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ABSTRACT

This speech reports on data collected by the Early Intervention Collaborative Study (EICS), which is a longitudinal study following the development of 190 young children with disabilities (and their families) who entered 29 publicly funded early intervention programs in Massachusetts and New Hampshire in the period from 1985 to 1987. The children's disabilities included Down syndrome, motor impairment, and developmental delays. Evaluation of service trends indicated: average service hours amounted to 8 hours per month; families participated in early intervention programs an average of 2 years; lower income, less well educated, single mothers received less service; the child's developmental level and diagnosis at entry were highly associated with total service hours; mothers experiencing more parenting stress and poorer teaching skills received less service than mothers with more social support; however, families with lower incomes, unmarried mothers, and families reporting more stress received more outside services (i.e., case management and financial assistance) than did other families. Possible reasons for these patterns are suggested and include the medical model training received by most early intervention staff and funding mechanisms which do not recognize less formal family services. Attached tables provide details of the study's findings. (DB)

DIFFERENCES IN FAMILY PARTICIPATION IN EARLY INTERVENTION SERVICES

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The research reported in this paper is part of the Early Intervention Collaborative Study (EICS), University of Massachusetts Medical School, Dr. Jack P. Shonkoff, Principal Investigator. EICS has received support from the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services, the Massachusetts Department of Education, Early Childhood Division, and the Jessie B. Cox Trust, Boston, MA.

Good morning and welcome to Boston

I am going to be discussing early intervention services for children with disabilities today. Such services are designed to 1) assist children to obtain better developmental outcomes; 2) prevent secondary handicapping conditions; and 3) support families. All states have participated in a national incentive program put in place in 1987 through P.L. 99-457 to develop comprehensive systems for providing early intervention services for children with disabilities. States are at different stages of development of services. Massachusetts and New Hampshire, the two states which provided data which I will discuss today, however, had fairly comprehensive, publicly funded programs in place by the mid-1980s.

I am going to describe some data that were collected by the Early Intervention Collaborative Study (EICS) about a group of 190 families in Massachusetts and New Hampshire who entered 29 publicly funded early intervention programs in the period 1985-1987. Of these families, 54 had children with Down syndrome, 77 had children with motor impairment, and 59 had children with developmental delay of unknown etiology (as assessed by EI programs). I will be describing the types of early intervention and other services these families received through their child's third birthday.

The EICS study is a longitudinal study of the development of young children with disabilities and their families. We are now assessing the children as they turn eight years old, and have received funding to follow them through their 10th birthdays. The study is complex and multifaceted. It started as a study of the outcomes of early intervention services. However, as you will see shortly, studying children and families in a natural laboratory, in operating programs, without any experimental control, creates a situation where it is very difficult to associate services received with specific child and family outcomes.

The focus on my presentation today is to describe how families participated in formal early intervention services, and to examine different child and family characteristics associated with different patterns of service receipt. A second important focus is on the constellation of other services received by families. We discovered early on in our study that EI is not the only service received by families, and thus looking at the outcomes of early intervention services was made even more complex.

The primary questions I will focus on today, are:

1) HOW DOES PARTICIPATION IN EARLY INTERVENTION SERVICES VARY BY CHILD AND FAMILY CHARACTERISTICS?

2) HOW DOES USE OF OTHER SERVICES VARY BY CHILD AND FAMILY CHARACTERISTICS?

The data I will report represent information collected on a monthly basis from early intervention programs from the date of entry to the date of discharge from EI for each of 190 children and their families. I will also report what families told us about services outside of EI they were receiving at the time of their child's third birthday, which is when children are discharged from EI in both Massachusetts and New Hampshire.

About 3 years ago, I gave a similar presentation at AAMR in Atlanta, in which I reported on services received during the first year of enrollment in early intervention services, both within formal EI programs, and from other service systems. At that time, there were no demographic differences found in terms of receipt of EI services, and few in terms of outside services. However, at that time I reported that the intensity of EI services was highly correlated with the child's developmental level at entry to EI: families of children with more severe impairments were provided many more service hours than families of children with less severe impairments. On the other hand, families which were experiencing more stress around caring for their child with disabilities (as measured through self-report by parents using instruments selected by our study) were not receiving more services. In contrast, parents who were experiencing more stress did receive many more services outside of EI. I should note that programs were not provided copies of our research evaluations of families, so that they could target high stress families. However, we assumed that programs' own family assessment procedures could have identified such families.

It took us until about a year ago to finally collect and analyze the data on the entire EI experience for our sample, and so I decided to look at the total EI experience to see if the patterns found for the first year of EI held for families across their 1-3 years in EI programs.

Page 1 of the handout describes some of the background characteristics of the sample. You can see that children entered EI at an average of 10.6 months (children with Down syndrome entered at an average of 3 months). Families were spread across the income range, but were primarily middle income, and most were EuroAmerican and well educated (over half the mothers had some college education).

The next table shows the great diversity in intensity of services received. The average service hours was a modest 8 hours per month, however, families ranged from less than 1 hour per month to over 29 hours per month of services received during the course of their EI experience. Most of the hours were delivered through home visits (about 3 hours per month), child groups (a little over 2 hours per month), parent-child groups (about 1 hour per month), and through mothers' attendance at parent groups (about 1 hour per month).

Families participated in EI an average of just over two years, with a range of from 11 to 39 months. Most families left EI when their child reached age 3 because that is the official cut off for receipt of EI in Mass and NH. Some families, however, left EI sooner, either because they decided no longer to participate, or the staff suggested that their child no longer needed service.

The next table shows the relationship between intensity of different EI services and child and family characteristics. You can see that characteristics such as gender, only child status and prematurity status were not associated with service variations, however, the child's developmental level at entry to EI and his or her diagnosis were highly associated with total service hours and receipt of some of the other types of EI services.

At age three, children were regrouped by our study, because our initial groupings no longer seemed appropriate. For example. some children initially exhibiting motor impairments were no longer delayed in motor development, but may or may not have exhibited other impairments, while some children in the developmentally delayed group were no longer scoring below 75 on overall cognitive development. Based on age three assessments, children were thus regrouped. Children with Down syndrome remained in their own group, but the other children were grouped based on the AAMR definition of cognitive impairment, as mentally retarded or not mentally retarded. Children who were by age three not scoring at 75 or below on a cognitive assessment ended up receiving significantly less service hours than children with mental retardation, and in some services, also less than children with Down syndrome.

In terms of family characteristics, contrary to our findings of the first year of EI services, family income, mothers' education, and mothers' marital status were all associated with differential patterns of intensity of services. All the findings suggest that lower income, less well educated, single mothers received less services. The one exception is with mothers' health status. Mothers who indicated their health status at poorer at the end of EI services had received more home visits than other mothers, but not more total services.

These data are disturbing to me because they indicate that the family orientation required by PL 99-457 and subsequent reauthorizations didn't seem to be trickling down to the program level. It appears that child characteristics were highly associated with the type and intensity of EI services received, but that obvious family risk factors were not associated with the receipt of EI services, in fact, they were associated with receipt of <u>less</u> services.

This observation is further corroborated by the next table which shows that those mothers who reported more stress in the family, in their parenting roles, and with their child with a disability, also had not received more services. Further, those who had poorer child teaching skills also had not received more services. Those who had more social support and reported more helpfulness of social support, however, had received more EI services. The one clear outcome we have found for our overall sample, is that EI is associated with increases in the size of mothers' social networks and their reports of helpfulness of such networks.

Turning to services received outside of EI, you can see that over half the sample received at least one service outside of EI, and the proportion of families receiving outside services grew over the time they spent in EI. We do know that some of these families received these outside services because EI staff helped them to obtain them. Others told us they sought more services on their own. For still others, the protective services and welfare systems were heavily involved with the families. The patterns of receipt of outside service, are interesting, however, in that they are frequently related to the risk status of the family. Families with lower incomes and where the mother was unmarried or in poor health received more child support services (i.e. case management) and more medicaid and financial assistance. Mothers with lower education or in poor health received more family support services (counseling etc.) and more medicaid and financial supports. However, families which were lower income and where the mother was unmarried also less often had their child accepted into preschool special education programs (many of these children were also no longer scoring below 76 on developmental tests).

Turning to the last table, you can see that, in contrast to formal EI services, families who reported more stress in the three different ways it was measured,received more family support services and more total outside services.

What do we make of these different service participation patterns?

First, I think we see in these data a pattern similar to those of most service systems, that of more advantaged families being easier to serve and therefore receiving more services. Informally, service providers have told us that lower income and more disorganized families with children with disabilities are less compliant, less able to keep appointments and make center-based services, sometimes are not home when the home visitor shows up, won't answer the door etc. Early intervention services for economically disadvantaged families, thus must learn to accommodate and reach out more effectively. The traditional medical model, where the child's characteristics dictate the services, seems to be hanging on in EI, at least through the early 1990s, when our data were collected.

Second, families are involved with other service systems to a great extent, and seem to depend on services other than EI for family support. Much has been written and talked about in the past few years about developing family-centered EI services, and meeting the challenges of developing Individual Family Service Plans. These data either show that EI has a long way to go to become family as opposed to child-centered, or that EI is doing a wonderful job of seeking out and coordinating other services for families. I suspect that some of both is really the situation.

EI has the potential to provide a lifelong foundation for a range of family needs for families raising children with disabilities. I hope these data give food for thought about how to make sure programs are keeping the family focus as central and giving more consideration as to how to target more disadvantaged families.

Addendum: During the question and answer session, I was asked what was my explanation for these patterns of EI services. I suggest there are two reasons: 1) the medical model training that most EI staff receive in their educational programs (such as PT, OT, speech & language etc.) as opposed to family oriented training; and 2) the funding mechanisms which don't recognize or allow for less formal family services, or won't pay when the family isn't home, but staff have been sent out to do a home visit.

CHARACTERISTICS OF EICS SAMPLE AT ENTRY TO EARLY INTERVENTION SERVICES

CHARACTERISTICS	TOTAL SAMPLE (N=190)
Child's age at entry to EI	M= 10.6 months
Gender (% male)	56.3%
Ethnicity (% EuroAmerican)	89.5%
Only child (%)	35.3%
Living with both parents (%)	87.4%
Income: (%)	
<$10,000	19.4%
$10,000-19,999	19.4%
$20,000-29,999	25.7%
≥$30,000	35.5%
Mothers married (%)	81%
Mother's education:	
12 years or less (%)	47.3%
13-16 years (%)	38.9%
17+ years (%)	13.8%

EARLY INTERVENTION SERVICES RECEIVED
(N=190)*

TYPE OF SERVICE	TOTAL HOURS (SD)	AVERAGE HOURS/MONTH (SD)	PERCENT OF SAMPLE RECEIVING	RANGE OF HOURS PER MONTH
Total services	193.3 (128.9)	8.1 (4.9)	100%	.08-29.6
Home Visits	70.4 (48.3)	2.96 (1.9)	97.9%	0-9.4
Ind. Child	3.8 (9.2)	.17 (.5)	41.1%	0-3.3
Ind. Parent	.38 (3.4)	.01 (.1)	8.4%	0-1.4
Ind. Parent-Child	12.5 (20.7)	.5 (.8)	79.5%	0-5.6
Child Group	55.7 (65.6)	2.34 (2.8)	71.6%	0-13.5
Parent-Child Group	23.1 (39.5)	.96 (1.6)	65.3%	0-9.9
Parent Group-Mothers	25.4 (36.3)	1.1 (1.5)	68.4	0-5.7
Parent Group-Fathers	1.97 (8.4)	.08 (.3)	9.2%	0-2.7

*Note: Sample spent an average of 26.6 months in early intervention; Range of 11-39 months.

ASSOCIATIONS BETWEEN DEMOGRAPHIC CHARACTERISTICS AND RECEIPT OF EARLY INTERVENTION SERVICES
(AVERAGE MONTHLY HOURS)

x=.05; xx=.01; xxx=.001

CHARACTERISTIC	TOTAL EI SERVICES	HOME VISIT HOURS	CHILD GROUP HRS.	MOTHER GROUP HRS.
Prematurity	NS	NS	NS	NS
Gender	NS	NS	NS	NS
Only child	NS	NS	NS	NS
DQ at entry[1]	xxx	xxx	x	xx
Diagnosis at entry[2]	x	NS	NS	NS
Diagnosis at age three[3]	xx	xxx	NS	x
Family income[4]	xx	NS	xx	x
Mothers' education[5]	x	NS	x	NS

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[1] Higher DQ at entry, family receives fewer hours of service

[2] Children were placed into three subgroups based on diagnosis at entry to early intervention. Families of children with developmental delay of uncertain etiology receive more total hours of service than families of children with Down syndrome or motor impairment.

[3] At age three children were grouped into three subgroups: Down syndrome, mentally retarded and non mentally retarded. Children without mental retardation at age three had received fewer total service hours, fewer home visit hours, and fewer hours of mother's group.

[4] Families of children with higher incomes received more total services, more child group services and more hours of parent group attendance by mothers.

[5] The lower the mother's education level, the fewer total service hours and fewer child group hours received.

CHARACTERISTIC	**TOTAL EI SERVICES**	**HOME VISIT HOURS**	**CHILD GROUP HRS.**	**MOTHER GROUP HRS.**
Mothers' marital status[6]	.07	NS	NS	xx
Mothers' health[7]	NS	x	NS	NS

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[6] Unmarried mothers received fewer total service hours and fewer horus of mother's group.

[7] Mother's with poorer health received more hours of home visits.

ASSOCIATIONS BETWEEN EARLY INTERVENTION SERVICES AND MOTHERS' STRESS, SOCIAL SUPPORT AND TEACHING SKILLS

MOTHERS' SCORES AT T3	TOTAL EI SERVICES	HOME VISIT HOURS	CHILD GROUP HRS.	MOTHER GROUP HRS.
Effects on Family	NS	NS	NS	NS
Parenting Stress	NS	NS	NS	NS
Child Stress[1]	NS	NS	NS	xxx
Total social support[2]	x	NS	xx	xxx
Social support helpfulness[3]	x	NS	xx	xx
Parent teaching skills[4]	NS	NS	NS	NS

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[1] Higher child related stress associated with more hours of mothers' attendance at parent groups.

[2] Larger number of social supports associated with higher total service hours, higher child group hours and higher mother attendance at parent groups.

[3] Higher ratings of helpfulness of social support associated with higher total service horus, higher child group hours and more hours of mothers' attendance at parent groups.

[4] Lower parent teaching skills associated with more home visit hours.

TYPES OF SERVICES OUTSIDE OF EI RECEIVED AFTER ONE YEAR OF EARLY INTERVENTION AND AT DISCHARGE FROM EARLY INTERVENTION

TYPE OF SERVICE	% SAMPLE RECEIVED AT 1 YEAR	% SAMPLE RECEIVED AT DISCHARGE
Child therapies[1]	15.8%	18.9%
Child support[2]	19.5%	8.9%
Child care[3]	10.5%	18.3%
Family support[4]	31.6%	36.6%
Medicaid	24.7%	26.1%
Financial assistance[5]	36.3%	32.8%
Received at least one service	52.6% (Range 1-6)	71.7% (Range 1-5)

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[1] Physical therapy, occupational therapy, speech & language

[2] Case management, VNA

[3] Family and group day care

[4] Family counseling, respite care, homemaker, case management for adult, VNA for adult in household

[5] AFDC, WIC, SSI, SSDI, Social security retirement

ASSOCIATIONS BETWEEN DEMOGRAPHIC CHARACTERISTICS AND RECEIPT OF SERVICES OUTSIDE OF EI

CHARACTERISTIC	SPED	CHILD THERAPY	CHILD SUPPORT	FAMILY SUPPORT	MED-ICAID	FINAN	TOT #
Prematurity	NS	NS	NS	NS	NS	NS	NS
Gender[1]	xx	NS	NS	NS	NS	NS	NS
Only child	NS	NS	NS	NS	NS	NS	NS
Diagnosis at entry[2]	xx	NS	x	NS	NS	NS	NS
Diagnosis at age three[3]	xxx	NS	xx	NS	NS	NS	x
Family income[4]	xxx	NS	xx	NS	xxx	xxx	NS
Mothers' education[5]	NS	xx	NS	xx	xxx	xxx	xx

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[1] Males less often placed in special education

[2] 100% of children with Down syndrome placed in special education; less than 100% of children with motor impairment and developmental delay. Families of children with Down syndrome and motor impairment receive more child support services.

[3] Families of children with mental retardation receive more child support services than children with Down syndrome, and more total services.

[4] Lower placement into special education for lower income groups; more child support, medicaid and financial supports for lower income families.

[5] Families with mothers with more education receive more child therapies, and higher numbers of total services, but less financial and medicaid support. Families with mothers with less education received more family support services.

Mothers' marital status[6]	xx	NS	x	NS	xx	xxx	NS
Mothers' health[7]	x	NS	x	xx	xx	xx	x

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[6] Children of unmarried mothers less often were placed into special education, but received more child support services, and more financial and medicaid services.

[7] Children of mothers with poor health less often were placed in special education, yet these families received more child support, more family support, and a greater number of total services.

ASSOCIATION BETWEEN SERVICES OUTSIDE OF EI AND MOTHERS' STRESS, SOCIAL SUPPORT AND TEACHING SKILLS

MOTHERS' SCORES AT T3	SPED	CHILD THERAPY	CHILD SUPPORT	FAMILY SUPPORT	MED-ICAID	FINAN	TOT #
Effects on Family[1]	x	NS	NS	x	NS	NS	x
Parenting stress[2]	NS	NS	NS	x	NS	NS	x
Child stress[3]	NS	NS	NS	xx	NS	NS	x
Total social support[4]	xxx	xx	NS	NS	NS	NS	NS
Social support helpfulness[5]	xx	.06	NS	NS	NS	NS	NS
Parent teaching skills[6]	NS	NS	xx	NS	xxx	xxx	NS

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[1] The more stressful effects on the family reported by mothers, the greater child placement in special education and the family received more family support services and more total services.

[2] The higher the reported parenting stress, the more family support services received and the more total services.

[3] The higher the reported child stress by mothers, the more family support services received and the more total services.

[4] The larger the social support network reported by mothers, the greater the placement of the child in special education, and the more child therapies received by the child.

[5] The higher the helpfulness of social support reported by mothers, the greater the placement of the child in special education, and the more individual therapies received by the child.

[6] The lower the parent teaching skills, the higher the child support services and the higher the medicaid and financial support.