



# Survey Examines Experiences of Families Entering Early Intervention

## FPG Snapshot

#14 April 2004

A recent FPG study looked at families' initial experiences in determining their child's eligibility for early intervention (EI) services as mandated by Part C (IDEA), interactions with medical professionals, effort required to get services, participation in planning for services, satisfaction with services, and interactions with professionals.

We used a national representative sample of 3,338 parents of young children with or at risk of disability. All the children had recently entered an EI program operated under Part C.

Because the data are based on a nationally representative sample, this is the first such study that can be said to reflect the state of the nation on these variables.

<b>Mean, minimum and maximum ages for events related to identification and enrollment in EI services</b>			
<b>EVENT</b>	<b>MEAN AGE (MONTHS)</b>	<b>MINIMUM AGE (MONTHS)</b>	<b>MAXIMUM AGE (MONTHS)</b>
First concern about health or development	7.4	(5 weeks prior to birth)	30
First diagnosis or identification	8.8	(5 weeks prior to birth)	30
First looked for EI	11.9	0.0	31
First referred for EI	14.0	0.0	31
Age at which IFSP was developed	15.7	.26	31.3

## Findings and implications

Children begin early intervention (EI) services at all ages between birth and 36 months of age. About 25% of children entered Part C services before 7 months of age.

Fewer children enter at the end of the first year of life and then the numbers increase again around 24 months and then decrease slightly up to 31 months, the age span covered by the study, with a slight slowing of the rate of entry during the middle 10 months.

Retrospectively caregivers reported a relatively short period of time between first concerns and first diagnosis. However, the mean time difference between caregiver report of diagnosis and agency report of referral for early intervention was 5 months.

The gap between parent report of first diagnosis and a signed IFSP was 7.5 months, and the gap between initial concerns and a signed IFSP averaged 9 months.

In analyzing these findings, it appears that the problem lies not in the length of time between concerns and diagnosis (which on average was only about 1.5 months), but rather in the length of time from diagnosis to referral for services (which averaged 5.2 months).

Also, the length of time from concern to EI is much longer for children with developmental delays who enter EI at 20 months, a later average age than other children.

Despite these patterns, most families (about three-fourths of those entering EI)

said that finding EI programs and getting services started required little or no effort. Only about 10 percent reported that both finding and securing services required a lot of effort.

Parents of children with developmental delays had more difficulty than parents of children with established conditions or children at risk. This may reflect the fact that children qualifying under the at risk or established conditions criteria of Part C are eligible due to specific conditions or experiences that are relatively well defined and mandated by legislation at the state level.

Children who qualify due to developmental delays must first demonstrate a delay, and pediatricians or other professionals may be reluctant to say that a child is delayed unless the delay is severe.

CONTINUED

Analyses of the referral data indicated that although only a small percentage of any group experienced difficulties, the likelihood of having a negative experience was higher for families who were minority, with limited income or limited education.

Although criteria for study participation included the existence of an IFSP, nearly 1 out of 5 (18%) caregivers was not aware of a written plan for goals and services.

Of those parents who knew of such a plan, most (81%) reported that families and professionals together developed the goals. About 22% of the families beginning EI wanted more involvement in decision-making, but the rest felt their involvement was about right.

Almost all (97%) families felt that the services they received were somewhat or highly individualized. Most families felt that their child was getting the right amount of therapy and other intervention services. About 14%, however, wanted more in the way of speech, occupational or physical therapy. ■

This *Snapshot* is based on the article "First Experiences with Early Intervention; A National Perspective" by Don Bailey & Anita Scarborough of the FPG Child Development Institute at UNC-Chapel Hill, and Kathleen Hebbeler, Donna Spiker & Sangeeta Mallik, all of SRI International. It was published in the April, 2004 *Pediatrics*, Vol. 113, pp. 887-896.

## Conclusions

Collectively these data suggest that the U.S. early intervention system operated under Part C (IDEA) provides a positive and supportive entry into services for the vast majority of families enrolled in EI programs. Families, like EI professionals, report relative ease in accessing participation in EI programs, perceive that services are based on individual child and family needs, and feel that they have a role in making key decisions about child and family goals.

A few aspects of the process warrant closer examination and possible changes. The average time of 5.2 months between diagnosis and referral seems unnecessarily long. Pediatricians should move from developmental surveillance to a more proactive model of developmental screening of infants and young children, followed by more prompt referral to EI.

A small percentage of families experienced difficulties in accessing services, feel the amount of services received is inadequate, and 18% were not aware of a written plan for goals and services.

Also, families of children with developmental delays report more frustration with accessing services and getting the desired amount of services versus families of children with diagnosed conditions or at risk for developmental delays. This suggests the need to examine the challenges faced by families whose children must demonstrate the need for special services due to behavioral or developmental status and develop more supportive systems for earlier identification of children with delays.

Also of particular concern is the finding that minority families and those with limited income and education levels were associated with less positive experiences. This suggests the need to develop models, practices, and professional skills that are more supportive of the entire array of families who need to access the EI service delivery system. ■

## If you want to know more

NEILS web site: <[www.sri.com/neils/](http://www.sri.com/neils/)>

Bailey, D.B., Aytch, L.S., Odom, S.L., Symons F., & Wolery, M. (1999). Early intervention as we know it. *Mental Retardation and Developmental Disabilities Research Reviews*, 5, 11-20

Bailey, D.B., Skinner, D., Hatton, D., & Roberts, J. (2000). Family experience and factors associated with the diagnosis of fragile X syndrome. *Journal of Developmental and Behavioral Pediatrics*, 21, 315-321.

Javitz, H., Spiker, D., & Hebbeler, K. (2002). *Sampling and Weighting Procedures: Enrollment form, family interview, service records*. Menlo Park, CA: SRI International.

Committee on Children with Disabilities. (2001). Developmental surveillance and screen of infants and young children. *Pediatrics*, 108: 192-196.



*Snapshots* are summaries of research articles, books and other publications by researchers at the FPG Child Development Institute at UNC-Chapel Hill. Permission is granted to reprint this article if you acknowledge FPG and the authors of the article on which this Snapshot is based. For more information, call the FPG Publications Office at 919-966-4221 or email <[FPGpublications@unc.edu](mailto:FPGpublications@unc.edu)>.



THE UNIVERSITY  
of NORTH CAROLINA  
at CHAPEL HILL