

Young Handicapped Children: Their Prevalence and Experiences with Early Intervention Services

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Fine, M. A., & Swift, C. F. (1986). Young handicapped children: Their prevalence and experiences with early intervention services. *Journal of the Division of Early Childhood*, 10(1), 73-83.

*****Note: *Journal of the Division of Early Childhood* is now titled the *Journal of Early Intervention***

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<http://dx.doi.org/10.1177/105381518601000108>

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Abstract:

The present study assessed the prevalence of handicapping conditions among young children (0 through 4) in Ohio and explored the experiences these handicapped children and their families have had with early intervention services. Using a telephone interview procedure, parents from 1,551 families in Ohio having 2,133 children were administered a survey instrument. Results indicated that 6.1% of the young children had functionally handicapping conditions. Approximately two-thirds (63%) of these children had received early intervention services as a result of their conditions. Parents of those served reported that service was initiated soon after conditions were noticed and that they were satisfied with their quality. Planning implications for the general public, professionals, legislators, and administrators are discussed.

Keywords: Child Development | Special Needs | Early Intervention Services

Article:

Estimates of the number of young children who have handicapping conditions have typically employed categorical definitions of the disorders. For example, Verhaaren and Connor (1981) estimate that there are 400,000 children with cerebral palsy living in the United States, Hayden and Beck (1980) report that there are three to five severely mentally retarded children born out of every 1,000 live births, and Shapiro and Shapiro (1980) have suggested that there are one to five children with Tourette's Syndrome out of every 10,000 born. Prevalence estimates for other recognized handicapping conditions have also been reported.

Attempts to aggregate these estimates into an overall prevalence rate for handicapping conditions among young children have been frustrated for a variety of reasons. One major factor is that handicapped children often have more than one type of problem, making it impossible to simply summate prevalence rates for individual categories. In addition, different investigators have employed varying methods of obtaining their estimates, which make comparison across studies difficult.

For these reasons, recent attempts have employed functional definitions of handicapping conditions. According to this approach, children are defined as handicapped only if their conditions place limits on their growth and development. The emphasis is not on the particular category of disability. An implication of this approach is that one child with asthma, for example, may be considered handicapped because the condition is functionally limiting, while another asthmatic child with excellent family support would not be handicapped if he or she is provided with the opportunity for normal development. Despite the advantage of focusing on the level of dysfunction, functional definitions require somewhat arbitrary decisions as to which symptoms are actually limiting and which are not. Furthermore, they are not typically useful in determining individualized treatment plans, because a large number of heterogeneous conditions are grouped together. For program planning, however, functional definitions are very useful in that they allow for nonoverlapping estimates of the number of children needing services.

Prevalence rates using functional definitions are rare and vary considerably according to the definitions employed. According to the United States Department of Education (P.L. 94-142), 12% of school-aged children are handicapped. Due to difficulties in detecting problems among young children, Garland, Stone, Swanson, and Woodruff (1980) suggest that 7.5% of preschool children have a handicapping condition. This lower prevalence rate for younger children is consistent with Abromowicz and Richardson (1975), who found that the rate of mental retardation is lower for preschool children than for the school-aged population.

While there is a growing body of evidence that early intervention services have a positive impact on child development (Battelle Report, 1976; Rynders & Horrobin, 1979), a number of specialists in the area have suggested that there are major gaps in service to young children. Bartel and Ogle (1981), in their review of federal early intervention programs, conclude that young children are less well served than their older counterparts.

The purpose of this study was twofold: (1) To further knowledge concerning the number of young children who have functionally limiting handicapping conditions and to do this through an extensive empirical investigation aimed specifically at the 0-4 preschool population; and (2) To explore parental perceptions regarding the experiences that these young children have with the early intervention service delivery system.

METHODOLOGY

Subjects

The sample consisted of 1,551 families in Ohio having 2,133 children under the age of five years. Because the procedure involved telephone interviews, the sample was somewhat skewed in the direction of middle-class homeowners. Fortunately, there were sufficient numbers of lower-income and/or renting families in the study to warrant the use of a weighting procedure; an artificial “random sample” was created.

To create this sample, demographic data were gathered from the 1980 Census for the 605,538 Ohio families having children less than five years old. While these data revealed that the actual sample was very similar to the population on most variables, it underrepresented renters and black families. Fortunately, the renters and black families in the sample were similar to their counterparts in the general population on important demographic dimensions (income, education, marital status). Consequently, the number of black families and renters was multiplied by a factor greater than one and the number of white families and homeowners was multiplied by a factor less than one to create a sample which more accurately reflected the population which these results were to generalize.

By design, the final “weighted” sample closely paralleled the population on the weighted variables (race and home ownership), as well as on the other dimensions presented in Table 1. All data subsequently reported in this paper are based on the weighted sample.

Survey Instrument

For purposes of this study, handicapping conditions were defined according to the federal Developmental Disabilities definition. The critical factors necessary to identify a young child as handicapped by this functional approach are: (1) chronicity, (2) restriction of normal child development, and (3) the resultant need for special attention as a result of the condition.

Chronicity-The condition must last for a considerable length of time, anywhere from several years to a lifetime.

Limitations in Normal Child Development- The condition must place restrictions on the extent to which young children develop and mature. According to this federal definition, there must be substantial limitations in several of the following areas: (1) self-care; (2) receptive and expressive language; (3) learning; (4) mobility; and (5) self-direction.

Table 1. Demographic Characteristics of Weighted Sample of Households with Children under Five Years of Age

	<i>Percentage of Children 0 through 4 Years</i>
Ages	30% 0-2; 35% 3; 35% 4 years
Sex	51% male; 49% female
Household Annual Income*	11% less than \$10,000; 26% have \$10,000 to \$20,000; 34% have \$20,000 to \$30,000; 15% have \$30,000 to \$40,000; and 8% have in excess of \$40,000
Child in Preschool of Daycare	32% yes; 68% no

Regularly Attend Church	71% yes; 29% no
Home Status	66% own home; 34% rent or other
Respondent Education	7% some high school or less; 42% high school graduate; 27% some college; 17% college graduate; 8% post college graduates
Marital Status	93% married; 7% single
Ethnicity	88% white; 12% non-white

*6% either did not know or refused to respond NOTE: Percentages based on 2,133 young children in weighted sample.

Need for Special Attention-An underlying assumption in this study is that the limiting nature of the condition necessitates some form of special attention.

The survey instrument was developed by the principal investigators and a private research firm, Appropriate Solutions, Inc. in Columbus, Ohio, with input from an advisory committee consisting of statewide professionals with expertise in the areas of handicapping conditions and early intervention services. One of the later drafts was subjected to a pilot test of 16 families having young children who were participants in a Columbus early intervention program. The instrument consisted of eight sections, described below:

(1) Health Status

One of the strategies employed to obtain maximum cooperation from respondents was to describe the study as exploring children's health and health care. Questions relating to health care tend to be less sensitive and increase the likelihood that the more personal questions would be answered honestly. Consequently, these initial questions requested information relating to whether the children had regular doctors, had taken certain shots, and had received a variety of physical examination tests.

(2) “;At-Risk”; Screens

These questions dealt with factors identified in the literature as placing children “at-risk” for the later development of handicapping conditions. The results generated from these items (Fine & Swift, 1985) are not directly related to the experiences of children presently having handicapping conditions.

(3) Handicapping Condition Screens

These questions determined whether the young children had functionally limiting handicapping conditions. Toward this goal, five screening questions relating to the child's progress were asked of survey respondents: (1) Whether the child had difficulties in walking, eating, talking, or becoming toilet trained; (2) Whether the child had been tested for the possibility of a learning problem; (3) Whether the child had had an EEG or brain wave test; (4) Whether the child had any physical, emotional, or learning difficulties that required special attention; and (5) Whether the child was limited in play activities. If the child had none of these problems, respondents were

asked if they had ever noticed or been told that their children might have a handicapping condition. At this point in the survey, the goal was to include children who were reported to have even the slightest degree of dysfunction in the handicapping condition group. Therefore, a positive response to any of these screens placed the child in this group. As described below, if further questioning suggested that the child was not functionally handicapped, he or she was removed from the handicapped group.

(4) Specification of Handicapping Condition

If a child was screened into the handicapping condition group, the condition the child had was then explored with a series of structured questions. Respondents were given an opportunity to specify the nature of the problem in great depth. At this point, if parental description of the condition revealed that it was not functionally limiting, the child was removed from the handicapping conditions group.

(5) Experiences of Families Having a Child with a Handicapping Condition

This set of questions was asked only of those families who were identified as having a child with a handicapping condition. Accordingly, parents of 131 children (6.1% of the total) were asked (1) when the child's condition was noticed, (2) who noticed it, and (3) whether the child had received any services as a result of the condition. If the child had been involved in any special services, the family was subsequently asked a series of questions relating to the nature, frequency, and quality of service provision. Due to time limits and the heterogeneity of handicapping conditions sampled, data relating to the specific services received were not gathered. Finally, the difficulties families experienced as a result of the child's condition and perceived barriers to meeting family needs were explored.

(6) Perceptions of Families Having "At-Risk" Children

These questions were asked of only those families who were identified as having an "at risk" child (Fine & Swift, 1985).

(7) Perceptions of Families Having Children Not Suspected of Being "At-Risk"

This set was asked of all families who did not have handicapped or "at-risk" children. The questions explored their concerns and their explanations of what they would do if their children developed problems.

(8) Demographics

Routine demographic data-(1) education, (2) occupation, (3) ethnicity, (4) homeownership, and (5) religious involvement were gathered from all respondents.

Procedure

For reasons of cost effectiveness, a phone interview technique was chosen over personal interviews and mailed surveys. The sample was obtained from the R. L. Polk Company, which maintains a regularly updated listing of approximately 30% of Ohio families having children under the age of six years. Developed largely from home and auto ownership records, the sample was overrepresented with middle-class families. All socioeconomic groups were included in the sample, however.

Respondents were contacted evenings and weekends by interviewers trained and employed by the private research firm. All interviewers received an initial nine hours of training in survey methods and, in addition, three hours in the areas of handicapping conditions, early intervention services, and administration of this specific instrument. After each interviewer had completed five surveys, individual meetings were held with supervisors to review completed questionnaires and discuss any problems encountered. The 21 interviewers completed 1,551 surveys in a three week period. Only 15.6% of household contacted refused to participate.

Data Analysis

The data were analyzed in two ways. First, frequencies were generated for all responses to survey questions. Second, these frequencies were computed for a number of subgroups in the sample: the age, sex, and ethnicity of the child, urban/rural status, socioeconomic status, and the risk category of the child (handicapping condition, "at-risk" no suspected risk). Thus, the proportion of children 0 through 4 in Ohio having a handicapping condition was separately calculated for boys and girls; 0-2, 3- and 4-yearolds; black and white children; children in urban, semi-rural, and rural areas; and children from low-, middle-, and upper-income families.

RESULTS

Prevalence of Handicapping Conditions Table 2 presents the prevalence of handicapping conditions among the children in the weighted sample. Of the 2,133 children, 6.1% had a functionally limiting condition as defined in this study. As shown in the table, the only statistically significant differences ($p < .05$) among groups were that children from lower-income families and from urban areas were most likely to have a handicapping condition and that relatively few rural children were so identified. Table 3 reveals the percentage of young children who were screened into the handicapping condition group for each of the six questions in the instrument designed to identify such children.

The most common functional difficulties identified are presented in Table 4. At this early age, visible and tangible problems (vision, speech, hearing, muscular, and breathing difficulties) were more apparent than those related to emotional development, which were so infrequently reported that they do not appear in the table.

Table 2. Percentage of Sample of Children having Handicapping Conditions by Demographic Groups

Demographic Groups	Total Number of Young Children in Each Demographic Group	Percentage within each Demographic Group having Handicapping Conditions
Age		
0-2 years	638	6.2
3 years	751	5.2
4 years	744	7.0
Sex		
Male	1,095	5.9
Female	1,032	6.5
Race		
White	1,867	6.1
Non-white	258	5.9
Income		
Less than \$10,000	226	11.6
\$10,000-20,000	551	7.2
\$20,000-30,000	735	3.4
\$30,000-40,000	325	7.4
More than \$40,000	161	2.6
Region		
Urban	1,302	8.0
Semi-Urban	388	5.3
Rural	443	1.4
Statewide Average	2,133	6.1

Experience with Early Intervention Services

This section presents data from those young children who were identified as having a handicapping condition. There were 131 children meeting the criteria in the sample.

Identification of Conditions

A majority (78.7%) of young children were identified as having a limiting condition in their first year of life. More specifically, 14.9% were identified at birth, 33.4% between birth and six months, and 30.4% between 6 months and one year. Only 21.3% were identified between one and four years of age. Consequently, the majority of children aged 0 through 4 who were identified as handicapped were picked up relatively early in their lives.

The only statistically significant differences ($p < .05$) in age at identification occurred on the sex and region variables. Girls were almost twice as likely as boys to be identified at an early age. Of the boys, 33.7% were identified at birth or from birth to six months, while 61.8% of the girls were similarly picked up. In urban areas, 51.6% of children were identified before the age of six months, as compared with 34.6% for semi-urban and 28.6% for rural children.

A pattern emerges in the data related to who first noticed the condition. For the most part, among all demographic groups studied, parents were the first to notice the handicapping condition. Almost half (46%) of these conditions were first identified by mothers. An additional 14.9% were first noticed by both parents. A fifth of these cases (20.5%) were first noticed by someone else. Only 18.5% of these cases were first identified by doctors. Several exceptions to this trend should be noted. First, doctors were far more likely to identify girls as having a handicapping condition than boys (29.7% of the handicapped girls as compared to 6.8% of the boys). Second, non-white and children from lower-income families were somewhat less likely to be identified by doctors and more likely by others, including friends and relatives.

Table 3. Percentages of Sample of Children Screened into Handicapping Condition Group by Question

Question	Portion of Screened into ¹ Handicapping Condition Group
Difficulties walking, talking, eating, or becoming toilet trained	4.0%
Tested for learning difficulty	4.7%
EEG test	3.8%
Need for Special Care/Attention	3.1%
Play Limitations	1.1%
Suspected or told of possible handicap	0.8%

NOTE: Percentages based on 2,133 young children in sample. ¹Because many young children were screened into the handicapping condition group on more than one question, the percentages are not independent of each other and are thus not mutually exclusive.

Table 4. Most Common Functional Difficulties Identified in Sample

Functional Difficulties	Percentage of Total Number of Functional Difficulties
Speech Disorder	14.1
Muscular/Joint Problems	13.7
Vision Problems	7.1
Breathing Difficulties	6.0
Bowel/Bladder Difficulties	5.2
Hearing Problems	5.2
Neurological Problems	4.9
Cerebral Palsy	4.2
Hyperactivity	4.2
Epilepsy	4.1
Sitting/Moving Problems	4.1
Diet Restrictions	4.1
Mental Retardation	3.0
Asthma	3.0
Allergies	2.9
Physical Deformities	2.9

Note: Percentages based on 252 total functionally difficulties identified among 131 children with handicapping conditions. Because some children had more than one functional difficulty identified,

percentages are overlapping and are not mutually exclusive. For example, 14% of all the problems identified were related to speech disorders.

Participation in Early Intervention Services

Almost two-thirds (63.4%) of the children with handicapping conditions in the-sample either had received or were presently receiving services as a result of having the condition. These results are presented in Table 5. As shown, there were statistically significant differences ($p < .05$) among the various demographic groups. First, non-white children were proportionally more likely to receive services than were their white counterparts. Second, children from low-income families were more likely to receive services than were children from moderate- to high-income families.

Of the young children served, respondents reported that service was initiated soon after the conditions were noticed. Almost half (49.5%) were served within one month, 31.9% were served between two and six months, and 18.7% were served seven months or more after the condition was identified. Non-white children faced longer delays before being served than did white children: 54% of non-white children were served within six months as compared to 87.8% of the white children.

The majority of families had experiences with a limited number of service organizations. Fifty-five percent dealt with one or two agencies, while the remaining 45% received services from three to five programs. Older children were served by more agencies than were their younger counterparts. Non-white children, on average, received services from significantly more organizations than did white children.

In general, parents expressed satisfaction with the quality of services provided. These data are presented in Table 6. As the table shows, almost half (48.8%) reported being very satisfied with the services provided, and an additional 28.5% reported being satisfied. Statistically significant differences ($p < .05$) among the groups included, first, the fact that parents of females were less satisfied than those of males. Second, non-white parents were less satisfied than were their white counterparts. And finally, although all families with annual incomes of less than \$10,000 were satisfied, low-middle income parents were on the average less satisfied than those with greater family incomes.

Table 5. Percentage of Sample of Handicapped Children Receiving Services by Demographic Groups

Demographic Groups	Total number of Handicapped Children in each Demographic Group	Percentage who had or were receiving services at the time of the study
Age		
0-2 years	39	61.4%
3 years	39	64.6
4 years	52	64.1

Sex		
Male	64	61.5
Female	65	65.3
Race		
White	113	58.2
Non-white	15	100.0
Income		
Less than \$10,000	26	86.9
\$10,000-20,000	40	41.3
\$30,000-40,000	24	51.1
More than \$40,000	3	75.0
Region		
Urban	104	61.7
Semi-Urban	19	71.4
Rural	8	66.7
Statewide Average	131	63.4

When asked what service features they were most satisfied with, the common responses were positive qualities on the part of the staff (understanding, patience, friendliness, helpfulness) and the quality of special services. Less frequently the opportunity for parental involvement and positive effects were also reported.

Those program features with which parents were most dissatisfied included treatment procedures, bureaucracy, and inappropriate referral. Other characteristics cited included poor quality, lack of program facilities, lack of information, and waiting for services.

A large number of recommendations were made by parents to program planners and designers. Those most frequently mentioned were improved parent education, information sharing, and more personal contact between staff and children/parents. Other suggestions included paying closer attention to children's unique needs, providing support groups, testing more quickly, and simplifying paperwork.

Parents found out about programs in a number of ways. Most commonly, information sources were schools, friends, hospitals, and health departments.

Table 6. Level of Parental Satisfaction with Quality of Early Intervention by Demographic Groups

Demographic Groups	Level of Satisfaction		
	Very Satisfied	Satisfied	Dissatisfied
Age			
0-2 years	60.6%	15.1%	24.3%
3 years	67.1%	30.1%	2.7%

4 years	26.0%	36.8%	27.3%
Sex			
Male	63.3%	27.5%	9.2%
Female	35.9%	29.4%	24.7%
Race			
White	59.8%	22.8%	17.4%
Non-white	0	54.1%	45.9%
Income			
Less than \$10,000	66.3%	33.7%	0
\$10,000-20,000	12.5%	45.8%	41.8%
\$20,000-30,000	52.6%	29.9%	17.5%
\$30,000-40,000	77.9%	11.1%	11.1%
More than \$40,000	100.0%	0	0
Region			
Urban	46.4%	29.9%	23.7%
Semi-Urban	55.6%	22.2%	22.2%
Rural	75.0%	25.0%	0
Statewide Average	48.8%	28.5%	22.7%

NOTE: Percentages based on 80 handicapped young children whose parents responded to this question.

Perceptions of Family Problems and Needs

A series of questions assessing perceptions of the family's greatest problems and needs were asked of all families having young children with handicapping conditions. The first question identified the greatest problems facing the children (as perceived by their parents) as a result of their conditions. The most pressing difficulties reported were communication, mobility, frustration, play restrictions, toilet problems, adjustment to treatment, and discipline. On the other hand, the most crucial problems experienced by the remaining family members were (a) time demands related to childcare and (b) negative emotions including worries and fears about the condition, medical visits, financial burdens, transportation, spoiling the child, and difficulties communicating with the child.

The parents reported having a number of worries related to caring for their children over the next three years. Of prime concern were children's health and educational development. Children's intellectual development and the parents' abilities to implement appropriate discipline were also frequently identified.

Despite these concerns, parents generally reported that they were well informed about their children's conditions. Almost three quarters (72.1%) felt very well informed, with an additional quarter (25.2%) somewhat informed. Only 3% felt uninformed.

DISCUSSION

Major Findings

Prevalence Rates

The telephone survey data suggest that 6.1% of children ages 0 through 4 years in Ohio have a functionally limiting handicapping condition. This figure is consistent with several prevalence rates presented in the research literature, particularly Garland, Stone, Swanson, and Woodruff's (1980) estimate that 7.5% of preschool children are handicapped. With respect to subgroup differences, children from lower-income families and those from urban areas were most likely to be identified as having a handicapping condition.

Identifying Handicapped Children

The results clearly indicate that parents, typically mothers, are the first to notice that their children are having developmental problems. It appears that day-to-day contact renders parents more sensitive to the development of their children than are professionals who have only brief and periodic exposure to them. Many families reported that their initial contact with professionals, if they suspected their children had problems, would be with physicians. It appears crucial that medical professionals, primarily pediatricians and nurses, be aware of early intervention options and make appropriate referrals.

The study supports the conclusion that the identification process is most successful with children having more severe handicaps, since most of the young children identified as having handicapping conditions were less than one year old. Unfortunately, those having milder difficulties may not be identified until the demands of school are placed on them.

Experiences with Early Intervention Service System

Approximately two-thirds of the handicapped children identified in this study had received or were presently receiving services as a result of their condition. For those children receiving services, parents were generally satisfied with their quality. However, a substantial number (37%) of the handicapped children remain unserved by these programs.

Limitations of the Study

In interpreting these results, the reader should be aware of several limitations of this study. (1) The use of parental report, usually mothers, is not as objective a method as conducting formal assessments of developmental functioning. Parents are certainly not unbiased observers of their children. Some, afraid of their own or other's stigmatization, may have underreported their children's difficulties, while others, attempting to access help, may have overreported symptoms. (2) The use of phone interviews may have placed restrictions on the extent to which the interviewers could establish rapport and ensure that their questions were clearly understood. (3) The focus on young children makes identification of handicapping conditions particularly difficult, because it is not until the rigors of school that many learning problems become evident. (4) Difficulties interpreting the definitions of handicapping conditions occur because it is often not clear among preschool children whether a particular child characteristic is or is not functionally limiting. This judgement depends on environmental and family circumstances not

directly assessed in this study. (5) Families not having telephones were not sampled in this study. While the weighting procedure was designed to address this deficiency, it may not have done so because families without phone services are likely to have very different experiences than their counterparts with telephones. In addition, the sample was potentially biased due to the 15% of those called who refused to participate. While there are many possible reasons for declining a phone interview, one factor may be that those not participating were more skeptical and guarded in discussing the health of their children, because of unsatisfactory experiences with service agencies. (6) These findings from parents need to be corroborated from different data sources in future investigations. For example, data from early intervention service providers could contribute to our understanding of the range of services available to handicapped children and parental satisfaction with their quality.

Implications

For the general public, greater awareness of the milestones of normal child development should be developed, and indicators of delays, as well as the need for and availability of early intervention services, should be publicized. If lack of awareness and information is responsible for poor service utilization, the proposed efforts should increase the number of children receiving services.

For professionals, activities designed to increase their knowledge of (1) early indicators of developmental delays and (2) early intervention services should result in greater numbers of young children identified and served. Because of their prestige and early contact with young children, physicians and nurses should be prime targets of this training.

For legislators and administrators major system-wide changes should be strongly pursued. While these data do not directly indicate which changes might be made, one possible change would be the enactment of a legislative mandate to provide early intervention services for children 0 through 4 who have handicapping conditions. With an appropriate funding base, such a mandate could reduce the number of unserved children.

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