

First Experiences With Early Intervention: A National Perspective

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ABSTRACT. *Background.* Families of young children with disabilities are eligible for early intervention services as mandated by Part C of the Individuals With Disabilities Education Act. Although prior research has shown that families are generally satisfied with early intervention, this research has not been based on a nationally representative sample of families, nor has it systematically examined perceptions of the initial experiences entering early intervention.

Objective. This study was designed to determine families' initial experiences in determining their child's eligibility, interactions with medical professionals, effort required to obtain services, participation in planning for services, satisfaction with services, and interactions with professionals.

Method. We interviewed a nationally representative sample of 3338 parents of young children with or at risk for disability. All the children had recently entered an early intervention program operated under the auspices of Part C of the Individuals With Disabilities Education Act.

Results. The average age at which families reported a concern about their child was 7.4 months. A diagnosis was made, on average, 1.4 months later, the child was referred for early intervention an average of 5.2 months after the diagnosis, and the individualized family service plan was developed 1.7 months later or at an average age of 15.7 months. Most families were very positive about their entry into early intervention programs. They reported discussing their concerns with a medical professional and finding that person helpful. Families reported relative ease in accessing services, felt that services were related to their perceived needs, rated positively the professionals working in early intervention, and felt that they had a role in making key decisions about child and family goals. A small percentage of families experienced significant delays in getting services, wanted more involvement in service planning, or felt that services were inadequate, and nearly 20% were unaware of the existence of a written plan for services. Minority families, families with limited income, and families with less-educated mothers were more likely to report negative experiences.

Conclusions. We conclude that the beginning of early intervention services generally is highly successful and responsive, a finding that should give pediatricians more confidence in referring families for early intervention

services. However, research and local evaluation efforts are needed to develop strategies to assure that all families receive services in a timely and appropriate fashion. *Pediatrics* 2004;113:887–896; *early intervention, early identification, families, disability.*

ABBREVIATIONS. IDEA, Individuals With Disabilities Education Act; NEILS, National Early Intervention Longitudinal Study; IFSP, individualized family service plan.

Families of children who have or are at risk for a disability must, at some point, go through a process of becoming concerned about their child, finding out about problems, and getting services. The timing of these experiences varies widely as a function of age, locale, and disability type.¹ Proportionately far more older children are receiving special education for a disability than younger children. More than 1 in 10 school-aged children (~11% of the total 6- to 17-year-old population) are served in any given year during the early elementary years when behavioral or academic problems become evident in the context of expectations for school performance. In contrast, only ~5% of the preschool-age population (3–5 years) and 1.8% of the infant-toddler population (birth through 2 years) receive special education or early intervention services.²

Slightly more than 200 000 children are identified as having or being at risk for a disability before 36 months of age and are enrolled in early intervention programs under Part C of the Individuals With Disabilities Education Act (IDEA).² The IDEA mandates 16 components of early intervention and provides an accompanying set of regulations to guide program implementation. However, considerable variability exists across states in the nature and extent of services provided.^{3,4}

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 even before the child is born. For some families, the discovery of disability 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 pediatricians 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.

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Pediatricians play a central role in this process, because they are the professional to whom parents are most likely to express initial concerns about their child's behavior or development.⁵ Studies suggest that, although early identification of children with clearly obvious developmental problems (eg, Down syndrome or spina bifida) is an efficient and rapid process, identifying children with less obvious delays and disabilities can be challenging for both pediatricians and families, because the nature and presence of disability only gradually become obvious over time.⁶ For a variety of reasons, pediatricians rarely use developmental or behavioral screening tests,^{7,8} preferring to rely more on developmental surveillance in the context of normal health care provision.^{9,10} As a result, pediatricians generally are more likely to identify and refer children who are >3 years old and children with more severe disabilities for special services.^{11,12}

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. The extent to which parents are satisfied with early identification processes and subsequent services would be important information for pediatricians to know as they make decisions about problems in early development and decide whether and when to refer parents and children to early intervention programs. Although evidence of the usefulness of a program of services must come from a variety of sources including clinical trials of intervention efficacy, there is almost universal consensus that parent satisfaction constitutes a key component of any evaluation of early intervention services.¹³⁻¹⁶ Although a few studies¹⁷ report that some families would like more services than they are receiving, most research using a variety of measurement approaches in this country as well as internationally shows that families are highly satisfied with early intervention programs.¹⁸⁻²³

Such information should give pediatricians more confidence in referring families for early intervention services. However, 2 key limitations of existing research are noteworthy. First, all studies to date have been limited to certain geographic regions or populations of convenience. No assessment of satisfaction has been based on a nationally representative sample of families. Second, all studies conducted to date have consisted of families who have been in intervention programs for varying lengths of time. No longitudinal research has systematically examined patterns of experiences and parents' reactions to those experiences at entry into and throughout the early intervention experience. Because it is likely that perceptions of services might change throughout the course of experience with those services,²¹ research is needed that is both time specific and longitudinal.

This article draws on a nationally representative sample of US parents whose children were enrolled in Part C early intervention programs. Information about parents' experiences and reactions was collected within 16 weeks of program entry. We address 7 questions about the process by which families en-

tered early intervention: 1) What is the timing of first concerns, diagnosis, referral, and service entry for families participating in Part C early intervention programs? 2) What kind of contact do families have with medical professionals when first concerned about their child's development? 3) How much effort does it take for parents to find out about and receive early intervention services? 4) What roles do parents play in developing a plan for services? 5) Are parents satisfied that the services provided are those that are needed? 6) Are parents satisfied with early interactions with early intervention professionals? 7) Does the process of entering early intervention differ for families as a function of selected child or family characteristics? As part of a longitudinal study of early intervention, the data provide initial baseline information, against which later longitudinal data can be evaluated.

STUDY OVERVIEW AND METHODS

The data were collected as part of the National Early Intervention Longitudinal Study (NEILS). NEILS was designed to describe who is participating in Part C early intervention programs, the services they receive, the costs of those services, the outcomes experienced by children and families, and the characteristics of children, families, and services that relate to outcomes attained. The study will follow a nationally representative cohort of children and families from the time that the children enter early intervention until they complete kindergarten.

Procedure

A 3-stage, stratified sampling procedure was used to identify the sample for the study. In the first stage, 20 states were selected based on the 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 they served at-risk children.⁴ 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.

The third stage of the sampling involved selection of the children and families. Between September 1997 and November 1998, all families ($N = 5668$) who enrolled in the early intervention programs in the sampled counties and met the study eligibility criteria were asked to participate in the study. In addition to having an adult provide written consent for the child's and family's participation, study criteria required that the child be <31 months old at the time the individualized family service plan (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). A total of 3338 families agreed to participate.

A 40-minute telephone interview was conducted with "the person able to answer questions about the child and the child's program" for each family. 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. Questions included in the interview are described in "Results." A complete copy of the interview can be obtained at www.sri.com/neils/datacollect.html.

An experienced survey research unit that had undergone rigorous training and ongoing supervision of the interview process conducted interviews. Families were offered the option to complete the interview in English or Spanish. The interviews were conducted by using computer-assisted telephone interviewing, meaning that the interviewers 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.

As part of the planned longitudinal study, the initial family interview was to be completed within 16 weeks after the development of the IFSP. For most respondents, the interview occurred much earlier. Of the interviews, 14% were conducted within 2 weeks of the IFSP, 36% between 2 and 4 weeks after the IFSP, 18% between 4 and 6 weeks after the IFSP, and 25% between 6 and 16 weeks after the IFSP. Initial interviews were completed with 89% of the families who agreed to be in the study ($n = 2974$). 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 contacted successfully for the next scheduled interview 1 year later. They were asked some of the questions from the first interview during this interview. Approximately 7% of the sample responded to the mail survey or were interviewed >16 weeks after the development of the IFSP. Only appropriate information from these delayed interviews is included here.

Sample

This article is based on 2974 telephone interviews completed within 16 weeks of enrollment and 250 telephone and/or mail surveys for those who consented to participate in the longitudinal study but who could not be interviewed within 16 weeks of enrollment. Most (83.1%) of the respondents were the children's biological mothers. 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.

Analysis

The population estimates presented here are statistically weighted to represent all children entering Part C early intervention services in the United States. All analyses were conducted by using Software for the Statistical Analysis of Correlated Data (SUDAAN)²⁴ to account for the complex probability sampling used in the NEELS study. Additional information about the sampling and analyses is provided at www.sri.com/neils.²⁵

RESULTS

Characteristics of Children and Families

The children entering early intervention services were 60% male and ethnically diverse. Just over half of the children in early intervention were white, non-Hispanic (53%), with 21% black, non-Hispanic, 16% Hispanic, 4% Asian/Pacific Islander, and 5% mixed race or "other."²⁶

According to state and federal regulations, children are eligible for Part C services due to developmental delay, diagnosed physical or mental conditions with a high probability of resulting in delay (eg, cerebral palsy), and high-risk factors that might lead to developmental problems without the provision of intervention services. Although considerable variability exists across states in the definitions and criteria used for these categories, we were able to assign children to 1 category reliably. Most of the children were eligible for early intervention services because of a developmental delay (62%), with 22% eligible because of a diagnosed condition with a high prob-

ability of resulting in a delay and 17% eligible because of ≥ 1 risk factors (eg, low birth weight). Approximately 32% of the families had received welfare payments or food stamps in the past year, and 43% had an annual family income of less than \$25 000.²⁶

Questions About Early Intervention Entrance

1. What is the Timing of First Concerns, Diagnosis, Referral, and Service Entry for Families Participating in Part C Early Intervention Programs?

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 at which they first looked for early intervention. The date of referral to early intervention and the date for the IFSP were reported by the agency that enrolled the child in early intervention. Means, minimums, and maximums for each event are presented in Table 1. On average, first concerns were expressed at 7.4 months of age, the first diagnosis was at 8.8 months, early intervention was first sought at 11.9 months, referral to early intervention occurred at 14 months, and the IFSP was developed at 15.7 months. (Standard errors for these and other data reported here can be found in ref 27.) These data are based on children who, by study eligibility criteria, had to be <31 months of age at the time of the IFSP. Had we also included in the study the children who enrolled in early intervention between 32 and 36 months of age, these averages would be higher.

The average age at which first concerns are expressed or an IFSP is developed mask the extreme variability in age with which these events occur over the entire population of children who enter early intervention. The percentage of entrants for whom an IFSP was developed at a particular month of age is shown in Fig. 1. These data are derived on the full sample of children who entered early intervention at the enrolling agencies ($N = 5668$) and show clearly that the percentage of entrants differs for children of different ages. There are large clusters of children who begin early intervention services by 7 months of age (25% of early intervention entrants) and between 23 and 30 months of age (28% of entrants). Children who begin services very young are more likely to be children with diagnosed conditions or risk conditions, whereas those who enter later tend to be children with developmental delays.²⁶

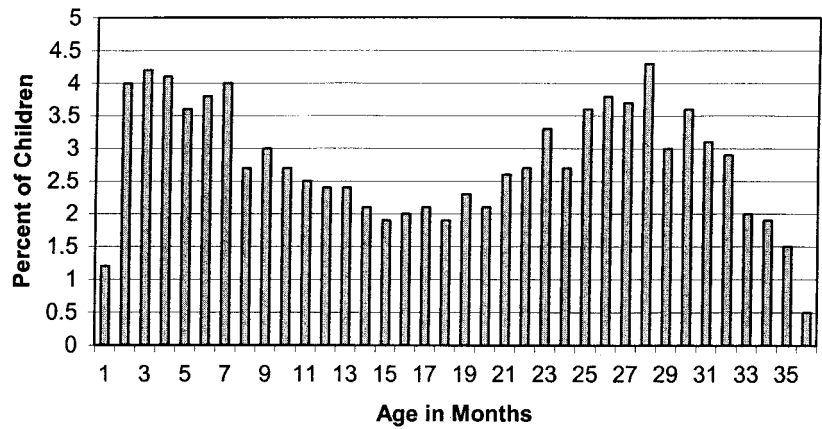
The IDEA mandates that a meeting to develop the IFSP be held within 45 days of referral to early intervention. The distribution in the number of weeks

TABLE 1. Mean, Minimum, and Maximum Age in Months for Events Related to Identification and Enrollment in Services

Event	Mean Age (Months)	Minimum Age (Months)	Maximum Age (Months)
First concern about health or development	7.4	(5 weeks prior to birth)	30.0
First diagnosis or identification	8.8	(5 weeks prior to birth)	30.0
First looked for early intervention	11.9	0.0	31.0
First referred for early intervention	14.0	0.0	31.0
Age at which IFSP was developed	15.7	0.26	31.3

Note that means represent a nationally weighted sample of all children entering Part C services.

Fig 1. Percentage of children beginning early intervention services at each month of age.



between referral and the development of the IFSP is displayed in Fig. 2. The earliest IFSPs were developed within 1 week of the referral. Approximately 60% of the IFSPs were developed within 45 days of referral. Seventy percent were developed within 8 weeks of referral, 79% within 10 weeks, and 90% within 14 weeks.

2. *What Kind of Contact Did Families Have With Medical Professionals When First Concerned About Their Child's Development?*

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. Respondents were not asked whether they had discussed concerns with the doctor if someone first became concerned about the child when the child was <1 month old, on the assumption that the medical profession would be involved in all cases in which the child's disability 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 concerns 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 that the medical professional was very helpful, and another 22% said the person was somewhat helpful. One in 8 (12%) said the person was not at all helpful, and a small fraction (2%) were initially involved with >1 medical professional and said that some were helpful and others were not.

3. *How Much Effort Did it Take for Parents to Find out About and Receive Early Intervention Services?*

Respondents were asked 2 questions regarding the effort needed to obtain services: 1) About how much effort did it take to find out where to go to try to get early intervention services? 2) After you knew where to go for services, how much effort did it take on your part to get services started? For each question, respondents indicated that a lot, some, little, or no effort was required.

Results are displayed in Table 2. Approximately half of the respondents indicated that it took no effort at all to find early intervention, with slightly less (43%) indicating that, once they found early intervention, no effort was required to get services started. Approximately 11% of the respondents reported that a lot of effort was required to find out about services, and 9% reported that a lot of effort was required to get services started once they had been identified.

4. *What Roles Did Parents Play in Developing a Plan for Services?*

Although all interviews were conducted after an IFSP had been developed, a substantial proportion of the respondents (18%) reported that they were not aware of "a written plan that describes goals for the child and services to be provided." The respondents who were aware of the IFSP were asked to describe who suggested 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.

Fig 2. Number of weeks from referral to IFSP (cumulative percentage of children).

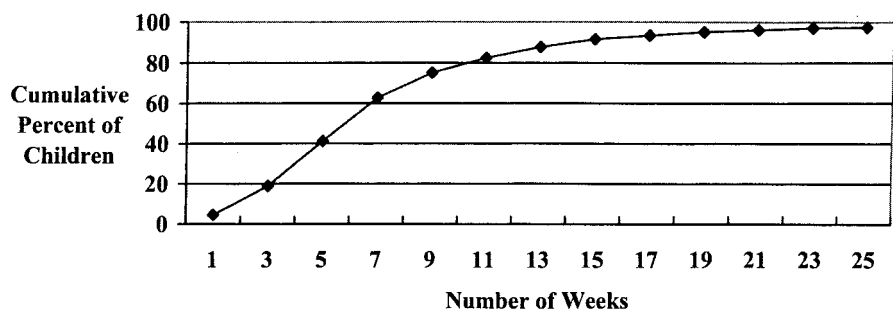


TABLE 2. Ratings of Effort Required to Find and Receive Services (Percentage of Caregivers)

Task	No Effort Required	Little Required	Some Required	A Lot Required
Effort to find early intervention	50	25	14	11
Effort to get services started	43	34	14	9

Note that percentages represent a nationally weighted sample and may not add to 100 because of rounding and/or missing data.

The results are displayed in Fig. 3. For all 3 decisions (goals, kinds of services, and amount of services) ~7% to 8% of the respondents reported that mostly the family made the decisions. However, a shifting balance of decision-making was evident among the remainder of the respondents across the 3 types of decisions. With respect to goals, 81% of the respondents indicated that decisions were made jointly by families and professionals, with professionals mostly deciding only 12% of the time. Less joint decision-making was reported for determining the kinds of services (64% joint and 27% mostly professionals) and even less for determining the amount of services (43% joint and 49% mostly professionals).

5. Are Parents Satisfied That the Services Provided Are Those That Are Needed?

Respondents were asked to rate the extent to which they felt that speech, occupational, and physical therapy as well as other early intervention services were sufficient in amount (about right, more than needed, less than needed, or enough for some but not others), whether they were individualized to their child's needs (highly, somewhat, not at all, or mixed), and whether there were services that the respondent felt were needed but the child was not getting (yes or no; if yes, what other services were needed?). Also, although their child had only begun to receive early intervention services recently, respondents were asked to rate the perceived level of quality of those services.

Most respondents reported that their child was getting about the right amount of therapy (76%) and other early intervention services (82%). However, 1

in 5 respondents (20%) indicated that their child was getting less therapy than needed, and 13% reported that their child was getting less other early intervention services than needed. Approximately two thirds (69%) rated services as highly individualized, and 28% rated services as somewhat individualized. Only 3% felt that services were not individualized at all. Some (14%) of the respondents reported that there were services the child needed but was not receiving. Of the services considered needed but not provided, the most common were speech therapy (39% of those indicating a need for other services), physical therapy (23%), occupational therapy (22%), play groups or play therapy (9%), and behavioral therapy (8%). Respondents were allowed to name as many needed therapies as they wished; thus, percentages sum to >100%.

With respect to quality of services, 93% of the respondents indicated that both therapy services and other early intervention services were excellent or good. Less than 1% reported that the quality of services was poor.

6. Are Parents Satisfied With Early Interactions With Early Intervention Professionals?

Respondents were asked how they felt about their involvement in decisions about services and whether they felt that professionals had been communicating well 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

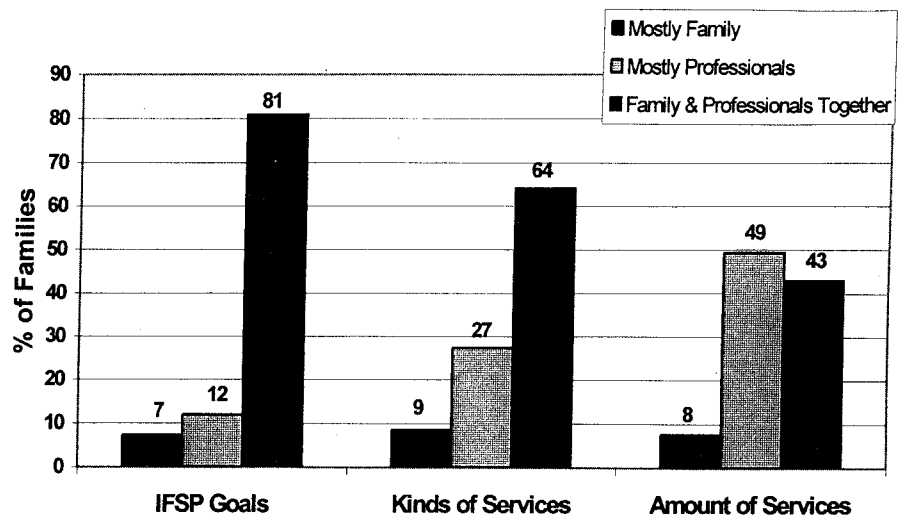


Fig 3. Percentage of parents indicating that mostly family, mostly professionals, or family and professionals together made decisions about goals, kinds of services, and amount of services.

TABLE 3. Ratings of Early Intervention Professionals (Percentage of Caregivers)

Characteristic	Strongly Agree	Agree	Disagree	Strongly Disagree
I have good feelings about professionals who work with children with special needs and their families	63	35	1	0.2
Early intervention professionals respect the values and cultural background of my family	61	38	1	0.1
Early intervention professionals providing services to my family ignore my opinions	3	4	40	53
Early intervention professionals make me feel optimistic and hopeful about my child's future	58	38	3	1

Note that percentages represent a nationally weighted sample and may not add to 100 because of rounding and/or missing data.

their opinions, and whether early intervention professionals made them feel optimistic and hopeful about their child's future.

Most respondents (77%) felt that their involvement in the decision-making was about right, but a substantial proportion (22%) wanted more involvement. Approximately half (53%) reported that communication among professionals was excellent, with the remainder rated as good (37%), fair (7%), poor (3%), or some okay and some not okay (<1%). A notable proportion of families reported working with only 1 professional (8%).

We assessed whether the nature of family involvement in decisions about services was related to their satisfaction with involvement. Parents were more likely to describe their involvement in decision-making as "about right" when decisions were characterized as being made jointly by both families and professionals (80.5% of these respondents rated their involvement as "about right"), as compared with families who reported decisions being made mostly by parents (68% about right) or mostly by professionals (72.4% about right) ($\chi^2[4] = 17.726; P = .011$).

The overall ratings of early intervention professionals given by families in their beginning weeks of early intervention service are displayed in Table 3. Respondents reported a very high degree of satisfaction with early intervention professionals, with >98% 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. Approximately 7% agreed or strongly agreed that professionals ignored their opinions, but most families disagreed with this statement.

7. Does the Process of Entering Early Intervention Differ for Families as a Function of Selected Child or Family Characteristics?

The data reported thus far are for the entire group of families receiving early intervention services, but there was variability in the outcomes observed. For this report, we examined differences among families as a function of 4 child variables (age at IFSP, eligibility category, gender, and race/ethnicity) and 2 family variables (household income and education level of the primary caregiver). The descriptive statistics were considered from the perspective of corroborating previous findings of factors associated

with parent satisfaction with early intervention services. Differences among response groups were tested by using χ^2 .

Age at IFSP

Age at IFSP reflects the child's age when services were initiated, with 31 months being the maximum age at entry for this study. Families of older entrants had a more difficult time connecting to services than families of younger children. Families of older entrants were less likely to have discussed their concerns with a medical professional (83% for families with entrants over 24 months vs 89% for those <12 months of age at entry; $P < .05$) and less likely to find that person helpful (56% vs 74%; $P < .001$), and it took more effort for them to find out about early intervention services (40% of the families of older entrants reporting no effort at all vs 59% of families of younger entrants; $P < .001$). Some of the difficulties experienced by these families could be the reason that their child began services at a later age. There were several other differences related to child's age at entry, but aside from the convergence of findings that pointed to a more difficult entry process for the families of older children, there were no other consistent trends in the differences between families of older and younger entrants into early intervention.

Eligibility Category

Across the 3 eligibility categories, developmental delay, diagnosed condition, and risk condition, there were striking differences in the age at which someone 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 with 11 months for children with developmental delays. For children with diagnosed conditions, the IFSP was developed an average of 7.1 months later or when the child was 9.4 months olds. For children with developmental delays, the process took nearly 9 months, for an average age of 20 months at the time of the first IFSP. Given that the oldest children entering early intervention are those most likely to be diagnosed with developmental delay and the sample excluded children between the ages of 32 and 36 months, the average age of entry for children with developmental delays certainly would have been several months older if the entire age range of children served in

early intervention had been included in the study sample.

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 3 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. Nearly all families of children with diagnosed conditions (94%) discussed their concerns with a medical professional, compared with only 85% of those with developmental delays and 80% of those with risk conditions ($P < .001$). Fewer families of children with developmental delays found the doctor or other medical professional to be very helpful (60%), compared with the other 2 groups (66% for families of children with a diagnosed condition and 79% for children with risk conditions; $P < .001$). 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 >2 to 3 years old.^{6,11-12} Possibly, families perceived this initial reluctance as not helpful for children who were eventually diagnosed as developmentally delayed.

Families of children with risk conditions were less aware of the IFSP than families of children from the other 2 groups (76% vs 84% for developmental delay and 82% for diagnosed conditions; $P < .01$). 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). Fifty-three percent of families of children with developmental delays thought the decisions were made mostly by professionals, compared with 41% for families of children with diagnosed conditions and 42% for families of children with risk conditions ($P < .001$). There were a few other statistically significant differences in the perceptions examined, but the numerical differences were fairly small.

Gender

The process of entering early intervention seems to be very similar for parents of boys and girls. Only 1 statistically significant difference was found across all the dimensions examined, and the numerical difference was small. Parents of girls were more likely to feel that professionals ignored their opinions (9% vs 6%; $P < .05$).

Race/Ethnicity, Education Level, and Household Income

Race/ethnicity, education level of the primary caregiver, and household income are related within the population of children receiving early intervention services. The relationship of these 3 characteristics to the process of entering early intervention is similar, and thus the findings are reported together.

Unlike the other characteristics discussed thus far, race/ethnicity showed a consistent pattern across many aspects of the process of beginning early inter-

vention services. For most of these differences, minority families had a more negative experience than other families. The pattern for families of different levels of education was similar in that nearly all 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. Household income showed a linear relationship to the quality of the experience entering early intervention. In many of the dimensions examined, as income increased, the family was more likely to report a positive experience.

The outcomes with the most striking differences by race/ethnicity, household income, and education are displayed in Table 4. To simplify the presentation, not all the categories for these variables are displayed. As the data in Table 4 indicate, the findings are remarkably consistent across outcomes. For example, with regard to the amount of effort required to find out about early intervention services, 8% of the white families reported that it took a lot of effort, compared with 13% of the black and 13% of the Hispanic families. With regard to household income, 13% of those making less than \$15 000 annually reported that it took a lot of effort, compared with only 7% of those making \$50 000 to \$75 000. Education level showed the same pattern: 12% of families in which the primary caregiver had less than a high school education reported that it took a lot of effort, compared with 9% of those with a bachelor's degree or higher. The demographic differences in how families experienced the process of beginning early intervention were especially strong with regard to awareness of the IFSP, wanting more involvement in the decision-making process, perceiving services as highly individualized, and whether early intervention professionals ignored the caregiver's opinion.

On 2 of the outcome areas, the pattern was reversed in that the white or more-advantaged families had more negative opinions. When rating the helpfulness of the doctor or other medical professional, 61% of the white caregivers found the person to be very helpful, compared with 69% of the black and 67% of the Hispanic caregivers. The differences were even greater by income and education level. Seventy percent of those making less than \$15 000 per year found the medical professional to be very helpful, compared with only 59% of those making \$50 000 to \$75 000. Of those with a bachelor's degree or more, 59% found the person to be very helpful, compared with 69% of those who did not graduate from high school. The other area in which the white and more-advantaged families were more negative was the amount of therapy being received. White and more-advantaged families were more likely to say that their child was receiving less therapy than needed.

DISCUSSION AND IMPLICATIONS

This article summarizes families' experiences in beginning early intervention services based on interviews with a sample of families participating in Part

TABLE 4. Ratings on Selected Outcomes by Race/Ethnicity, Household Income, and Education of the Primary Caregiver (Percentage of Caregivers)

Outcome	Race/Ethnicity			Household Income		Education of Primary Caregiver	
	White	Black	Hispanic	<\$15 000	\$50 000–\$75 000	Did Not Finish High School	Bachelor's Degree or More
Discussed concerns with a doctor/medical professional	87	81	86*	80	92†	76	90†
<i>Medical professional was very helpful</i>	61	69	67†	70	59†	69	59†
A lot of effort to find out about early intervention services	8	13	13†	13	7†	12	9†
A lot of effort to get services started	5	14	13†	14	5†	11	7†
Aware of IFSP	89	77	63†	71	92†	69	92†
Decisions about goals and outcomes made jointly by family and professionals	82	80	76‡	79	84†	78	82
Wanted more involvement in decision-making	13	37	29†	34	11†	34	10†
<i>Receiving less therapy than needed</i>	22	17	16†	18	25†	10	25†
Saw services as highly individualized	72	61	65†	62	73‡	67	71‡
<i>Professionals' communication with each other was excellent</i>	52	56	49†	61	44†	57	46†
Have good feelings about professionals who work with children with special needs and their families	65	64	55†	58	67†	52	65†
Early intervention professionals respect the cultural background of my family	65	56	55†	56	67*	52	64*
Strongly disagree that early intervention professionals ignore my opinion	58	45	41†	38	61†	35	66†
Strongly agree that early intervention professionals make me hopeful about my child's future	62	54	57†	57	58†	48	61†

Italicized statements indicate those areas counter to the general trend (ie, where the more negative perceptions were reported by white families, by those with an upper income, and/or by the families with more educated caregivers). To simplify the presentation, not all categories are displayed. The other race/ethnicity categories were Asian or Pacific Islander and mixed race or other. The other household income categories were: \$15 001 to \$25 000, \$25 001 to \$50 000, and >\$75 000. The other education categories were: GED or high school diploma and some college. The statistical significance level indicates that there is a statistically significance difference within the full range of the categories. The difference was not always between the categories displayed in the table.

* $P < .05$; † $P < .001$; ‡ $P < .01$.

C early intervention programs in the United States. Described are 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 variables. However, this statement must be tempered by at least 2 noteworthy limitations. First, the findings are based on a few questions conducted in the context of a telephone survey. More detailed information about family perceptions, especially specific concerns about programs or service providers, could only be captured through a more extensive series of interviews. Furthermore, the study only includes those families actually enrolled in early intervention programs. Families preferring not to participate in Part C early intervention, those who were not able to access services, those whose children were referred but not determined to be eligible, and those who were not yet aware of their child's disability were not included in the study. Their perceptions of early intervention might be different from those of the families who receive early intervention services. Given these limitations, however, a number of conclusions can be drawn about early intervention programs along with several qualifiers and recommendations.

Timing and Entry Into Early Intervention

Children begin early intervention services at all ages between birth and 36 months of age. Approximately 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 31 months of age, the age span covered by the study, with a slight slowing of the rate of entry during the middle 10 months. Characteristics of children who enter early intervention at various ages will be the topic of another article. Here we focus on the time lag between key events and parent perceptions of those events for children who enter early intervention at ≤ 31 months of age.

Retrospectively, caregivers reported a relatively short period of time between first concerns and first diagnosis (mean difference: 1.5 months). However, the mean time difference between caregiver report of diagnosis and agency report of referral for early intervention was >5 months. The gap between parent report of first diagnosis and a signed IFSP was 7.5 months, and the gap between initial concerns and a signed IFSP averaged 9 months.

In analyzing these findings, it seems that the problem lies not in the length of time between concerns and diagnosis (which, on average, was only ~1.5 months) but rather in the length of time from diagnosis to referral for services (which averaged 5.2 months). Also, the length of time from concern to early intervention is much longer for children with

developmental delays who enter early intervention at 20 months, a later average age than other children.

The reasons for delays in entering early intervention cannot be ascertained from this study. Possible reasons could include parent preferences, distress, or uncertain desire for services,²⁸ lack of coordination among the various agencies involved in early intervention,²⁹ failure to incorporate developmental or behavioral screening in standard pediatric examinations,^{7,8} or pediatrician reluctance to refer for early intervention younger children and those with less severe developmental delays.^{11,12} 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 the referral process takes so long. Research can help identify the types of barriers and the conditions under which they are likely to occur, but local service providers also will need to conduct their own evaluations to determine which factors are especially important in their communities or with certain families. The fact that only 60% of the IFSPs were developed within 45 days of referral to early intervention needs to be studied further to determine whether delays are caused by the program or family preferences and participation.

Despite these patterns, most families (approximately three fourths of those entering early intervention) reported that finding early intervention programs and getting services started required little or no effort on their part. Only ~10% reported that both finding and securing services required a lot of effort. As would be expected, parents of children who were older when they entered early intervention (>24 months) were less likely to report no effort required to obtain early intervention than parents of children who entered when they were <1 year old. Also, parents of children with developmental delay had more difficulty than parents of children with established conditions or children at risk. This may reflect the fact that children qualifying under the at-risk or established conditions criteria of Part C are eligible because of specific conditions or experiences that are relatively well defined and mandated by legislation at the state level. Children who qualify because of developmental delays must first demonstrate a delay, and pediatricians or other professionals may be reluctant to say that a child is delayed unless the delay is severe.⁶

Analyses of the referral data indicate that sociodemographic characteristics such as ethnicity, household income, and caregiver education level were related to having more difficulty entering the early intervention service system. Although only a small percentage of any group experienced difficulties, the likelihood of having a negative experience was higher for families who were minority or had limited income or limited education. This finding is consistent with other research indicating that having more education, being white, and having a higher income were associated with earlier identification of disability.³⁰

Satisfaction With Services and Involvement

Although criteria for study participation included the existence of an IFSP, nearly 1 of 5 (18%) caregivers was not aware of the existence of a written plan for goals and services (the IFSP). Poor families, ethnic minority families, and families in which the caregiver did not graduate from high school were much less likely to be aware of the existence of a written plan than were more affluent and white families.

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 (64% parents and professionals together) or amount (43% families and professionals together) of services provided.

Approximately 22% of the families beginning early intervention wanted more involvement in decision-making, but the rest felt that their involvement was about right. Poor families and ethnic minority families, particularly black families and families in which the primary caregiver had limited education, were much more likely to want more involvement in decision-making. The finding that sociodemographic characteristics play such important roles in the awareness of a written plan and the desire to be more involved in determining goals and services is consistent with a recent study of Latino families in which it was found that only 39% of parents were rated as mostly or very satisfied with early intervention services.¹⁸

Almost all families (97%) felt that the services they received were somewhat or highly individualized, although again those least likely to see services as highly individualized were minority families and those with limited resources. Families reported a high degree of satisfaction with early intervention professionals. Most families felt that their child was getting the right amount of therapy and other early intervention services. Approximately 14%, however, wanted more in the way of speech, occupational, or physical therapy.

CONCLUSIONS

Collectively, these data suggest that the US early intervention system operated under Part C of the IDEA provides a positive and supportive entry into services for the vast majority of families who are enrolled in early intervention programs. Families like early intervention professionals, report relative ease in accessing participation in 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. The extent to which these perceptions remain stable will be assessed in subsequent interviews at age 3 and in kindergarten.

A few aspects of the process of beginning early intervention warrant closer examination and possible changes. The average time of 5.2 months between diagnosis and referral seems unnecessarily long. As recommended by a recent report on developmental surveillance and screening by the American Acad-

emy of Pediatrics' Committee on Children With Disabilities,¹⁰ pediatricians should move from developmental surveillance to a more proactive model of development screening of infants and young children, followed by more prompt referral to early intervention.

A small percentage of families experience difficulties in accessing services and feel that the amount of services received is inadequate, and nearly one fifth were not aware of a written plan for goals and services. Research and program-evaluation efforts are needed to identify more precisely those families or service systems in which these problems are most likely to occur and further explore the underlying causes. Strategies to alleviate these problems need to be developed and implemented. Of note is the fact that families of children with developmental delays experienced more frustration with accessing services and getting the desired amount of services, compared with families of children with diagnosed conditions or at risk for developmental delay. This suggests the need to examine the challenges faced by families whose children must demonstrate the need for special services due to behavioral or developmental status (as opposed to the existence of biological or environmental risk status) and develop more supportive systems for earlier identification of children with delays.⁵ Also of particular concern is the finding that ethnicity, income, and education level were associated with less positive experiences. This suggests the need to develop models, practices, and professional skills that are more supportive of the entire array of families who need to access the early intervention service delivery system.

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