

IV. RESULTS

High School Graduation Among Students With Disabilities

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

State Improvement and Monitoring

High School Graduation Among Students With Disabilities

The percentage of students with disabilities exiting school with a regular high school diploma and the percentage who drop out are performance indicators that the Office of Special Education Programs (OSEP) uses to measure progress in improving results for students with disabilities. This module reports graduation and dropout rates for students with disabilities age 14 and older during the 1999-2000 school year and examines changes in these rates since 1995-96. The module also discusses graduation and dropout rates by disability category and by race/ethnicity.

Graduation and Dropout Rates for Students With Disabilities

According to the National Center for Education Statistics (NCES), there are many different ways to calculate graduation and dropout rates (NCES, 2000). The appropriate method largely depends on the data available and the questions to be addressed. For the purpose of establishing performance indicators under the Government Performance and Results Act (GPRA), OSEP calculates the graduation rate by dividing the number of students age 14 and older who graduated with a standard diploma by the total number of students in the same age group who are known to have left school (i.e., graduated with a standard diploma, received a certificate of completion, reached the maximum age for services, died, or dropped out). The dropout rate is calculated in the same manner but with the number of dropouts in the numerator.

Most states use several types of diplomas or certificates to document that a student has completed high school. Although a standard diploma is considered the most desirable outcome for all students, including those with disabilities, the definition of a standard diploma and the criteria for earning it vary by state. In general, there are four categories of diploma options. The first is a standard diploma or better with a single set of criteria for all students. Under this option, a standard diploma or a more rigorous alternative, such as an honors diploma, is available to all students. All students must meet the same criteria in order to receive a diploma, including adequate performance on any tests required for graduation (Thurlow & Thompson, 1999).

The second option also involves a standard diploma or better, but includes multiple criteria for earning it. This alternative allows some students to earn the diploma by meeting different criteria, such as completing their IEP goals. A third option is a

certificate of attendance, completion, or achievement, which is available to all students. Certificate requirements can vary considerably from state to state, and students with IEPs may or may not be allowed to meet the criteria in different ways. The fourth alternative is a special education diploma or certificate that is available only to students with IEPs. This type of diploma is usually added to other diploma options for students without disabilities. All four diploma options vary in rigor and have specific benefits and drawbacks for students with IEPs (Thurlow & Thompson, 1999).

In 1999-2000, the standard diploma graduation rate for students with disabilities age 14 and older was 56.2%. As shown in Figure IV-1, although the graduation rate was down slightly from the previous year, on the whole it has steadily improved since 1995-96.¹ During this period, the graduation rate rose from 52.6% to 56.2%. During the same period, the dropout rate declined from 34.1% to 29.4%. Figure IV-2 shows the change in the dropout rate.

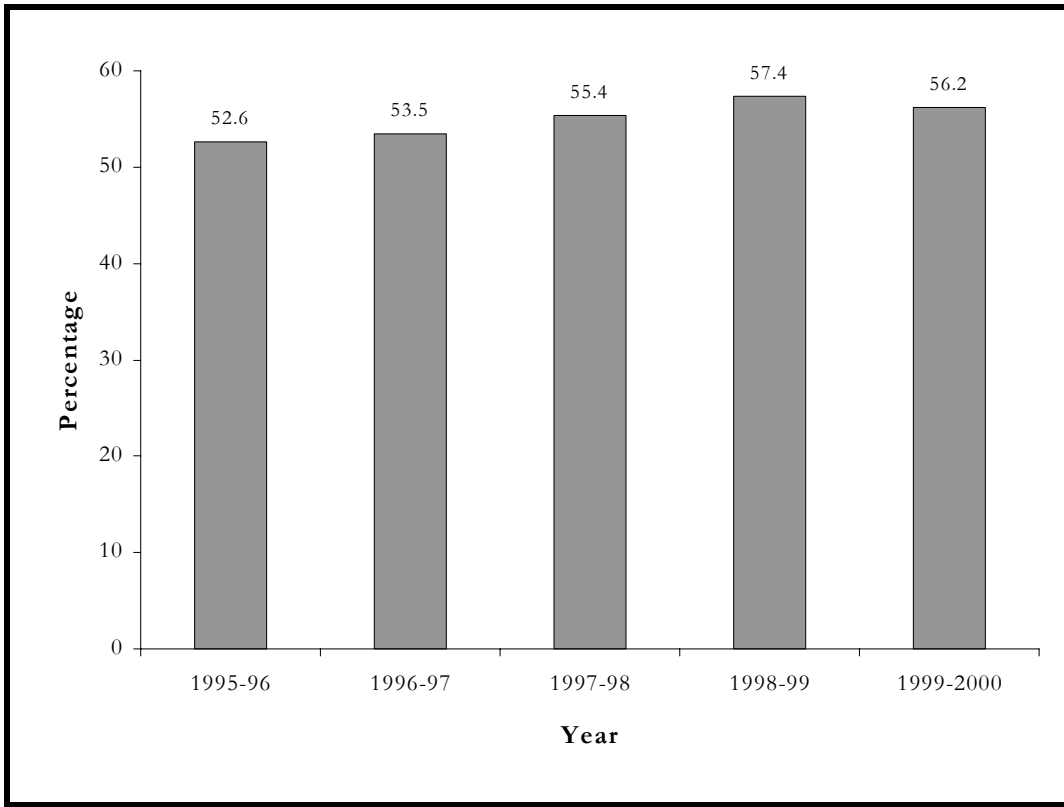
Graduation and Dropout Rates by Disability

In 1999-2000, the graduation rate varied considerably by disability category. Graduation rates ranged from a low of 39.5% for students with mental retardation to a high of 73.4% for students with visual impairments. Seven of the 12 disability categories had graduation rates above 60% (visual impairments, hearing impairments, other health impairments, speech/language impairments, traumatic brain injury, orthopedic impairments, and specific learning disabilities). The remaining disability categories (deaf-blindness, multiple disabilities, autism, emotional disturbance, and mental retardation) had graduation rates below that for all students with disabilities. Table IV-1 presents the graduation rates for each of the 12 disability categories (see Table AD2).

Table IV-1 also shows that the dropout rate varied by disability category. Only one disability category, emotional disturbance, had a dropout rate (51.4%) above the rate for all students with disabilities. The rate for all students is largely dependent on the number of students with learning disabilities, since they account for more than half of the total number of students served under IDEA. Four disability categories had dropout rates below 15%: deaf-blindness, autism, visual impairments, and hearing impairments (see Table AD2).

¹ The decline in the graduation rate for 1999-2000 is the result of a slightly inflated graduation rate for 1998-99. During that year, a number of states appear to have underreported the number of dropouts and certificates received. This in turn reduced the size of the denominator and increased the graduation rate.

Figure IV-1
Percentage of Students Age 14 and Older Graduating With a Standard Diploma, 1995-96 to 1999-2000

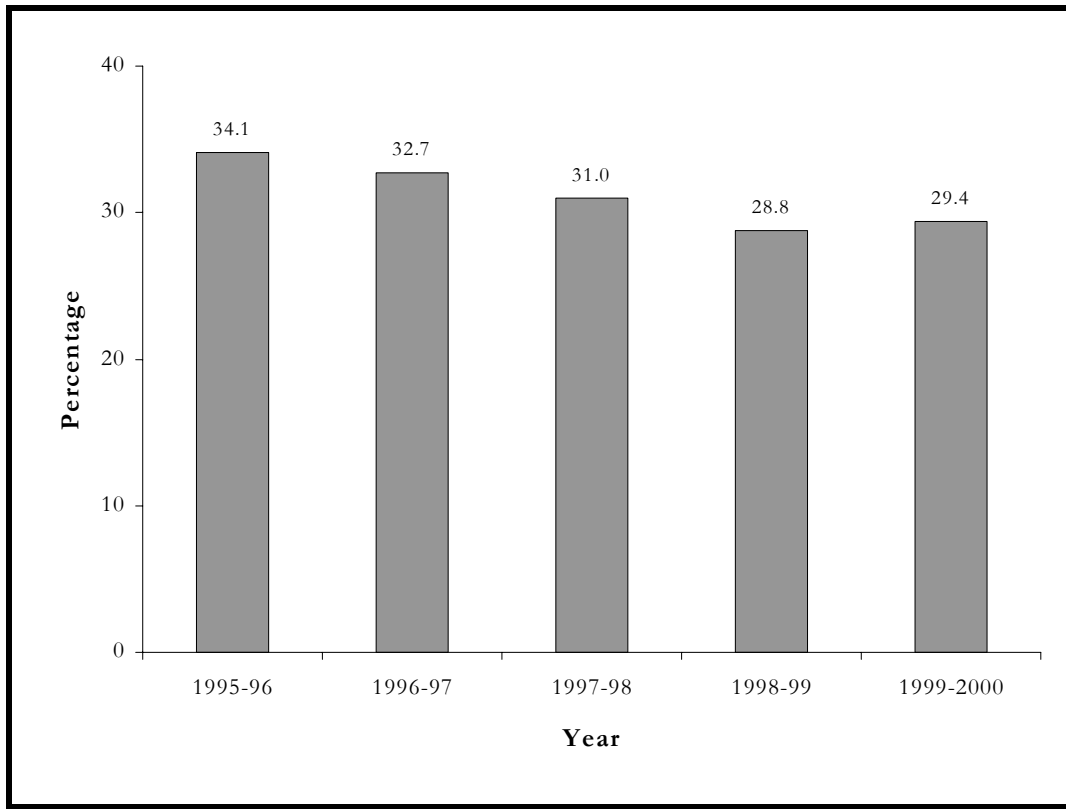


Note: Graduation rates were calculated by dividing the number of students 14 and older who graduated with a standard diploma by the number of students 14 and older who graduated with a standard diploma, received a certificate, reached the maximum age for services, died, or dropped out.

Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

During the period 1995-96 to 1999-2000, the rate of change in the graduation rate was different across disability categories. As shown in Table IV-2, some categories experienced noticeable improvement in the graduation rate, but for other categories the rate remained stable. The rate of improvement in the graduation rate was highest for students with multiple disabilities, speech or language impairments, emotional disturbance, autism, and deaf-blindness. With the exception of speech or language impairments, these are all disability categories mentioned above as having graduation rates below the average for all disability categories combined. Students with hearing impairments, orthopedic impairments, mental retardation, visual impairments, or

Figure IV-2
Percentage of Students Age 14 and Older Dropping Out,
1995-96 to 1999-2000



Note: Dropout rates were calculated by dividing the number of students 14 and older who dropped out by the number of students 14 and older who graduated with a diploma, received a certificate, reached the maximum age for services, died, or dropped out.

Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

traumatic brain injury experienced almost no change in the graduation rate. With the exception of mental retardation, these are all disability categories described above as having graduation rates above the rate for disabled students as a whole.

With two exceptions, since 1995-96 all disability categories experienced an improvement in dropout rate. One notable exception is deaf-blindness which, as shown in Table IV-2, had a dramatic increase in the dropout rate between 1995-96 and 1999-2000. Deaf-blindness is one of the smallest disability categories, and the dropout rate for this category varies widely from one year to the next. In 1995-96 and 1997-98, the dropout rate for students with deaf-blindness was notably lower

Table IV-1
Number and Percentage of Students Age 14 and Older With Disabilities
Graduating With a Standard Diploma or Dropping Out, 1999-2000

Disability category	Graduated with a standard diploma		Dropped out	
	Number	Percentage	Number	Percentage
Specific learning disabilities	109,012	62.1	48,490	27.6
Speech or language impairments	4,802	66.1	1,787	24.6
Mental retardation	16,425	39.5	10,812	26.0
Emotional disturbance	14,842	40.1	19,032	51.4
Multiple disabilities	2,676	48.0	896	16.1
Hearing impairments	2,862	68.4	620	14.8
Orthopedic impairments	2,055	62.5	506	15.4
Other health impairments	7,325	67.7	2,423	22.4
Visual impairments	1,157	73.4	187	11.9
Autism	578	47.3	135	11.1
Deaf-blindness	47	48.5	10	10.3
Traumatic brain injury	799	65.3	221	18.1
All disabilities	162,580	56.2	85,119	29.4

Notes: The percentages in this table were calculated by dividing the number of students age 14 and older who graduated with a standard diploma by the number of students age 14 and older who are known to have left special education (i.e., graduated with a standard diploma, received a certificate of completion, reached the maximum age for services, died, or dropped out).

Washington State data based on previous year's data.

Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

than in other years. The reason for this difference is unclear. The disability categories that experienced the most improvement in the dropout rate were speech or language impairments, specific learning disabilities, orthopedic impairments, hearing impairments, and emotional disturbance.

Table IV-2
Change in the Percentage of Students Age 14 and Older With Disabilities
Graduating With a Standard Diploma or Dropping Out, 1995-96 and
1999-2000

Disability category	Graduated with a standard diploma			Dropped out		
	1995-96	1999-2000	Percent change	1995-96	1999-2000	Percent change
Specific learning disabilities	58.6	62.1	6.0	32.4	27.6	-14.8
Speech or language impairments	58.2	66.1	13.6	31.5	24.6	-21.9
Mental retardation	39.7	39.5	-0.5	27.7	26.0	-6.1
Emotional disturbance	35.7	40.1	12.3	57.1	51.4	-10.0
Multiple disabilities	40.6	48.0	18.2	16.4	16.1	-1.8
Hearing impairments	68.2	68.4	0.3	16.7	14.8	-11.4
Orthopedic impairments	62.2	62.5	0.5	17.5	15.4	-12.0
Other health impairments	64.0	67.7	5.8	23.8	22.4	-5.9
Visual impairments	72.6	73.4	1.1	13.2	11.9	-9.8
Autism	42.2	47.3	12.1	11.8	11.1	-5.9
Deaf-blindness	43.6	48.5	11.2	3.8	10.3	171.1
Traumatic brain injury	64.0	65.3	2.0	17.9	18.1	1.1
All disabilities	52.6	56.2	6.8	34.1	29.4	-13.8

Notes: The percentages in this table were calculated by dividing the number of students age 14 and older who graduated with a standard diploma by the number of students age 14 and older who are known to have left special education (i.e., graduated with a standard diploma, received a certificate of completion, reached the maximum age for services, died, or dropped out).

Percent change was calculated by dividing the difference between the 1999-2000 percentage and the 1995-96 percentage by the 1995-96 percentage.

Washington State data based on previous year's data.

Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

Graduation and Dropout Rates by Race/Ethnicity

The race/ethnicity of students exiting school was first collected for the 1998-99 school year. This section uses these data to describe the graduation and dropout rates

Table IV-3
Number and Percentage of Students Age 14 and Older With Disabilities
Graduating With a Standard Diploma or Dropping Out, by Race/Ethnicity
1999-2000

Race/ethnicity	Graduated with a standard diploma		Dropped out	
	Number	Percentage	Number	Percentage
American Indian/Alaska Native	1,823	48.2	1,666	44.0
Asian/Pacific Islander	2,531	56.3	869	19.3
Black	23,652	39.7	22,051	37.0
Hispanic	16,802	51.8	10,745	33.1
White	117,605	62.5	49,768	26.5

Notes: The percentages in this table were calculated by dividing the number of students age 14 and older in each racial/ethnic group who graduated with a standard diploma by the number of students age 14 and older in that racial/ethnic group who are known to have left special education (i.e., graduated with a standard diploma, received a certificate of completion, reached the maximum age for services, died, or dropped out).

Washington State data based on previous year's data.

Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

for students of different racial/ethnic backgrounds. However, because this was only the second year these data were collected, caution should be used when interpreting the results. In the next year or two, a clearer picture of these data should emerge.

As described in Table IV-3, the graduation and dropout rates varied for students in different racial/ethnic groups. The graduation rate was highest, and the dropout rate lowest, for White and Asian/Pacific Islander students. Both groups graduated at a rate that was higher, and dropped out at a rate that was lower, than those for all students with disabilities. The graduation rate for White students was 62.5%; for Asian/Pacific Islander students it was 56.3%. The dropout rate was 19.3% for Asian/Pacific Islander students, and 26.5% for White students. The lowest graduation rate was for Black students (39.7%). The dropout rate was highest for American Indian/Alaska Native students (44.0%) (see Table AD4).

Summary

Between 1995-96 and 1999-2000, the high school graduation rate for students with disabilities increased from 52.6% to 56.2%. The percentage of students dropping out

declined from 34.1% to 29.4% during the same period. These improvements were more notable in some disability categories than in others. The biggest gains in the graduation rate were for students with multiple disabilities, speech/language impairments, emotional disturbance, autism, and deaf-blindness. Most of these are disability categories with the lowest graduation rates. It is unclear why some of the most significant disabilities showed increases in graduation rate; OSEP's longitudinal studies should help explain the change. Similarly, improvement in the dropout rate took place in almost every disability category, most notably among students with speech/language impairments, specific learning disabilities, orthopedic impairments, hearing impairments, and emotional disturbance. Graduation and dropout rates also varied by racial/ethnic group. White students had the highest graduation rate, and Asian/Pacific Islander students had the lowest dropout rate.

References

- National Center for Education Statistics (NCES). (2000). *A recommended approach to providing high school dropout and completion rates at the state level.* (NCES 2000-305). Washington, DC: Author. Retrieved January 11, 2002, from <http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2000305>
- Thurlow, M., & Thompson, S. (1999). *Diploma options and graduation policies for students with disabilities* (Policy Directions No. 10). Minneapolis, MN: University of Minnesota, National Center on Educational Outcomes.

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

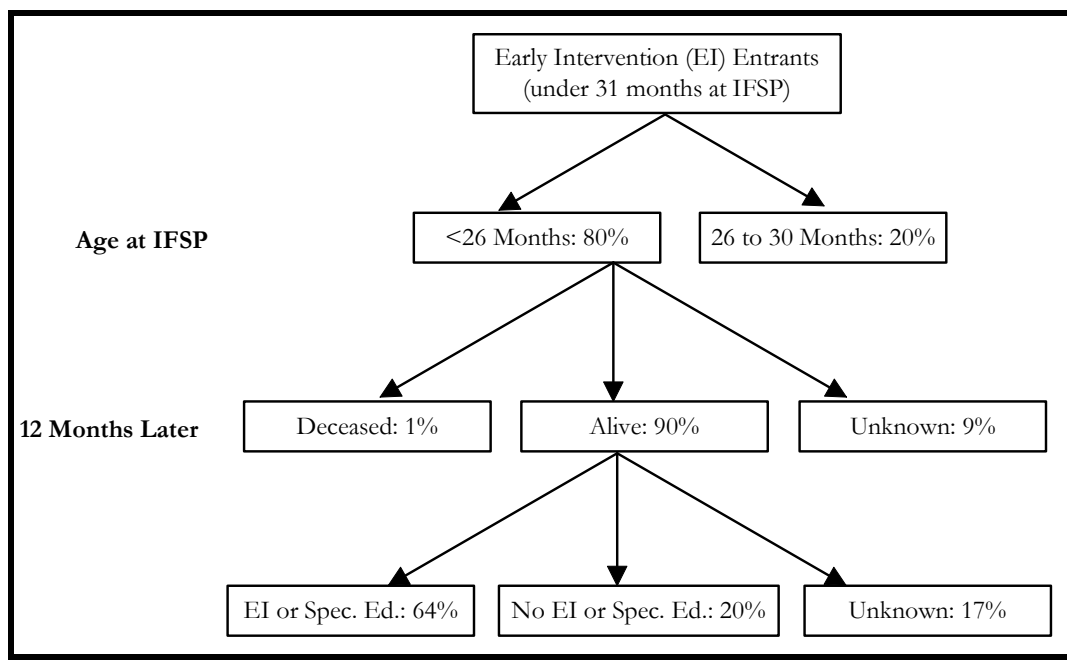
This chapter examines the results for children and families approximately 12 months after they began early intervention services. The information is based on two telephone interviews conducted with a family member of the child enrolled in early intervention.¹ The first interview was conducted within 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.

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.

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

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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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, NEELS 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

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

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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State Improvement and Monitoring

One primary function of the Office of Special Education Programs (OSEP), Monitoring and State Improvement Planning (MSIP) Division is to assess the impact and effectiveness of state and local implementation of Parts B and C of the Individuals with Disabilities Education Act (IDEA) in ensuring positive results for infants, toddlers, children, and youth with disabilities and their families. OSEP, a component of the Office of Special Education and Rehabilitative Services (OSERS), provides grants to state educational agencies (SEA) and lead agencies (LA) according to congressional appropriations to assist in implementation of programs and services; in addition, OSEP provides the states and territories technical assistance, policy support, and monitoring oversight. To accomplish these activities, OSEP works in partnership with states, parents, local service providers, technical assistance providers, institutes of higher education, advocacy groups, professional organizations, and others to provide state and local early intervention providers and educational agencies with scientifically based accurate information and effective tools designed to assist them in improving results.

After the passage of IDEA '97 that placed greater emphasis on improving results for children, OSEP began to redesign its monitoring process. The Continuous Improvement Monitoring Process (CIMP) incorporated strategies designed to foster greater state accountability, increase parental involvement, establish a data-driven process to inform improvement planning, and ensure public awareness and dissemination. The CIMP activities focus around groupings of required activities under the IDEA called "cluster areas." The cluster areas for Part B are: Free Appropriate Public Education in the Least Restrictive Environment, Parental Involvement, Secondary Transition, and General Supervision. For Part C, the cluster areas are Child Find and Public Awareness, Early Intervention Services in the Natural Environment, Family Centered Services, Early Childhood Transition, and General Supervision. The cluster areas contain objectives, components, indicators, and potential state and local data sources for measuring progress in the implementation of IDEA in each of the aforementioned cluster areas.

OSEP initiated the CIMP with the 12 states scheduled for on-site monitoring visits in 1998-1999. Table IV-13 below provides a schedule of states' involvement in the CIMP. In 1998-2000, the CIMP consisted of seven phases: self-assessment, validation planning, validation data collection, improvement planning, implementation of improvement strategies, verification and consequences, and review and revision of the self-assessment. States established steering committees, representing both Part B and Part C constituents that participated in the development of a self-assessment submitted to OSEP. The self-assessment

presented the status of the state’s implementation and results for both programs. During 1998-1999 and 1999-2000, OSEP traveled to 21 states to conduct focused public input meetings prior to conducting an on-site data collection visit. In a report describing the on-site data collection visit, OSEP identified areas of noncompliance, suggestions for improved results, and promising practices in the state. OSEP and the state steering committee assisted the SEA and LA in each state in developing an Improvement Plan that addressed both identified noncompliance issues and other areas in need of improvement. States that failed to correct noncompliance identified by OSEP in the on-site data collection visit were subject to enforcement actions such as OSEP-directed corrective actions, special conditions on grant awards, or compliance agreements.

Table IV-13
Schedule of States’
Continuous Improvement Monitoring Process

1998-1999 Self-Assessment, On-site Data Collection, Improvement Plan	1999-2000 Self-Assessment, On- site Data Collection, Improvement Plan	2000-2001 Self-Assessment, *On- Site Data Collection, Improvement Plan	2001-2002 Self-Assessment, Improvement Plan
Arizona Bureau of Indian Affairs (Part B Only) Massachusetts Montana Nebraska New Mexico New York North Dakota South Dakota Utah Washington Wisconsin	Arkansas Colorado Florida Hawaii Louisiana Maryland New Jersey Ohio Pennsylvania	Connecticut *District of Columbia Delaware Georgia Idaho *Illinois *Iowa Michigan Minnesota New Hampshire *Puerto Rico (Part C Only) *South Carolina *Texas Virginia Wyoming	Alabama California Indiana Kentucky Nevada North Carolina Oklahoma Oregon Rhode Island Tennessee

Source: U.S. Department of Education, Office of Special Education Programs, Division of Monitoring and State Improvement Planning.

During the summers of 2000 (in Salt Lake City and Chicago) and 2001 (in Seattle and Atlanta), OSEP and the OSEP-funded Regional Resource Centers (RRCs) and the National Early Childhood Technical Assistance System (NECTAS), conducted institutes to provide states with information about the self-assessment and improvement planning processes. Generally, a team from each state attended the

institutes. State teams included representatives from the SEAs and LAs, parents, state Steering Committee, and others.

In 2000, OSEP modified several aspects of the CIMP. The modifications were based on what OSEP had learned from 2 years of implementing CIMP and from informal input from state directors and coordinators. These modifications also reflected a response to the report issued by the National Council on Disability (NCD) entitled “Back to School on Civil Rights,” which documents that no state is currently in compliance with the IDEA, and OSEP monitoring needed to change to address this national noncompliance.

Accountability. During 1998-2000, information about a state’s implementation practices was collected primarily through OSEP public input and on-site data collection visits. OSEP then reported strengths and weaknesses to the state. Mandated areas for the state to address in a corrective action plan were addressed by OSEP in the monitoring reports. After 2000, the states, through their self-assessment and comprehensive planning activities in active collaboration with OSEP, have assumed shared accountability for the identification of issues needing improvement, including areas of noncompliance identified through a comprehensive review of evidence conducted by stakeholders.

Public Involvement. In 1998-2000, public input during OSEP’s monitoring and oversight activities primarily involved OSEP-directed public meetings. Since 2000, OSEP, states, state Steering Committees and OSEP-funded technical assistance providers (RRCs and NECTAS) are working in partnership to share information and solicit public input into the monitoring process. The expanded involvement of other constituents has led to greater public awareness of the states’ implementation issues and to enhanced partnerships between OSEP, states, technical assistance providers, and other key stakeholders.

Focus. Prior to 1997, IDEA focused on process and procedural requirements in its monitoring efforts. The 1997 amendments of IDEA placed emphasis on accountability and results for children. OSEP, during 1998-2000, looked at a combination of process and procedural requirements when conducting an on-site data collection visit. After 2000, OSEP focused on the elements of a state’s implementation of IDEA with the strongest relationship to positive results for children such as participation in state- and district-wide assessments and access to the general curriculum. OSEP’s procedures now emphasize results by looking at documented performance data in those areas.

Scope. Prior to 1998, OSEP selected states for a comprehensive visit on a cyclical basis. During 1998-2000, states were selected for an on-site data collection visit based on indicators suggesting that a state may have systemic problems implementing the IDEA. The indicators included last data monitored, previous noncompliance, number of infants and toddlers served in Part C, graduation rates for children with disabilities, and dropout rates. The specific issues for examination during an on-site monitoring visit were determined through an analysis of information obtained from the states' self-assessment and the validation planning (public input) sessions. In 2000, OSEP moved to an approach based on information obtained through state-reported data and through self-assessment, including public input, and results of improvement planning. Careful consideration is given to an analysis of several factors, including previous history of compliance within the state, successful efforts of the state in correcting noncompliance, and likelihood of suggested improvement strategies being implemented which lead to positive results for children. Of the 15 states that submitted a self-assessment in 2000, OSEP made on-site data collection visits to six (see Table IV-13). OSEP visited other states to assist Steering Committees and SEA/LA staff develop improvement plans using the CIMP monitoring model.

Improvement. Prior to 1998, OSEP required states to develop and implement corrective action plans (CAPs) to address noncompliance issues and to report to MSIP the results of the implementation efforts. The activities included in CAPs were often procedural in nature and may not have demonstrated direct impact leading to improved results for children. Beginning in 1998, states were required to develop improvements plans that, at a minimum, address areas of noncompliance and measure the effect of improvement strategies on improved results for children. In addition, the CIMP is fostering state ownership of areas needing improvement identified at the state level by stakeholders and a shared partnership between SEAs, LAs, local educational agencies (LEAs), and stakeholders, leading to accountability for improving results for children and their families

Technical assistance and support. Prior to 1998, staff of MSIP, RRCs, and NECTAS individually responded to states' requests for assistance. Since 1998, the staffs of OSEP, RRCs and NECTAS are working in a coordinated framework to provide ongoing support and guidance to the state in their involvement in CIMP as well as responding to specific state requests for technical assistance. The process is moving toward OSEP, RRCs, and NECTAS coordinating with other Federal, state, and regional technical assistance networks to provide comprehensive support to states in diagnosing system deficiencies, implementing improvement strategies, and

evaluating the effects of those efforts in demonstrating improved results for children in the Parts C and B programs under the IDEA.

Consequences. As previously discussed, prior to 1998, states developed CAPs with activities designed to correct areas of noncompliance identified by OSEP during an on-site monitoring visit. Since 1998, all states are developing improvement plans to address issues identified in their self-assessments. Some states are involved in OSEP data collection visits designed to identify areas of noncompliance. OSEP is visiting other states for improvement planning purposes, including assisting the states in filling data gaps, identifying system barriers, verifying conflicting data, or determining the need for an enforcement action. Some states visited by OSEP have compliance agreements or special conditions under their IDEA grant award. The CIMP is moving toward a system of positive and negative consequences, ensuring that all states have an improvement plan focused on accountability to demonstrate improved results for infants, toddlers, children and youth with disabilities and their families.

State Part B and Part C staff, parents, members of steering committees, and OSEP staff presented “lessons learned” at the 2001 summer institute. Collectively, the panels were successful in providing insights to states on how to effectively implement CIMP. Comments of the panelists included:

“Our state learned lessons about holes in our data. We had a lot of data but not all of it was valid. We are now doing a better job with data collection, and mining it more thoroughly than before.”

“Collaboration between Parts C and B have been strengthened considerably through these efforts.”

“We used public data to validate and triangulate quantitative data. That strengthened the conclusions we could draw.”

“The process helps to focus on what priorities are important and how it is connected to other efforts.”

“Unanticipated result has been accountability to [state advisory] council on quality of improvement plan.”

“It’s very good to have parents participating in all activities as key stakeholders.”

“Opportunity to get parents involved in self-assessment and planning the effort. Will lead to significant systems change. Involvement from OSEP has been very powerful. OSEP has been a real collaborative partner in the process.”

“This is the state’s work; it’s part of what states do, not something added on.”

OSEP is assisting states in completing a self-assessment, designing and implementing effective improvement planning, and obtaining data to support program accountability, OSEP’s future technical assistance efforts with states will be concentrated on three primary activities:

- **Assistance in analyzing barriers to achieving results.** OSEP and states have successfully gathered data to demonstrate the results achieved through IDEA implementation in the state. For example, states gather data to indicate the number of students with disabilities who drop out of school. If the number of dropouts exceeds the state’s goal, the state develops and implements activities to ensure that students with disabilities remain in school until receipt of a regular diploma. The challenge for a state is in identifying the factors that cause students to drop out. Activities leading to decreasing the dropout rate would differ if the reason for a high dropout rate is that the students have been placed in regular classrooms without supports and services necessary to ensure student success; if the school climate does not encourage students with more significant disabilities to participate in school activities; or the state law permits a student to drop out at an early age prior to receiving the standard diploma. The analysis of the barriers to achieving the desired result is a critical factor in designing effective strategies to ensure successful implementation of the IDEA. OSEP, the RRCs, and NECTAS are currently working with states to develop procedures to assist in identifying barriers to achieving successful IDEA implementation. While states and their steering committees have flexibility in designing improvement strategies, OSEP is reviewing improvement plans to ensure that states are addressing, as appropriate, a range of implementation barriers, including state and local administration factors, personnel issues, and procedural errors. By understanding and documenting barriers, states can then identify evidence-based strategies designed to remove these barriers, thereby improving accountability for results.

- **Assistance in designing, implementing, and evaluating improvement planning.** OSEP provides states assistance and guidance in developing, implementing, and evaluating improvement plans. After an analysis of barriers to achieving positive results and development of an improvement plan reasonably designed to address the identified issue, the state must conduct an evaluation of the effects of the strategies implemented. Benchmarks contained in the state's improvement plan enable the state to ensure that the improvement strategies selected and implemented achieve the desired results. OSEP is working closely with states and their steering committees to ensure that appropriate methods of data gathering are used to provide information about the success of their improvement plans. States must gather data on the impact and effect of the activity, not just data on the effort. For example, if training is used as an improvement strategy, the state should not rely solely on data such as attendance to indicate success. The state must design and implement strategies to gather "impact" data such as changes in practices that resulted from training activities. The impact data indicate if the identified benchmarks are met. If states are unable to reach an established "benchmark," they must work with OSEP to revise the improvement plan, constantly monitoring progress designed to ensure improved accountability for results.
- **OSEP technical assistance and funded technical assistance providers.** OSEP is increasing its capacity to help states identify issues that need improvement, barriers to achieving positive results for children and their families, and strategies to evaluate the effects of implemented improvement strategies. OSEP's internal planning process gives strong consideration to monitoring findings as well as issues identified by states' self-assessments in determining funding priorities for subsequent fiscal years. OSEP's Research to Practice (RTP) and MSIP Divisions are forging stronger links so that state contacts in MSIP use information from project officers in RTP to disseminate best practice and current research information to states. MSIP and RTP recently established crosscutting workgroups in specialized areas (early childhood, secondary transition, personnel) to ensure a coordinated approach to providing states information on evidence-based practices and technical assistance. OSEP has completed a pilot of a model for providing comprehensive technical assistance to states using MSIP and RTP staff combined with OSEP-funded technical assistance, research, and outreach projects.

Through analyses of monitoring reports¹ from OSEP's on-site monitoring visits during 1998-99 and 1999-00 and information from OSEP's ongoing work with SEA and LA staff and document reviews, OSEP has identified some major systemic challenges for Part B and Part C programs which must be successfully addressed to ensure accountability for improved results throughout the United States.

Services to Infants and Toddlers Under Part C

The CIMP process has documented the fact that significant challenges remain for state LAs in administering Part C programs. Many states have not implemented an effective interagency system of care for young children with disabilities and their families. States have established a program of early intervention services administered by an LA. However, in many states, OSEP has observed two or more state programs designed to serve infants and toddlers, usually administered by different state agencies, operating side-by-side with little or no coordination. Only children served by the lead agency are reported to OSEP as receiving services. This practice may contribute to a depressed national count of children receiving services under Part C. Another potential outcome of this documented fragmentation in the service delivery system for infants and toddlers with disabilities is that all children may not be receiving services to meet all their identified needs if either program does not offer the full array of needed services. A lack of coordination among programs in a state may also lead to other systemic issues, including ineffective utilization of fiscal resources, families not receiving the procedural safeguards to which they are entitled under Part C, duplicative service provision and processes, and confusion for providers. States are beginning to address these concerns through establishment of more inclusive steering committees, greater public input into identification of issues that need to be addressed in creating effective infant and toddler service systems, and strategies for improvement. States are developing improvement strategies to coordinate services to children and their families. The creation of shared, interagency data systems is allowing state programs to collaborate in making programmatic decisions based on knowledge of all state resources and to avoid duplicative activities. This enhanced collaboration will result in increased accountability for results and maximization of resource utilization in Part C programs.

One challenge for states is to develop and implement effective state general supervision and administration practices, specifically in the monitoring and oversight of programs providing early intervention services to eligible children and families. An analysis of the results of the OSEP on-site monitoring in 20 states from the 1998-1999 and 1999-2000 monitoring cycles indicates challenges that remain in this area. Eleven (55%) of the states had monitoring procedures that were ineffective in

¹ Monitoring reports are available online at <http://www.ed.gov/offices/OSERS/OSEP> or by writing to the OSEP Director at the Department of Education.

identifying noncompliance issues or did not address all the Part C requirements. Two (10%) of the states had monitoring procedures that identified noncompliance, but the states has not been effective in ensuring correction of the identified issues. Four (20%) of the states had procedures that did not include the monitoring of all programs used by the state to provide early intervention services. The programs not being monitored were usually programs administered by a state agency other than the LA. This lack of monitoring data is a barrier to states in conducting a comprehensive self-assessment and developing improvement plans that will assist in improving results for young children and their families. OSEP is currently working with these states to develop effective monitoring procedures, explore strategies for interagency monitoring, utilize the results of monitoring to inform state staff and steering committees about implementation issues, and develop improvement strategies to ensure the correction of issues identified by state or Federal monitoring activities, leading to increased accountability for results.

Child Find efforts continue to be a challenge in some states. Seven (35%) of the states were found in noncompliance for the lack of effective statewide systems to ensuring Child Find efforts were coordinated among state agencies. Nine (45%) of these states did not have effective Child Find or public awareness programs. Five (25%) were not disseminating Child Find materials to primary referral sources. These states were not ensuring that physicians and other critical primary referral sources refer children to the state's early intervention program in a timely manner. OSEP continues to hear from parents that their child's physician told them to "wait and see" after the parents expressed concerns about their child's development. OSEP is working with states to examine the population of children served through the Part C program to determine if the population of children served reflects the demographics of their state and to ensure that all segments of the population are gaining access to services. The 1998-2000 states that were cited for noncompliance in Child Find have made significant progress in identifying eligible children. The 1998-1999 states were serving an average of 1.13% of the general population at the time of OSEP's visit. In December 2000, the 1998-1999 states were serving an average of 1.57%. The 1999-2000 states have made similar gains. At the time of OSEP's visit, the 1999-2000 states were serving 2.18% of the general population of infants and toddlers in the state. In December 2000, an average of 2.59% was being served in the 1999-2000 states. OSEP's work with states is leading to the implementation of coordinated, interagency Child Find and public awareness activities resulting in an increased number of children receiving services.

Service coordination remains a significant challenge for states in implementing their Part C program. A majority (55%) of the states visited during 1998-2000 were not implementing the Federal service coordination requirements. In many of these states, the failure to complete service coordination functions was attributed to high caseloads. Families reported to OSEP that they must coordinate their own services.

The documented failure to provide effective service coordination may affect the state's compliance in other areas. For example, one required service coordination activity is facilitating and participating in the development, review, and evaluation of individualized family service plans (IFSPs). In the monitored states, 11 (55%) were found in noncompliance with requirements related to the development of IFSPs, including the failure to identify and provide services designed to meet the unique needs of the child and family. Another service coordination activity is the coordination of evaluations and assessments. Thirty percent (30%) of these states had not ensured the timely completion of evaluations and assessments in the required areas. OSEP is working with states to gather data to determine if service coordinators are fulfilling their responsibilities and if not, determine the barriers. Once this evidence-based process is completed, OSEP will help provide technical assistance to states targeted to remove these barriers and improve accountability for results.

States continue to concentrate on establishing procedures to ensure a “seamless” transition from Part C to Part B or other appropriate services. The early childhood transition requirements are not being fully implemented in some states, with transition during the spring or summer months being especially difficult. Sixty percent of the states monitored between 1998-2000 were not including transition steps in the IFSPs or convening transition conferences at least 90 days before the child's third birthday. OSEP is working with states to develop procedures to ensure that effective transition occurs, including the development of shared data systems to track children as they move successfully through transition activities required by Part C.

The identification and provision of services and supports to enhance families' capacity to meet the developmental needs of their children is a challenge in some states. Over one-third (35%) of the 1998-2000 states had failed to identify family needs and services on the IFSPs. In addition, families in many states told OSEP they did not have an opportunity to participate in planning and evaluation activities in their states. OSEP is working with states to implement family-directed assessments that will identify supports and services needed to enhance family capacity. OSEP is encouraging states to ensure that parents and other family members, including families from culturally and linguistically diverse populations, become full partners in policymaking, planning, and training activities at the state and local levels.

Services to Children and Youth Under Part B

As indicated by the results of the on-site monitoring visits to 21 states during 1998-2000, SEAs continue to identify challenges in the area of general supervision and administration of programs. More than one-fifth (24%) were identified as not implementing the Part B complaint resolution requirements within required timelines. Fifty-seven percent were not implementing an effective monitoring system that identifies all systemic noncompliance by local school districts. Fifty-four percent of states monitored had not ensured the correction of noncompliance identified through their complaint and monitoring systems. OSEP is assisting these states to develop/modify monitoring procedures and to implement complaint procedures that meet Federal requirements to ensure compliance designed to enhance accountability for results.

Challenges for states in ensuring FAPE include issues related to provision of counseling, psychological services, speech language therapy, occupational and physical therapy and other related services to students who need those services to benefit from special education. A majority (57%) of the 1998-00 states had not ensured the provision of one or more related services, with counseling services/psychological counseling being the most common service not being provided. In 43% of the states, shortages of teachers and related services providers contribute to a failure to provide needed special education services, including the provision of extended school year services. Twenty percent of the states were not providing adequate supports for enabling students with disabilities to access the general curriculum and learn in regular education classrooms; 20% of the states were not including students with disabilities in state and district assessments.

Forty-seven percent of the states were not addressing the secondary transition requirements on students' individual education programs (IEPs). Representatives of other agencies likely to be responsible for providing or paying for transition services were not invited to IEP meetings in 34% of the states. Students were not invited to IEP meetings when postschool transition was discussed in 24% of the states monitored. OSEP is assisting SEAs in designing secondary transition processes to address Federal requirements, tracking the impact of successful implementation of secondary transition procedures, and establishing collaborative relationships with other agencies that are involved with postsecondary programs for young adults with disabilities.

Even though only 3 of the 21 (14%) states monitored in 1998-2000 were in noncompliance with the requirements related to parents attending IEP meetings or participating in placement decisions, maintaining active involvement of parents in their children's educational programs continues to be a priority in many states. SEA

staff report to OSEP that the participation of parents from underrepresented segments of the population is especially problematic. States are currently developing strategies designed to increase parental involvement in developing educational programs for children and in advisory and policymaking groups at state and local levels. Many are entering into partnerships with Parent Training and Information Centers (PTIs) and other parent groups to provide training to parents, to foster parent-professional partnerships, and to conduct parent leadership forums. States are utilizing parents as trainers or co-trainers for staff development activities in school districts as part of an effort to improve the quality of professional development activities conducted by schools.

To assist states in meeting these challenges, MSIP continues to work in partnership with SEAs, LAs, steering committees, RTP, external-funded technical assistance providers, and others to enhance efforts currently used in collecting and analyzing data and developing improvement plans that will ensure positive outcomes for children with disabilities and their families. Implementation of the CIMP has increased accountability of states, ensured public involvement and input, focused on processes with the strongest relationship to positive results, created mechanisms for making data-driven decisions, and increased emphasis on accountability for improving results for children with disabilities and their families.