
Results Experienced by Children and Families 1 Year After Beginning Early Intervention

The recognition of the importance of early experiences on the future development of young children with special needs was an underpinning of Part C of the Individuals with Disabilities Education Act (IDEA). Part C was enacted because of the urgent and substantial need:

- (1) to enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay;
- (2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services when infants and toddlers with disabilities reach school age;
- (3) to minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential for their independently living in society;
- (4) to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities (§631(a)).

To examine what happens to infants and toddlers with special needs and their families during and after early intervention, the Office of Special Education Programs (OSEP) commissioned the National Early Intervention Longitudinal Study (NEILS). NEILS is following a nationally representative sample of 3,338 infants and toddlers who received early intervention services for the first time between September 1997 and November 1998. Information is being collected repeatedly on these children and their families throughout the early intervention years and then again when the children enter kindergarten. The sample consists of children from four birth years. The oldest children in the study exited early intervention in 1998 and started kindergarten in 2000-01. The youngest exited the early intervention service system in 2001 and will probably begin kindergarten in 2003-04. Data from NEILS will play a key role in efforts to improve early intervention services and results for infants and toddlers with disabilities. Descriptive information about the characteristics of children and families receiving early intervention were presented in the 22nd and 23rd *Annual Reports to Congress*. This chapter provides data about child and family results 1 year after entry into early intervention services.

Progression of Children Through Services

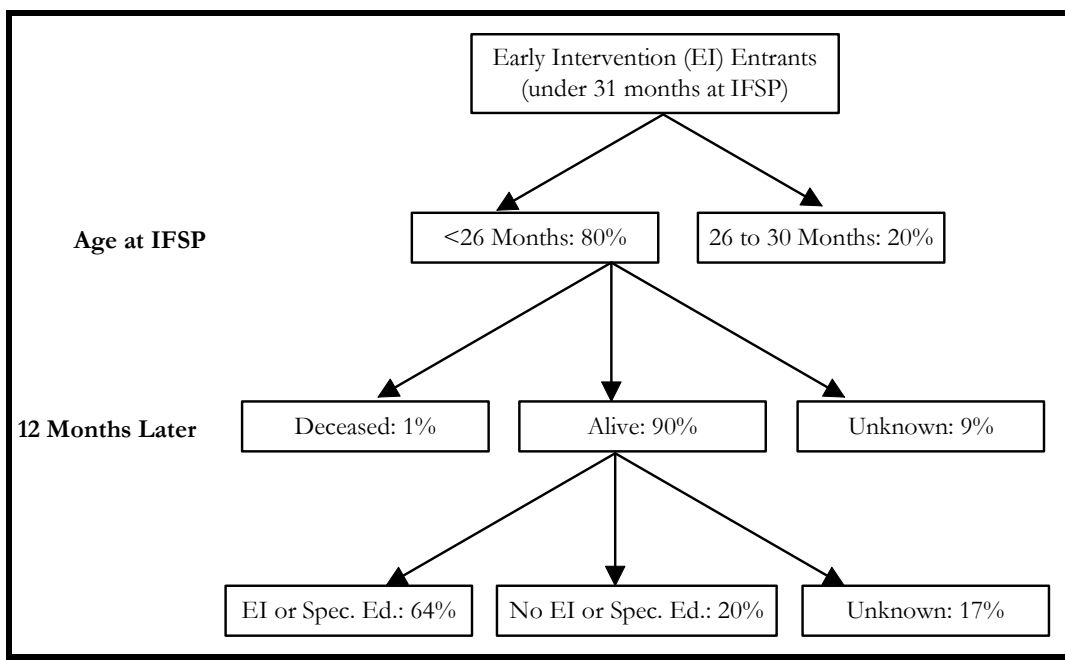
This chapter examines the results for children and families approximately 12 months after they began early intervention services. The information is based on two telephone interviews conducted with a family member of the child enrolled in early intervention.¹ The first interview was conducted within the first 4 months after the initial individualized family service plan (IFSP). Most (68%) were conducted within 6 weeks of the IFSP. For younger children, a second interview was conducted about 12 months after the first IFSP. We began trying to contact the families at approximately 11 months after the IFSP and continued until 15 months. For older children, those who turned 36 months of age within the year after the first interview, an interview was conducted around the time the child turned 36 months of age. Thirty-six months is the age when children would be expected to leave early intervention services, and the study design called for interviewing the families of all children at this critical juncture. Nearly all (94%) of these interviews were conducted within 3 months of the child's 3-year birthday. For the first interview and the 36-month interview, if a family member could not be reached for the interview, the family was sent a mail questionnaire containing a subset of the questions in the interview. Eighty families returned the survey associated with the first interview, and 84 returned the survey for the 36-month interview. The data from the mail questionnaires were always collected at least 5 months after the intended data collection point because the questionnaires were only mailed out after months of unsuccessfully trying to reach the family by telephone.

This module describes results for children and families that had the potential, based on the child's age at IFSP, to spend roughly a year in early intervention. The findings are based on those families who had a family interview (or mail questionnaire) at entry and about 12 months later ($n=2,235$, 67% of the original sample). The actual time between the first and second data collections ranged from 35 to 69 weeks, with a median of 46 weeks. This timeframe is less than 12 months for most children because all of the first interviews were conducted *after* the IFSP, and some of the second interviews were conducted before a complete year had passed. For convenience, we refer to these data as describing the status of children "12 months later" because the second data collection was approximately a year after the first IFSP.

By definition, the data presented in this chapter exclude the oldest children entering early intervention. (Consider a child who entered early intervention at 29 months of

¹ The adult best able to talk about each child and his/her early intervention experiences was the respondent for the telephone interview; the vast majority were the child's biological, adoptive, or foster mother (90%), and respondents are referred to as parents here.

Figure IV-3
Status of Children Less Than 26 Months of Age 12 Months After Initial IFSP



Source: National Early Intervention Longitudinal Study.

age. The first interview could have been conducted when the child was 30 months and the second interview at 36 months so only 6 months would have passed between the first and second interview.) Data on all children at 36 months will be included in subsequent NEILS reports, but these analyses focus on the group of children for whom there were data at two time points, with the second being roughly a year after the initial IFSP. NEILS used 26 months of age at IFSP or younger as the cutoff to define the group. All findings are weighted data.

Children and Families Included in This Chapter. About 80% of the early intervention entrants¹ were under 26 months at the time the IFSP was developed (see Figure IV-3). Because there are substantial differences within the early intervention population between children who enter early intervention at younger and older ages, it is important to emphasize that these children do not represent the entire population of children in early intervention. The children who have the potential to spend at least a year in early intervention and for whom data are presented in this chapter differ from the general population of early intervention

¹ Children in the sample had to be younger than 31 months at study enrollment because those entering later than that would not have participated in early intervention long enough to justify following them longitudinally.

entrants with regard to why they are eligible for early intervention. About half of children under 26 months of age at IFSP (52%) are eligible because of a developmental delay compared with 85% of the older group. Conversely, 24% of the younger group were eligible because of a diagnosed condition compared to only 7% of the older group. For almost half of the older group (49%), a speech or communication problem was listed as their only reason for being eligible for early intervention. This was the case for only 17% of the younger children.

The groups also varied in regard to gender. (At least one study has examined the association between gender and reason for eligibility; see Hebbeler, Wagner, Spiker, Scarborough, Simeonsson, & Collier, 2001.) Seventy-one percent of the older children were male compared to 58% of the younger children. The groups also differed in regard to whether the family had received public assistance. The families of the younger children were poorer: 42% of them were receiving public assistance at the time of the IFSP compared to 30% of the older children. Children who have the potential to receive a year of early intervention service are a fundamentally different group of children from those who enter in late toddlerhood (and therefore cannot receive at least a year of service). The significance of these differences for the findings presented cannot be easily understood without additional analyses (which will be forthcoming), but it is important to reiterate that these results only reflect information about the 80 families surveyed and do not generalize to *all* children in early intervention.

Continuing Receipt of Services After 12 Months. Among children who began early intervention services at less than 26 months of age, about 1% died over the next 12 months, and the status of another 9% was unknown (see Figure IV-3). Of the 90% known to be living 12 months after entering early intervention, about two thirds (64%) were reported by their parents to be receiving either early intervention or preschool special education at the time. Another 20% were reported to be receiving no service, and the service status of 17% was unknown.² Although the age of transition out of early intervention approximates 36 months, it can vary by several months in either direction depending on state and local policies and where the child's birthday falls relative to the school year. Therefore, early intervention and preschool special education were combined to identify the group of children still receiving services 12 months later. Again, other NEILS analyses will focus exclusively on the transition at 36 months and provide detailed information about what happens to children as they leave early intervention.

² These figures could change as additional NEILS data sets are analyzed and merged with the family data. For example, data from the service providers might confirm that a child was alive and receiving services 12 months later even though there are no data from the family.

The remainder of this chapter presents many different kinds of results for both children and families. For children, we look at health, functioning, behavior, and developmental attainments. For families, we address family satisfaction with services, parenting skills, family and community supports, and child and family situation. Because many of the findings are quite different for children of different ages, especially in regard to the child result areas, the findings are presented separately for four groups of children. The four groups are based on the child's age at the time of entry into early intervention (the signing of the initial IFSP): under 6 months, 6 to under 12 months, 12 to under 18 months, and 18 months to under 26 months.

For each individual result area, we compare what the group looked like at entry and 12 months later. Statistically significant changes in the group between these two time periods are highlighted in the tables with bolding and described in the text.

Results for Children

Child Functioning

To describe the nature of the abilities and disabilities of children receiving early intervention services, parents were asked a series of questions about various aspects of their child's functioning, including vision, hearing, mobility, and communication. In some of these areas, it is reasonable to expect that the number of problems would actually increase over time, especially for the youngest children, who began services as tiny babies. For example, as these children grow and develop, some of the problems associated with poor birth histories may manifest themselves.

For all four age groups, the small proportion of children with a diagnosed hearing problem is similar at entry and 1 year later (see Table IV-4). For the two youngest and the oldest age group, there was a significant increase in the number of infants who had a diagnosed vision problem by 1 year after beginning early intervention. This is a positive finding in that children with suspected problems with vision are being identified and referred for formal evaluations.

The percentage of infants and toddlers having trouble using their arms and hands at the time of entry into early intervention and 1 year later is similar for those in the youngest age group and in the two oldest age groups. There was a significant increase in the proportion of those infants who entered between 6 and 12 months and were reported to have normal use of their arms and hands 1 year later.

Table IV-4
Functional Characteristics of Children Entering Early Intervention
and a Year Later by Age Group at Entry

Age group at entry	0 to 6 Months		6 to 12 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
N=	552		465		338		880	
Diagnosed hearing problem								
Yes	9	10	8	8	13	12	6	7
Diagnosed vision problem								
Yes	13	19	13	18	12	12	4	7
Use of arms and hands								
Uses both normally	69	69	55	70	70	72	89	86
Has a little trouble	23	20	34	20	19	19	8	11
Has a lot of trouble or no use of one or both	8	10	11	10	12	9	3	3
Use of legs and feet								
Uses both normally	79	63	58	64	55	64	81	85
Has a little trouble	15	24	28	20	29	24	15	11
Has a lot of trouble or no use of one or both	6	12	14	16	16	12	4	4
How well does child make needs known								
Communicates just as well as other children	--	60	8	49	42	49	26	35
Has a little trouble communicating	--	29	3	32	40	33	40	43
Has a lot of trouble communicating	--	6	2	14	14	16	30	22
Doesn't communicate at all	--	4	1	5	4	2	4	1
Not asked (if child < 12 months at interview)	100	<1	86	--	--	--	--	--
When child talks to people s/he doesn't know, child is								
Very easy to understand	--	6	<1	13	6	15	4	10
Fairly easy to understand	--	12	1	16	6	25	11	26
Somewhat hard to understand	--	5	1	10	9	20	14	32
Very hard to understand	--	5	1	6	7	10	13	11
Has no words	--	71	10	55	72	31	58	22
Not asked (if child < 12 months at interview)	100	<1	87	--	--	--	--	--

Note: *N*s refer to the number in each age group. The *N*s for the individual items vary slightly because of missing data. The data highlighted in bold reflect statistically significant changes at $p < .05$ level or greater. Statistical significance was not tested if an item was not asked for all or most children in an age group.

Source: National Early Intervention Longitudinal Study.

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In all four age groups, there were significant changes in the children's reported use of their legs and feet over time. For the youngest age group, more children are reported to be having some difficulty using legs and feet 1 year later. Many of these infants were eligible due to low birth weight or perinatal complications for which gross motor delays may not be apparent until the later half of the first year of life. In contrast, for the other three age groups, 1 year later, more children were reported to have normal functioning of their legs and feet.

Many of the children in all groups were reported as having trouble communicating.³ The change over time results are only meaningful for the two oldest age groups since the items about communication were not asked for infants less than 12 months of age. Nevertheless, for the two youngest age groups, 1 year later, many of them were having communication difficulties (39% and 51%, respectively). In the two oldest age groups, many of whom had a speech and language delay as a primary reason for referral to early intervention, there was a significant increase in the proportion of children who were reported to communicate just as well as other children. Both the improvement and the pervasiveness of language problems among the 18- to 26-month olds are apparent. The percentage of children reported to communicate as well as other children in this age group rose from 26% to 35%. This is a significant increase, but it means, however, that 65% of the children are not communicating as well as other children. Parents were also asked about how easy the child is to understand when talking to people he or she doesn't know. Many of the children entering after 12 months of age were not yet using words to communicate, but many more of them were speaking 1 year later. One year later, many of those older toddlers were now speaking, but many of them were somewhat or very hard to understand.

General Health and Health Care

Parents were asked several questions regarding their child's current health, health care, and health insurance status. Although some children receive early intervention for disabling conditions related to their health, many children are eligible for services because of developmental problems rather than health per se. For most of these health measures, there were few changes over time (Table IV-5). Most parents in all age groups reported their children's health to be good, very good, or excellent (see Table IV-5). These percentages are lower, however, than reported for the general

³ The questions about communication and articulation were only asked for children over 12 months of age. Note that the small percentage of infants in the 6- to 12-month age group at entry with responses to these communication items are for children who had their initial IFSP when they were less than 12 months old, but the entry parent interview was conducted after the child reached his or her first birthday, just a short time thereafter.

Table IV-5
Health Status of Children Entering Early Intervention and a Year Later by
Age Group at Entry

Age group at entry:	0 to 6 Months		6 to 12 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
N =	552		465		338		880	
Health Status								
Excellent	31	34	27	29	40	40	44	46
Very good	28	24	23	26	24	27	25	27
Good	22	24	25	29	22	20	20	17
Fair	13	15	17	11	10	9	9	9
Poor	5	4	8	6	5	3	2	1
Hospitalized since coming home from hospital after birth								
No	68	45	54	45	62	54	71	65
1 to 4 days	14	21	19	19	17	20	16	19
5 to 14 days	12	18	15	17	11	14	9	10
15 to 30 days	5	10	5	9	5	6	2	4
More than 30 days	2	6	7	11	5	7	1	2
Regularly taking any prescription medication for a specific condition or problem	37	31	37	31	29	28	16	16
Uses any kind of medical device like an oxygen tank, catheter, or a breathing monitor	30	22	22	21	11	13	7	7
Has a place to go for regular medical care	98	99	99	98	98	99	96	97
Covered by any health insurance	96	98	96	96	94	97	93	96
Covered by government-assisted health insurance	53	54	57	56	45	49	34	37
Ever tried to get insurance to pay for something for child that it wouldn't pay for	16	18	20	21	20	17	19	21

Note: *N*s refer to the number in each age group. The *N*s for the individual items vary slightly because of missing data. The data highlighted in bold reflect statistically significant changes at $p < .05$ level or greater.

Source: National Early Intervention Longitudinal Study.

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population, in which nearly all parents (98%) report their children to be in good, very good, or excellent health.⁴ It is also notable that more of the children in the two youngest age groups are rated as having fair or poor general health at both times compared to the children in the two oldest age groups. The only group with a change over time was the children who began early intervention between 6 and 12 months: 1 year later, fewer of them were rated as having fair or poor health.

Another measure of health is how many nights the child has been hospitalized since coming home from the hospital at birth. These data can only increase over time since the measure is a cumulative count over the child's life, and it did significantly increase for each of the age groups. The more extensive medical involvement of the children who began early intervention as infants compared to those who begin over 18 months is also captured in these data. A year after beginning early intervention, 34% of the youngest group had been hospitalized 5 or more days compared to only 16% for the children who began as 18- to 26-month-olds.

Consistent with the ratings of overall health, many children in early intervention were reported to be taking prescription medication for a chronic condition (about one third of the first three age groups, and nearly one fifth of the oldest toddlers). The percentages of each age group taking medication did not change over time. For the youngest infants, those who entered early intervention under 6 months of age, the percentage reported to be using a medical device of some sort (with the most common medical devices being respirators, breathing monitors, and nebulizers) was smaller 1 year later.

With regard to health care, families of nearly all children in early intervention reported that their children had a place to go for regular medical care, and there was no change over the first year in early intervention. Similarly, nearly all children were covered by health insurance, and the percentages of children with coverage did not change over this first year. Finally, about one in five families in each age group reported that their insurance company had refused to pay for something they tried to get for their child, and there were no changes in this proportion from entry to 1 year later.

⁴ The available national data are for children under age 5 (Adams, Hendershot, & Marano, 1999). For this reason, some of the difference between the national data and these early intervention data could be due to the older children included in the national data.

Behavior

Children vary in temperament and personality style from a very early age. The importance of some of these differences is not readily apparent. Does a 2-year-old who pays attention for a long period of time become the child who stays focused in first grade? Does the aggressive toddler become the 5-year-old with behavior problems? Part of the significance of the NEELS behavioral data rests in their stability or the extent to which early behavior serves as a predictor of later behavior. Parents were asked to rate their child's behavior across a number of dimensions; some of the items were not relevant for the youngest infants (e.g., trouble playing with other children), so it is important to describe these behaviors within each of the four age groups and over time.

For those infants who entered early intervention under 6 months of age, 1 year later significantly fewer of them were described as being jumpy or easily startled, perhaps reflecting maturation (see Table IV-6). About half of these youngest infants were described as having trouble paying attention and staying focused, both at entry and 1 year later. Similarly, about half were reported to have sleep problems, both at entry and 1 year later. Families' ratings of how easy it was to take the child places were similar at entry and 1 year later. Note that for other behavior ratings that were only relevant for this group 1 year later, such as does things on his own, or trouble playing with or being aggressive with other children, between 10% and 30% of them are having significant troubles with some of these behaviors as they enter toddlerhood.

For infants who entered early intervention between 6 and 12 months of age, the patterns on the behavior ratings were similar to those for the younger infants. A notable difference, however, was that more of these children were rated as a little difficult to take places 1 year later than they had been at entry to early intervention. This change may reflect a developmental change from being an infant to a toddler rather than indicating anything about the child's disability or functioning.

For the two oldest age groups, across many different behavior items, a similar pattern emerged. Some children, usually about half, were reported by their caregiver to have no trouble with a given behavior. Another third of the children were reported as having some difficulty, and 10% to 40% of the children are described as having behavioral challenges. As for significant changes over time, for those who entered between 12 and 18 months, more of them were described 1 year later as having some trouble playing with peers and with being aggressive with peers, and fewer were described as being jumpy or easily startled. Only two ratings were different over time for the oldest age group: 1 year later, more of them were described as being very active and excitable, and more of them were harder to take places.

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Beginning Early Intervention

Table IV-6
Behaviors of Children Entering Early Intervention and a Year Later by Age Group at Entry

Age group at entry	0 to 6 Months		6 to 12 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
N=	552		465		338		880	
Does things on own even if hard								
Very much like this child	--	45	6	48	42	51	57	56
A little like this child	--	34	4	34	35	31	32	33
Not like this child	--	21	4	18	23	18	11	11
Not asked (if < 12 months at interview)	100	<1	86	--	--	--	--	--
Pays attention and stays focused								
Very much like this child	46	45	44	40	41	40	41	39
A little like this child	38	38	35	39	41	42	39	39
Not like this child	16	17	21	21	18	18	20	22
Jumpy and easily startled								
Very much like this child	35	24	29	23	23	17	18	18
A little like this child	33	29	33	31	31	32	27	26
Not like this child	32	47	38	46	46	51	56	56
Very active and excitable								
Very much like this child	--	34	6	36	37	31	38	41
A little like this child	--	34	2	31	31	34	34	29
Not like this child	--	32	5	33	32	34	29	30
Not asked (if < 12 months at interview)	100	<1	86	--	--	--	--	--
Trouble playing with other children								
No trouble	--	66	9	62	64	55	55	56
Some trouble	--	18	3	24	23	34	35	33
A lot of trouble	--	12	1	10	8	11	9	10
Not around other children	--	4	1	4	4	1	2	1
Not asked (if < 12 months at interview)	100	<1	87	--	--	--	--	--
Aggressive with other children								
Not at all	--	55	9	51	51	37	37	37
Sometimes	--	36	3	42	42	51	53	54
Often	--	8	1	7	7	12	10	9
Not asked (if < 12 months at interview)	100	<1	87	--	--	--	--	--

Table IV-6 (continued)

Age group at entry	0 to 6 Months		12 to 18 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
Child has sleep trouble								
Rarely or never	51	56	49	55	53	46	56	54
Sometimes	30	26	33	26	26	32	25	29
Often	20	18	19	19	21	21	19	17
How easy is it to take child to the store or an appointment								
Easier than other children his/her age	22	25	26	21	28	21	21	16
Just as easy	48	46	47	49	43	45	43	42
A little harder	20	20	18	23	21	23	24	27
Much harder	10	8	9	7	9	11	12	15

Note: *N*s refer to the number in each age group. The *N*s for the individual items vary slightly because of missing data. The data highlighted in bold reflect statistically significant changes at $p < .05$ level or greater. Statistical significance was not tested if an item was not asked for all or most children in an age group.

Source: National Early Intervention Longitudinal Study.

It is important to note that these are not all the same children having difficulties in different behavioral areas; rather the findings suggest that there are numerous ways for young children to present challenges within their families, and a minority of early intervention children present each of these challenges. Additional longitudinal data will reveal whether these challenges persist over time and thus their importance for future growth and development.

Developmental Accomplishments

Attaining age-appropriate developmental competencies is an important accomplishment for all infants and toddlers. It is significant for children under 3 because it facilitates interaction with the environment, which forms the foundation of individual child development. The developmental accomplishments of infancy and toddlerhood are also important because they lay the groundwork for the next level of developmental skills children must master as they move through the preschool years and then enter elementary school. For example, communication and mobility are important developmental tasks for young children. Acquiring beginning communication skills allows the child to more effectively communicate his or her needs. Similarly, becoming mobile provides access to a much broader range of environments and objects to explore and enjoy. On the other hand, the child without adequate communication skills is limited in his or her ability to interact with

caregivers and others in his or her social world and is possibly frustrated by this limitation. A child who is not mobile is restricted to where he or she is placed and reliant on what others bring for the child to explore.

NEILS examined developmental attainments by asking parents to report on a set of child behavior and skills in several domains. For each item, the parent was to report whether the child “does it well,” “does it but not well,” or “doesn’t do it at all.” The specific milestones were selected because they were judged to have face validity as markers of developmental attainment, to be universal in expression with minimal cultural/socioeconomic bias, and to be observable in everyday activities.

The status of children upon entry into early intervention and 1 year later on a select set of the milestones is shown in Tables IV-7 and IV-8. In interpreting these data, it is important to remember that these age groups at entry into early intervention reflect different groups of children with regard to the nature of their disability or delay. (See 23rd *Annual Report to Congress* for further details.) Children who began early intervention and whose families were interviewed when the child was less than 12 months of age are not just younger than the other two age groups. Children who begin early intervention at less than 12 months of age are much more likely to have a diagnosed condition or a risk condition such as low birth weight. Children older than 12 months are much more likely to have a communication-related disability or delay. Some of the milestone items were too advanced or too young for some age groups and therefore were not asked for these children.

For all age groups, the children are advancing developmentally, with significantly higher percentages of children in every age group showing mastery for the milestones shown 1 year after entering early intervention. For the children who were less than 6 months old at entry, for instance, 1 year later, most were able to grasp and let go of objects, crawl, creep or scoot, sit up alone, eat bite-size pieces of food, babble, and play peek-a-boo. However, 1 year later, only about one third were able to walk without holding on to anything, about half could lift a cup and drink from it, and about one fourth of them could repeat or imitate a word.

For the children who entered early intervention between 6 and 12 months and between 12 and 18 months of age, a significant percentage had mastered many of the motor and self-help milestones by 1 year later. For instance, while few of those entering between 6 and 12 months could walk independently at entry, 1 year later over half could do so. For the 12- and 18-month-olds, about one third could walk independently at entry, and nearly three fourths could do so 1 year later. Children in these two age groups also showed progress with communication and cognition

Table IV-7
Milestone Attainment in Motor and Self-Help Domains of Children Entering
Early Intervention and a Year Later by Age Group at Entry to Early
Intervention Services

Age group at entry	Percentage of children reported able to do milestone well							
	0 to 6 Months		6 to 12 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
N=	552		465		338		880	
Motor								
Grasp objects and let go of them (10)	40	90	73	95	95	97	99	100
Crawl, scoot, or creep (11)	13	82	32	87	86	92	99	99
Sit up (11)	6	81	39	87	86	91	99	99
Pick up small objects with finger and thumb (12)	8	66	38	75	68	79	84	87
Hold a crayon or pencil (16)	1	28	8	46	28	66	66	76
Walk without holding on (17)	<1	33	4	59	34	73	86	93
Walk quickly or run (25)	<1	24	2	44	22	61	77	85
Take paper off candy to unwrap (25)	<1	11	3	21	10	33	41	58
Self-Help								
Eats bite size pieces with fingers (11)	3	80	31	85	86	92	98	99
Lifts a cup and drinks from it (18)	1	54	15	62	54	75	86	92
Takes off socks without help (23)	--	--	38	60	64	66	74	80
Washes and dries hands thoroughly (28)	--	--	--	--	--	--	34	55

Note: *N*s refer to the number in each age group. The *N*s for the individual items vary slightly because of missing data. The data highlighted in bold reflect statistically significant changes at $p < .05$ level or greater. The number in parentheses after the milestone is the age in months by which almost all children in the general population (approximately 90%) have attained this milestone. Some milestones are too advanced for some age groups and were not asked for these children. Statistical significance was not tested if an item was not asked for all or most children in an age group.

Source: National Early Intervention Longitudinal Study.

milestones. For instance, at entry, almost none of those who entered at 6-12 months of age could follow a two-step verbal direction, but 1 year later, nearly half could do this. For those who entered between 12 and 18 months of age, 26% could do this at entry and 62% could do it 1 year later. However, about one fourth of children still

Table IV-8
Milestone Attainment in Communication and Cognition Domains of Children
Entering Early Intervention and a Year Later by Age Group at Entry
to Early Intervention Services

Age group at entry	Percentage of children reported able to do milestone well							
	0 to 6 Months		6 to 12 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
N=	552		465		338		880	
Communication								
Babbles (3)	62	89	71	93	87	95	95	97
Says “mama” or “dada” (12)	2	64	31	73	55	81	74	87
Responds to simple gestures like someone waving “bye-bye” (17)	11	67	34	77	63	87	84	91
Repeats or imitates a word (18)	1	26	11	39	22	55	25	65
Follows a 2-step verbal direction (24)	0	24	1	46	26	62	61	74
Says 2 or 3 words in a sentence (25)	0	4	1	16	3	40	13	57
Cognition								
Laughs in response to peek-a-boo (8)	36	95	73	96	97	97	98	99
Explores objects by shaking and banging (11)	20	91	70	93	93	95	98	99
Puts things into and takes them out of things (12)	<1	56	18	70	59	88	91	97
Does simple pretending in play like feeding a doll (18)	0	13	4	34	16	61	57	78
Shows that knows two body parts (28)	<1	28	4	57	23	76	73	89
Refers to things as “mine” (30)	0	13	2	33	14	56	40	76
Gives his or her first name (35)	<1	7	3	17	5	31	11	54

Note: *N*s refer to the number in each age group. The *N*s for the individual items vary slightly because of missing data. The data highlighted in bold reflect statistically significant changes at $p < .05$ level or greater. The number in parentheses after the milestone is the age in months by which almost all children in the general population (approximately 90%) have attained this milestone. Some milestones are too advanced for some age groups and were not asked for these children. Statistical significance was not tested if an item was not asked for all or most children in an age group.

Source: National Early Intervention Longitudinal Study.

had significant delays after 1 year. A similar pattern of progress can be seen for both of these age groups for the percentages of children who were able to show that they knew at least two body parts.

Nearly all children who entered early intervention between 18 and 26 months had mastered milestones in the motor domain by the time they entered early intervention. The patterns of mastery for these two domains do show, however, that some of these oldest children have significant delays (e.g., 1 year later, only 58% can take paper off candy to unwrap it; only 80% can take off their socks without help). It is notable, furthermore, that even among these children in the oldest age group, 7% were not walking independently 1 year later. These could well be children with limited use of their legs, some of whom may never walk.

In this oldest age group, many of whom entered early intervention because of language and communication delays, a significant number of children showed improvements on communication and cognition milestones. For instance, at entry, only 25% could repeat or imitate a word, but 1 year later, 65% could do so. This is a significant change over time, but there are still about one third of the children in this oldest age group who have not yet attained this language milestone that is reached by almost all children in the general population by 18 months of age. This oldest age group also showed significant gains in the percentage of children who could say two or three words in a sentence and who could give their first name. However, it is also notable that a little more than half of these oldest children still had not attained these two communication milestones. Finally, a significantly higher percentage of these children (78%) were able to engage in simple pretend play 1 year later than they did at entry (57%).

Across all four age groups, children were showing progress in mastering key developmental milestones in all of the domains. In future analyses, NEILS will examine how differences in milestone attainment are related to the child's particular disabilities, other child and family characteristics, and the services received. NEILS is also developing composite indices for the four developmental domains that can be used to describe developmental change over time.

Results for Families

Early intervention is a program designed for both children and families. Family-centered practices are mandated as an integral part of early intervention services and are expected to permeate all aspects of service delivery (Bailey, Buysse, Edmondson, & Smith, 1992). To address the need for an approach that could be applied in evaluating family results across many families and programs, Bailey et al. (1998) proposed a general framework for assessing family results. The framework identifies

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two general types of family results and corresponding questions that reflect current values and the results early intervention could be expected to affect. The two general categories of results are the family's perception of their early intervention experience and of how participation in early intervention services may be affecting their child and family. This framework was used to develop the family outcome measures in NEILS. As with the child outcome data, the NEILS data presented here refer to the family's initial perception of the early intervention experiences and their perceptions 1 year later.

NEILS examined a number of issues related to the families' satisfaction with the services they received in early intervention. These data are shown in Table IV-9. The great majority of families were generally pleased with the quality and quantity of the early intervention services they were receiving, both at entry and 1 year later, with few changes over time. Two of the three ratings that showed changes over time were for the group of families whose children were under 6 months old at entry. More of these families rated the quality of therapy services received as excellent 1 year later than they did at entry. In contrast, however, more of these families rated the help and information they received as being fair or poor after 1 year than at entry. The only other significant change over time in families' ratings of the quality or quantity of services was that more of the families of the younger toddlers (12 through 18 months old at entry) wanted more therapy services 1 year later. Overall, these ratings indicate that the majority of families are pleased with the quantity and quality of the services they are receiving both at entry and 1 year later. For the few differences that did occur, future analyses will be conducted to explore the relationships between these family perceptions about services and the actual services the families are receiving.

NEILS also collected data on the parents' perceptions of their parenting and their ability to work well with professionals (see Table IV-10). Overall, the families begin and remain confident about their ability to care for their child, help the child learn and develop, and understand the child's behavior, as well as how to work well with professionals. Notably, for all four age groups, after 1 year, significantly more families felt confident about their ability to help their child learn and develop. For three of the age groups, 1 year later, more of them felt positive about working with professionals and advocating for their child. Additionally, for families of children who entered between 6 and 12 months, 1 year later, significantly more of them felt that they knew how to go about getting good services if needed.

Table IV-9
Families' Satisfaction With Their Early Intervention Services at Entry
and a Year Later

Age group at entry	0 to 6 Months		6 to 12 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
N =	552		465		338		880	
Rating of amount of therapy services								
More than needed	2	2	2	4	8	5	3	3
About the right amount	79	80	74	72	73	69	77	78
Less than needed	19	19	23	24	19	25	20	18
Quality of therapy services								
Excellent	61	67	61	64	59	54	60	64
Good	33	25	32	27	32	33	35	31
Fair or poor	6	7	6	8	9	12	5	5
Rating of amount of other early intervention services								
More than needed	4	6	2	3	6	3	4	4
About the right amount	90	85	83	83	85	92	82	84
Less than needed	5	9	15	14	8	5	13	12
Quality of other early intervention services								
Excellent	61	63	43	56	54	45	61	59
Good	35	31	48	40	38	46	34	36
Fair or poor	4	6	9	4	8	10	5	5
Rating of number of professionals working with child								
Too many	3	5	4	4	2	2	1	4
About the right amount	94	89	86	90	92	89	92	90
Not enough	3	6	10	6	6	9	7	7
Rating of help and information family had received								
Excellent	56	55	54	52	60	52	58	55
Good	38	36	38	40	32	42	33	34
Fair or poor	6	9	9	8	8	6	8	11

Note: *N*s refer to the number in each age group. The *N*s for the individual items vary slightly because of missing data. The data highlighted in bold reflect statistically significant changes at $p < .05$ level or greater. Numbers may not sum to 100 due to rounding.

Source: National Early Intervention Longitudinal Study.

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Table IV-10
Families' Perceptions of Their Parenting and Their Ability To Work With Professionals at Entry and a Year Later

Age group at entry	0 to 6 Months		6 to 12 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
<i>N</i> =	552		465		338		880	
<u>Parenting skills</u>								
I know how to care for child's basic needs, like feeding, bathing, and dressing.								
Strongly agree	84	86	78	83	78	84	83	83
Agree	15	14	21	15	21	15	16	16
Disagree	1	<1	<1	1	1	<1	<1	<1
Strongly disagree	<1	<1	1	1	<1	<1	0	1
I know how to help child learn and develop.								
Strongly agree	50	63	44	58	47	64	47	60
Agree	40	34	46	37	45	32	43	34
Disagree	9	3	10	4	7	3	8	5
Strongly disagree	1	<1	1	1	1	1	1	2
I often have a difficult time figuring out what to do about child's behavior.								
Strongly agree	12	8	7	7	9	9	12	12
Agree	13	16	20	18	19	23	29	26
Disagree	42	36	38	39	40	37	32	35
Strongly disagree	33	39	35	37	32	32	28	27
<u>Ability to work with professionals</u>								
I know how to work with professionals and advocate for what child needs.								
Strongly agree	59	69	50	64	63	68	56	61
Agree	36	28	44	31	34	29	39	34
Disagree	4	3	5	3	3	2	4	3
Strongly disagree	1	<1	1	1	1	1	1	1
I know what to do if I'm worried that child isn't getting good services.								
Strongly agree	50	52	41	50	47	49	45	48
Agree	38	37	42	40	45	40	45	40
Disagree	9	9	14	8	6	9	7	8
Strongly disagree	2	2	3	2	2	2	3	4

Note: *N*s refer to the number in each age group. The *N*s for the individual items vary slightly because of missing data. The data highlighted in bold reflect statistically significant changes at $p < .05$ level or greater.

Source: National Early Intervention Longitudinal Study.

Parents were also asked about the support they have from their family, relatives, friends, and community (see Table IV-11). This is an important area of results because it is hypothesized that early intervention may serve to help families build and make use of the informal social and community support systems available to them. At both entry and 1 year later, the majority of families felt supported by relatives and friends and involved in activities in their communities. It is noteworthy, however, that about one in five families across all age groups at both time points did not feel they had family and friends who help them deal with challenges related to their child's special needs.

There were only a few changes over time in perceived support. After 1 year, more of the families whose children were 6-12 months and 12-18 months at entry felt supported by relatives and friends. For the two youngest age groups, 1 year later, more of the families felt that they were able to take part in community activities than they did at the time their children entered early intervention. Once again, future analyses will examine how these family perceptions and changes over time are related to the child's disabilities and functioning and the services received.

Finally, NEILS asked about the families' perceptions of the impact of early intervention on their child and their family and on the child and family's quality of life (Table IV-12). Across all four age groups, 1 year later, more families felt that early intervention had had a lot of impact on their child and their family. Some families had been unable to really judge the impact of services on the child at the first interview, which took place shortly after the child was enrolled in early intervention, but for all four age groups, by 1 year later, two thirds or more of them felt that early intervention had had a lot of impact on their child.

Families were asked to rate the quality of their child's current and future life situation and also the current and future quality of their family's life situation (Table IV-12). For all four age groups, the families were generally optimistic about their child and their family, both currently and in the future. Most of the changes over time for these ratings were for the families whose children entered early intervention under 6 months of age. For these families, 1 year later, more of them were more optimistic. Interestingly, families of children in all groups are hopeful in that they are more optimistic about the future than they are about the present, for both their child and for their family.

Table IV-11
**Families' Perceptions of Their Family and Community Support at Entry
and a Year Later**

Age group at entry	0 to 6 Months		6 to 12 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
N=	552		465		338		880	
I have relatives or friends to turn to for help or support when I need it.								
Strongly agree	63	62	51	57	59	62	56	60
Agree	27	29	37	33	31	24	32	28
Disagree	7	6	8	8	6	10	8	8
Strongly disagree	3	4	5	3	5	4	3	4
I have relatives, friends, or others who help me deal with the challenges I face because of child's special needs.								
Strongly agree	47	42	37	37	42	44	41	39
Agree	42	40	40	44	39	38	40	44
Disagree	6	13	18	15	12	14	13	12
Strongly disagree	5	5	5	4	7	5	6	6
I have little chance to take part in community activities, such as religious, school, or social events.								
Strongly agree	22	11	17	14	16	12	11	11
Agree	23	27	29	30	24	24	25	24
Disagree	32	37	39	33	35	37	40	37
Strongly disagree	23	25	15	23	25	26	25	28
Our ability to work and to play together as a family is pretty normal, even though we have a child with special needs.								
Strongly agree	55	58	52	54	58	55	55	56
Agree	38	37	43	40	38	38	41	38
Disagree	7	4	3	5	4	5	3	5
Strongly disagree	1	1	2	2	1	2	1	1

Note: *N*s refer to the number in each age group. The *N*s for the individual items vary slightly because of missing data. The data highlighted in bold reflect statistically significant changes at $p < .05$ level or greater.

Source: National Early Intervention Longitudinal Study.

Table IV-12
Families' Perceptions of the Impact of Early Intervention on the Child
and Family and Their Quality of Life at Entry and a Year Later

Age group at entry	0 to 6 Months		6 to 12 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
N =	552		465		338		880	
How much impact have the services had on the child's development?								
No impact	6	6	2	2	5	3	4	2
Some impact	37	30	38	30	37	28	38	17
A lot of impact	34	64	43	68	39	68	30	79
Too soon to tell	23	<1	18	0	18	<1	28	1
Rating of how help and information has affected family								
Much better off	49	55	50	56	56	53	46	61
Somewhat better off	26	21	24	22	19	24	26	22
About the same	19	23	20	21	15	20	16	15
Worse off	1	<1	1	1	3	3	1	1
Too soon to tell	5	<1	5	<1	7	0	11	1
Family ratings on child's <u>current</u> overall life situation								
Excellent	33	44	34	39	35	36	32	39
Very good	33	26	27	27	27	32	33	32
Good	25	22	30	26	28	26	27	22
Fair	8	7	8	7	8	6	7	6
Poor	1	1	2	1	2	1	1	1
Family ratings on family's <u>current</u> overall life situation								
Excellent	33	39	33	34	35	33	32	38
Very good	29	27	25	28	31	34	31	30
Good	25	26	29	26	23	26	28	23
Fair	11	7	9	10	10	6	8	8
Poor	2	<1	4	1	2	1	1	1
Family's ratings on child's <u>future</u> overall life situation								
Excellent	50	54	47	49	53	48	54	55
Very good	32	27	29	28	26	33	32	28
Good	14	15	19	20	15	15	11	13
Fair	3	3	3	2	3	1	3	4
Poor	1	1	2	1	2	2	<1	<1

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Table IV-12 (continued)

Age group at entry	0 to 6 Months		6 to 12 Months		12 to 18 Months		18 to 26 Months	
	At entry	Year later	At entry	Year later	At entry	Year later	At entry	Year later
Family's ratings on family's <u>future</u> overall life situation								
Excellent	46	55	46	46	50	44	53	52
Very good	33	27	32	32	30	34	29	30
Good	18	16	17	18	18	20	16	16
Fair	3	2	3	3	2	<1	2	3
Poor	1	0	1	<1	<1	<1	0	<1

Note: *N*s refer to the number in each age group. The *N*s for the individual items vary slightly because of missing data. The data highlighted in bold reflect statistically significant changes at $p < .05$ level or greater.

Source: National Early Intervention Longitudinal Study.

Conclusion

These findings from NEILS document numerous positive results for both children and their families. One year after entry in early intervention, many children have mastered additional developmental milestones and have shown improvements in their behavior. Families report their child's communication and motor skills have improved, and over two thirds of families report that early intervention has had a lot of impact on the child's development. Most families are satisfied with numerous facets of their early intervention experience when they begin services, including the quantity and quality of services received, and they continued to be satisfied 1 year later. Families are confident about parenting issues and remain confident a year later. More families, however, do report knowing how to help their child learn and develop and how to work with professionals and advocate for their child's needs a year after beginning early intervention. Shortly after they began services, about half the families felt they were much better off because of the help and information provided through early intervention. A year later even more families felt this way.

What emerges from these data is a picture of child progress and family satisfaction 12 months after beginning early intervention. These findings describe the experiences of those children who were 26 months or younger at the first IFSP meeting and could have received approximately a year of early intervention services. Even this relatively simple picture is not straightforward since some trends only apply to some age groups—which is not surprising given age is a powerful developmental predictor and that age in this population is strongly related to the identification of the nature of the child's disability. Understanding who achieves what

results under what circumstances continues to be one of the primary purposes of the study. Understanding the results of early intervention will continue to get more challenging with time as children age and no longer receive early intervention services. Some of these children will stop receiving services before 36 months of age and others at 36 months. For the children reported on here, those less than 26 months of age at IFSP, one in five were no longer receiving services a year later. Additional NEILS analyses will continue to examine the complex relationship between age of child, age of entry to services, nature of the child's delay or disability, nature of services received, age at exit from services, family characteristics and the results achieved. Forthcoming analyses will look at results when the children are 36 months of age and when they reach kindergarten.

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