	0.0001
Gross-motor	50	4.6	1.97	54	3.26	1.42	3.96	0.0002

Profile Graph

Name _____ Birth Date _____

Evaluation Dates _____

Developmental Level in Months	*Perceptual Fine Motor*	*Cognition*	*Language*	*Social Emotional*	*Self-care*			*Gross Motor*
					Feeding	Toileting	Dressing	
32–35	48*	94		173			223	299
	↑	↑	138	↑	202	210	↑	↑
	46	91		171			221	294
28–31	45	90	134	170		209		293
	↑	↑	↑	↑	201		220	↑
	43	88	132	168		208		290
24–27	42	87	131	167				289
	↑	↑	↑	↑	200	207	219	↑
	38	84	129	165				286
20–23	37	83	128	164	199		218	285
	↑	↑	↑	↑		206	↑	
	32	79	124	161	198		216	284
16–19	31	78	123	160	197		215	283
	↑	↑	↑	↑	↑	205		↑
	28	73	117	158	195		214	276
12–15	27	72	116	157	194	204	213	275
	↑	↑	↑	↑	↑		↑	↑
	22	69	111	154	192	203	211	269
9–11	21	68	110	153	191			268
	↑	↑	↑	↑	↑			↑
	17	62	105	150	185			259
6–8	16	61	104	149	184			258
	↑	↑	↑	↑	↑			↑
	13	56	101	146	180			241
3–5	12	55	100	145	179			240
	↑	↑	↑	↑	↑			↑
	8	52	97	140	176			230
0–2	4	51	96	139	175			229
	↑	↑		↑				↑
	1	49	95	136	174			224

*Profile item numbers

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Figure 1. A Profile Graft. Used with permission from Schafer DS, Moersch MS, eds. Developmental programming for infants and young children. Ann Arbor, MI: University of Michigan Press, 1981:9.

ages or birthweights of children at delivery between our two groups (Table 1).

The mechanisms by which intervention might be more successful before the age of 9 months are not apparent in our research, but we speculate that the explanation probably consists of numerous factors. First, the plasticity of the nervous system in early development has been demonstrated in numerous animal studies.[18-21] Second, older children struggling with the developmental task of establishing independence might be less compliant with treatment than younger infants. Third, it appears easier to establish good habits than to reform bad habits. Perhaps, correct components of movement are more easily learned if abnormal patterns are not already ingrained. Fourth, parental factors might play a strong role in more successful intervention at a young age. As Scrutton has written, "Most parents expect to devote a large proportion of their time to the young baby, so it is easier to involve them in treatment."[16] It is also a time when parents are learning: (1) to cope with the reality of their child's handicaps, and they need a constructive format in which to deal with their feelings of inadequacy, and (2) to establish a good parent-child relationship. The program's impact upon the parents might be one of the essential ingredi-

Table 4. Physicians' Reasons for Referral of Children.

Reason	Early Group (n = 50)	Late Group (n = 55)
Evaluate—no diagnosis	7	4
Prematurity	15	8
Developmental delay	6	15
Cerebral palsy	4	12
Seizure disorder	5	0
Specific syndrome (i.e., Down, trisomy E, Möbius)	4	9
Spina bifida	5	2
Erb's palsy	1	0
Tetralogy of Fallot	1	0
Muscle weakness on left side	1	0
Hydrocephalus	0	1
Cytomegalic virus	0	1
Pulmonary atresia	0	1
Cystic fibrosis	0	1
Inspiratory stridor	0	1

ents for the greater success of early intervention rather than direct infant treatment. All these factors need to be addressed in order to study the actual mechanisms that enable early intervention to have more of an impact on the child before 9 months of life.

Table 4 presents the reasons children in the study were referred for treatment. Children should be referred for early intervention if they have central nervous system injury or dysfunction (i.e., cerebral palsy, myelomeningocele, neonatal seizures), Down syndrome, or other chromosomal abnormalities associated with neurologic handicap, or damage because of intrauterine exposure to drugs or alcohol (i.e., fetal alcohol syndrome, cocaine exposure). Table 4 also shows that many of the children were referred to the program with predisposing risk factors, such as prematurity or developmental delay rather than with a clear diagnosis of a specific neurologic disease.

Implications for Family Physicians

Family physicians need to evaluate carefully infants at high risk for needed early intervention. Such infants include those with birthweights less than 1750 grams, birth asphyxia (i.e., Apgar scores that are 4 or less at 5 minutes), the presence of neonatal intracerebral hemorrhage, and infants small-sized for gestational age. For children at high risk, the Denver Developmental Screening Test lacks adequate sensitivity to identify children who could benefit from early intervention programs.[22] Because many family physicians have not received adequate training in more sensitive testing of children's developmental status, most early intervention programs will provide the additional service of interdisciplinary evaluation for possible developmental delay.

One additional service family physicians can provide is to review a child's treatment and progress with parents during routine care. They can advocate for the parents through consultation with the therapists, insuring that treatment is not placing excessive burdens on parents and siblings and that treatment goals are clarified so that parents' and therapists' goals coincide.

Because there appears to be a critical age for treatment of the young handicapped child, family physicians must identify children with neurological deficits early and refer them to intervention programs for optimum benefit from treatment.

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Appendix

Classification for Diagnosis of Cerebral Palsy

1. Spastic – Exaggerated stretch reflex, increased tendon jerks, and persistently increased tone in muscle groups.
2. Athetoid (includes dystonia) – Fluctuating tone, which can alternate between high and low, involuntary movement, tone at rest usually low.
3. Ataxia – Incoordination and perhaps tremor upon movement, (drunken appearance). No involuntary movements, child's resting tone can be normal to hypotonic.
4. Hypotonia – Generalized low tone. No involuntary movements. Muscles overall lack firmness of the normally relaxed muscle. Weak stretch reflexes.