

Synthesis Brief

The National Early Intervention Longitudinal Study (NEILS): Child and Family Outcomes at 36 Months

Prepared by Joy Markowitz

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Background

The National Early Intervention Longitudinal Study (NEILS) is following more than 3,300 children with disabilities or at risk for disabilities and their families from the time Part C early intervention services were initiated through kindergarten. The study will provide information about the characteristics of children and families, the services they receive and the outcomes they experience. NEILS is funded by the U.S. Department of Education, Office of Special Education Programs (OSEP).¹

The NEILS sample is nationally representative and includes children from three to seven counties in each of 20 states. The children and families in the sample began receiving early intervention services between September 1997 and November 1998. The children ranged in age from birth to 30 months when their services began—38 percent were up to 12 months of age, 28 percent were 12-23 months of age and 34 percent were 24 months or older. The children in the study were born in four

different calendar years; the youngest entered kindergarten in the fall of 2003.

Purpose and Overview

This document summarizes some of the NEILS child and family outcomes when the children were 36 months of age.² This synthesis brief was written, produced and disseminated by Project Forum at the National Association of State Directors of Special Education (NASDSE) as part of its Cooperative Agreement with OSEP.

The findings presented in this document are based on data from telephone interviews with families at two points in time—when early intervention services began and when the children were 36 months of age.³ The findings included are:

- functional status when services began and when the child was 3 years of age;

¹ SRI International, Frank Porter Graham Child Development Center, Research Triangle Institute and American Institutes for Research are conducting NEILS. Published reports and presentations can be found at www.sri.com/neils.

² These data were presented by Kathleen Hebbeler and Donna Spiker, NEILS investigators, at the OSEP National Early Childhood Conference in November 2003. Their assistance with the preparation of this document is most appreciated.

³ The exact ages of the children ranged from 36 to 40 months of age.

- health and related factors when services began and when the child was 3 years of age; and
- family perceptions when the child was 3 years of age.

Functional Status

Few children were reported by families to have problems in the areas of vision, hearing or motor skills when the children began early intervention services and the proportion of problems stayed relatively constant through 36 months of age. A far greater number of children receiving early intervention services had problems in communication when services began and continued to have challenges in this area, although many children showed improvement over time. Specific findings related to functional status are summarized below.

Hearing

Eighty-seven percent of families reported that their children had normal hearing both when services began and at 36 months; five percent reported a hearing problem at both time points. Nine percent of families reported a *change* in hearing status over this time period—five percent of the children had a hearing problem diagnosed and four percent no longer had a hearing problem.⁴

⁴ Percentages may not sum to 100 due to rounding.

Vision

Eighty-four percent of families reported that their children had normal vision both when services began and at 36 months; five percent reported a vision problem at both time points. Eleven percent of families reported a *change* in vision status over this time period—eight percent of the children had a vision problem diagnosed and three percent no longer had a vision problem.

Use of Arms and Hands

Sixty-eight percent of families reported that their children used their arms and hands as well as other children both when services began and at 36 months; nine percent reported the same level of difficulty using arms and hands at both time points. Twenty-three percent reported a *change* in their children's use of arms and hands over this time period—13 percent improved their use and 10 percent got worse.

Use of Legs and Feet

Sixty-three percent of families reported that their children used their legs and feet as well as other children both when services began and at 36 months; 10 percent reported the same level of difficulty using legs and feet at both time points. Twenty-seven percent reported a *change* in their children's use of legs and feet over this time period—14 percent improved their use and 13 percent got worse.

Communication – Making Needs Known

For children under 12 months of age when services began:

At 36 months of age, 46 percent of families reported that their children made their needs known as well as other children, 32 reported their children had a little trouble and 22 percent reported a lot of trouble or no communication at all. No data were collected on making needs known for this group of children when their services began because these children were too young.

For children older than 12 months of age when services began:

Twenty-one percent of families reported that their children made their needs known as well as other children both when services began and at 36 months; 33 percent reported their children had the same degree of trouble making needs known at both time points. Forty-six percent reported a *change* in their children's ability to make their needs known—30 percent improved and 16 percent got worse.

Communication – Others' Understanding of Speech

For children under 12 months of age when services began:

At 36 months of age, 25 percent of families reported that their children's speech was very easy for others to understand, 22 percent reported fairly easy to understand, 19 percent somewhat hard, five percent very hard and 29 percent said their child did not use words. No data were collected on others'

understanding of speech for this group of children when their services began because the children were not speaking.

For children older than 12 months of age when services began:

Only two percent of families reported that their children's speech was easy to understand when services began and again at 36 months old, and 30 percent reported others had the same degree of trouble understanding their children's speech at both time points. Sixty-eight percent reported a *change* in others' understanding of their children's speech—59 percent became more understandable and nine percent became less understandable.

Health Status

The family interviews that were conducted when early intervention services began and at 36 months of age included a question about their child's health compared to other children.⁵

When early intervention services began, 84 percent of children were reported to be in excellent, very good or good health; and 16 percent in fair or poor health. These percentages were 98 and 2, respectively, for the general population of children birth to four in 1997.

⁵ This question was taken from the National Health Interview Survey conducted by the National Center for Health Statistics and comparison data are from this data set.

Twenty-three percent of families reported that their children were in excellent health when services began and at 36 months old. Another 21 percent reported less than excellent health both at entry and 36 months. Fifty-six percent reported a *change* in their children's health status over this time period—32 percent improved and 24 percent declined.

Family Perceptions

When children in the NEILS sample were 3 years old, families were asked to reflect back on their entire experience with early intervention services. Overall, families were extremely pleased with early intervention. Families indicated that they had received about the right amount of services and that the services were of high quality. In addition, most families were satisfied with their early intervention professionals, reported that services had made a positive impact on their children and their family and were hopeful about the family's future. Specific findings related to family perceptions are summarized below.

Amount of Services

Seventy-one percent of families reported that their children received about the right amount of therapy services (e.g., speech, occupational or physical therapy) during their time in early intervention, 22 percent reported their child received less than needed, five percent reported more than needed and two percent had enough of some services but not others. In regard to other early intervention services, 81 percent reported about the right amount, 13 percent reported less than needed, five

percent reported more than needed and one percent had enough of some services but not others.

Quality of Services

Ninety-one percent of families reported that the quality of their children's therapy services was excellent or good, seven percent rated it fair or poor and two percent reported mixed quality. Similarly high ratings were given for other early intervention services—91 percent reported the quality as excellent or good, eight percent reported fair or poor and less than one percent reported mixed quality.

Eighty-nine percent of families rated the help and information received through early intervention services as excellent or good, 10 percent fair or poor and less than one percent gave a mixed rating.

Early Intervention Professionals

Ninety-nine percent of families strongly agreed or agreed with the statement "I feel good about the early intervention professionals." Ninety-eight percent of families strongly agreed or agreed that early intervention professionals respected their values and culture. Ninety-two percent of families disagreed or strongly disagreed that early intervention professionals ignored their opinions.

Impact of Services

Seventy-five percent of families reported that overall, early intervention services had a lot of impact on their children's development. Twenty-one percent reported some impact, four percent no impact and only one percent reported it was too soon to tell the impact.

Sixty percent of families reported that their family was much better off as a result of help and information received from early intervention services. Twenty-three reported they were somewhat better off, 16 percent about the same and one percent worse off.

Family Capacity

When their children were 36 months old, 98 percent of families strongly agreed or agreed that they knew how to care for their children's basic needs and 96 percent of families strongly agreed or agreed that they knew how to help their children learn and develop. Families were less comfortable with behavior issues—35 percent strongly agreed or agreed that they often had a difficult time figuring out what to do about their children's behavior.

Ninety-six percent of families strongly agreed or agreed that they knew how to work with professionals and advocate for their children's needs. Eighty-nine percent strongly agreed or agreed that they knew what to do if they were worried about services.

Families also reported on their family and community functioning when their children were 36 months old. Ninety-four percent of families reported they strongly agreed or agreed that in regard to their family working and playing together, they were pretty normal even though they had a child with special needs. Eighty-nine percent strongly agreed or agreed that they had relatives and friends to turn to when they needed help. Eighty-two percent strongly agreed or agreed that they had relatives and friends who helped them with the challenges related to their child with special needs. Only 36 percent of families strongly agreed or agreed that they had little chance to take part in community activities, such as religious school or social events.

The Family's Future

Generally, families feel their future will be better than their current situation. When their child was 36 months old, 95 percent of families strongly agreed or agreed that early intervention professionals helped them feel optimistic and hopeful about their child's future. In terms of the family's overall life situation, 67 percent of families reported it was excellent or very good, 23 percent reported good and 10 percent fair or poor. Looking to the future, 81 percent of families expected the family's overall life situation to be excellent or very good, 16 percent expected it to be good and only three percent expected it to be fair.

Next Steps for NEILS

As the children in the NEILS study reach their kindergarten year, data are being collected from families and teachers. Kindergarten is the final data collection point. Forthcoming reports from NEILS will reflect the kindergarten teacher data and other data that are currently being analyzed. Longitudinal findings and implications for policy and practice will also be included in future NEILS reports and presentations.

More information about NEILS—including study design, data collection, published reports, presentations and related links—is available on the project’s website: www.sri.com/neils.

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NASDSE, 1800 Diagonal Road, Suite 320, Alexandria, VA 22314
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