



NATIONAL EARLY INTERVENTION LONGITUDINAL STUDY

FAMILIES' FIRST EXPERIENCES WITH EARLY INTERVENTION

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INTRODUCTION

Families are a key focus of the federal early intervention legislation for young children with disabilities. Part C of IDEA (Individuals with Disabilities Education Act) repeatedly uses the phrase “infants and toddlers with disabilities and their families.” The law notes the need to enhance the capacity of families to meet the needs of their children and addresses this need through the development of an Individualized Family Service Plan (IFSP) and the provision of services for families. Recent amendments to Part C (P.L. 105-107, 1997) further reinforce the role of early intervention in supporting the needs of the entire family. Although research on children’s development had long recognized the importance of the family, the emphasis on the family in Part C constituted a policy milestone in that the critical role of the family in children’s development was now recognized in legislation as well.

Families play many roles with regard to early intervention services. In addition to the obvious one of caring for their children, they also are their child’s connection to the early intervention service system. The family needs to be committed to the necessity and value of seeking and finding services for the child in their community. The family needs to apply and be willing to participate in the process of service delivery for what could be an extended period of time in order for the child to receive services.

This report examines families’ initial experiences with obtaining early intervention services. It is based on data from the National Early Intervention Longitudinal Study (NEILS). Funded by the U.S. Department of Education, NEILS is following a nationally representative sample of 3,338 infants and toddlers and their families from the time they enter early intervention until they complete kindergarten.

Families of children who have or are at risk for a disability at some point must go through a process of becoming concerned about their child, finding out about possible problems, and getting services. The timing of these experiences varies widely as a function of age, locale, and disability type (Reschly, 1996). In 1998, nearly 200,000 children were enrolled in early intervention programs under Part C of the IDEA because of a disability or because they were at risk for a developmental delay (U.S. Department of Education, 2000). Each of these families had gone through some sort of process by which they found out about early intervention services and entered the service system.

The timing of identification and entry into early intervention spans the birth- to 36-month age period. For a few families, prenatal screening or problems during pregnancy indicate the possibility of disability or the risk of disability even before the child is born. For some families, the discovery of disability or a risk condition occurs at or shortly after birth due to prematurity, problems with labor and delivery, or the presence of obvious impairments not detected by prenatal screening efforts. Most families, however, give birth to a child that they and their physician consider to be normal. They, along with physicians and other specialists, must later discover

the presence of disability by observing the child and making sense of emerging concerns about health, development, or behavior.

Ideally the process of discovering disability and entering early intervention should be timely and supportive of families. Parents need professionals who attend to their concerns and help them gain access to services when needed. Part C programs should help families by providing a responsive system for (a) identifying children who have or are at-risk for having a developmental disability, and (b) providing a comprehensive and individualized set of services for both children and families. There is almost universal consensus that parent satisfaction constitutes a key component of any evaluation of early intervention services (Bailey et al., 1998; McConnell et al., 1998; Roberts, Innocenti, & Goetz, 1999; Turnbull, Turbiville, & Turnbull, 2000). Research using a variety of measurement approaches in a number of areas of this country as well as internationally shows that families are highly satisfied with early intervention programs (Bailey, Skinner, Rodriguez, Gut, & Correa, 1999; Lanners & Mombaerts, 2000; McNaughton, 1994; McWilliam et al., 1995; Minke & Scott, 1995; Wesley, Buysse, & Tyndall, 1997). Some studies (e.g., Mahoney & Filer, 1996) report that a discrepancy exists between services deemed important and the services actually received.

Little is currently known about families' experiences in finding and beginning early intervention services. Since it is likely that perceptions of services might change throughout the course of experience with those services (McWilliam et al., 1995), research on how families perceive special services that is both time-specific and longitudinal is needed. This report addresses several questions about the process by which families enter early intervention:

- What is the timing of first concerns, diagnosis, referral, and service entry for families participating in Part C early intervention programs?
- What kind of contact do families have with medical professionals when first concerned about their child's development?
- How much effort does it take for parents to find out about and get early intervention services?
- What roles do parents play in developing the Individualized Family Service Plan (IFSP)?
- Are parents satisfied that the services provided are those that are needed?
- Are parents satisfied with initial interactions with early intervention professionals?

Descriptive findings for the six questions are presented. For each question, the experiences for different kinds of children and families are compared. Experiences are compared for families with children who were eligible for early intervention for different reasons (developmental delay, diagnosed condition, risk condition) and who began early intervention at different ages. Findings are also compared by gender and ethnicity. Family characteristics examined included household income,

caregiver education level, number of adults in the household, and language of the respondent.

Sample

The nationally representative sample for the study consisted of 3,338 children who entered early intervention for the first time between September 1997 and November 1998. Families were recruited through early intervention programs located in 93 counties in 20 states. Local program providers explained the study to families at or near the time of the IFSP. All families who met the study criteria (child less than 31 months of age and an adult in the household who spoke English or Spanish) were invited to participate. If a family had more than one child entering early intervention, only one child was selected for the study. Programs invited 4,653 families to participate in the study and 3,338 (71%) agreed.

Data Collection

The findings presented in this report are based on a 40-minute telephone interview conducted with “the person best able to answer questions about the child and the child’s program.” Fourteen percent of the interviews were conducted within two weeks of the initial Individual Family Service Plan (IFSP) meeting, 36% between 2 and 4 weeks of the IFSP, 18% between 4 to 6 weeks of the IFSP, and 25% between 6 to 16 weeks of the IFSP. Telephone interviews were completed with 89% of the families (n= 2,974). Families who could not be reached by phone were sent a questionnaire in the mail. Some families who could not be contacted for the initial interview were successfully contacted for the next scheduled interview a year later. These families were asked some of the questions from the first interview during this interview. Interview or mail survey data was available for 3200 children or 96% of the sample. Some data such as date of the IFSP meeting were available for 100% of the sample. Individual items will have fewer respondents because of missing data. Additional information about the study’s methodology is presented in Appendix A and at www.sri.com/neils.

This report is based on the telephone interviews conducted within 16 weeks of enrollment and some data from an additional telephone and/or mail surveys for those who could not be interviewed within 16 weeks of enrollment. Most (83%) of the respondents were the child’s biological mother. Other respondents included foster mothers (5.1%), grandmothers (3.9%), adoptive mothers (2.9%), and biological fathers (3.5%). Seven percent of the interviews were conducted in Spanish.

Limitations

The study’s findings are limited in that they are based only on the experiences of families who actually entered the early intervention system. Families preferring not to participate in Part C early intervention programs, those whose children were

referred but not determined to be eligible, and those who did not persist in finding or entering services were not included in the study. It is reasonable to assume that if there are families who did not enter early intervention services because of serious obstacles they encountered, then their perceptions of the entry process would be far more negative than those of families who obtained service. Also, these findings are based on a few questions asked in the context of a telephone survey. More detailed information about family perceptions, especially specific concerns about programs or service providers, could not be captured with this methodology. A more extensive series of interactions with families might be needed to thoroughly explore the complexity of the process involved in finding and beginning early intervention services. These limitations notwithstanding, a number of conclusions can be drawn about the experiences of families entering early intervention programs, along with several qualifiers and recommendations.

FAMILIES' EXPERIENCES

Timing of Events Related to Enrollment in Early Intervention

A typical sequence for families with an infant or toddler with special needs is: someone has concerns about a child's development, the child is seen by some number of professionals, a diagnosis is made, followed by a referral to an early intervention program. By law, within 45 days of the referral, a meeting to develop an Individualized Family Service Plan (IFSP) must be held and shortly thereafter the child and family begins to receive services. Although this order of events is typical, it is certainly not the only possible sequence. For some families, the child's special need is health-related and is diagnosed before or at birth. For these families, the diagnosis is the first event. For other families, the nature of the child's difficulties may not be fully understood until after a referral to early intervention or, in the case of some syndromes, until several months or years after services begin. Whatever the family's particular sequence and time span between events, the goal is always to identify developmental needs and get services started as early in the child's life as possible.

The timing and sequence for entering early intervention were explored by looking at the dates for several critical events. Families were asked at what age someone first became concerned about the child's health, development, or behavior; the age of first diagnosis or identification as potentially eligible for services; and the age when they first looked for early intervention. The date of the referral to early intervention and date of the IFSP was reported by the agency. The mean, minimum, and the maximum ages for each of these events are presented in Table 1 along with other descriptive data.

On average, first concerns were expressed at 7 months of age, the first diagnosis was at 9 months, early intervention was first sought at 12 months, referral to early intervention occurred at 14 months, and the IFSP was developed at 16 months. The average length of time between first concern and IFSP was 8.3 months. The data on the minimum and maximum highlight the extreme variation within the population of children receiving early intervention. Some children in early intervention are identified as needing services before they are born while others are not identified until the third year of life. This is consistent with other NEILS' findings that indicate the population in early intervention is quite diverse and in need of service for a variety of reasons.

The findings in Table 1 are based on children who were recruited for the study, and who by definition had to be younger than 31 months of age at the time of the first IFSP. From other study data, we know that the average age at referral was 15.5 months and the average age at first IFSP was 17.1 months for the full age range of children (i.e., up to 36 months of age) entering early intervention. Nearly nine percent of children enter early intervention between 31 and 36 months of age. The study has no data on the other events (concerns, diagnosis, when family

sought early intervention) reported on for children who enter after 31 months of age. We can estimate, by comparing the data on children who begin early intervention as infants with those who enter later, that if these data were available, they would likely raise the averages slightly for the three unknown events and also increase the average distance between average time of the first concern to first IFSP from that reported in Table 1.

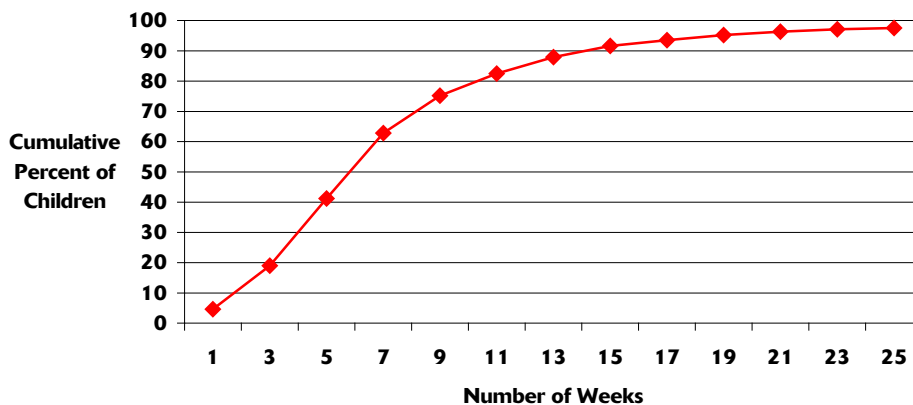
Table 1
MEAN AGES FOR EVENTS RELATED TO IDENTIFICATION
AND ENROLLMENT IN EARLY INTERVENTION SERVICES

Event	Mean Age (months)	Minimum Age	25 th percentile	Median	75 th percentile	Maximum Age (months)
First concern about health or development	7.4	(5 wks. prior to birth)	0	4	15	30
First diagnosis or identification	8.8	(5 wks. prior to birth)	0	6	18	30
First looked for early intervention	11.9	0	3	11	21	31
Referral received by early intervention program	14.0	0	4	14	23	31
Age at which IFSP is signed	15.7	.3	6	16	25	31

N = 3,056 to 3,235.

Although the difference between any two of these events is interesting, a particularly important policy time difference is the time from the referral to the IFSP. Both of these time points were reported by the program. IDEA mandates that the meeting to develop the IFSP be held within 45 days of referral to early intervention. About 60% of the IFSPs were written within 45 days of referral (See Figure 1). Seventy percent were written within 8 weeks of referral, 79% within 10 weeks, and 90% within 14 weeks. The study has no additional information on why the length of time between the referral and IFSP was more than 45 days for so many families.

Figure 1
CUMULATIVE PERCENTAGE OF CHILDREN
FOR GIVEN NUMBER OF WEEKS FROM REFERRAL TO IFSP

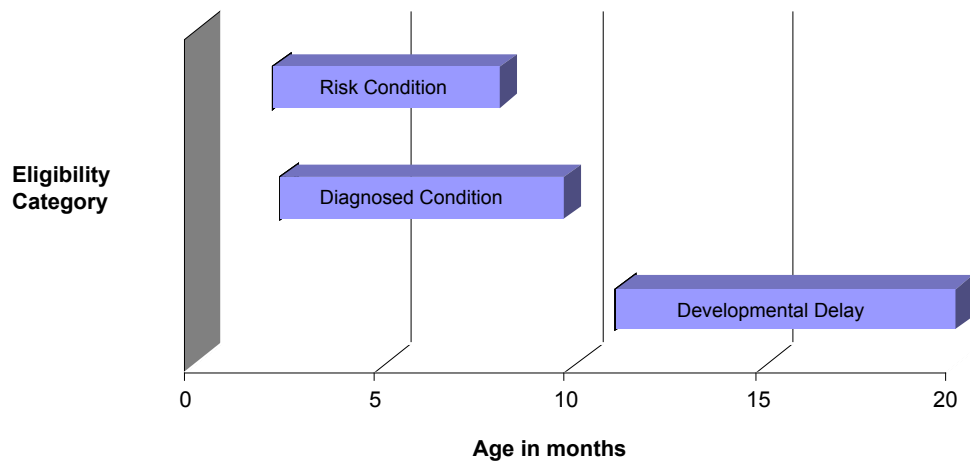


The timing of these critical events varied considerably for children eligible for early intervention services for different reasons. Other data from NEILS indicates that the children with developmental delays were older than children with diagnosed conditions and risk conditions at the time of the IFSP (Hebbeler et al., 2001). For children with developmental delays who entered early intervention at less than 31 months, the average age at IFSP was 20 months (See Table 2) as compared to 9.4 months for children with diagnosed conditions, and 8 months for children with risk conditions. Not surprisingly, the age at first concern also was later, 11.1 months for children with developmental delays compared to 2.3 months for children with diagnosed conditions, and 2.1 months for children with risk conditions. The time between first concern and IFSP was also longer for children with developmental delays, 8.9 months, compared to 7.1 for children with diagnosed conditions and 5.9 for children with risk conditions. Figure 2 illustrates both the difference in age at first concern and the time to IFSP for these three groups.

Table 2
MEAN AGE IN MONTHS OF THE TIMING OF CRITICAL EVENTS
BY ELIGIBILITY CATEGORY

Event	Eligibility Category		
	Developmental Delay	Diagnosed Condition	Risk Condition
First concern about health or development	11.1	2.3	2.1
First diagnosis or identification	12.9	35.	2.5
First looked for early intervention	16.0	5.7	5.2
Referral received by early intervention program	18.2	7.8	6.1
Age at which IFSP was developed	20.0	9.4	8.0
Difference between first concern and IFSP	8.9	7.1	5.9
N =	1,826 to 1,923	638 to 675	436 to 463

Figure 2
TIME BETWEEN MEAN AGE AT FIRST CONCERN AND MEAN AGE AT IFSP BY ELIGIBILITY CATEGORY



The difference in time lag is also apparent when we compare children for whom the IFSP was completed at different ages. Children who begin early intervention within the first year of life have a shorter time lag between first concern and IFSP than do children who begin in the third year of life. The average age of the critical events for children who enter early intervention at less than 12 months, 12 to less than 24 months, and 24 to 31 months of age is shown in Table 3. The timing and span is illustrated in Figure 3.

For most children who begin early intervention at less than 12 months of age, the first concerns appear very early. Half of this group had a first concern identified at or before birth; 75% had a first concern identified by two months of age. The relatively short time span for this group suggests that these children and their families are being connected to early intervention programs relatively quickly, and by 6 months of age the IFSP has been developed. It is difficult to know whether 6 months from concern to IFSP is a reasonable period of time. On one hand, it seems like a long time for a child whose special needs were identified at or before birth. On the other hand, many of these infants were also very sick and spent weeks in the hospital after they were born and connecting with early intervention services might not have been a top priority for the family at that point. The longest time span between events for the youngest children was 1.8 months between the diagnosis and when the family first looked for early intervention, which is consistent with the notion that the family was not ready to seek out an early intervention program immediately after the child's birth.

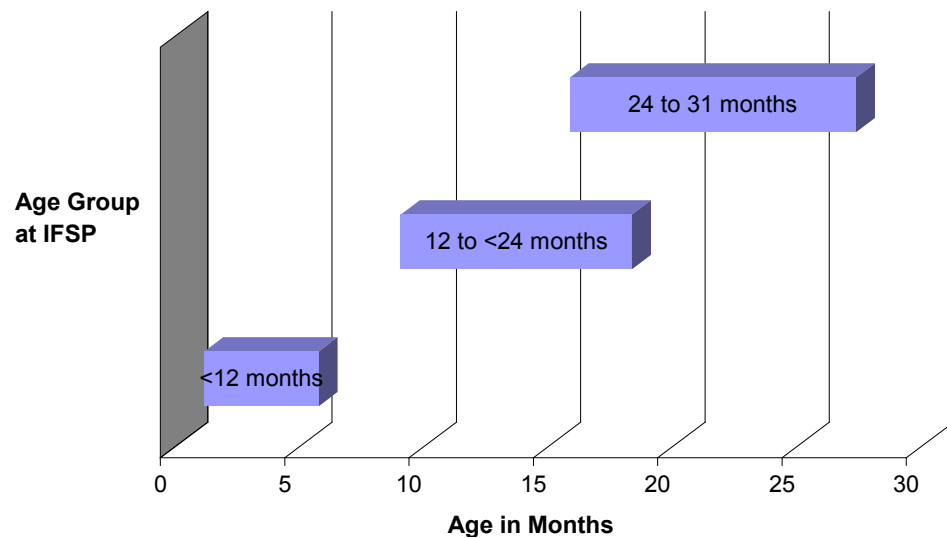
Table 3
MEAN AGE IN MONTHS OF TIMING OF CRITICAL EVENTS
BY AGE GROUP AT IFSP

Event	Age Group at IFSP		
	Less than 12 months	12 to less than 24 months	24 months to 31 months
First concern about health or development	1.2	9.1	15.9
First diagnosis or identification	1.7	10.8	18.3
First looked for early intervention	3.5	14.1	22.1
Referral received by early intervention program	4.2	16.4	25.7
Age at which IFSP is signed	5.8	18.4	27.4
Difference between first concern and IFSP	4.6	9.3	11.5
N =	1,235 to 1,313	963 to 1020	858 to 902

The time spans in Figure 3 clearly illustrate the differences between children who enter early intervention in infancy versus later in toddlerhood. The time span between first concern and IFSP for the oldest children, 11.5 months, was over twice that of the youngest children at 4.6 months. This reflects some of the same issues that apply to the identification of developmental delay, because the majority of the children who enter early intervention at the older ages do so because of a developmental delay. Delays emerge over time. Someone has to be concerned and then pursue a course to diagnosis and intervention. There can be many months of uncertainty about the significance of a problem that might contribute to the longer time lag for this group. Nearly every one of the average time spans between critical events was longer for children who entered after 24 months. The

longest was 3.8 months, which was the average time between first diagnosis and looking for early intervention. This study has no additional information on why this time span should be so long. Interestingly, the time span between referral and IFSP was comparable across the three age groups: 1.6 months for those under 12 months; 2 months for those 12 to 24 months; and 1.7 months for those 24 to 31 months. This suggests the entry process into programs is comparable for children of different ages.

Figure 3
TIME BETWEEN MEAN AGE AT FIRST CONCERN AND MEAN AGE AT IFSP
BY AGE GROUP AT IFSP

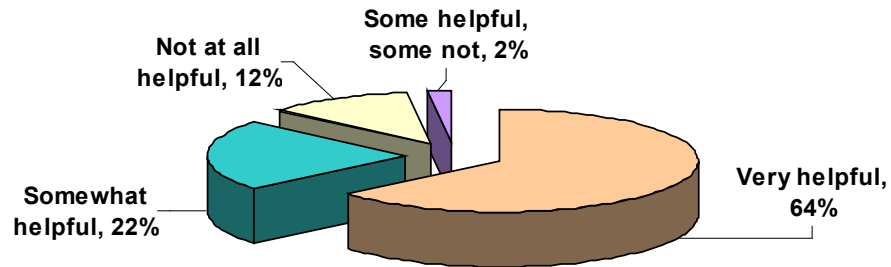


Helpfulness of Doctor or Other Medical Professional

After being asked how old the child was when someone first became concerned about his or her development, families were asked if they discussed these concerns with a doctor or other medical professional and, if so, how helpful the person was at that time. The question about discussing concerns with the doctor was not asked if someone first became concerned about the child when the child was less than one month old, on the assumption that the medical profession would be involved in all cases where the concern was manifest prenatally, at birth, or shortly thereafter.

Among families who first became concerned about their child after the first month of the child's life, 86% discussed their concern with a doctor or other medical professional. Those who discussed their concerns with a medical professional generally found this person to be helpful. Two-thirds of the families (64%) reported the medical professional was very helpful and another 22% said the person was somewhat helpful. One in eight (12%) said the person was not at all helpful and a small fraction (2%) were initially involved with more than one medical professional and said some were helpful and others were not (See Figure 4).

Figure 4
FAMILIES' RATING OF HELPFULNESS OF DOCTOR OR OTHER MEDICAL PROFESSIONAL



The likelihood of the family discussing their concern with a doctor or other medical professional was related to several child and family characteristics, including reason for eligibility for early intervention, age at IFSP, the ethnicity of the child, the education level of the primary caregiver, and household income.¹ Families of children with diagnosed conditions were more likely to discuss their concerns with a medical professional (94% compared to 85% for developmental delay and 80% for children with risk conditions). The younger the child at IFSP, the more likely the parent was to have discussed a concern with a medical professional. Eighty-nine percent of children who entered early intervention prior to 12 months came from families who had discussed their concerns with a doctor or other medical professional, compared to 86 percent for children who began services between 12 and 24 months, and 83 percent for those 24 months and older at IFSP.

African American families were least likely to have discussed their concerns with a medical professional (81% compared, for example, to 87% for Caucasian families). Both caregiver education and household income were directly linked to likelihood of discussing a concern about the child with a medical professional, with those with the least education or income being least likely to discuss their concerns. Only 76% of those who did not graduate from high school discussed their concerns with a medical professional, compared to 90% for those with at least a bachelor's degree. Only 80% of families with household income of less than \$15,000 discussed their concerns with a doctor, compared to 93% for those with incomes over \$75,000. The interview did not probe as to why the family had not discussed their concerns with a doctor or other medical professional. Even among highly educated or wealthy households, about one in ten families did not choose to discuss their concerns about their child with a doctor or other medical professional. This finding also could be related to reasons for receipt of early intervention, with children from higher income families being more likely to be receiving early intervention for difficulties perceived to be "less medical," such as communication difficulties (Spiker et al., 2002).

¹ See Appendix B for additional data on child and family characteristics.

These same child and family characteristics were related to how helpful the family thought the medical professional was when the concerns were raised. Parents of children with developmental delays were less likely than other families to perceive the medical professional as very helpful (60% compared to 79% for parents of children with risk conditions). Possibly some doctors did not take seriously the initial concerns of the parents of children later found to have developmental delays. Developmental delays are typically more challenging to diagnose than are specific medical conditions. Children with risk conditions also might have primarily medical conditions rather than developmental conditions or they might not have had any medical or developmental problems at the time they began early intervention services.

This hypothesis is also consistent with the ratings of families of children who were older at IFSP. Only 56% of families of children whose first IFSP was signed at 24 months or older found their doctor or other medical professional to have been very helpful, compared to 74% for parents of children who began early intervention at less than a year. Again, the developmental needs of the older children tend to be more difficult to recognize, which could explain why families found their doctor less helpful. Also, the lack of helpfulness of the doctor or other medical professional could have contributed to the late date of these families' entry into early intervention if the families were initially told not to be concerned about the child's development.

The analysis by race and ethnicity showed that Caucasian families were least likely to report their doctor or other medical professional as very helpful (61% compared to 69% for African Americans and 67% for Hispanics). More-educated families were less likely to see their doctor or other medical professional as very helpful: only 59% of children with caregivers with at least a bachelor's degree found their doctor or other medical professional to be very helpful, compared to 69% of those who did not finish high school. The same socioeconomic pattern was seen with household income. Whereas 70% of those with incomes of less than \$15,000 perceived their doctor or other medical professional to be very helpful, only 61% of those with incomes over \$75,000 did so. Interestingly, the families with the highest household income were more likely to find the person somewhat helpful (the middle category) than the other groups and thus they were the least likely to rate the medical professional as "not at all" helpful.

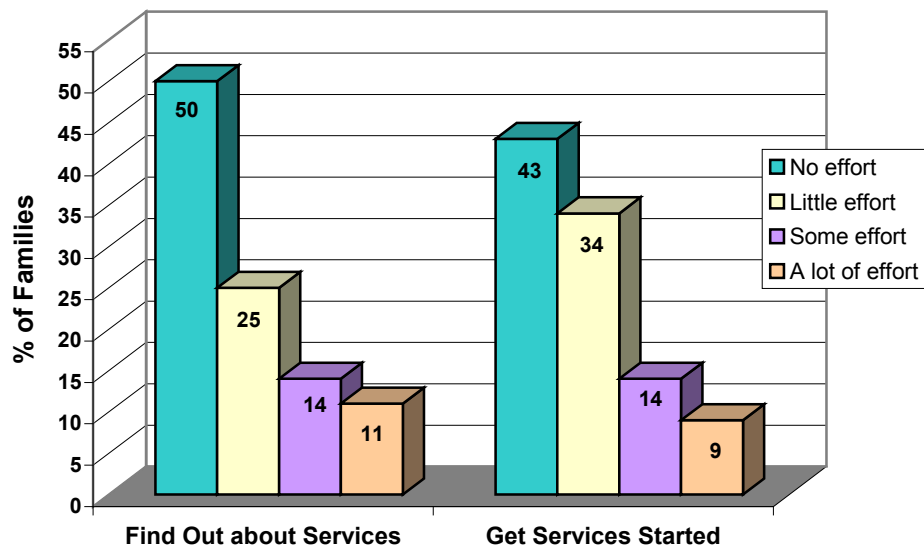
Several of the child and family characteristics are correlated with each other, which makes it difficult to know how much importance to place on any one finding of difference across groups. As has been noted, reason for eligibility was related to age at entry, with children with developmental delays beginning early intervention services later than those with diagnosed conditions or risk conditions. The socio-demographic makeup of families of children receiving early intervention reflect society at large in that minority families tend to have lower incomes and to have less-educated female caregivers (Moore and Redd, 2002).

Amount of Effort

Families were asked two questions related to the effort needed to get services: (a) About how much effort did it take to find out where to go to get early intervention services? and (b) After you knew where to go for services, how much effort did it take on your part to get services started? For each question, the family member being interviewed indicated either: a lot, some, little, or no effort required.

Half of the families (50%) entering early intervention indicated that it took no effort at all to find early intervention, with another 25% indicating it took little effort (See Figure 5). A little over one in ten (11%) of families reported that it took a lot of effort to find early intervention services. Looking at the amount of effort to get services started once families knew about them, (43%) reported that no effort was required to get services started. Another third (34%) reported that some effort was required. Again, around one in ten (9%) reported that a lot of effort was required to get services started once they had been identified. For both of these indicators, it is important to remember that all of these families were families who had actually entered early intervention. It is reasonable to conjecture that families who experienced serious difficulty finding out about or getting services might not persist enough to actually begin services, therefore they were not available for the study.

Figure 5
AMOUNT OF EFFORT REPORTED BY FAMILIES TO FIND SERVICES AND GET SERVICES STARTED

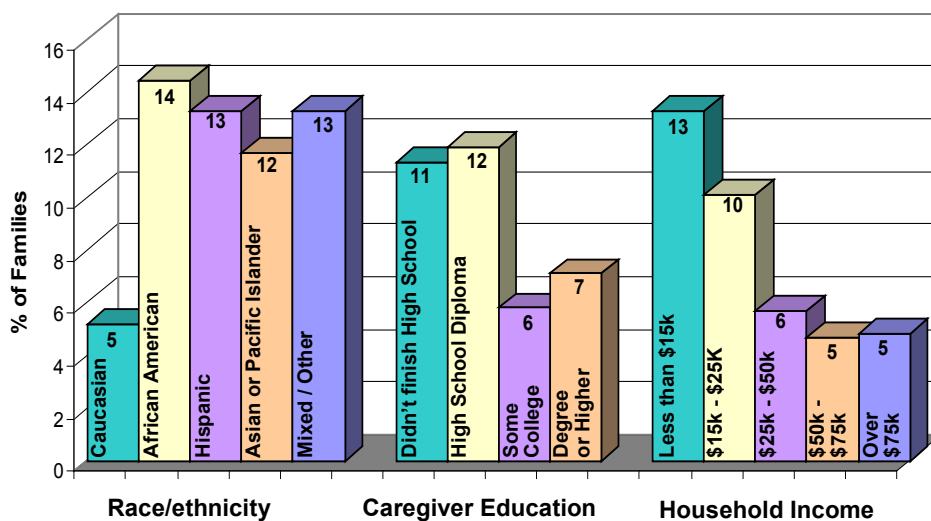


Even though finding early intervention and getting early intervention services started was a relatively easy process for most families, there were some differences in the level of reported effort for different kinds of families. The younger the child, the easier it was for families to find out about early intervention services. Fifty-nine

percent of parents of children who entered at less than 12 months reported no effort at all compared to 48% for those whose children entered between 12 and 24 months compared to only 40% for families with children who entered at greater than 24 months. The older children are more likely to be children with developmental delays; however, there were no differences among families of children with different eligibility reasons for early intervention so the nature of the child's condition was not associated with difficulty in finding out about early intervention. The older children are seen by pediatricians less often which might have given their families less access to information. Also, the very fact that the families had more difficulty finding out about early intervention may have contributed to them beginning services at a later age. There were no differences related to age of child at entry with regard to the amount of effort to get services started once the family knew about services.

Overall only 11% of families reported that it took a lot of effort to find out about services started, but families of minority children were more likely to give this response. Whereas 8% of the families of Caucasian children said it took a lot of effort to find out about early intervention services, 13% of the African American and Hispanic families and 18% of the Asian or Pacific Islander families had trouble finding out about services. The pattern was similar for amount of effort to get services started. Only 5% of the Caucasian families reported a lot of effort was needed to get services started. The comparable figures for African American, Hispanic, and Asian or Pacific Islander families were 14, 13 and 12%, respectively (See Figure 6).

Figure 6
PERCENTAGE OF FAMILIES WHO REPORTED A LOT OF EFFORT
TO GET SERVICES STARTED



Families with less-educated caregivers and less household income were also more likely to have had to put forth a lot of effort to find out about services and to get services started. For families where the caregivers had less than a high school diploma, 12% reported it took a lot of effort to find out about services, compared to 9% of those with a bachelor's degree. Similarly, 13% of families with household incomes of less than \$15,000 needed a lot of effort to find out about early intervention services, compared to 9% of those with incomes over \$75,000. The pattern was identical for amount of effort to get services started, with 11% of families with caregivers with less than a high school diploma reporting a lot of effort, compared to 7% for caregivers with a bachelor's degree. The comparable figures for families with household incomes below \$15,000 and above \$75,000 were 14% and 5%, respectively.

Developing a Plan for Services

The Individualized Family Service Plan is one of the key features (as well as a required component) of Part C services. The process of developing the plan should reflect a partnership between parents and professionals. Parents should be fully informed of their options and their rights so they can meaningfully participate in the decision-making that will result in services for their child and family (McGonigel, Kaufman, and Johnson 1991)

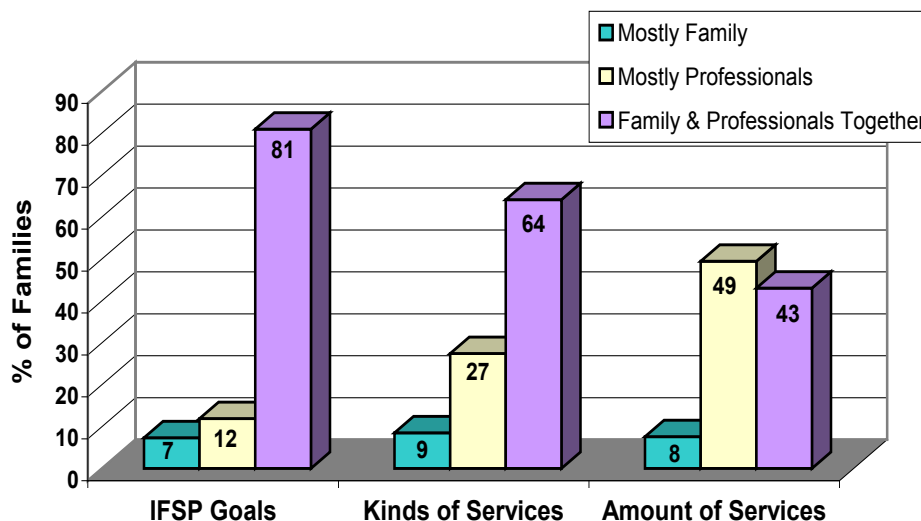
Families were asked whether they were "aware of a written plan that describes goals for (name of child) and the services (he/she) should receive? It might have been called an IFSP, a Child and Family Service Plan, or something like that." Although all interviews were conducted within 4 months after an IFSP had been completed, a substantial proportion of families (18%) reported that they were not aware of such a plan.

Family members who were aware of the IFSP were asked to describe who decided on the goals or outcomes for the child or family, who decided on the kinds of services, and who decided the amount of services: mostly the family, mostly professionals, or families and professionals together. They were also asked how they felt about their level of involvement in the decision-making process.

The extent of joint decision-making across the three kinds of decisions shows an interesting pattern (see Figure 7). For all three decisions (goals, kinds of services, amount of services) a small minority of families (7-8%) reported that mostly the family made the decisions. A shifting balance of decision-making was evident across the three types of decisions. With respect to goals, four out of five families (81%) felt this decision was made jointly by families and professionals, with professionals mostly deciding for only 12% of the families. Less joint decision-making was reported for determining the kinds of services: two-thirds of the families (64%) felt the decision-making was joint and 27% thought the decision was made mostly by professionals. Even less joint decision-making was perceived for the amount of service. Only 43% of families thought this decision was made jointly and half (49%) thought it was made by professionals. Most families (77%)

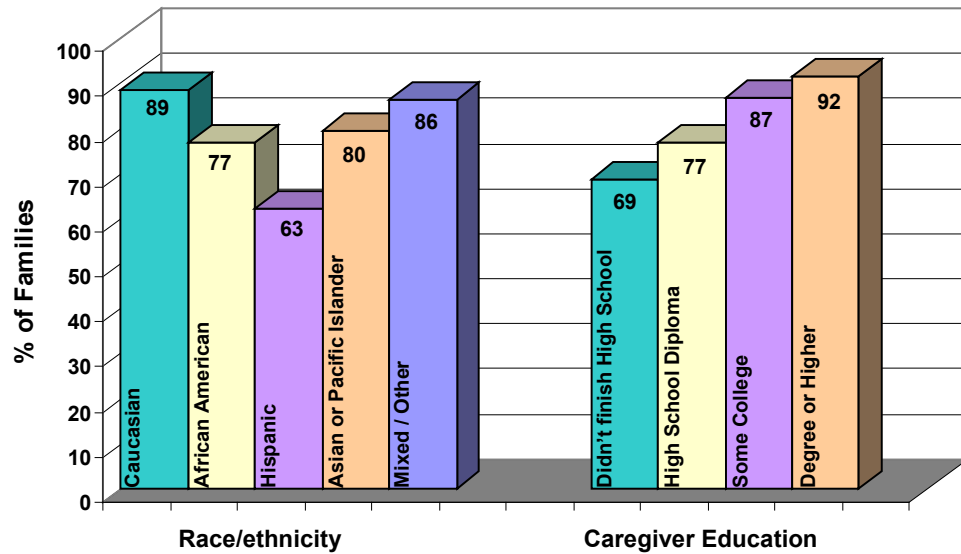
thought they were involved in the decision-making process although over one in five (22%) wanted more involvement, with only 1% wanting less.

Figure 7
FAMILIES' REPORTS OF WHO MADE DECISIONS ABOUT GOALS, KINDS, AND AMOUNT OF SERVICE



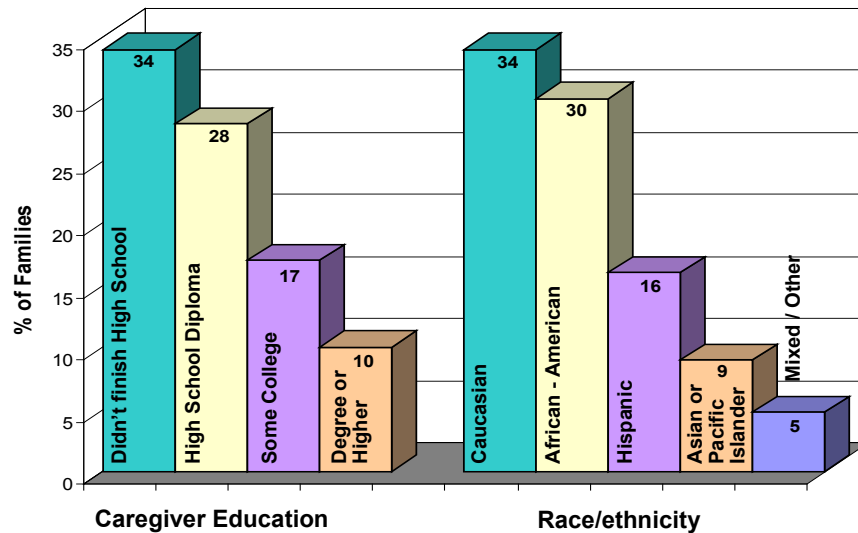
There were some striking differences across families concerning who was and was not aware of the IFSP. Families of at-risk children were slightly less likely to be aware than families of children with developmental delays or diagnosed conditions (80% compared to 83% for the latter two groups). Minority families, families with less-educated caregivers, families with less household income, and families where the language of the interview was Spanish were also less aware (see Figure 8). Eighty-nine percent of Caucasian families were aware of the IFSP, compared to 77% for African Americans, 63% for Hispanic families, and 80% for Asian or Pacific Islanders. Only 69% of families with a caregiver with less than a high school diploma were aware of the IFSP, which was much less than the 92% of those with a bachelor's degree. Whereas only 71% of low-income families (less than \$15,000) were aware of the IFSP, 94% of those with household incomes over \$75,000 reported such awareness. The differences for those interviewed in English or Spanish were the most dramatic: 84% awareness for English-speaking families compared to only 35% for Spanish-speaking families. This difference is so large it could indicate the Spanish-speaking families did not understand the interview question or that it was translated inappropriately. Alternately, the finding could be valid. The language differences between the family and the program could have meant the IFSP process was not explained to the family in a way that they understood.

Figure 8
FAMILIES' AWARENESS OF THE IFSP
BY RACE/ETHNICITY AND CAREGIVER EDUCATION



There were numerous differences across families with regard to how they perceived the decision-making process. Families with infants (less than 12 months) were more likely to report they wanted more involvement as compared to families of children 12 to less than 24 months (24% and 19% respectively). More minority families reported that they wanted more involvement. Only 13% of the Caucasian families wanted more involvement, compared to 37% of the African American families, and 29% of the Hispanic and Asian or Pacific Islander families. The differences by caregiver education level and household income were equally striking (See Figure 9). Over a third (35%) of the families where the caregiver had less than a high school diploma reported wanting more involvement. The comparable figures for families with caregivers with a bachelor's degree or more was only 10%. Similarly, one-third (34%) of families with household incomes of less than \$15,000 wanted more involvement, compared to 6% for families with incomes of \$75,000. There was also a difference with regard to the number of adults in the home. Thirty percent of families with one adult wanted more decision-making, compared to 20% for households with two or more adults.

Figure 9
PERCENTAGE OF FAMILIES WHO WANTED MORE INVOLVEMENT IN THE
DECISION-MAKING BY CAREGIVER'S EDUCATION AND HOUSEHOLD INCOME



Parent Satisfaction

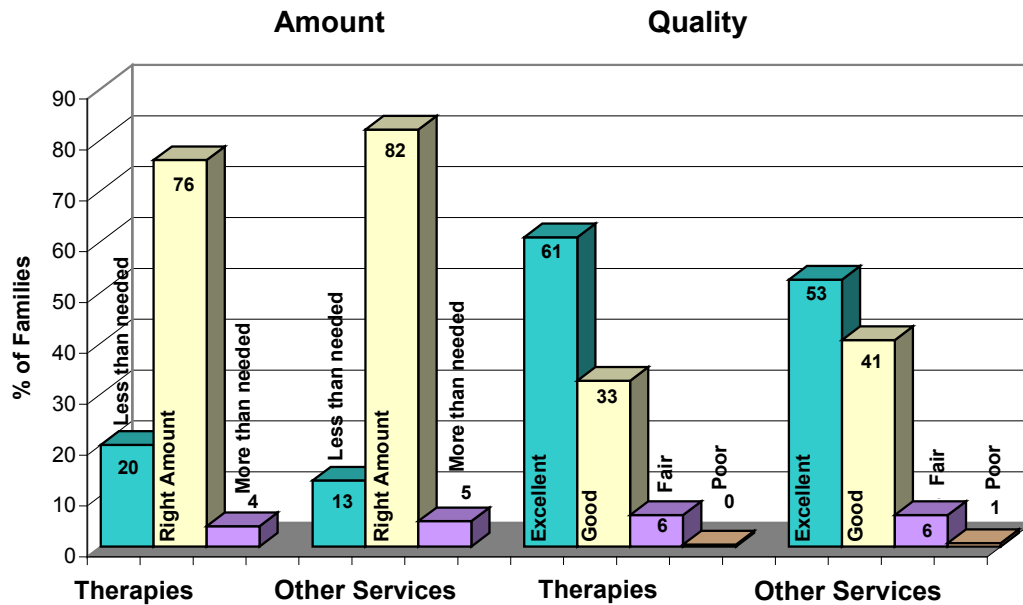
Families had been receiving service for only a short time when the interview was conducted. In fact, 27% of the families were not yet receiving any service. Nevertheless, it was important to get a sense of how satisfied families were with their first experience with early intervention services. Family members were asked to indicate whether they felt their child's speech, occupational and physical therapy, as well as other early intervention services were sufficient in amount (about right, more than needed, less than needed, enough for some but not others), whether they were individualized to their child's needs (highly, somewhat, not at all, mixed), and whether there were services that the family felt were needed but the child was not getting (yes or no; if yes, what other services were needed?). Families also were asked to rate the perceived level of quality of those services.

Families were generally pleased with the amount of service being provided. Over half of the families (55%) reported that their child was receiving speech, occupational, physical therapy, or some combination of the three. Of those receiving one or more of these services, three-fourths reported that their child was getting about the right amount of therapy (76%, See Figure 10). Most of the families whose child was receiving an early intervention service other than one of the three therapies thought the amount was about right (82%). However, 1 in 5 families (20%) indicated that their child was getting less therapy than needed and 1 in 6 (13%) reported that their child was getting less other early intervention service than needed.

One in 7 families (14%) reported that there were services their child needed but wasn't getting. These families were asked what other service they thought their

child needed. The most common additional services were speech therapy (39% of those indicating a need for other services), occupational therapy (22%), physical therapy (23%), play groups or play therapy (9%), and behavioral therapy (8%). Families were allowed to name as many additional services as they wished, thus percentages sum to more than 100%. Families were also to rate the quality of the service they were receiving. The overwhelming majority of families (93%) indicated that both their therapy services and other early intervention services were excellent or good. Less than 1% rated the quality of services as poor. About two-thirds (69%) rated services as highly individualized and another 28% rated the services as somewhat individualized. Only 3% felt that services were not individualized at all.

Figure 10
FAMILIES' SATISFACTION WITH THE AMOUNT AND QUALITY OF SERVICE



Child and family characteristics were associated with families' perceptions of the amount of service their child was receiving. Families of children with diagnosed conditions were more likely to report their child was receiving less therapy than needed (22% compared to 20% for developmental delay and 18% for risk conditions). Caucasian families also were more likely than minority families to see their child as receiving less therapy than needed. Twenty-two percent of Caucasian families reported less therapy service than needed, compared to 17% for African American families, 16% for Hispanic families, and 14% for Asian or Pacific Islander families. The higher the level of caregiver education, the more likely the family was to report the child was receiving less therapy than needed, i.e., 10% of the families with caregivers with less than a high school diploma compared to 25% for families where the caregiver had at least a bachelor's degree. Household income showed the same relationship with higher income families more likely to report more therapy services were needed.

Eighteen percent of families with household incomes below \$15,000 wanted more therapy service, compared to 25% for families with incomes between \$50 and 75,000. The exception to the income relationship was families with incomes over \$75,000 where only 18% reported their child was receiving less therapy than needed. One possible explanation could be that the families with the highest incomes were purchasing additional therapies; however, other data from the family interview did not show that higher income families were more likely to have used their own funds or their insurance to obtain additional service.

There were also numerous differences across families with regard to the amount of non-therapy services. Minority families were more likely to report their child was receiving more services than needed (9% African American and Hispanic, 13% Asian or Pacific Islander compared to only 2% Caucasian). The more education the caregiver had, the more likely the family was to report the child was not receiving enough service. For example, 9% of families with caregivers with less than a high school diploma reported their child was receiving less service than needed compared to 16% of those with at least a bachelor's degree.

Different kinds of families also viewed the individualization of services and the quality of services differently. African Americans saw the services as less individualized compared to other groups. Only 60% of the African American families saw the services as highly individualized compared to 72% of Caucasian families. Low-income families also saw the services as less individualized; 62% of low-income families rated the services as highly individualized compared to 72% for families with incomes over \$25,000.

Families of children with developmental delays or risk conditions were more likely to rate their services as fair or poor compared to families of children with diagnosed conditions (7% and 11% vs. 3%). African American and Hispanic families were less pleased with their non-therapy services with 11% and 8% giving fair or poor ratings compared to only 5% of the Caucasian families and 3% of the Asian/Pacific Islander families. Low-income families were also more likely to give fair or poor ratings to their non-therapy services compared to upper income families (10% for families with incomes of less than \$15,000 compared to 3% for those with incomes over \$75,000). There were no differences for any of the child or family characteristics with regard to whether the family said there were services the child needed but was not receiving.

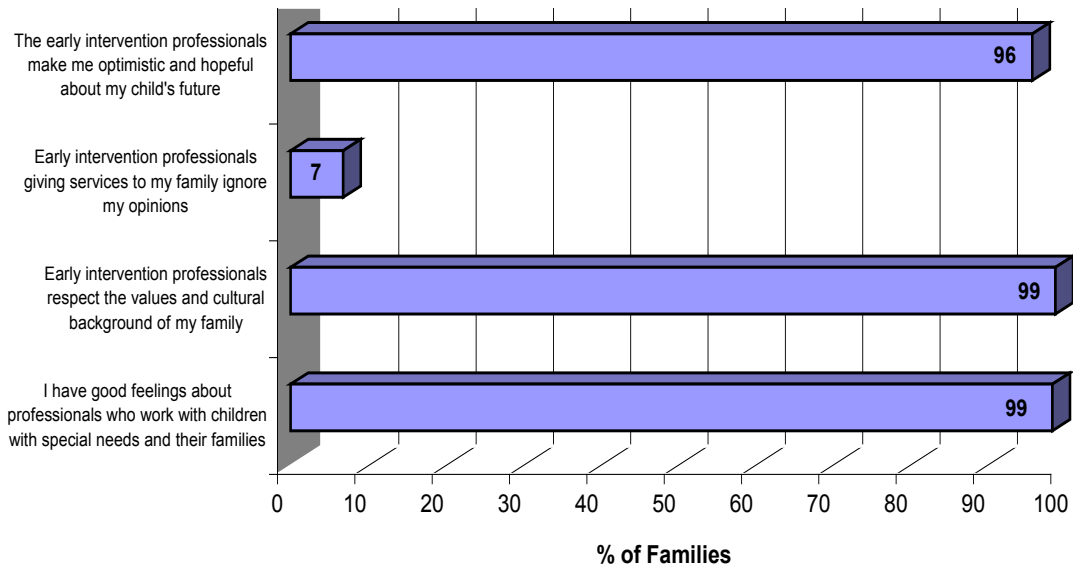
Interactions with Early Intervention Professionals

Families were asked how well they felt professionals who worked with their family had been communicating with each other about needs and services. They were also asked to rate the extent to which they had good feelings about professionals who work with children with special needs and their families; whether early intervention professionals respected the values and cultural background of their family; whether early intervention professionals ignored their opinions; and whether early intervention professionals made them feel optimistic and hopeful about their child's future.

Over half of the families (53%) reported that communication among professionals was excellent, with most of the remainder rating it as good (37%) and a minority rating it as fair (7%), poor (3%), or some OK and some not (<1%). One in twelve families reported working with only one professional (8%).

The families' ratings of early intervention professionals on several characteristics are displayed in Figure 11. Families reported a very high degree of satisfaction with early intervention professionals, with more than 96% agreeing or agreeing strongly that they have good feelings about early intervention professionals, that these professionals respected their families values and cultural background, and that they helped them feel optimistic about their child's future. Families also felt that professionals were not ignoring the families' opinions. Only 7% agreed that professionals ignored their opinions.

Figure 11
PERCENTAGE OF FAMILIES WHO AGREED OR STRONGLY AGREED WITH STATEMENTS ABOUT EARLY INTERVENTION PROFESSIONALS

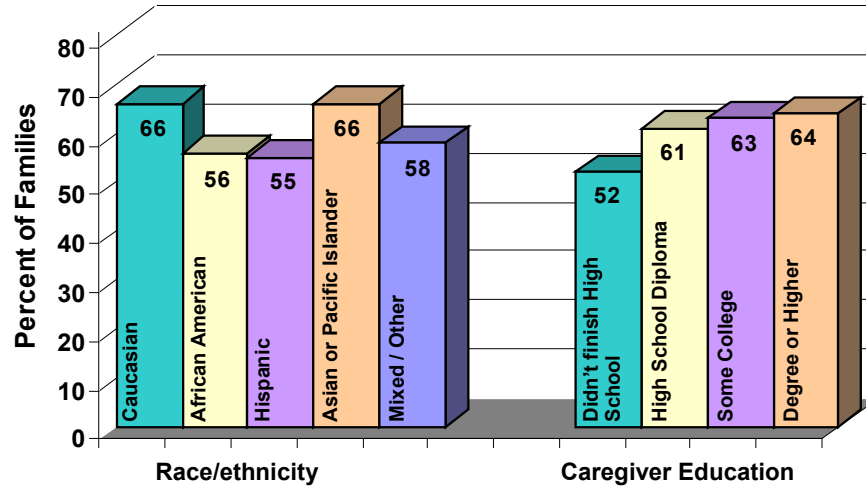


Families' opinions about the level of communication among professionals differed across different types of families. Families of children with risk conditions were more likely to rate the communication as excellent (61%), compared to families of children with developmental delays (51%) or diagnosed conditions (52%). More Asian or Pacific Islander families gave ratings of excellent (66%) than African American (56%), Caucasian (52%), or Hispanic (49%). Families with caregivers with a bachelor's degree were less likely to give a rating of excellent (46%), compared to other education levels (54 to 57%). Low-income families were the most pleased with the level of communication (61% rated it excellent, compared to 44 to 55% for the other groups). English-speaking families were also more pleased than Spanish-speaking families with the level of communication among professionals (54% rated it excellent compared to 34%).

Families' feelings about professionals were also related to family characteristics. Slightly more families of children with risk conditions had better feelings about special needs professional than those of children with developmental delay or diagnosed conditions (68% strongly agree to 64% and 59%). Hispanic families and those for whom the interview was conducted in Spanish were less strong in their feelings about professionals (55% strongly agree, compared to 62 to 67% for the other groups; 39% for Spanish-speaking families compared to 65% for English-speaking). The likelihood of having good feelings about special needs professionals was related to both education and household income, with fewer less-educated and lowest-income families having good feelings.

There were also differences among families in how they perceived professionals' respect for their families' values and background. Families of children with risk conditions gave professionals higher ratings than families of the children from the other two eligibility groups (64% strongly agree, compared to 61 and 60%). Ethnicity, education level and income were all related to families' perception of professionals respect for their backgrounds. Hispanic and African American families gave professionals lower marks than Asian or Pacific Islander and Caucasian families (55 and 56% strongly agree compared to 66 and 65%; See Figure 12). Families with more education and more income were more likely to see professionals as respecting their backgrounds. These families, of course, were closer to the professionals in education and income level and possibly race and ethnicity as well.

Figure 12
FAMILIES WHO STRONGLY AGREED THAT “EARLY INTERVENTION
PROFESSIONALS RESPECT THE VALUES AND CULTURAL BACKGROUND OF MY
FAMILY”



SUMMARY AND CONCLUSIONS

This report describes several aspects of families' experiences in beginning early intervention services. The findings are based on interviews with a nationally representative sample of families participating in U.S. Part C early intervention programs. The report describes the timing of concerns, diagnosis, and entry into early intervention, as well as parent perceptions of the identification process, the professionals with whom they interacted, and the resulting plan for goals and services. The study is unique in that it is the first to reflect parental perspectives shortly after entry into early intervention. Furthermore, because the data are based on a nationally representative sample, it is the first such study that can be said to reflect the state of the nation on these issues.

The findings indicate that the process of entering early intervention is working well for many families. There also is evidence, however, to suggest that the process does not work equally well for all families and that this is related to characteristics of the child and family. The general findings are summarized first followed by the findings related to differences among families with different types of children and different demographic characteristics.

The Process of Beginning Early Intervention

Children begin early intervention services at all ages between birth and 36 months of age. About 25% of children entered Part C services before 7 months of age. Fewer children enter at the end of the first year of life, and then the numbers increase again around 24 months of age, and then decrease slightly up to 36 months of age. The study looked at the time span between five critical events in the process of beginning early intervention services: first concern, diagnosis, looking for early intervention, referral date, and date of the IFSP. The data for the entire series of events refer only to children who entered early intervention before 31 months of age because that was the maximum age of children recruited into the study.

Retrospectively, caregivers reported a relatively short period of time between first concerns and first diagnosis (mean difference of 1.5 months). However, the mean time difference between caregiver report of diagnosis and agency report of referral for early intervention was over 5 months. The span between parent report of first diagnosis and a signed IFSP was 7.5 months, and the span between initial concerns and a signed IFSP averaged 9 months. The delay in getting children and families into the early intervention system lies not in the length of time between concerns and diagnosis (which on average was only about 1.5 months), but rather in the length of time from diagnosis to referral for services (which averaged 5.5 months). Unfortunately, the reasons for this delay cannot be ascertained from this study. Possible reasons could include parent preferences, distress, or uncertainty over desire for services (Abrams & Goodman, 1998); lack of coordination among the various agencies involved in early intervention (Harbin, McWilliam, & Gallagher, 2000); failure to incorporate developmental or behavioral screening in standard

pediatric examinations (Dobbs, Dworkin, & Bernstein, 1994; Li & Logan, 1996); or the fact that pediatricians as a group are more likely to refer for early intervention children with severe developmental delays or children who are older than 3 years of age (Epps & Kroeker, 1995a; 1995b). In reality, all of these and other factors likely play important roles, but the salience of each may vary by family and community. More detailed examinations of systems of services are needed to identify why it is taking so long to refer families to early intervention programs. Research can help identify the various types of barriers and the conditions under which they are likely to occur, but local service providers will also need to conduct their own evaluations to determine which factors are especially important in their community or with certain families. Most families (86%) reported that they discussed their concerns with a doctor or other medical professional and most found this person to be very helpful (64%) although 1 in 8 (12%) said the person was "not at all helpful." Most families (about three-fourths) reported that finding early intervention programs and getting services started required little or no effort on their part. Only about 10% each reported that finding or securing services required a lot of effort.

Although all families in the study had recently had an Individualized Family Service Plan developed, nearly 1 out of 5 (18%) was not aware of the existence of a written plan for goals and services (the IFSP). Of those parents who were aware of such a plan, most (81%) reported that families and professionals together developed the goals. However, less collaboration was reported in determining the kind of services (64% parents and professionals together) or amount of services provided (43% families and professionals together). Families were pleased with the decision-making process. Over three-fourths (77%) were satisfied with their level of involvement in the process. Over one in 5 (22%), however, wanted more involvement.

Families were also very satisfied with the services they were receiving. It is important to remember that families were very early in their early intervention experience; 27% of families were not yet receiving any service. Almost all (97%) of families who were receiving any services felt that the services they received were somewhat or highly individualized. Families were pleased with the amount and quality of the therapy service (speech, occupational, physical) as well as the other early intervention services provided. Three-fourths (76%) thought their child was receiving the right amount of therapy but 1 in 5 (20%) reported their child was getting less therapy than needed. One in 7 (14%) thought their child needed a service that he or she was not getting. For these families, speech therapy (39% of those who believed child needed another service), physical therapy (23%), and occupational therapy (22%) were most often seen as needed but not provided.

Families reported a high degree of satisfaction with early intervention professionals. They found the communication among the professionals who worked with their family to be good. Nearly all had good feelings about early intervention professionals and agreed that they respected their values and cultural backgrounds. Families thought their opinions were being listened to and that professionals helped them feel hopeful about their child's future.

Differences among Families

For the majority of families, their first experiences with early intervention were very positive. There are some families for whom this was not the case, however, and often these differences were systematically related to the characteristics of the child or the sociodemographic characteristics of the family. The reader is reminded that there may be other families, as well, who had such a difficult or unpleasant experience entering early intervention that they opted not to pursue services. This latter group of families are not represented in these data because the study sample included only families for whom an IFSP was developed. In this section, we summarize the data for each of the family and child characteristics examined to see how the process of beginning early intervention services differed across families.

Eligibility Category. Children are eligible for early intervention under Part C of IDEA because of a developmental delay, a diagnosed condition or, in some states, a risk condition. Across these three groups, there were striking differences in the ages at which someone first became concerned about the child and the length of time between first concern and the development of the IFSP. The average age of first concern for children with diagnosed conditions or a risk condition was in the second month of life compared to the 11 months for children with developmental delays. For children with diagnosed conditions, the IFSP was developed an average of 7.4 months later or when the child was 9.7 months olds. For children with developmental delays, the process took nearly nine months for an average age of 20 months at the time of the first IFSP.²

The family's perception of the process of entering early intervention differed by eligibility category with regard to several dimensions of the experience but none of the three groups consistently had the most positive or negative experience. Eligibility category was related to the likelihood of discussing concerns about the child with a doctor or other medical professional and the perceived helpfulness of that person. Families of children with diagnosed conditions were most likely to discuss their concerns with a doctor. Families of children with developmental delays found the doctor or other medical professional to be less helpful compared to the other two groups.

Families of children with risk conditions were less aware of the IFSP than families of children from the other two groups and less likely to see the decisions about goals as jointly made by families and professionals. Families of children with developmental delays were far more likely to think that professionals made the decisions about the amount of early intervention services (as opposed to seeing the decision as made by families and professionals jointly), but families of children with diagnosed conditions were more likely to think their child was receiving less therapy than needed. There were a few other statistically significant differences in the perceptions examined but the numerical differences were fairly small.

² The NEILS sample only included children under 31 months of age or younger at IFSP, and it is the oldest children at IFSP who are most likely to have developmental delays. The average ages of critical events for children with developmental delays would certainly be even older if the sample had included children up to 36 months of age at IFSP.

Age at IFSP. Families of older entrants to early intervention had a more difficult time connecting to services than parents of children who began early intervention services prior to one year of age. Families of older entrants were less likely to discuss their concerns with a doctor or other medical professional, less likely to find their doctor helpful, and it took them more effort to find out about early intervention services. Their difficulties might be due to an unwillingness to recognize a delay on the part of the medical profession. Research shows that pediatricians and other professionals may be reluctant to say that a child is delayed unless the delay is severe or the child is over 2-3 years of age (Bailey, Skinner, Hatton, & Roberts, 2000; Epps & Kroeker, 1995a; 1995b). Some of these difficulties may explain why the children are beginning early intervention services at a later age.

Child's age at entry was related to several other aspects of beginning early intervention. Families of older children were less likely to see decision-making about amount of service as made jointly by families and professionals. They were more likely to think their child was receiving less non-therapy service than was needed and more likely to think that professionals ignored their opinion. Families of 12- to -24-month-olds at entry were more likely to be satisfied with their amount of involvement in the decision-making but less likely to think professionals made them feel hopeful about their child's future. In sum, aside from the convergence of findings that point to a more difficult entry process for older children, there were no consistent trends with regard to how families of children of different ages perceived their early experiences.

Gender. The process of entering early intervention appears to be very similar for parents of boys and girls. Only one statistically significant difference was found across all the dimensions examined: Parents of girls were more likely to feel professionals ignored their opinions.

Race/Ethnicity. Unlike the other child and family characteristics discussed thus far, race/ethnicity showed a consistent pattern across many aspects of the process of beginning early intervention services. For most of these differences, minority families had a more negative experience than other families. Many of the differences were only a few percentage points but the reoccurrence over so many different items in the family interview suggests these differences are real and need to be addressed.

The experience of minority families differed in numerous ways:

- It was more difficult for minority families to find out about early intervention services and to get services started.
- Minority families were less aware of the IFSP.
- Minority families were less likely to feel the decisions about types and amount of services were made jointly by both families and professionals, and were less likely to be pleased with their level of involvement in the decision-making.
- Minority families were less likely to think services were individualized.

- Minority families rated the quality of non-therapy early intervention services lower.
- Minority families were less likely to think that professionals respected their backgrounds and culture and more likely to think professionals ignored their opinions.
- Fewer minority families reported that professionals make them feel hopeful about their child's future.

For each of these aspects at least two of the four minority groups examined had a more negative experience than the Caucasian families.

There were also some interesting deviations from this pattern. More Caucasian families felt their doctor or other medical professional was not helpful when they were discussing their initial concerns about their child. Interestingly, Caucasian families were more likely than minority families to say their child was receiving less therapy than needed, and minority families were more likely than Caucasian families to say their child was receiving more therapy than needed.

Educational Level of the Primary Caregiver. The pattern for families of different levels of education (and income, as will be discussed in the next section) was similar to those just discussed. Nearly all of the comparisons examined showed differences in experiences and perceptions of services based on education level of the primary caregiver, with families with less-educated caregivers generally having a more negative experience. The following aspects of beginning early intervention showed a linear relationship with education of the caregiver, that is, as education went up, the percentage of families with positive experiences increased. Those with less education were:

- Less likely to discuss concerns about their child with a doctor.
- More likely to report that it took a lot of effort to find early intervention and get service started.
- Less aware of the IFSP.
- Less satisfied with degree of involvement in the decision-making.
- Less likely to have good feelings about professionals.
- More likely to feel that professionals did not respect their cultural background and ignored the family's opinion.
- Less likely to believe professionals help them feel hopeful about their child's future.

The reverse pattern occurred in three areas. Families with more highly educated caregivers were less likely to see their doctor as helpful and more likely to report their child was receiving less therapy service than needed. More highly educated caregivers more frequently rated the level of communication among professionals as "fair" or "poor."

Household Income. Household income, which is correlated with both race/ethnicity and level of education, showed the same pattern as the previous two family characteristics. In each of the following, as household income increased, the percentage of families with a positive experience increased. Low-income families were:

- Less likely to discuss their concerns about their child with a doctor.
- More likely to report that it took a lot of effort to find out about services and get services started.
- Less aware of the IFSP.
- Less satisfied with their degree of involvement in the decision-making.
- Less likely to see services as individualized.
- Less likely to have good feelings about professionals.
- More likely to feel that professionals did not respect their cultural background and ignored the family's opinion.
- Less likely to believe professionals help them feel hopeful about their child's future.

For a few of the aspects of entering early intervention, the pattern was reversed. Upper-income families were less likely to report that their doctor was helpful when discussing initial concerns about the child. In general, the higher the income, the more likely the family was to report the child was receiving less therapy than needed. The exception was families with household incomes over \$75,000 a year, whose responses to this question resembled those of the lowest income families.

Number of Adults in the Household. The process of entering early intervention differed little based on the number of adults in the household. Households with one adult were more likely to report the need to put forth a lot of effort to get early intervention services started, and more likely to have wanted more involvement in the decision-making.

Language of the Respondent. Several differences were found between families who were interviewed in English compared to those who were interviewed in Spanish. Spanish-speaking families had to put forth more effort to get early intervention services started and were far less aware of the IFSP. Spanish-speaking families were more likely to report that mostly professionals made the decisions about types of services. English-speaking families were more likely to report that the communication among professionals working with their families was excellent, but they were also more likely to report that it was fair or poor (i.e., the Spanish-speaking families were more clustered in the middle rating of good). Finally, Spanish-speaking families were less likely to have good feelings about professionals, less likely to believe that professionals respect their families' values and background, and more likely to feel professionals ignored their opinion.

Conclusion

Collectively these data suggest that the U.S. early intervention system operated under Part C of the Individuals with Disabilities Education Act provides a positive and supportive entry into services for the vast majority of families who are enrolled in early intervention programs. They report relative ease in accessing early intervention programs, perceive that services are based on individual child and family needs, and feel that they have a role in making key decisions about child and family goals. Families report that they like early intervention professionals and that professionals make them feel hopeful about their child's future. The extent to which these perceptions remain stable over time will be assessed in subsequent interviews over the course of early intervention, at age three, and in kindergarten.

A few aspects of the process of beginning early intervention warrant closer examination and possible changes. The average time of 11.5 months between diagnosis and IFSP for children who begin early intervention after 24 months seems unnecessarily long. Families of children with developmental delays and even those with diagnosed conditions needed more help from their doctors when they first discussed their concerns about their child. A small percentage of families experience difficulties in accessing services, feel the amount of services received is inadequate, and nearly one-fifth were not aware of a written plan for goals and services. The recurring relationship between race/ethnicity, caregiver education level, and household income with so many different aspects of the entry process is especially troubling. None of the differences are large but the persistence of these relationships across so many different items suggests that the process of entering early intervention is not as supportive for families who are minority, less educated, and/or low income. Furthermore, all of these findings are based only on families who actually began early intervention service. We have no data on the number or experiences of families who do not successfully complete the entry process.

Much of the process of beginning early intervention is working well for most families but there is room for improvement. Research needs to continue to explore some of the barriers to swifter and smoother access to early intervention services, especially for some families. National, state and local evaluation efforts need to continue to focus on the effectiveness of policies and procedures related to the entry process. These findings suggest the need for models, practices, and professional skills that are more supportive of families who are poor or less educated and come from diverse ethnic backgrounds. The goals of easy access to information and services, family-professional partnerships, and quality services have already been achieved for many families. Now strategies need to be put in place to insure that they are achieved for all families.

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APPENDIX A

METHODOLOGY

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Procedure

A three-stage stratified sampling procedure was used to identify the sample for the study. In the first stage, 20 states were selected based on number of children served in early intervention and region of the country. The 20 sampled states also represented considerable variation with regard to lead agency and whether or not they served children at risk (Spiker et al., 2000). The second stage of the sampling involved the selection of counties based on the estimated number of children served in Part C programs. Within a state, 3 to 7 counties were selected, for a total of 93 counties. All points of entry or programs in a county for early intervention were invited to participate in the study.

The third stage of the sampling involved selection of the children and families. Each county was assigned a target number of families to recruit based on the number of families served. Study recruitment occurred on a staggered schedule in the 93 counties between September, 1997, and November, 1998. Demographic data without personal identifiers was collected on all families (N=5,668) who had never received early intervention services before and who enrolled in the early intervention programs in the sampled counties during the county's recruitment period. All families who met the study eligibility criteria (N=4,867) were to be invited by local early intervention staff to participate in the study. Study criteria required that the child be less than 31 months of age at the time the IFSP was signed, have an English- or Spanish-speaking adult in the household who could answer questions about the child and family, and be the only child in the family recruited for the study (siblings and other children of multiple birth sets were excluded). Not all families were invited within the required timeframe for various reasons. A total of 3,338 families or 68.6% of those invited (N=4,653) agreed to participate. Written consent and basic contact information for the family was then sent to the research team.

The contact information was used to try to reach the family for a telephone interview. The interview, developed by the research team, covered a variety of topics, including characteristics of the child, characteristics of the family, the early identification process, initial services being provided, and respondent perceptions of the early identification and early intervention experience thus far. A complete copy of the survey can be obtained at the NEELS Web site: www.sri.com/neels/.

An experienced survey research unit that had undergone rigorous training and ongoing supervision of the interview process conducted the interviews. Families were offered the option to complete the interview in English or Spanish. The interviews were conducted using computer-assisted telephone interviewing (CATI), meaning the interviewer read questions from the computer screen and entered responses directly into the computer. The computer provided the interviewer with the appropriate interview question based on the respondent's answer to earlier questions. The initial family interview was to be completed within 16 weeks after

the development of the first Individualized Family Service Plan (IFSP) with the person the family previously identified as able to answer questions about the child. If that person was not available, the interview was completed with another household member who indicated he or she could answer questions about the child. Fourteen percent of the interviews were conducted within two weeks of the (IFSP), 36% between 2 and 4 weeks of the IFSP, 18% between 4 to 6 weeks of the IFSP, and 25% between 6 to 16 weeks of the IFSP. Initial interviews were completed with 89% of the families (n= 2,974).

Families who could not be reached for an interview within 16 weeks were sent a mail survey. Information that was not considered to be time-sensitive such as the birth weight of the child was collected through a subsequent interview if the interview team was able to reach the family for the next scheduled interview. Some data on family experiences was available for 3,224 families or 97% of the study sample. Additional information about the study's methodology is presented at www.sri.com/neils.

Analysis. The data from the interviews, mail surveys, and subsequent interviews were combined. The data were weighted to represent all children entering Part C services in the United States during the recruitment period. All analyses were conducted using Software for the Statistical Analysis of Correlated Data (SUDAAN) (Shah, Barnwell, & Bieler, 1997) to account for the complex probability sampling used in the design.