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ABSTRACT

This report presents the findings of a study that investigated the scope and nature of early childhood service delivery systems in three states (Pennsylvania, North Carolina, and Colorado). The study followed 75 children with disabilities for 18 months and surveyed 170 service providers of infants and toddlers and 186 service providers of preschool children. Findings from the study indicate: (1) utilization of infant and toddler and preschool services is high, particularly in comparison to the utilization rates of other federal entitlement programs; (2) percentages of children served indicate that not all eligible children are being served; (3) the average amount of specialized intervention services provided to infants and toddlers is 1.7 hours a week, while preschool children receive an average of 18 hours if they are in segregated settings, and 11 hours if they are in inclusive settings; (4) most systems have failed to put together a sufficient array of services to address the diverse needs of both the child and the family; (5) a significant proportion of the services occur in inclusive settings; and (6) better service outcomes for children and their families occurred in the more comprehensive and coordinated service delivery models. (Contains 59 references and a list of publications.) (CR)

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Early Childhood Research Institute on Service Utilization

Implementing Federal Policy for Young Children with Disabilities: How Are We Doing?

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An Institute for the Study of Education, Health Care, & Social Service Utilization of Infants, Preschool Children, and Their Families

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Acknowledgements

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Implementing Federal Policy for Young Children With Disabilities: How Are We Doing?

Gloria L. Harbin, Thomas T. Kochanek, R. A. McWilliam, James J. Gallagher, Dave Shaw, Lynn Tocci, Stephen L. Buka, Tracey West, John Sideris, and Kristi Clark

Remarkable progress has been made in the development of comprehensive and coordinated services to young children with disabilities (Smith & McKenna, 1994). Thirty years ago early intervention programs were virtually non-existent; today, families in every community nationwide can make use of services that are designed to meet the developmental needs of their child and to support families in enhancing their child's development. A combination of interacting factors has enabled the growth and evolution of services (Harbin, 1993; Meisels & Shonkoff, 1990). Research, technical assistance, advocacy, as well as the political and social context have resulted in the enactment of sweeping federal legislation (Harbin, 1993; Garwood & Sheehan, 1989). This public policy, now entitled Part C of the Individuals with Disabilities Education Act (IDEA) and the Preschool provisions contained in Part B of the same act, are intended to *increase* the number of children receiving services, to *identify* children as early as possible, and to *improve* services for children and families by making them more comprehensive, coordinated, and family-centered. The legislation required numerous changes in service delivery, necessitating modifications in how many professionals perform their jobs (Gallagher, Harbin, Thomas, Clifford, & Wenger, 1988; Gallagher, Trohanis, & Clifford, 1989; Meisels & Shonkoff, 1990).

Implementation of this federal policy required major changes in thirteen areas related to service delivery (Gallagher et al., 1988; Harbin, Gallagher, Clifford, Place, & Eckland, 1993). (See Table 1). First, prior to this legislation, programs were restricted to serving only those children with identifiable disabilities. Part C of IDEA recognized that there were some conditions, such as Down Syndrome, in which infants might develop normally for a time, but eventually would exhibit developmental delays. This legislation instructed providers to begin intervention for children with established conditions upon diagnosis. In addition, the law permits states to serve children at risk of developmental delays. The most recent amendments encourage states to expand opportunities for children under three years of age who would be at-risk of having a substantial developmental delay if early intervention services were not provided. However, services to this population remain at the discretion of the states.

Second, in many states there was a group of children defined as eligible to receive services. Yet, programs historically provided services to only a portion of these children due to limited funds. This created long waiting lists for services. Now all eligible children must be served, including infants and toddlers and their families residing on reservations located in the state.

The third area of change relates to the timing of identification. Prior to this law, most early intervention programs did not conduct aggressive child find activities, relying primarily upon other agencies (e.g., Health Department or

Table 1
Paradigm Shift In Service Delivery As a Result of Enactment of P. L. 99-457

COMPONENTS	WHAT SERVICES WERE LIKE	HOW SERVICES ARE SUPPOSED TO BE
Entitlement	• served only some of the eligible children	• serve all eligible children
Eligibility	• served only disabled children and waited until children evidenced measurable delays	• serve children with diagnosed conditions regardless of whether measurable delays are present • may serve at-risk children in order to prevent developmental delay
Early Identification	• waited until children came to program	• find children as early as possible
Service Array	• confined services to what program offered	• provide an array of services across programs
System	• provided separate, autonomous *programs*	• provide comprehensive, coordinated, interagency *system* of services
Focus	• child-centered	• family-centered
Individualization	• offered a package of services	• offer individualized services
Inclusion	• established segregated, self-contained programs	• establish inclusive programs and use of community resources
Disciplines	• disciplines worked autonomously	• disciplines working together to integrate all services (interdisciplinary, transdisciplinary)
Therapies	• provided separate and sometimes insufficient therapies	• provide sufficient integrated therapies
Procedural Safeguards	• families had no recourse for complaints	• procedural safeguards in place
Transition	• unplanned traumatic transitions	• planned transition from infant and toddler program to preschool program
Funding	• single primary funding source	• coordinate and use all possible funding sources

programs have the responsibility to conduct comprehensive and coordinated child find activities in order to identify children as early as possible.

Previously, when children were enrolled in early intervention services, services were confined to what was offered by the program. Each agency worked autonomously and had a package of services that it offered to eligible children , and services were fragmented as well. However, children with disabilities and their families often require services from more than one discipline and agency. Part C of IDEA requires a comprehensive, coordinated, interagency system of early intervention services. This system is to be composed of an array of services and resources to meet the individual needs of both the child and family (Trivette, Dunst, & Deal, 1997), and further requires that a service coordinator be assigned to ensure coordination.

The law also requires a shift in the recipients of services. Previously, services were provided to the child only. Part C of IDEA establishes the child *and* family as legitimate recipients. Thus, the law requires the development of an Individualized Family Service Plan (IFSP). Previously, assessment focused on the child, took place in unfamiliar settings, and sometimes used assessment devices inappropriately (e.g., using a criterion-referenced test as if it were a norm-referenced test or using a screening device to make a placement decision). Provisions of the law sought to reverse these practices by assessing the family's strengths and needs in addition to the child's, conducting assessments in multiple environments and using multiple sources, and using instruments for the purpose for which they were developed.

Prior to the legislation, some services were provided in the child's home or in specialized centers where only children with disabilities received services. The new legislation required children and families to be assessed and served in settings where children without disabilities are found. The legislation requires justification when services are not provided in a natural environment.

Parts B and C of IDEA also provided procedural safeguards for the child with disabilities and his family. Previously families had no place to turn if they had complaints about the services (e.g., being on a waiting list, lack of therapies). The procedural safeguards section of the law instructs that parents will be informed of their rights. Finally, before the enactment of this legislation, when the child had to transition from one program into a program provided by a different agency, the burden to make this transition was placed upon the family. Neither the sending or receiving agencies had any responsibility; nor was a plan required. This legislation attempts to correct this situation by instructing that the sending agency will inform the receiving agency (usually the public schools) six months in advance of the child's third birthday and requires the development of a transition plan.

WHY WAS THIS STUDY CONDUCTED? (Purpose)

Clearly, enactment of IDEA requires major changes in many areas of service provision. The extent of changes and the number of changes have presented obstacles in early phases of policy development (Harbin, et al., 1993).

Eleven years after the passage of the legislation, parents, service providers, administrators, policy makers, and researchers are eager to gain a better understanding of the full range of its effects for diverse communities, and, more importantly, for young children birth through age five and their families.

HOW WAS THIS STUDY CONDUCTED? (Methods)

The Early Childhood Research Institute on Service Utilization (ECRI:SU) is an interrelated group of longitudinal studies designed to identify and *describe* the status of services and service delivery (across agencies and programs) to young children with special needs. In addition, ECRI:SU has sought to identify, understand and *explain* the factors which influence service delivery. A team of researchers from Rhode Island College and from the University of North Carolina at Chapel Hill designed and conducted studies which utilized an ecological, systems-based, multi-dimensional conceptual framework for examining services used by families. These studies identify and examine the multiplicity of factors that are believed to affect services provided primarily through early intervention and preschool programs and secondarily through a variety of health care and community-based resources for children and families.

Over the course of the last five years, data generated from ECRI:SU studies have led to numerous findings which can inform policy, training, and practice. This paper presents a *synopsis* of the most important of these findings. Readers interested in more detailed descriptions of these findings can consult

the papers and publications referred in the text, as well as those listed in the **Bibliography.** For a more in-depth explanation of the methodologies used to generate these data the reader may refer to the projects final report (Harbin & Kochanek, 1998).

Who Was Studied?

States and Communities. Three diverse states and nine disparate communities with varying sociodemographics, service configurations, and available resources serve as the principal sites for this Institute, and provide the opportunity to examine the scope and nature of service delivery systems in a variety of contexts. The three states selected included a large Northeastern industrial "rustbelt" state (PA), a growing South Atlantic state with a history of textiles and tobacco (NC), and a scenic Western state in the Rockies (CO). Each state's study sites include high, medium, and low population and resource density community, and range in size from a large urban environment with a population of 2,403,676 to a remote rural county with a population of 6,007.

The selected *low* population/resource density communities include: a remote rural, economically adaptive post-mining mountain town; an economically depressed and isolated community with an "Appalachian feel" (Appalachian Center, 1986; Bradshaw, 1992; Peoples Appalachian Research Collective, 1971); and a foothills county with traditional mountain values (e.g., independence, privacy), consisting of historically self-contained townships. The selected *medium* population/resource density communities are also distinct: a

prison-based economically poor town with a history of a boom-bust economy based on mining; a community whose culture is a mix of Mid-Western and Appalachian values, and whose favorite son is a classic movie actor; and a wealthy community with a very high per capita income and a very low average wage. The *high* population/resource density communities include: a large metropolitan city with 88 separate ethnic neighborhoods; a western achievement-oriented city, struggling with issues of achievement and growth; and a "genteel" and economically thriving city with a history of strong corporate involvement in community. Table 2 presents a comparison of the study communities with regard to several socio-demographic variables.

Table 2
Descriptive Portrait of Study Communities

	COLORADO			NORTH CAROLINA			PENNSYLVANIA		
	HI	**MOD**	**LOW**	**HI**	**MOD**	**LOW**	**HI**	**MOD**	**LOW**
Total Population	225,339	32,273	6,007	347,420	59,013	61,704	1,336,446	89,994	78,097
Total Minority (%)	10.5	13.9	25.1	28.6	19.9	5.7	13.1	2.5	0.6
% Child Poverty	9.5	19.8	16.4	14.3	17.7	12.9	17.1	21.0	18.6
Per Capita Income	$17,359.	$9,971.	$11,269.	$18,117.	$16,274.	$13,370.	$15,115.	$10,260.	$10,430.
Children in Single Parent Families (%)	16.4	28.5	23.8	23.0	20.0	15.0	23.9	16.7	16.4
Low Birthweight Rate (%)	6.4	9.3	15.8	8.6	7.7	6.0	8.0	6.0	6.1

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Children. A large purposive sample of 300 children and families were selected across nine communities. In each of these communities, a minimum of 8 case study children (N=75) were selected from the larger sample (N=300). All were followed for an 18 month period of time from January 1994 through June, 1995. All children in the study were purposively selected to represent diversity with regard to age, race, socioeconomic status, type of disability, and level of complexity of service needs. Table 3 presents a description of the infants and toddlers and preschool children participating in the study.

Service Providers. In addition, all service providers (N=170) of the Infants & Toddlers participating in the study, as well as the service providers (N=186) of Preschool children completed service use protocols and scales regarding their beliefs and experiences with service delivery. Out of the 356 service providers participating in the study, a group of 49 were identified to be interviewed as part of the case studies of the 75 children and their families, because families identified them as the primary service provider. In addition, another 67 service providers participated in focus groups relating to issues in service delivery.

Service providers in the 9 programs participating in the ECRI:SU study were for the most part white, college-educated females from the middle class, who represented many different disciplines. The mean age for providers serving Infants & Toddlers (N=170) was approximately 36 years; while service providers (N=186) serving Preschoolers were approximately 38 years of age. Staffing

Table 3
Characteristics of Infants, Toddlers, and Preschool Children and Their Families Participating In The Study From Nine Diverse Communities

Characteristic	Infant & Toddler Sample	Characteristic	Preschool Sample
Age		Age	
Birth - 1	24 (15%)	3 - 4	84 (50%)
1 - 2	64 (41%)	4 - 5	85 (50%)
2 - 3	70 (44%)		
Gender		Gender	
Male	88 (56%)	Male	103 (65%)
Female	68 (44%)	Female	55 (35%)
Eligibility		Eligibility	
Dev. Del.	76 (49%)	Dev. Del.	84 (54%)
Est. Cond.	67 (43%)	IDEA Category	85 (50%)
At Risk	12 (8%)	At Risk	3 (2%)
Need Complexity		Need Complexity	
Low	52 (34%)	Low	51 (38%)
Moderate	66 (43%)	Moderate	44 (32%)
High	37 (24%)	High	41 (30%)
Race		Race	
White	106 (68%)	White	119 (75%)
African Amer.	38 (24%)	African Amer.	32 (20%)
Latino	5 (3%)	Latino	5 (3%)
Other	7 (5%)	Other	2 (1%)
Mothers Age (Mean)	29.5	Mothers Age (Mean)	30.9
Employment Status of Mother		Employment Status of Mother	
FT Employ	33 (25%)	FT Employ	41 (28%)
PT Employ	13 (10%)	PT Employ	18 (12%)
Unemploy, seeking	4 (3%)	Unemploy, seeking	4 (3%)
Unemploy	4 (3%)	Unemploy	4 (3%)
Manage Home	77 (59%)	Manage Home	79 (54%)
Annual Income		Annual Income	
< $10,000	25 (20%)	< $10,000	37 (25%)
$10 - 19,999	49 (39%)	$10 - 19,999	44 (30%)
$20 - 29,999	23 (18%)	$20 - 29,999	20 (13%)
$30 - 39,999	7 (6%)	$30 - 39,999	22 (15%)
> $40,000	23 (18%)	> $40,000	26 (18%)
Single vs. Dual Parent Family		Single vs. Dual Parent Family	
Single	39 (32%)	Single	54 (36%)
Dual	82 (68%)	Dual	95 (64%)

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patterns varied based upon philosophy and focus of the program. Some programs employed a higher proportion of specialists and therapists, while other programs made more use of paraprofessionals. Table 4 presents the characteristics of the service providers for Infant & Toddler and Preschool programs respectively.

How Were Data Collected, Analyzed, And Integrated?

In order to gain a better understanding of the process of service delivery, data from multiple methods were collected, analyzed, and integrated to more accurately understand the complexities of service delivery. ECRI:SU examined the major variables comprising the ecology of early intervention and preschool services (see Figure 1). Multiple quantitative and qualitative methods were used to gain a description and understanding of each variable, as well as understanding its influence on service delivery (see Table 5).

Each study within the Institute collected and analyzed data utilizing appropriate quantitative and qualitative techniques. Findings from individual studies have been reported elsewhere (see list of publications). Then data were integrated across studies in three stages: 1) quantitative data on the 300 children in the larger system; 2) qualitative data at the community level; and 3) qualitative data for the 75 case study children and families. *Quantitative* data reduction and integration utilized a series of statistical analyses designed to identify the most statistically significant variables to enter into multiple regression models. *Qualitative* data reduction and integration was done by a

Table 4
Characteristics of Service Providers in the Study from Infant & Toddler and Preschool Service Systems

Characteristic	Infant & Toddler Programs	Preschool Programs
Mean Age	36.4	37.8
Gender		
Male	4 (2%)	5 (3%)
Female	166 (98%)	181 (97%)
Race		
White	161 (95%)	166 (89%)
African American	5 (3%)	15 (8%)
Latino	3 (2%)	3 (2%)
Other	1 (1%)	2 (1%)
Marital Status		
Single	42 (25%)	32 (17%)
Married	115 (68%)	140 (75%)
Sep./Div.	12 (7%)	14 (8%)
Education		
High School	26 (15%)	29 (16%)
Assoc	11 (7%)	14 (8%)
BA	66 (39%)	71 (38%)
MA	61 (36%)	71 (38%)
Doctoral	6 (4%)	-
Academic Discipline		
Ancillary	28 (17%)	10 (5%)
Educator	50 (31%)	88 (41%)
Motor	30 (18%)	31 (14%)
Paraprofessional	31 (19%)	44 (21%)
Speech/Lang.	24 (15%)	42 (20%)
Children with Disability		
Yes	16 (9%)	17 (9%)
No	154 (91%)	168 (91%)
Family Member with Disability		
Yes	38 (22%)	41 (18%)
No	138 (78%)	187 (82%)
Years in Early Childhood		
<1	28 (17%)	24 (13%)
1-5	61 (36%)	72 (39%)
6-10	30 (18%)	45 (24%)
>10	51 (30%)	45 (24%)
Current Certificate/License		
Yes	95 (71%)	138 (86%)
No	38 (29%)	23 (14%)

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FIGURE 1
ECOLOGY OF SERVICE DELIVERY

Relationship Between Family and Service Provider

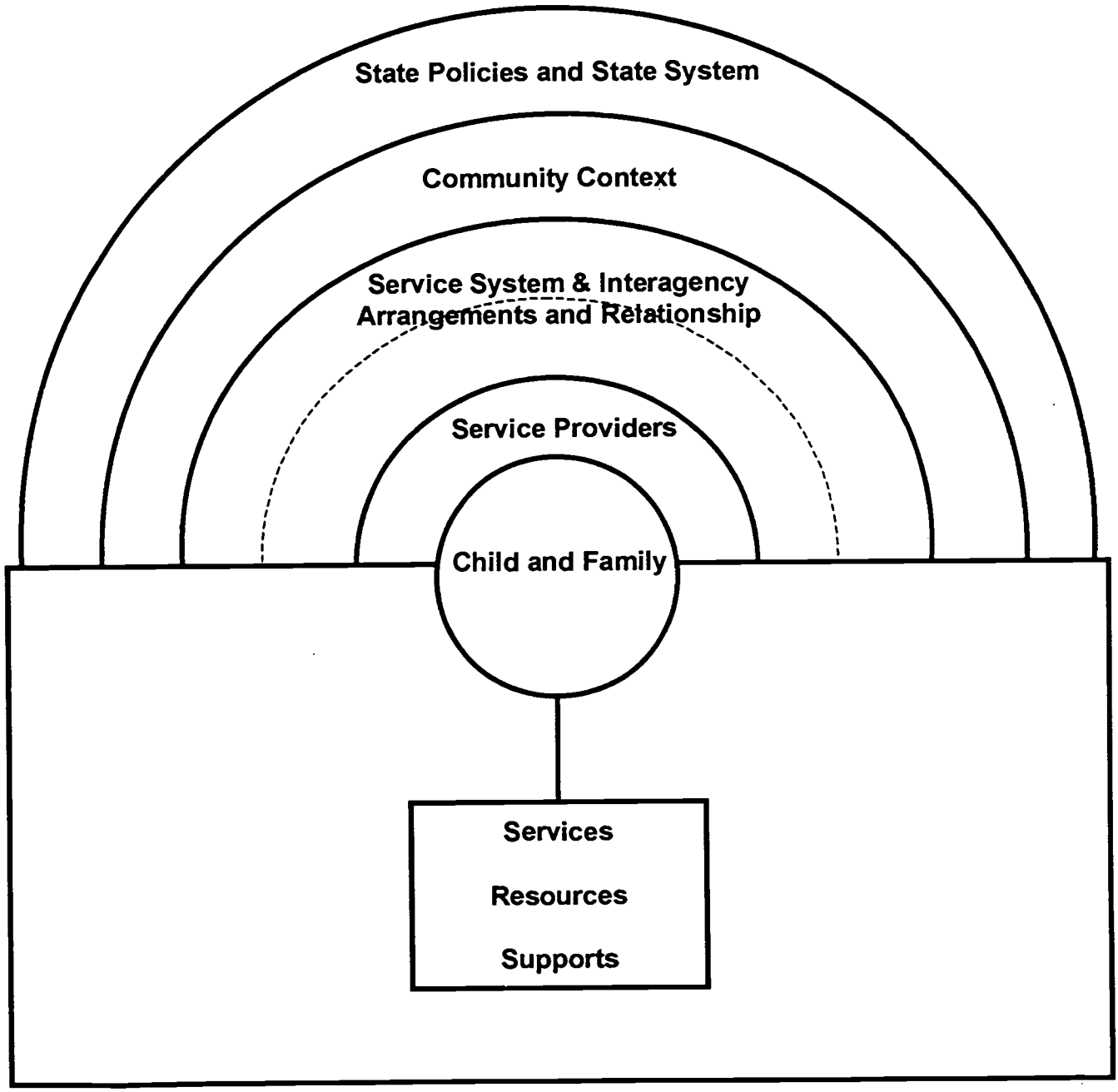

Table 5
Variables Addressed and Methods Used

	Methods								
VARIABLES	Demographic Information Form	Data Bases	Service Use Protocol	Scales and Questionnaires	Focus Groups	Document Analysis	Interviews	Case* Studies	Observation
Service Use		X	X X	Q	X			X	X
Child Characteristics	X	X			X			X	X
Family Characteristics	X	X		S	X			X	X
Service Provider	X	X		S	X			X	X
Child's Program						X		X	X
Transaction Between Child/Family/SP					X			X	X
Service System				X	X	X	X	X	
Interagency Arrangements				S & Q		X	X		
Constellation of Available Programs			X			X	X		
Policy				X	X	X	X		
Finances				X		X	X		
Context		X			X	X	X		

★Case Studies Used Multiple Methods

Interviews of Families
Interviews of Service Providers
Development & Analysis of Family Support Diagram
Analysis of Assessment Data
Analysis of Service Use (Quantitative Data)
Analysis of Scales by Families and Service Providers

team of researchers representing all studies within the Institute. Through discussion, word tables were constructed based on preliminary analyses in which key variables were identified by individual investigators in initial stages of the analysis. These word tables, using reduced data, were used to identify more specific and detailed patterns. A more complete description of the methodology for each study, as well as for the data integration procedures can be found in the project's final report (Harbin & Kochanek, 1998).

FINDINGS

ELEMENTS OF SERVICE DELIVERY

How Many Children Are Served?

The percentage of children served differs by program (i.e., Infant & Toddler or Preschool), state, and community.

Infant & Toddler. Reports to the Department of Education, Office of Special Education Programs, indicated that in 1993 states served 154,065 Infants & Toddlers (U.S. Department of Education, 1995). This is 1.31% of children in the total population, and an increase of 7.4% over the number served in the previous year. Very little is known regarding the incidence and prevalence of risk and disability for children under three years of age (Meisels & Wasik, 1990). However, three different groups of investigators have independently arrived at estimations, using three different methods. Estimates for the prevalence of disabled children between birth and three years of age ranged

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from 1.5% (Benn, 1991) using a review of birth records in one Michigan County, to 2.2% (Center for Disease Control, 1995) using data from the 1991-1992 Survey of Income and Program Participation (SIPP), to 2.5 – 3% (Harbin, 1989) based upon a review of the literature. Similarly, estimations of risk factors ranged from 5 – 7% for three or more risk factors (Harbin, 1989) to 3% using four or more risk factors (Benn, 1991). Estimates of prevalence using single risk factors ranged from 19% (Benn, 1991) to 30% (Harbin, 1989).

The Infant & Toddler programs in the three communities in North Carolina served an average of 1.99% of children in the population, compared to 1.83% in the three communities in Colorado, and .96% in the three communities in Pennsylvania. These state differences imply a possible link between the percentage of children served and the breadth of the state's eligibility policy; North Carolina's policy is the broadest of those in our study and includes children with multiple risk factors in addition to developmental delay, while Pennsylvania's policy is the narrowest of the three states studied. Although the percentage of children served in the study communities is not identical to the mean percentage reported for all communities in the state, the trends are similar. In the Seventeenth Annual Report to Congress (U.S. Department of Education, 1995), statewide percentages also differed for the three states: North Carolina reported 2.35%, Colorado reported 2.07%, and Pennsylvania reported 1.29%, also indicating a possible link to state eligibility policy.

There also are differences in the percentages of children served by communities *within* the same state. Interestingly, the largest population and

resource density communities within each state served the lowest percentages of children, each under 1% (.25%, .31%, and .78%). It appears that the community differences in the percentage of children served might be linked to the strength of the Child Find efforts, as well as the nature of the service delivery model – how comprehensive and coordinated the model is. In general, the broader the service delivery model, the higher the percentage of children served. More information of differences in service delivery models and service outcomes associated with the models is provided later on page 59.

Preschool. There were also differences by state and community with regard to the percentage of children served in Preschool programs for children with disabilities. Once again, the two communities that served the highest percentage of infants and toddlers also served the highest percentage of preschool children with disabilities. Table 6 presents the percentages of children served by program, state, and community.

Who Is Served?

Previously, Table 3 presented various characteristics of children served in the 9 Infant & Toddler programs and a similar description of children and families in the 9 Preschool programs for young children with disabilities. A comparison between the children and families selected for this study and the characteristics of all children served across the nine communities revealed no significant differences. Thus, the data presented in Table 3 closely reflect the

Table 6
Percentage of Children Served In Nine Communities

	Colorado	North Carolina	Pennsylvania
High Population			
Infant/Toddler	.31	.78	.25
Preschool	1.72	4.46	.92
Medium Population			
Infant/Toddler	3.38	2.86	.97
Preschool	13.08	9.82	3.27
Low Population			
Infant/Toddler	1.81	2.34	1.65
Preschool	5.91	5.80	7.44
Mean % in Study Communities			
Infant/Toddler	1.83	1.99	.96
Preschool	6.93	6.69	3.87

characteristics of all of the children served in the 18 programs (9 Infant & Toddler and 9 Preschool) in the 9 communities. It is interesting to note that approximately 60% of the children served come from poverty or working poor families. It was beyond the scope of this study to determine whether children in poverty are over-represented because of the cumulative effects of various poverty factors as many have suggested, or whether children from middle and upper income families are not being served by public programs, choosing instead individual private providers.

Also of interest is the fact that only 25% of the mothers of infants and toddlers and 28% of the mothers of preschool children are employed full time. Even when the numbers of full-time and part-time mothers are combined (35% for infants and toddlers and 40% for preschoolers), the number of working mothers is less than the national average.

How Are Children Found?

The variance in the percentage of children served in the communities in this study suggests the possibility of the differential effectiveness of child find. A cross site analysis of Child Find efforts reveals both similarities and differences across communities. All communities rely upon referrals from other agencies and private physicians. Although some communities were using additional Child Find strategies (e.g., brochures, media, presentations to community and service organizations, public screenings or health fairs, etc.), none of the communities was conducting a *comprehensive, coordinated, and systematic* Child Find

(Harbin & Bourland, 1987; Wolery, 1989). Considerable effort needs to be made in this area.

Primary referral sources to the Infant & Toddler program are health care providers (58%) and parents (13%); child care, Mental Health, and Child Protective Services each only refers approximately 1% of the children served. For Preschool Programs, primary referral sources are Infant & Toddler Programs (46%), parents (16%), Headstart (9%), physicians (9%), and the public schools' Child Find screening efforts (10%).

Some communities reported attempts to use a single portal of entry, but have met with only limited success. Lack of utilization of common forms complicates identifying all programs for which a child and family are eligible. In addition, many parents report troubling initial interactions with physicians in securing diagnoses and information about finding services; many parents report that primary care physicians (family practice and pediatricians) were reluctant to refer children to early intervention or were unable to detect the need for early intervention.

More children, however, are being identified at younger ages; mean referral age for Infants & Toddlers was 10 months, and their average age at program entry was one year of age. The time *between* referral and program entry for children in the three states was: North Carolina, 1.2 months; Pennsylvania, 1.4 months; Colorado 1.7 months. The mean age of program entry for Preschoolers was 3.2 years.

How Are Children Assessed?

Once children are referred to Infant & Toddler or Preschool programs, the law requires a multidisciplinary assessment. In addition to the law, much has been written about best practice in conducting comprehensive assessments (Neisworth, 1993; Meisels & Provence, 1989; Greenspan & Meisels, 1996). Children in our study typically receive assessments from more than one discipline, though many of the assessment practices focus primarily on the skills of the child. Some communities have developed an interagency assessment process in which different programs and agencies contribute staff to provide a particular portion of the assessment, much like models used by screening programs which utilize specific stations designated for each area of development (e.g., motor, language, health history, etc.). However, there is little evidence of transdisciplinary, arena, or play-based assessment, or of systematic observation of children in non-clinical or natural environments. Equally worrisome is the use of some inappropriate assessment procedures, such as relying on a criterion-referenced assessment device, as the primary data to determine eligibility. In addition, few assessments include a systematic evaluation of child health and its effect on development. Nor are there systematic assessments of family needs and resources. One state's assessment policy (Colorado) provides additional specificity with regard to assessment procedures related to the child's development and the state agency staff also have emphasized best practice; consequently assessment practices more closely resemble best practice in two of the three communities in this state.

The amount of person-time spent on assessment for Infants & Toddlers is on average 2.0 hours based upon data collected during a three month summer period, with a range of 0.5 hours to 8.5 hours per child. Preschool teachers reported spending .24 hours (or approximately 15 minutes) per child in non-inclusive (segregated) settings; while they reported spending .14 hours per child for children served in inclusive settings. Our Institute found that all Infant & Toddler programs report difficulty in meeting the 45 day timeline, with the state requiring the most comprehensive assessment process experiencing the most difficulty. It appears two components of the law create a quandry for programs: prompt program entry vs. comprehensive assessment requiring the participation of different agencies from the public sector and different professionals (e.g. MDs and therapists) within the private sector as well.

How Are IFSPs And IEPs Developed?

Utilizing information obtained from the assessment process, IFSP and IEP goals primarily focus on the *educational* needs of the *child*. In their current form, IFSPs and IEPs might not be useful for families. Many families were unable to locate their child's IFSP or IEP and many rarely or never referred to it. Generally, families feel ill-prepared to participate in the IFSP meetings. It usually takes families some time to learn to be a participating member of the IFSP team, but when their child transitions to Preschool programs the rules change and families often again feel lost.

There is, however, some evidence that the IFSP or IEP *process* can be

more productive and useful when families are prepared for it by professionals prior to the process, and that the process itself may be more helpful than the product.

What Is The Amount Of Services Received?

Kochanek and Buka (in press-b) found that the amount of weekly specialized services received by children in Infant & Toddler programs was a mean of approximately 1.7 hours per child (N=133). Forty-five percent of the sample received less than one hour per week of service; 30% received 1-2 hours; and 25% received more than 2 hours per week. Toddlers tended to receive more services than infants, while families in which therapists serve as the primary service provider tend to receive fewer hours of services. In addition, children of mothers with higher levels of education and income, also tended to receive more services. Case studies of children and families indicated that the amount of services provided also appeared to be influenced by the skills and knowledge of individual service providers (i.e., those with broader knowledge of resources provided more services), as well as the characteristics of the service delivery model (i.e., the more comprehensive and coordinated models tended to provide more services).

Preschoolers (N=114) received on average approximately 14 hours of services per week. Means differed by placement, with those children in non-inclusive (segregated) settings (N=50) receiving approximately 18 hours of specialized services per week, and those in inclusive settings (N=64) receiving

approximately 11 hours of specialized services per week.

Although the study identified several variables which appear to influence service delivery (i.e., maternal sociodemographic characteristics, service provider characteristics, and service delivery model), three characteristics of case study families also appear to influence the amount and nature of service provision, as well as families' perceptions of control over service provision: (1) knowledge of the service system and how to navigate within it, (2) resourcefulness, and (3) the ability to advocate persistently for the needs of their child and family. The possession of these family skills was associated positively with service use; whereas the absence of these skills sometimes was associated with fewer services, particularly in those communities with a narrower, more insular service delivery model.

Kochanek and Buka (in press-a) found that approximately 1900 unique service encounters were reported over a four month period. Of these scheduled encounters, 69% of the families elected to use the majority (i.e., $\geq$ 75%) of services to which they were entitled. Only 18% of families used less than one half of scheduled services, and a small number of families (i.e., N=12(8%)) used less than 25% of scheduled encounters. Overall, therefore, these aggregate data suggest that the fidelity between services scheduled and those which actually occurred was quite high. It is critical to note however, that the range of family initiated cancelled services across study environments varied between 7-39%, and therefore, extreme caution must be used in assuming that this high aggregate utilization rate is a valid index of early intervention service use either

within study states or nationally as a whole.

When service utilization rates are examined, child (i.e., age, level of need/complexities, length of program involvement) and maternal characteristics (e.g., age, education, employment, etc.) were not significantly related to whether scheduled services were actually provided and used. However, utilization rates were associated with: a) providers who were younger and similar in age to study mothers; b) types of service provider, with families in which therapists served as the primary provider having the lowest rates; and c) mothers who expressed strong beliefs that service decisions should be made by professionals experienced higher utilization rates. Overall, these data by Kochanek and Buka (in press-a) confirm findings from case study families, which indicate assignment of a service provider to a family is a critical event in the early intervention experience. Furthermore, there were state and community differences in cancellation rates which are associated with differences in reimbursement and service delivery models.

What Types Of Services Are Provided and Used?

Infants & Toddlers. Infants, toddlers, and their families in our study received a variety of developmental intervention services (e.g., cognitive, language, etc.), including home visits, specialized therapies and developmental groups. (The amount of developmental intervention provided was addressed above). In addition to those services provided by the lead agency, families of infants and toddlers used an average of three other types of services per month.

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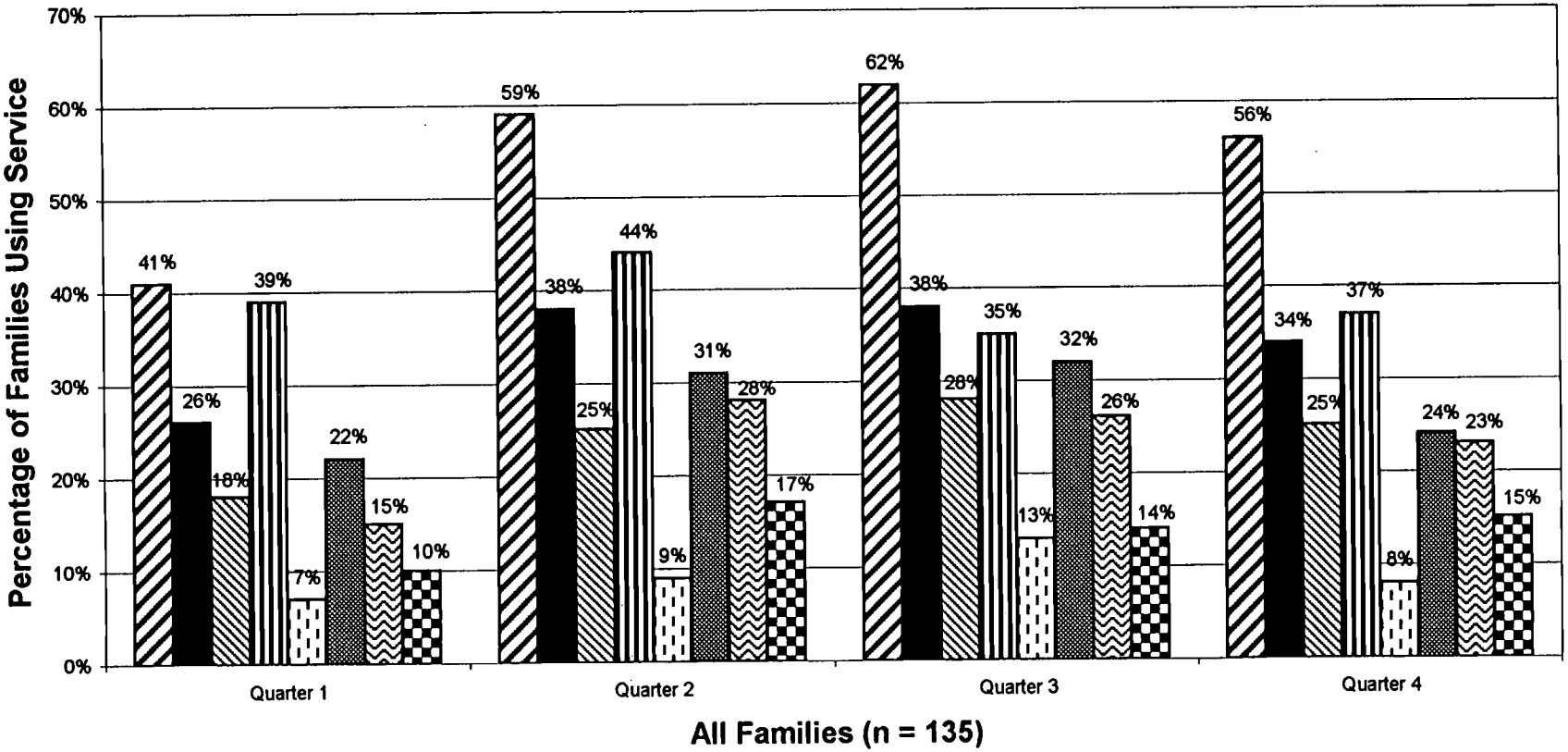
Those most often used are: child care, child therapy, and family need programs such as housing and food. Those least often used include: parent employment/education, family support, and broader community-based resources, such as respite care, substance abuse treatment, or vocational training. Clearly, the preponderance of services provided to, and used by, families focus on the needs of the child. Figure 2 presents the percentage of all infant and toddler families in the study using 8 different types of community resources over a one year period. It is interesting to note that the percentage of families using these resources changes somewhat over time, with the use of some types of resources changing more than others.

Preschool. Most of the Preschool children in the study received specialized services in some type of segregated classroom or inclusive group setting (e.g., Headstart, child care, regular preschool, etc.). Of the services received by Preschoolers, the greatest proportion could be characterized as developmental intervention (e.g., gross motor, cognitive, etc.). In addition, children in non-inclusive settings receive approximately 2.4 hours of individual therapy, while Preschoolers in inclusive settings receive 1.75 hours of therapy. In addition to the services provided by the school system (either directly or through contracting with other providers), families used other services as well. Those most often used are: child care (49% of families), child therapy (39%), and child recreation/socialization activities (26%). Examination of use of

Figure 2
Percentage of Infant & Toddler Families Using Community Resources Over (Four) Four-Month Time Periods

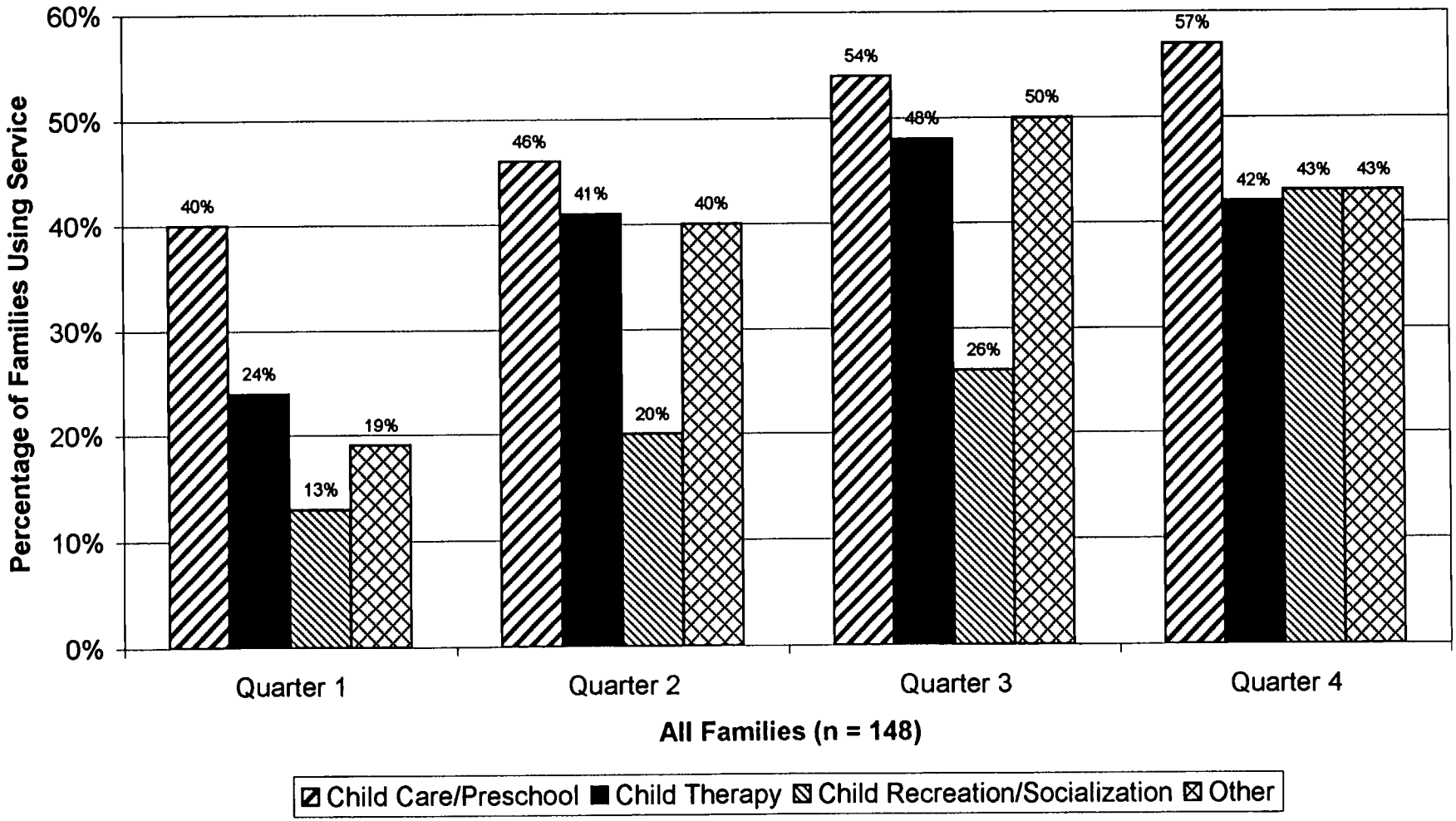


community resources over a 12 month period indicates that the use of resources increased over the course of the year. Figure 3 presents the percentage of all preschool families in the study using 4 different types of resources over a one year period.

Who Is The Focus Of Services?

Families usually enter Infant & Toddler and Preschool programs expecting services to focus on their child's disabilities. They need to be *informed* that services are available to address broader family concerns if they desire. However, data from the case studies indicates that families' early interactions with program administrators and service providers often revolve around their child's needs, including the assessment process, the selection of goals, and the educational placement. Even the services contained in the service system predominantly focus on the needs of the child. This appears to unwittingly "set the stage" for a child-centered approach to service delivery. Service providers in focus groups and case study interviews reported that they often hesitate to "open the door" to more family-oriented services for a variety of reasons, including: inadequate training and discomfort with crossing perceived (or actual) boundaries, fear of offending or alienating families by asking personal questions, lack of knowledge about resources within the community to meet family needs, or belief that there are no available resources to meet family needs. Those service providers who attempt to attend to broader family concerns most often do so by listening and offering some emotional support,

Figure 3
Percentage of Preschool Families Using Community Resources Over (Four) Four-Month Time Periods



rather than by connecting families to additional resources and supports.

Despite the challenges faced by service providers, some do manage to offer more family-focused services. These providers share many of the following characteristics: investment in the child; competence in working with the child; respect for families' values; investment in diverse families; connection with families, based upon something in common; provision of information and emotional support to families; and a positive, responsive, friendly, sensitive style. It appears this type of help-giving approach offers the best framework for family-centered service provision.

If future assessments, individualized plans, and services are to be family-centered in nature, service providers and administrators will have to assume the responsibility for "opening the door" to family-centered approaches, beginning with broad descriptions of the early intervention experience for parents and of the full range of services available to families.

What is the Nature of Family-Service Provider Relationships?

Previous findings by Kochanek and Buka (in press-a, in press-b) indicate that the relationship that is developed between the family and the service provider is an important influence in determining the amount and types of services provided to young children. Case studies of diverse families and their service providers further indicates that in early intervention (Infant & Toddler Program), the nature of the relationship powerfully affects the families' experiences and often forms the context for intervention. This was less the case

for preschool children who receive most of their services in a classroom setting, where parents interact infrequently with service providers (teachers and therapists).

Many families describe their service providers as caring and competent individuals who are supportive and responsive to their child's needs. Many of these same families describe their service provider as "more like a friend than a professional." In a study of 44 low income families (poverty and working poor), a group of Institute researchers (Harbin, Shaw, McWilliam, Westheafer, & Frazier, 1998) identified seven (7) possible service provider approaches, ranging from an approach which empowered and built capacity in children and families, to an approach which is characterized by a service provider who directs or dictates intervention and feels he or she "knows best." Analysis of the 42 service providers working with the 44 families indicated that 25 service providers fell into one of the three more empowering approaches, 12 seemed to fall into the professional (friendly yet distant) approach, and 7 fell into one of the three least empowering approaches. (See Table 7).

In general, early intervention (i.e., Infant & Toddler) service providers tended to have a more empowering approach, than Preschool teachers. However, both Infant & Toddler and Preschool teachers tended to have a more empowering approach than therapists and clinicians. However, there were some professionals who were exceptions to these broad findings.

Using the same set of 44 families mentioned above, researchers

Table 7
Comparison of Service Provider Typologies Across Nine Communities

	Pennsylvania			North Carolina			Colorado		
	Low	Med	High	Low	Med	High	Low	Med	High
Capacity Builder	1			1	1	1	2	2	1
Helper	1		1	2	2	1	1	3	1
Sympathizer		1	1			1	1		
Friendly Professional	1	4	1	1	1	2	1		1
Mechanic		2	1	1					
Savior									
Dictator		2				1			

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identified 7 types of family-service provider *relationships* ranging from an Empowering Alliance to an Authoritarian relationship. Analysis indicated that there were 22 relationships falling into one of the two most empowering types; there were 16 relationships classified as professional alliances; 3 were classified as detached relationships; while 4 were classified as discordant. There were no relationships which were classified as authoritarian. Not surprisingly, in those instances when service providers take responsibility for establishing enabling and empowering relationships with families, service delivery often tends to be a more positive experience for families. These relationships are built upon developing partnerships with mutual trust, emphasizing strengths, fostering independence, and also have emotional depth and significance for both parties. Relationships possessing these characteristics often result in families who not only feel positively about their experiences but more capable of coping with challenges. However, relationships constructed on paternalism and control, are often characterized by resignation, passivity, or dispirited family feelings.

Table 8 indicates some community differences regarding the types of relationships established between families and their service providers. Through case study analysis, it appears that the beliefs and skills not only of the service providers, but also those of the program coordinators, seemed to be associated with the quality of the relationship developed. Program leadership played an important role in setting expectations and shaping behaviors of service providers, which in turn influenced the relationship.

Table 8
Comparison of Relationship Typologies Across Nine Communities

	Pennsylvania			North Carolina			Colorado		
	Low	Med	High	Low	Med	High	Low	Med	High
Empowering	1				1	1	2	1	1
Supportive	1	1	1	4		1	2	4	1
Professional (Friendly, Yet Distant)	1	5	2		3	2	1		1
Detached		1	1			1			
Discordant		2		1		1			
Dependent									
Authoritarian									

Where Are Children Served?

Today, many children are served in inclusive settings, indicating progress in moving away from self-contained, segregated programs. Thirty-four percent (34%) of the infants and toddlers participating in ECRI:SU's studies received some type of developmental intervention in child care or play groups (Kochanek & Buka, in press-b). The number was much higher for preschoolers; approximately 56% of preschool children receive services in inclusive educational settings. However, less progress has been made to integrate the child and family into other community programs and activities used by typically developing children and their families.

There were both state and community differences with respect to the number of children served in inclusive settings. The state which emphasized inclusion for infants and toddlers in state-wide training, as well as in written policy, requiring segregated centers to become inclusive if they are to continue to receive state funds, serves a higher proportion of children in integrated settings. Case studies revealed that community differences in the amount of inclusion appeared to be linked to the philosophy of the local program coordinator.

When Children Receive Special Therapies, How Are They Provided?

Some children with disabilities are born with a variety of impairments which need specialized therapies. Much has been written about the scarcity of therapists, particularly physical and occupational therapists. As a result of this

personnel shortage, coupled with the knowledge of the interrelated nature of the child's development, many professionals began to recommend the transdisciplinary approach to the provision of therapies, or the use of therapists as consultants to those individuals who work more *regularly* with children (Bailey, 1989; Bruder, 1993; Bruder & Bologna, 1993; Garland, McGonigel, Frank, & Buck, 1989; Gilkerson, Hilliard, Schrag, & Shonkoff, 1987; Haynes, 1976; Klein & Campbell, 1990; Linder, 1990; McGonigel & Garland, 1988; McWilliam, 1991; McWilliam, 1996a/1996b; Woodruff, Hanson, McGonigel, & Sterzin, 1990; Woodruff & McGonigel, 1988; Yoder, Coleman, & Gallagher, 1990).

However, data from the case studies indicate that children most often continue to receive specialized therapies using traditional pull-out models, despite the understanding of many administrators that this is not best practice. Many program administrators believe they must continue to do business this way because many programs must contract out for the provision of therapies. Administrators report that many of these contracted therapists suffer from extreme time constraints and lack the knowledge and desire to use a more integrative approach to therapies. It also appears as if many administrators lack the knowledge necessary to set up an administrative structure for a more transdisciplinary and integrated mode of delivery. Finally, many families and service providers often believe that more hours of traditional therapy (e.g. pull-out) is better, despite the findings of current literature regarding how children learn best.

The infant and toddler service use protocols combined developmental intervention and therapy into a single category. Therefore, we are not able to separate those two types of services and report on the amount of therapy for infants and toddlers provided by the lead agency. However, preschool children in non-inclusive settings received 2.37 hours and preschoolers in inclusive settings received 1.75 hours. In general, infants, toddlers, and preschool children residing in low population density communities received fewer therapies than children in high population and resource density communities. Program administrators, service providers, and families in these communities complained about the lack of adequate therapists. In the most rural remote community in our study, parents had to transport their children over treacherous mountain roads to another community some distance away in order to receive physical or occupational therapy.

In every community studied, some children received therapies from other agencies (e.g., Health Department, Hospital, etc.) or from private providers. In some instances, parents were required to pay for these therapies. More therapies were sought and used outside of the developmental intervention program in some communities. Table 9 presents the mean percentage of infant, toddler, and preschool families that sought and used therapies provided by agencies and providers external to the Infant & Toddler and Preschool Programs. Table 9 reveals significant differences among the three study states in the number of infants and toddlers obtaining therapies outside of the lead

agency, while preschool children in one state use more therapies than the other two.

Table 9
Mean Percentage of Families Using Therapies Provided Outside of the Infant-Toddler and Preschool Programs

State	Infant-Toddler	Preschool
Colorado	57%	55%
North Carolina	30%	33%
Pennsylvania	21%	31%

In addition to the traditional therapies (i.e., occupational, physical, and speech/language) received by children in the study, a few children were receiving "alternative" therapies including massage, myofascial release, and macro-biotic diet. A few children were receiving drug therapies for which there is little or no data to substantiate the safety or effectiveness with young children. In one instance, Prozac had been prescribed for a two year old, and in another case a three year old was taking a combination of Ritalin and Prozac. Some service providers and program administrators expressed their concerns about the use of controversial drug therapies. They were concerned not only with the possible harmful side effects these medications might have, even if administered properly, but they were concerned as well about the potential for mistakes in the administration of these powerful drugs. Lastly, they questioned whether the medication was prescribed to benefit the child or the mother.

What Child Curricula Do Programs Use?

Curriculum activities for infant, toddler, and preschool children often

reflect a focus on a diagnostic-prescriptive model, in which criterion-referenced assessment items are used to guide intervention, instead of using a more routines-based focus for intervention (McWilliam & Strain, 1993). The latter approach is deemed by many experts to be more likely to facilitate the natural involvement of the family, child care personnel, and other members of the community, as well as facilitating the child's generalization and use of new skills in their normal contexts (McWilliam & Strain, 1993).

How Effective Is Service Coordination?

Service coordination is required for infants and toddlers and their families. Although there were differences in the amount of satisfaction reported by families in three states, service coordination for individual children nonetheless is generally less than adequate regardless of the approach used. ECRI:SU researchers identified four different approaches commonly utilized. The service coordinator is 1) the child and family's primary service provider; 2) someone other than the primary service provider who works within the same agency as the primary service provider; 3) a service provider from another agency; and 4) someone from an agency which provides no direct services, but is responsible for service coordination only. The experiences of families suggests that the third and fourth approaches are the *least successful*, since in both of these approaches the service coordinator saw families very infrequently and was too removed to develop an effective relationship with the family.

In general, families of preschool children reported higher levels of

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dissatisfaction with service coordination than did families of infants and toddlers. Parents of preschool children indicated this dissatisfaction in surveys, focus groups, and individual interviews. However, families residing in communities where the service delivery models were more comprehensive and coordinated reported a higher degree of satisfaction with service coordination than those families in communities where the service system was more fragmented.

In some of the Preschool programs, the program Coordinator attempts to play the role of service coordinator for many of the families in the program. This has become a daunting task. In interviews, many Preschool Program Coordinators indicated the need for additional human and fiscal resources to carry out the important task of service coordination.

What Are Families' Experiences With Transition?

Despite the intentions of state policymakers to develop seamless systems in the three states studied by ECRI:SU, parents often indicate extreme unhappiness with the current process. When their child turns three, parents often are confronted with a new set of programs, placements, and rules, necessitating new information, as well as unwilling severing the therapeutic relationship with their service provider. Often, parents become frustrated and angry as a result, viewing transition as "senseless." Clearly, the transition process can proceed smoothly from a bureaucratic point of view, but still can be traumatic from a personal point of view.

Some Preschool Program administrators worked to overcome the many

barriers within the transition process and attempted to initiate positive relationships with parents by: 1) holding informational meetings for families; 2) providing a list of possible service and placement options; 3) accompanying parents when they visit potential placements for their child; and 4) meeting with families to try to craft a plan for services that is tailored to meet the needs of their child and responds to their wishes. These Preschool Coordinators had made the shift in their thinking and behavior to viewing families as consumers, whom they want to satisfy, instead of having the more traditional view that parents should be grateful for what the school has to offer. In the more traditional view, school personnel believe that parents should accept what is offered because the school has the parents' best interest at heart.

MODELS FOR SERVICE DELIVERY

How Comprehensive Are The Service Systems?

The ecological model of development suggests the importance of addressing multiple areas that affect child development, family functioning and well-being (Bronfenbrenner, 1979; Garbarino, 1990). These broad areas include: child education, child care, child protection, medical and dental care, food and clothing, housing, adult education and information, cultural/social/religious development, transportation, economic security, legal services and recreation (McKnight, 1987; Trivette, Dunst, & Deal, 1997). These broad categories of resources taken together would constitute a comprehensive array of resources to meet child and family needs.

Infants & Toddlers. Most communities have expended efforts to put together an array of services to meet the needs of children with disabilities. Utilizing resource categories based on those developed by Trivette, Dunst, and Deal (1997), across the nine communities 60% of the service system resources address a variety of child needs (i.e., education, child care, health), while only 22% primarily address the needs of adult family members (e.g., information, parent education, job training, etc.). Approximately 13% of resources within the service system developed by program leaders address the needs of both the child and family (i.e., housing, food, etc.).

However, some communities have put together a broader array of services than others. Community program leaders were asked to identify the resources that were used *most often*, *sometimes*, and *rarely*. Figure 4 presents a comparison of the types of resources used *most often* across the three study states. There are also some community differences in the number and types of resource categories used (see Table 10). One of the communities studied identified eight broad types of resources that were used *most* frequently. These resource categories include: child education, child care, health, adult education, mental health, transportation, recreation, and other (e.g., resources from civic groups, technical assistance programs, business sector resources). It is disconcerting that only one of the nine communities had put together a comprehensive array of resources that were used frequently. Even when the resources in the *most* and *sometimes* categories are combined in five of the

Figure 4
State Comparison of Types of Resources Used Most Often to Serve Infants & Toddlers With Disabilities (1994-1995)

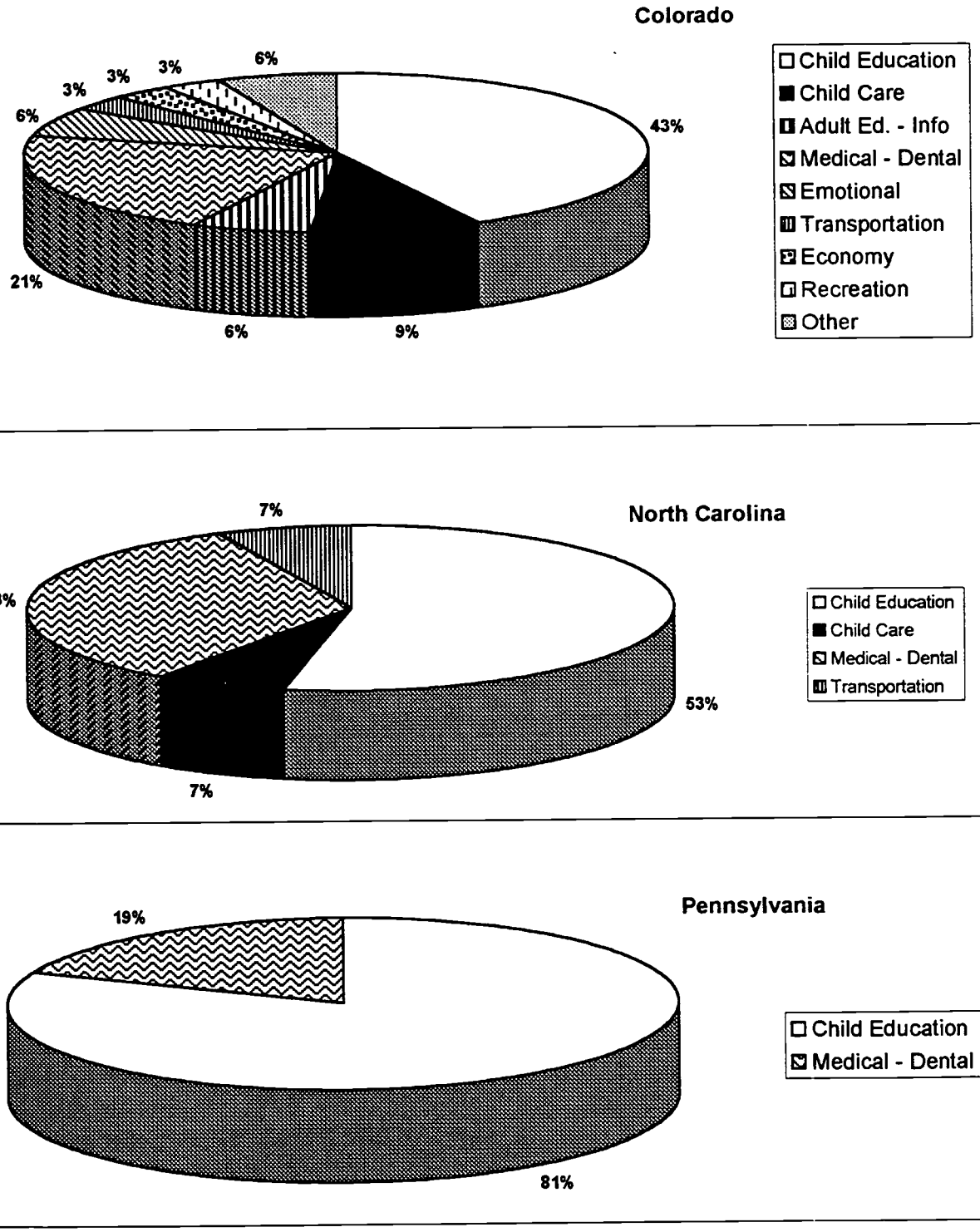


Table 10
Comparison of Types of Resources and Their Level of Involvement in Infant & Toddler Programs

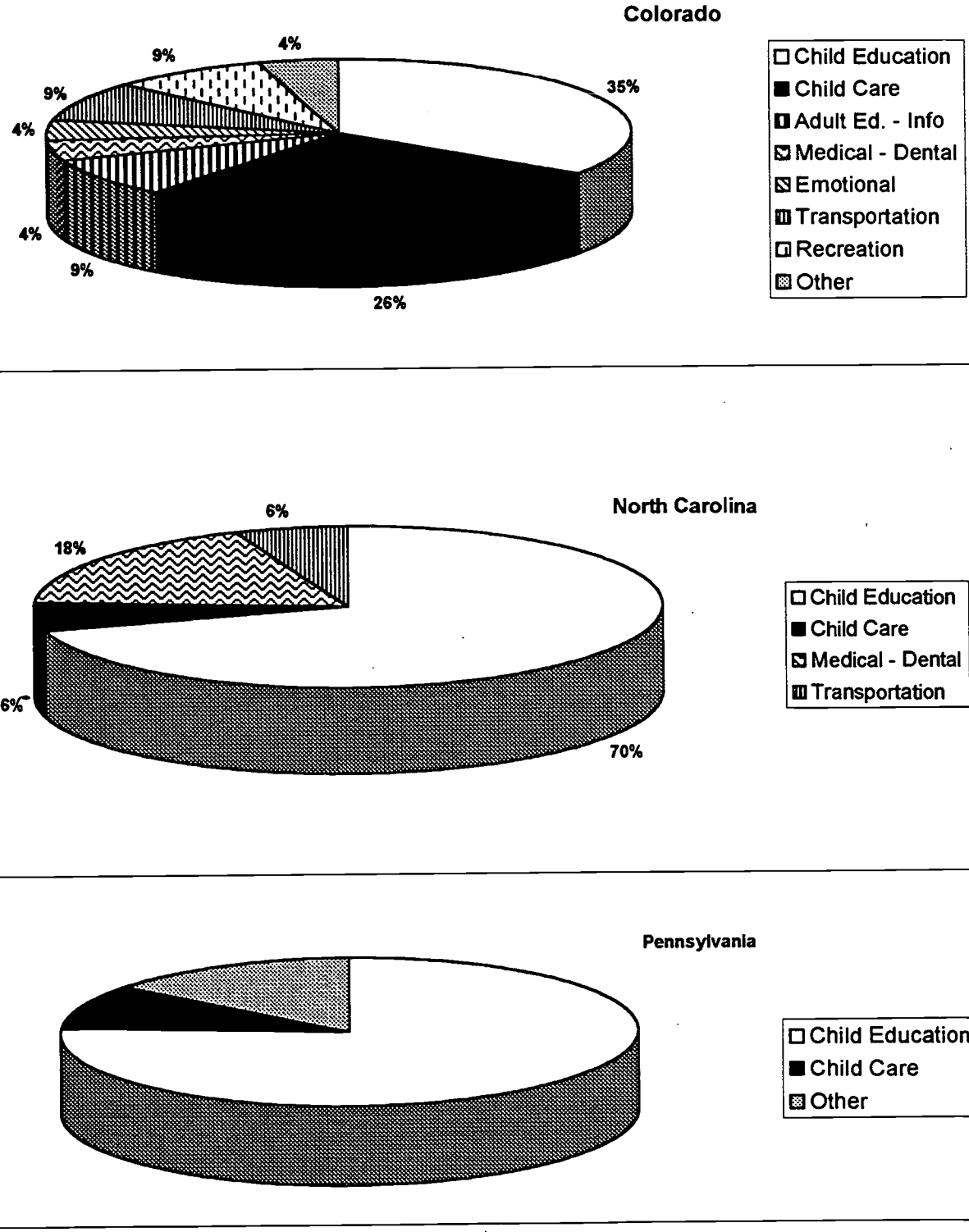
	Most	Sometimes	Rarely
Colorado			
High	**3** (CE, MD, O)	**8** (CE, CC, AEI, MD, EM, CSR, FC, R)	**6** (CP, AEI, FC, EC, L, O)
Medium	**8** (CE, CC, AEI, MD, EM, T, R, O)	**10** (CE, CC, CP, AEI, MD, T, FC, EC, P, R)	**2** (MD, EM)
Low	**4** (CE, CC, MD, EC)	**10** (CE, CP, AEI, MD, EM, FC, EC, P, R, O)	**4** (CE, AEI, MD, EM)
North Carolina			
High	**2** (CE, MD)	**4** (CE, AEI, MD, EM)	**8** (CE, CP, MD, EM, FC, EC, P, L)
Medium	**3** (CE, MD, T)	**6** (CE, CC, AEI, MD, EM, O)	**7** (CE, CP, AEI, EM, FC, EC, P)
Low	**3** (CE, CC, MD)	**5** (CE, AEI, MD, EM, O)	**7** (CE, CC, CP, EM, FC, EC, P)
Pennsylvania			
High	**2** (CE, MD)	**5** (CE, CC, CP, MD, EM)	**2** (CE, CC)
Medium	**1** (CE)	**6** (CE, CP, MD, FC, EC, P)	**4** (CC, AEI, MD, O)
Low	**2** (CE, MD)	**8** (CE, CP, AEI, EM, FC, EC, P, O)	**7** (CC, AEI, MD, EM, FC, P, L)

RESOURCE CATEGORY LEGEND	
CE	CHILD EDUCATION
CC	CHILD CARE
CP	CHILD PROTECTION
AEI	ADULT EDUCATION/INFORMATION
MD	MEDICAL/DENTAL
EM	EMOTIONAL
CSR	CULTURAL/SOCIAL/RELIGIOUS
T	TRANSPORTATION
FC	FOOD/CLOTHING
EC	ECONOMIC
P	PHYSICAL
R	RECREATION
L	LEGAL
O	OTHER

remaining communities, the array of resources utilized comprises approximately half of the resource categories. Although communities use new resources *sometimes* (e.g., parent information and education, basic needs, etc.), they also often use the same type of resources (e.g., child education) that were identified as being used *most* often. This occurs, for example, when the early intervention program is identified as being used most often, while state sponsored programs for hearing impaired and visually impaired children only are used sometimes. Both are classified as child education programs. Therefore, some child education programs are used "often," while additional child education programs are used "sometimes." Progress is needed if the rest of the communities are to become more ecologically and family oriented in service provision.

Preschool. Similar findings were revealed for Preschool programs for children with disabilities. The breadth of all resources used regardless of categories ranged from 15 to 72. Examination of the types of services and resources included in the Preschool System reveals: 65% of resources address child needs, with child education and care comprising 84% of the child resources; 18% address needs of child and family (e.g., housing, food, etc.), and 17% address needs of adult family members. With regard to the number of resource categories within a single community used *most* often, the number ranged from 1 (child education) to 6 (child education, child care, emotional, transportation, recreation, and technical assistance program). Figure 5 presents a comparison of the types of resources used *most* often across the three study

Figure 5
State Comparisons of Types of Resources Used Most Often to Serve Preschool Children With Disabilities (1994-1995)



states. The community that had set up the most comprehensive system for infants and toddlers is the same community using the largest number of resource categories *most often* in service delivery for preschool children with disabilities. Table 11 presents a comparison of the types of resources and their level of involvement in service delivery for the nine communities studied.

What Are The Service Delivery Models Being Used? How Are Services Organized?

The number and types of resources contained within the system paints only a partial picture of the service delivery system. Also of importance is how those resources are organized – the complexity of the organizational structure of the service system. **Infant & Toddler** Programs primarily use a home-based approach to service delivery, while some programs serve children in segregated centers, clinics, and child care. Harbin and West (1998) identified six *qualitatively different* service delivery models used across the nine communities, based upon the organization of programs and resources. The six service delivery models range from a traditional, single-program model (similar to service delivery models existing prior to the enactment of Part H of IDEA), to a comprehensive and coordinated model designed to provide services to *all* children in the community (Harbin, McWilliam, & Gallagher, in press). These six models differ with regard to the overall organizational structures which guide service delivery, the amount and nature of interagency decision-making, the scope of the target population, and the scope and nature of services and

Table 11
Comparison of Types of Resources and Their Level of Involvement in Preschool Programs

	Most	Sometimes	Rarely
Colorado			
High	*Not Available*	*Not Available*	*Not Available*
Medium	**6** (CE, CC, EM, T, R, O)	**10** (CE, CC, CP, AEI, MD, EM, FC, EC, P, R)	**2** (MD, EM)
Low	**5** (CE, CC, AEI, MD, R)	**9** (CE, CC, CP, AEI, MD, EM, FC, EC, P)	**4** (CE, MD, E, L)
North Carolina			
High	**2** (CE, MD)	**8** (CE, CC, CP, AEI, EM, FC, EC, P)	**3** (CE, MD, L)
Medium	**3** (CE, MD, T)	**5** (CE, CC, AEI, MD, EM)	**10** (CE, CP, AEI, MD, EM, CSR, FC, EC, P, O)
Low	**3** (CE, CC, MD)	**1** (CE)	**7** (CE, CP, MD, EM, FC, EC, P)
Pennsylvania			
High	**3** (CE, CC, O)	**14** (CE, CC, CP, AEI, MD, EM, CSR, T, FC, EC, P, R, L, O)	**1** (CE)
Medium	**3** (CE, CC, O)	**7** (CE, CC, AEI, MD, EM, EC, R)	**9** (CC, CP, MD, CSR, FC, EC, P, R, O)
Low	**1** (CE)	**6** (CE, CC, AEI, MD, L, O)	**3** (CC, MD, EM)

RESOURCE CATEGORY LEGEND	
CE	CHILD EDUCATION
CC	CHILD CARE
CP	CHILD PROTECTION
AEI	ADULT EDUCATION/INFORMATION
MD	MEDICAL/DENTAL
EM	EMOTIONAL
CSR	CULTURAL/SOCIAL/RELIGIOUS
T	TRANSPORTATION
FC	FOOD/CLOTHING
EC	ECONOMIC
P	PHYSICAL
R	RECREATION
L	LEGAL
O	OTHER

resources utilized (see Table 12).

Three of the six service delivery models identified by Harbin and West – the three which fall on the continuum nearest to the comprehensive system – offer coordination more in line with the preferences of families who advocated during the design of IDEA. However, only four of nine communities studied utilized these *more coordinated* service delivery models. Thus, there still exist deficiencies in many local service system models which inhibit the development of a comprehensive and coordinated system of services.

Preschool Programs primarily use classroom-based approach, which focuses on the education of the child. There were five *qualitatively different* Preschool models across nine communities, ranging from a single education program dominated model to an interagency system which looks beyond education providers. There were three communities that used one of the two more coordinated models. (See Table 13).

How Well Are The LICCs Functioning?

As can be seen from Tables 12 and 13, the Local Interagency Coordinating Council (LICC) plays differing roles across the nine communities. Eight of the nine communities had officially established LICCs to plan and facilitate service provision to children with disabilities from birth to five years of age. The remaining community had an informal group which met primarily to inform one another of initiatives and activities. The LICCs had been in existence for varying time periods, ranging from 15 years to those that had been created

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Table 12
Infant & Toddler Service System Models

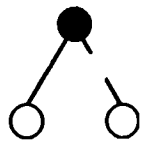
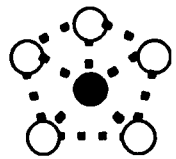
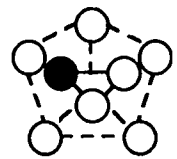
	Single Program	Network of Programs Beginning to Coordinate	*Loosely Coupled* Primary Coordination with Intervention, Secondary Coordination with Other Agencies
Visual Depictions:			
Organizational Structure:	Single intervention program provides most services and coordinates when necessary with other programs Links to other programs are weak to moderate Arrangements/agreements are usually informal	A network of programs from multiple agencies that plan and implement programs somewhat autonomously, but have recently established a local interagency coordinating council (LICC) and are beginning to do some cooperative and coordinated planning; system and services dominated by lead agency Agreements and arrangements are usually informal, but many have formalized a few agreements or procedures	Primary coordination occurs between and among two or more intervention programs designed to provide general developmental intervention either to children of all disabilities or to children with particular disabilities (e.g., language, motor, etc.) Local interagency coordinating council (LICC) is instrumental in cooperative design of intervention procedures/components to be used across all providers (e.g., IFSP, assessment, intervention). Focus is on educational intervention process more than on total coordination of educational intervention with health and welfare programs
Decision - Making:	Lead agency makes decisions, rarely asks other agencies for input, but primarily informs Lead agency dominates decision making	Lead agency dominates decision making. Other agencies participate so that they can be informed of decisions/policies of lead agency. Make some cooperative agreements around Public Awareness. Decisions often focus on dividing up service responsibilities.	The multiple intervention programs provide leadership/direction for LICC decisions (educational intervention predominates). Other agencies contribute, but secondarily.
Scope of Target:	Disability oriented in terms of population served	Disability oriented in terms of population served	Disability oriented in terms of population served
Scope of Resources:	Array consists primarily of those programs designed for disabled children	Focus of array and links depends upon the nature of the lead agency: poverty, disability, health, education	Focus of array primarily those programs designed for disabled children

Table 12 (continued)
Infant & Toddler Service System Models

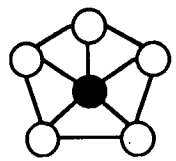
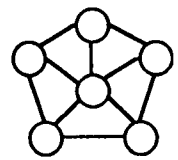
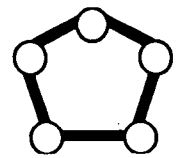
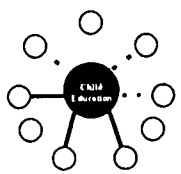
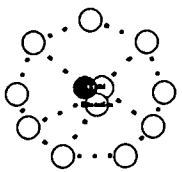
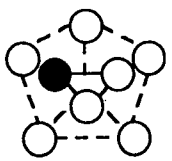
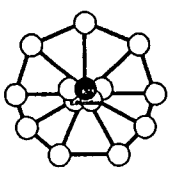
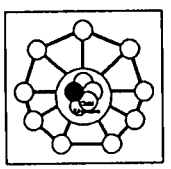
	Moderately Coupled Multi-Agency System with Some Leadership Coming from Lead Agency	*Strongly Coupled* Multi-Agency System-Leadership and Decision Making Dispersed Among Agencies	Comprehensive System for All: LICC Is Lead Agency for Comprehensive and Cohesive System for All Children
Visual Depictions:			
Organizational Structure:	Lead agency or core group of agencies facilitates coordinated planning and service delivery among multi-agency group which focuses not only on educational intervention but to some extent on the health and welfare needs A formal LICC has developed formal interagency procedures for service delivery	LICC chair, lead agency or core group of programs/agencies facilitate coordinated planning and service delivery. Many or most intervention activities are cooperative endeavors Multiple educational intervention programs work closely as if on same staff or part of single program Works like a well-operating machine	LICC is composed of a broad array of child and family services All programs and providers (public and private) share common values and have participated in planning equally System is the focus - all programs are designed to go together to form a cohesive whole Grants written to supplement what public agencies are not funded to do Use of a family center for ongoing coordination and co-location of programs
Decision - Making:	Agencies contribute fairly equally to decision making. However, leadership and direction come from lead agency.	Strong cooperative LICC is the vehicle for all participants to have equal say. Private programs and providers are also integrated in decision making	Cooperative, equal decision making
Scope of Target:	Population served can be disability oriented or disability and children at-risk	Population served can be disability oriented or include children at-risk but some activities focus on all children	Population addressed is all children and their families
Scope of Resources:	Array of programs designed to meet not only educational needs of child but health and welfare needs of child and potentially family needs as well	The array of programs and resources focuses on meeting educational, health, and welfare needs of children and their families	Comprehensive array including specialized and natural community programs and resources

Table 13
Preschool Service System Models

	Single Program Dominated	Network of Education Providers	*Loosely Coupled Interagency System* (Primary Coordination with Education Providers, Secondary Coord. with Other Agencies)	*Moderately Coupled Interagency System*	Comprehensive Interagency System for All Children
Visual Depictions					
Organizational Structure	Public schools provide all educational services or subcontract to a single provider (e.g., Headstart) to provide all educational services. Public schools coordinate with other agencies (e.g., health, Social Services) that provide non-educational services "when necessary". Linkages exist with other agencies but primarily for referral purposes. If there is an LICC, it is used primarily for agencies to inform one another of plans and activities. Rarely any cooperative planning.	A network of educational programs has begun to meet and engage in limited cooperative planning. Non-education agencies (e.g., Health, Social Services) may be part of this planning group (LICC), but involvement of these agencies focuses on assisting with the education process (i.e. screening, assessment, provision of therapies).	Primary coordination occurs between and among two or more educational intervention programs. LICC is instrumental in cooperative design of procedures/components to be used across all providers (e.g., IFSP, assessment, intervention). Focus is on educational intervention process more than total system (i.e., coordination of educational intervention with health and welfare programs is secondary).	Strong linkages among school and other educational programs to provide services in a similar manner. Multiple educational intervention programs work closely as if they are part of a single program. In addition, the LICC has developed a vision of an array of services to meet the needs of children (primarily) and their families (secondarily). Therefore, other agencies (health, social services) participate in planning in meaningful way.	LICC is composed of a broad array of child and family services. The LICC has developed a broad vision for a cohesive system of services to meet the needs of all children and their families. All programs and providers (public and private) share common values and have participated in planning this broad system. The LICC serves as the lead agency and write grants to supplement existing resources.
Decision-Making	Public school or agency sub-contracted to (e.g., Head Start) is primary decision-maker for child education services. School may be open to suggestions, but has final say.	Public school dominates decision-making for child education, although the primary providers of educational intervention may participate in some cooperative planning. All agencies on the LICC may engage in cooperative planning around areas such as Public Awareness, Child Find and screening. Decisions often focus on dividing up responsibilities.	The multiple educational intervention programs provide leadership/direction for LICC decisions (educational intervention predominates). Other agencies contribute, but secondarily.	Public School facilitates coordinated planning among education providers and other agencies. Agencies contribute fairly equally to decision-making.	Shared decision-making among interagency group with educational providers having an integral role in the collaborative planning and implementation.
Scope of Target	Education of child with disabilities.	Primary emphasis on education of the child with disabilities.	Primary emphasis on education of child with disabilities, may have a secondary emphasis on education of the child at-risk.	Primary emphasis on education of the child with disabilities and some emphasis on needs of child and his family beyond education (e.g., health, housing). Secondary emphasis on education of the child at risk and an occasional focus on all children in community.	Population addressed is all young children and their families. There is a strong emphasis on the education of the child, but also concerned about broader needs as well (e.g., health, basic needs, etc.).
Scope of Resources (Array)	School provides classroom intervention or subcontracts to a single provider (e.g. Head Start) for educational services.	Emphasis on educational needs of child. An array of public and private educational and therapeutic (OT, PT) sites. Occasionally refers child to selected non-educational services (e.g., Health Dept.).	An array of public and private educational and therapeutic (OT, PT) sites. A limited number of non-educational services and resources are recognized.	An array of public and private educational and therapeutic (OT, PT) sites. A moderate array of non-educational services and resources are recognized and used.	A comprehensive array including specialized and natural community resources to meet various child and family needs.

after the federal law was enacted. Use of an assessment instrument indicated that the nine LICCs were functioning at different levels. However, more careful analysis revealed that most of the LICCs had failed to accomplish important tasks at some of their earlier stages of development. Thus, intra- and interagency coordination appears to suffer because LICCs have accomplished the easier aspects of their organization and planning, and typically have yet to complete (or, in some cases, attempt) the most *difficult* tasks, which nonetheless are necessary to ensure coordination and development of the broadest possible array of services. This appears to be similar to Piaget's theory of cognitive development in children wherein the *quality* of development at one level influences the quality of development at subsequent developmental levels. However, it appears that when state policy places an e*mphasis* on mandating specific interagency structures and mechanisms, and when LICCs receive guidance in addressing the more difficult tasks, LICCs not only function more efficiently, but are able to create and maintain a more coordinated service system, as demonstrated by some communities in Tables 12 and 13 (Infant & Toddler, N=4; Preschool, N=3).

What Are The Barriers And Facilitators Of Interagency Coordination?

As stated above, the effectiveness of the LICC is an important factor in how comprehensive and coordinated the service system becomes. Evidence from a scale that measures the barriers and facilitators of coordination indicates a direct relationship between the amount and scope of interagency coordination

and a variety of factors. Coordination improves at the community service system level when there is continuity in leadership, because it takes time for administrators and LICC members to develop a shared vision and sense of trust. Forty three (43) respondents from LICCs across the 9 study communities completed a 5 point scale rating the presence (5) or the absence (1) of factors that could facilitate or hinder coordination in the 9 communities. The factors existing in communities which were reported to be present and facilitating coordination included: 1) a positive climate within the community and agencies to support coordinated activities; 2) the presence of leadership and participation of relevant stakeholders; and 3) a participatory planning process which encourages and respects the contributions of diverse constituencies. Conversely, limited resources (insufficient personnel and lack of time for coordination), conflicting or rigid policies, and the lack of adequate structural mechanisms appeared to hinder coordination at the community level.

Program administrators also state that coordination suffers because some key components of the system (Social Services, Mental Health, physicians, private providers, and parents) often are not as involved as leaders would like.

What Is The Strength of the Relationships Among Agencies?

Agency representatives from 9 different agencies / programs within the community were asked to use a 7 point scale to rate their relationship with all of the other agencies on 10 different dimensions (e.g., philosophy, program goals, structure of agency, management approach, communication, personnel, etc.). In

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general, the areas in which agencies perceived a closer relationship were: agency philosophy, agency goals, communication, and attitudes toward coordination. The areas in which agencies perceived more dissimilarity include: agency planning, agency structure, and management. Interestingly, agencies' ratings of one another indicate they believe that most agencies are minimally to moderately knowledgeable about the various programs within other agencies.

In addition, these individuals were asked to rate the general quality of their *working relationship* with all other agencies. In general, agencies indicated strong working relationships. However, there were some agencies / programs that did not enjoy as strong of a working relationship as others in many of the communities. These include: social services, hospitals or clinics, and various family programs (e.g., family center, parents training program, Even Start, and Parent to Parent programs).

How Much Does It Cost?

On the basis of data derived from services to 44 infants and toddlers across three programs, findings revealed an extremely wide range in annual cost of specialized intervention from $2,860 to $11,700 per child. The children selected for this analysis were diverse with regard to their disabilities, their level of service needs, and sociodemographic factors (i.e., race, age, gender, SES). The three programs included in the cost study represented differences in size, service delivery model, and approach to funding. In general, the more specialized the model, the higher the cost. Data from case studies and focus

groups reveal that the cost of service is *not* necessarily associated with satisfaction with services. Major factors that appear to influence the cost of services were: volume of service received, cancellation rate, staff salaries, program support costs (e.g., administration, transportation, supplies, equipment, staff travel, and indirect costs), as well as the percentage of time expended on indirect services (phone calls, meetings, etc.).

Do Parents Report a Financial Burden For Obtaining Services?

In the ECRI:SU sample (N=300) 47% of mothers with infants and toddlers have some type of private insurance; 40% of mothers are on Medicaid; and 13% have neither. For families with preschoolers, 52% of mothers have private insurance; 37% have Medicaid; and 11% are uninsured. Many parents from a low socio-economic status report that they carefully must watch their income for fear they unwittingly will exceed the cut-off line established by Medicaid and suddenly lose their valuable health benefits. Some parents must leave gainful employment or lose these benefits, and others with insurance complain that if they take new employment their child will be denied health care due to a "pre-existing condition." Obviously, it is rare that any family has the resources to meet health care costs without some type of insurance.

Families in some cases used their own financial resources to obtain services for their child more frequently than did other families. These services often were the traditional therapies (OT, PT, and speech/language).

OUTCOMES OF IMPLEMENTATION

Are Families Satisfied With Services?

In general, families are satisfied with the services they receive. Kochanek, Costa, McGinn and Cummins utilized a seven point rating scale to determine satisfaction. The mean scores across items in three factors (Parental Knowledge, Independence, and Provider Competency; Provider/Teacher Communication and Engagement; and Service Access and Adequacy) ranged from 4.7 to 6.5. The individual items with the lowest means, hence indicating the lowest satisfaction were: 1) sufficiency of services; 2) provision of information on the child's condition; 3) assisting families in the development of advocacy skills; 4) scheduling services at convenient times; and 5) helping families to feel more competent in addressing the needs of their child. In addition, families report that their service providers are caring, competent, respectful, truthful, and thoughtful individuals (more like "friends" than professionals). In particular, mothers reported that early intervention has resulted in a clearer understanding of their child's needs and development, and that they had acquired knowledge and confidence in using strategies at home to promote their child's development.

In some instances, families might not have been as satisfied with some aspects of service delivery if they had been more knowledgeable about best practice. Often, it seems that families are "uninformed consumers," unaware of what they are missing, and grateful to be receiving any services at all for their child. However, when pressed in interviews and focus groups, families

elucidated a variety of concerns and problems with services.

How Do Families Want Services To Be Improved?

Families suggested major improvements in four areas: provision of information, support, increased coordination, and more services.

Information. Families spend a significant amount of time trying to locate resources and services while navigating the service system. However, they want to be able to easily access information on their own when they need it. They do not want to depend on professionals' determinations of what is appropriate information to pass along. Instead, parents want comprehensive, organized information about all available resources and services, specialized and non-specialized, in an easily accessible and family-friendly directory of resources.

Support. Parents identified the need to speak and connect more often with other parents in similar circumstances. Often, according to many parents, traditional parent support groups reflect a clinical or therapy orientation with which parents are uncomfortable. Instead, parents would prefer more informal group gatherings (e.g. picnics), and the ability to connect with individual parents around specific topics on an as needed basis.

Coordination. Families desire a proactive, responsive, and knowledgeable service coordinator who is easily accessible. Many families have expressed their satisfaction when a number of services and resources are coordinated and offered at a single site (i.e., a Family Center). Families also

desire services coordinated to meet constraints of time, transportation, and child care.

Amount of Services. As mentioned above, in a survey of 233 parents which measured satisfaction with services, the item rated the lowest by parents related to the amount of services received by their child. In focus groups and interviews, parents indicated that they wanted more services, especially therapies for their children as well. Service providers also voiced concerns that they were not able to spend as much time with children and their families as they felt was needed. However, if the transdisciplinary model was used to support all of the individuals working with the child, integrating therapies and learning tasks into the child's normal activities and routines, the amount of intervention would likely increase.

Is There Variability In Service Delivery Across Communities?

Although IDEA is a single federal policy, the law sets a framework of requirements, but allows states the flexibility to develop their own approach to meeting these broad requirements. Consequently, findings from studies within this Institute indicate considerable variability in the implementation of this federal policy. As previous sections of this paper have indicated, there are differences in the outcomes of service delivery. First, in a quantitative analysis of service provision, Kochanek and Buka (in press-a, in press-b) reported state, community, and child and family differences in the amount and location of services. In addition, Harbin, Tocci, Shaw, and West integrated qualitative data

collected on 75 case study families, as well as the programs that served them, and identified other differences of service outcomes as well. Table 14 presents nine service outcomes and the nature of each outcome in each study community. These service outcomes are important indicators of the results of service delivery efforts at two important levels: 1) the consequences for individual children and their families, and 2) adequacy of the service system. It is important to recognize and examine the service outcomes at both of these levels, since to focus solely on one of these levels would provide an incomplete picture of the consequences of service delivery. Data analysis revealed variance in three system level outcomes: 1) the percentage of children with disabilities receiving services, 2) the scope of the array of services provided, and 3) the amount of coordination among all relevant agencies and sectors. These system outcomes are important indicators of whether all eligible children are being served; whether the system has put together a broad enough array of services and resources to meet the needs of diverse children and families; and whether there is sufficient coordination among agencies.

Equally important are the service outcomes at the individual level: 1) amount of services received; 2) the amount of individualization of service provision; 3) the use of inclusive settings; 4) the degree to which individual service needs of children and families are met; and 5) the ease with which families can navigate the system or whether families experience frustration as they *run into the walls* of the system. These outcomes are some of the important

Table 14
Comparison of Service Delivery Outcomes Across Nine Communities

OUTCOME	Community #1	Community #2	Community #3	Community #4	Community #5	Community #6	Community #7	Community #8	Community #9
Percent of Children Served	Low	Moderate	Moderate	Low	Low	Low	High	High	High
Array of Services	Narrow	Narrow-Moderate	Narrow	Narrow	Moderate	Narrow-Moderate	Moderate - Broad	Broad	Broad
Amount of Coordination	Low	Low-Moderate	Low	Low	Moderate	Moderate	Moderate-High	High	High
Amount of Services	Low	Low-Moderate	Moderate	Low	Moderate-High	Moderate	Low-Moderate	High	High
Individualization	Low	Moderate to High	Low	Low	Moderate	High	High	High	High
Use of Inclusive Settings	Low	High	Low	Low	Low - Moderate	High	Moderate	High	High
Navigability	Low	High	Low	Low	Low-Moderate	Moderate-High	Moderate-High	Moderate-High	High
Needs Met: Children and Families	(Child) Partial (Families) Low	(Child) High (Families) High	(Child) Partial (Families) Low	(Child) Partial (Families) Partial	(Child) Some (Families) Some	(Child) Most (Families) Most	(Child) Most (Families) Most	(Child) High (Families) High	(Child) High (Families) High
Service Delivery Model	Program	Program	Network	Network	Loosely-Coupled	Moderately-Coupled	Moderately-Coupled	Strongly-Coupled	Comprehensive

indicators as to whether children and families are receiving a sufficient amount of services and whether these services are sufficiently individualized to meet the needs of children with disabilities and their families. As is evident from the table, there was variability across nine communities regarding each of the service outcomes.

Nevertheless, linkages among outcomes can be seen. For example, in general the broader the array of services, the greater the amount of services received, the greater the individualization, and in turn, the greater the likelihood of meeting child and family needs. These patterns show that there are linkages between the system level outcomes and the outcomes for individual children and their families. Even more predictable than associations among positive outcomes are relationships among poor service outcomes. Communities having little success in a number of areas are likely to have challenges overall in providing high quality services. It is also interesting to note that there appears to be a linkage between the outcomes of service delivery listed in Table 14 and the service delivery models listed in Table 12. The order of the communities listed in Table 14 corresponds with the continuum of service delivery models presented in Table 12. In general, these findings indicate that the more comprehensive and coordinated the service delivery model, the higher the likelihood of positive service outcomes for children and their families. Despite this general trend, examination of Table 14 indicates that there is one community that does not fit this pattern. Although the formal service delivery model in Community #2 is more narrow and rigid, outcomes for children and families are

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positive. The effects of the system in this community seem to be moderated by the existence of a *single service provider* who: 1) is knowledgeable about and uses family-centered practices; 2) has excellent informal relationships with individuals in other agencies; and 3) shields families from the bureaucratic nature of the service system. It appears that the small size of the community in combination with a single highly skilled service provider makes this informal approach possible. However, it is also possible that a single service provider with a different set of skills might contribute to different findings.

Despite the existence of federal policy to guide service delivery, Table 14 indicates considerable variability in the outcomes of the implementation of this policy. This is noteworthy since the communities participating in this study were nominated as exemplary programs. It is possible that even more variability exists across all programs in the three study states. The inclusion of the service delivery model information provides a partial explanation of *why* this variability exists. The previous discussion of Community #2 demonstrates that information beyond what is included in Table 14 is necessary to more fully understand the complex set of factors influencing service delivery.

INFLUENTIAL FACTORS

Why Is There Variability In Services Provided and Received?

One of the most important findings from all of the ECRI:SU studies is that *no single factor* explains the variability of services across states and communities. Although the importance of the various components of the broader

ecology has been widely accepted (Bronfenbrenner, 1975; Garbarino, 1990; Odom & McLean, 1993), until recently there were little data to support this belief. As indicated in earlier sections of this paper, service delivery appears to be influenced by: specific characteristics of the families and service providers, as well as their relationship; the nature of the service delivery model, including the program leadership; and aspects of state policy. In addition, data analysis revealed that the context of the community also played a more subtle role in influencing the direction of and expectations for service delivery.

Specific elements contained in these broad factors seem to interact in complex ways to influence the process and results of service delivery. Central to the understanding of service delivery is the *interaction* of three factors: 1) the service delivery model, 2) the skills and characteristics of the service providers, and 3) the skills and characteristics of the families. These three factors interact influencing the relationship between the family and service provider, as well as the amount and nature of services provided. More comprehensive service delivery models and more highly skilled service providers tended to be associated with more optimal service delivery. Although skills and characteristics of families could enhance service delivery under optimum conditions, they appeared most influential in those circumstances where the service delivery model was narrower and service providers were less resourceful and lacked skills in many of the best practices.

The *leader* of the developmental intervention program as well as the leaders from the broader service system, appeared to exact a powerful influence

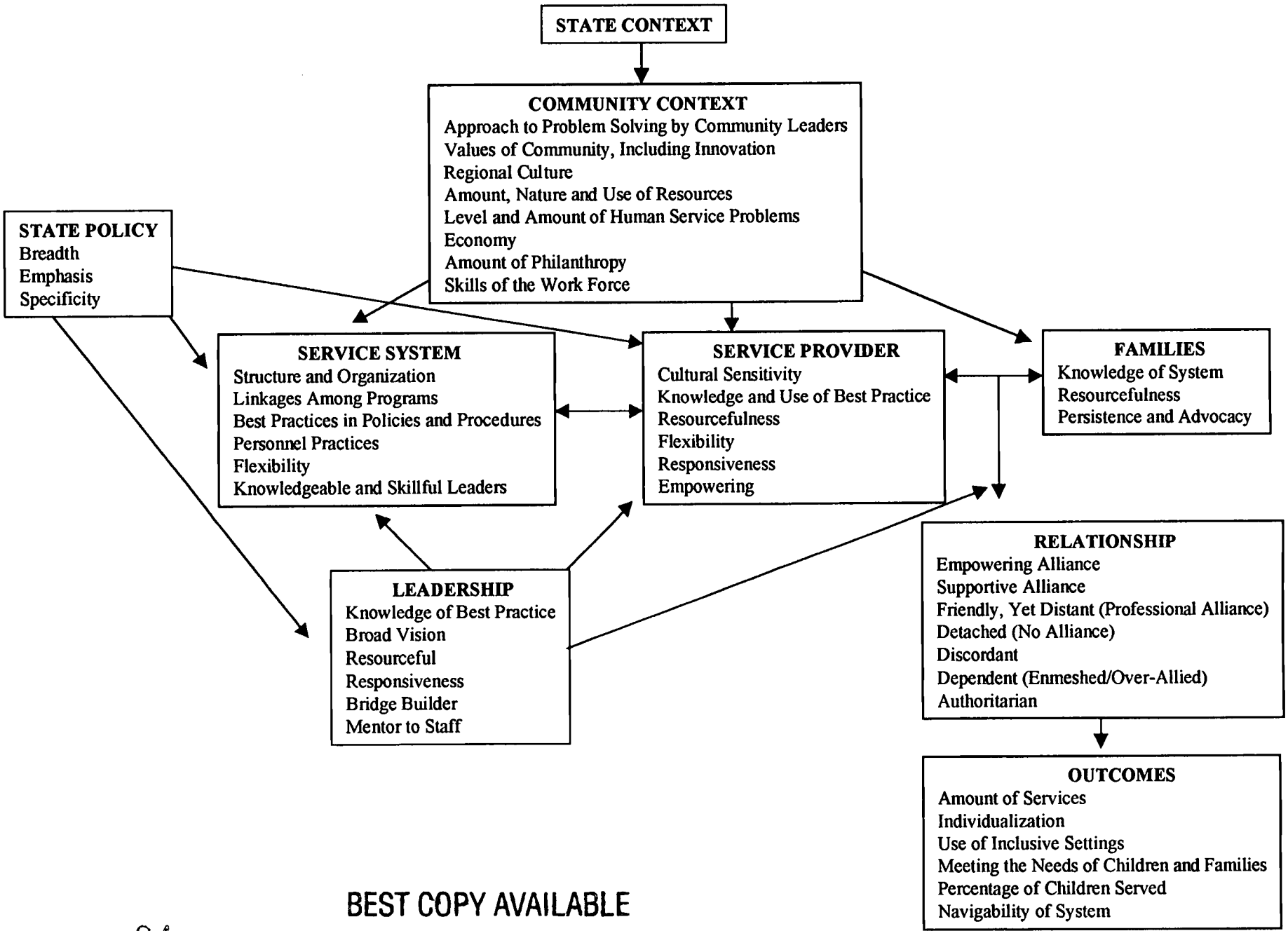
over the nature of the service delivery model. In addition, there was a strong link between the quality of the leaders and the quality of the service providers. In other words, knowledgeable and skillful leaders had selected and employed a higher proportion of quality service providers. Conversely, in communities where program coordinators lacked quality leadership skills, service providers also tended to lack important characteristics and skills as well.

The leaders and service delivery model are shaped partially by *state policies* which sets up the parameters and provides emphasis to aspects of the service system. Finally, program leaders, service providers and families are influenced by various factors within their community context. The resources, values, priorities and resourcefulness of the community shape the way things are done in each community. Figure 6 displays the interactions within the ecology of service delivery and includes the specific variables identified through data integration as being the most influential.

The multi-dimensional nature of service delivery therefore requires that all of these factors be addressed systematically if service delivery is to be improved. Each of the broader variables and the specific factors contained therein is discussed briefly below.

Service Delivery Model. Six aspects of the service delivery model contribute to the nature of services: 1) structure and organization, 2) linkages among programs and resources, 3) flexibility, 4) use of best practice in program policies and procedures, 5) personnel practices, and 6) leadership.

Figure 6
Factors Interacting To Influence Service Provision And Service Outcomes Across Nine Diverse Communities



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Particular patterns demonstrate ties between the system-level factors and the nature of service delivery. In general, the broader the array of services and the more coordinated the model, the better the service outcomes. Conversely, service delivery models which fail to meet the needs of children and families are more insular, have a narrower array of services, and have weaker linkages with other programs and resources.

Some service system models have made more progress than others in implementing family-centered practice. These systems are among the most comprehensive, with the broadest arrays available to ensure multiple options and individualized services. They also are the most responsive to meeting family needs by a wide variety of means, and generally operated with greater flexibility. Family-centered systems also possess both a high degree of interagency coordination and knowledgeable leadership which hires staff to reflect its values.

Service Provider. Cross site analysis revealed generally that in those communities with more positive service outcomes regarding the amount and nature of service delivery, many service providers shared several important characteristics. These characteristics are similar to those presented earlier with regard to family-centered practices and include: 1) sensitivity to families and cultures; 2) knowledge and use of best practice; 3) initiative and resourcefulness; 4) flexibility; 5) responsiveness; 6) a style of help-giving which is friendly and "enables" and "empowers" families. These help-giving skills and

attitudes were consistent with many of those identified by Dunst and his colleagues (1991).

Perhaps one of the most interesting and important findings in the study was the link between the qualities and competencies of the service providers and the qualities and competencies of the leadership of the developmental intervention program. (This person is often referred to as the program coordinator.) Consistently, where the leaders were skillful and knowledgeable, so too were all, or most of, the service providers employed by the program. Cross site analysis revealed that the successful coordinators used hiring practices to select staff who possessed knowledge of best practice (i.e., family-centered, inclusion, etc.), teamwork and partnership skills and attitudes, resourcefulness and flexibility (Garland & Linder, 1994). They also used in-service training, on-going supervision, and the provision of informational and emotional support as mechanisms to continue to facilitate further growth and improvement in the service providers' knowledge and skills.

These coordinators were not the traditional bureaucratic administrators who maintain distance between themselves and their staff by focusing on paperwork and meetings. Instead, successful Program Coordinators also served as mentors and educational leaders for their staff. One Program Coordinator for instance, not only provided opportunities for in-service training, but arranged with one of the universities in the state to have their community serve as an off-campus location for a graduate training program. Because this community is located two and one half hours from the closest university training program, it

otherwise would have been impossible for staff to take classes at night. By bringing this graduate program to the community, this Program Coordinator advocated for her staff, improved their knowledge and skills, and likely enhanced service delivery to children and families.

Families. There were three characteristics of families which appeared to influence the amount, type and location of service delivery for their child. First, the amount of knowledge related to available service resources, as well as knowing how to navigate the system played a role in what children and families received. Second, the ability of the parents to persistently advocate for their child often was instrumental in shaping service delivery. Third, the family's ability to be resourceful was also an important influential characteristic. The possession of these skills and abilities was more important in the communities with narrower and less coordinated service delivery models. Interestingly, these characteristics and skills are ones that can be developed. Parent training and support programs as well as developmental intervention providers can assist families in increasing their capabilities in these three important areas.

Relationships. Kochanek and Buka (in press-a, in press-b) noted that similarities in the age and education of the mother and service provider resulted in increased amount of services. These same authors also discovered that the children of mothers who believed that service decisions should be made by professionals also got more services. Both of these findings indicate that the service provider-family *relationship* is playing a role in determining the amount and types of services provided. As mentioned previously, through in-depth

analysis of interviews with 44 families and their service providers, ECRI:SU researchers identified 7 different types of family-service provider relationships. Some of these types of relationships were more empowering than others. In many instances, the more empowering relationships resulted in more family-centered, individualized services, as well as a broader array of services. Clearly, the nature of the relationship between the family and the service provider is an important factor in the experience of service delivery as well as the nature and results of service delivery.

Leadership. As described earlier, there was a strong connection between the quality of the program leadership and the characteristics and qualities of service providers. When leaders are skillful and knowledgeable, often their service providers are as well. These administrators select staff whose views of practice are consistent with their own, use in-service training, provide on-going supervision and mentoring, and provide information and emotional support in order to communicate their values as well as aspects of best practice. In short, these administrators serve as mentors and educational leaders for their staff.

The quality of leadership appeared to influence many components of the service delivery ecology: (1) the quality of the service delivery model; (2) the skills and knowledge of service providers; (3) the quality of the relationship; and thus, (4) the amount, array, and nature of service provision. In those communities where there were more positive service outcomes for children and families, leaders shared several qualities: a broad vision of the service system;

knowledge about recommended practices; communicators of recommended practices to staff through training, supervision, mentoring and modeling; resourceful and flexible; bridge-builders; adept at understanding complex situations, creating change and managing talent.

State Policy. Policy is defined as "the rules and standards that are established in order to allocate scarce public resources to meet a particular social need" (Gallagher, Harbin, Eckland, & Clifford, 1994). Three aspects of state policy are linked to service delivery: breadth, emphasis, and specificity. As discussed early in this paper, the *breadth* of the state's eligibility policy, in general, seemed to be linked to the percentage of children served in three states. The three states had differing levels of eligibility policy (broad, moderate, and narrow). The state with the broadest policy served the highest percentage, while the state with the narrowest policy served the lowest percentage of infants and toddlers with disabilities. However, there were differences among the three communities in each state with regard to the percentage of children served, indicating that state policy is only one of the influential factors related to the percentage of children deemed eligible and served.

Although all three states' policies addressed the components contained in the federal legislation (Part C and Part B of IDEA), the *emphasis* of the state policy, as well as the areas stressed by policy makers, were linked to variability in service delivery. As reported earlier in this paper, the state in which policy makers most *emphasized* serving children in inclusive settings served a higher proportion of children in these settings than the other two states (Kochanek &

Buka, 1995). Similarly, the communities in the state that had a policy *specifying* particular interagency structures and mechanisms, were among the more comprehensive and cohesive interagency service delivery models in the study.

Finally, one of the state's policies was written in bureaucratic language and contained processes that were more bureaucratic than the other two states' policies. This bureaucratic *emphasis* was associated with community service delivery models that were more insular and bureaucratic and lacked the necessary flexibility to establish an interagency system or to be responsive to families. Families in this state more frequently "ran into the walls" of the system than families in the other two states.

As discussed earlier, one state provided more *specificity* with regard to the assessment process than the other two states. Consequently, assessment practices in this state more closely resembled best practice than in the other two states. Although the policy characteristics of emphasis and specificity were discussed separately; they are usually intertwined. Those aspects that are emphasized in the written policy and by policy makers usually contain more policy specificity as well. The amount and nature of policy specificity and emphasis helped to shape the community service delivery models and processes, as well as the values of local program coordinators.

Context. Several contextual factors within the community play a role in influencing service delivery. These include: local economy, leadership, culture, population demographics, political climate, geography, history, and available resources. This cluster of contextual factors interact in unique ways in each of

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the communities. Merely by living in a particular community, service leaders, service providers and families receive powerful and unique messages influencing the way they think and behave, as well as influencing their expectations of individuals and institutions within the community. For example, as a result of the community context, individuals designing and implementing early intervention may expect to solve problems cooperatively and to generate resources, despite a poor local economy, believing that all people in the community can contribute to solutions. Conversely, in a different community, because of their experience with ineffective community leaders, individuals may feel that human service problems are insurmountable, resulting in lowered expectations and passivity, feeling they must accept what is provided.

Accordingly, those who seek to make changes in the design of the service system need to understand how the desired changes will fit with the context of the community. If the desired service system changes are different from the attitudes, values, and expectations of the community at large, these differences should be addressed, or those participating in service delivery as providers and recipients will experience significant barriers.

CONCLUSIONS: What Have We Learned From All Institute Studies?

Approximately 10 years after the enactment of the P. L. 99-457 (now included in the Individuals with Disabilities Education Act), a study of the implementation of this monumental federal policy in 9 select communities revealed that

communities have made progress in some areas, while much remains to be done in other areas. Taken together the findings of the various ECRI:SU studies indicate the following:

1. Utilization of Infant & Toddler and Preschool services is high, particularly in comparison to the utilization rates of other federal entitlement programs.
2. Percentages of children served, indicate that not all eligible children are being served.
3. The average amount of *specialized* intervention services provided to Infants & Toddlers is 1.7 hours for one week, while Preschool children receive an average of 18 hours if they are in segregated settings and 11 hours if they are in inclusive settings. Given the rate and nature of the development of the young child, it is possible that the amount of intervention needs to be increased for infants and toddlers.
4. Although many communities have put together an array of resources beyond the Infant & Toddler and Preschool intervention programs, most have failed to put together a sufficient array (specialized and non-specialized) to address the diverse needs of both the child and the family.
5. A significant proportion of Infant & Toddler (34%) and Preschool (56%) services (particularly education services) occur in inclusive settings.
6. Better service outcomes for children and their families occurred in the more comprehensive and coordinated service delivery models (N=4

communities) for Infants & Toddlers and (N=3 communities) for Preschool children with disabilities.

7. Despite attempts by program coordinators to develop a "seamless" system of services, only one of the study communities had developed a seamless system. In other communities, differences in the Infant & Toddler and Preschool systems posed substantial obstacles for families and service providers at the time of transition.
8. Many of the values which undergird the legislation and guide recommended practice have not been fully implemented.
    - Services continue to focus on the needs of the child, instead of being family-centered.
    - Therapies most often consist of a more traditional, clinical, pull-out model instead of being integrated into normally occurring activities.
    - Very little service integration, transdisciplinary or interdisciplinary service provision is occurring.
    - Reliance on items from criterion-referenced assessment devices to guide intervention has resulted in a curricular focus which does not always reflect child development principles, utilize naturally occurring routines or broader community resources.
9. Parents are highly satisfied with services, but also report that they are "uninformed consumers."
10. Intervention is influenced by a multiplicity of factors, supporting the ecological theory of development. However, the *leaders* of the Infant &

Toddler and Preschool Programs had a significant influence on the service delivery model, as well as the skills and attitudes of the service providers under their employment, and in turn on the relationships that were developed between families and service providers.

WHAT NEEDS TO HAPPEN NEXT?

Findings from the Institute and the conclusions that emerge from these findings support the ecological theory of development (Bronfenbrenner, 1979), indicating the need for systematic and concentrated efforts at all levels of the early intervention and early childhood ecology, in order to facilitate continued improvements in service delivery. Several improvements are needed if we are to better facilitate and maximize the development of young **children** with delays and disabilities. Although much of the current emphasis of the intervention is on the child, we need to change many of our intervention techniques and practices if we are to maximize child learning and development. Based on our knowledge of how children develop and learn, intervention activities should be more *integrated*. This can be accomplished through the increased use of the following practices: the transdisciplinary approach; interventions which capitalize on the child's natural routines and activities; use of natural community settings and resources; and therapies integrated into other intervention activities as well as the child's natural routine.

The transdisciplinary approach and the integration of therapies, requires developing an equal partnership with child care providers, as well as other

professionals. The typical "consultant" model sets up the consultant as the *expert* and the child care provider or the teacher as the consumer. It's a one up – one down model. Similar to relationships with families, partnerships with each party recognized as having valuable information and playing an important role is more likely to facilitate the integration of specialized activities into the child care experience.

Coupled with the increase in the use of the preceding practices, service providers need to reduce frequently used techniques such as reliance on the items from criterion-referenced assessment devices, the diagnostic prescriptive model, and pull-out therapies. Shifting the emphasis on the types of intervention practices requires the use of multiple strategies. These strategies need to utilize the knowledge of child development and break down the disciplinary boundaries. *Training* is needed so that service providers know how to use more transdisciplinary and integrated practices. In order to facilitate the ability of service providers use these practices, new administrative *models* need to be developed. Models of administrative structures that address the logistical difficulties encountered in facilitating cooperative planning and direct service provision also would be helpful. In addition, state policy makers need to develop new funding and reimbursement models that accompany *policies* which facilitate, not hinder, transdisciplinary, integrated service delivery across professionals and agencies.

The ecological approach also calls for an increased focus on the **family**. Although many service providers are consistently responsive to the wishes of

families regarding the education of their child, increased emphasis is needed in: 1) viewing the family as a legitimate recipient of services (Harbin, 1993; Winton, 1986); 2) enabling parents to be informed partners; and 3) building family capacity to independently address the needs of their child. Revisions to *policies* and *procedures* are needed to portray early intervention and preschool services in written descriptions as a comprehensive system of services with an array of resources to meet the diverse needs of children and their families. In addition, policy revisions are needed to require service providers to "open the door" to a family-centered approach by requiring and providing guidance in policy regarding the systematic, but unobtrusive assessment of families' strengths and needs. *Training* approaches which go beyond the awareness level, to developing the complex skills necessary to "open the door" to a more family-centered approach are needed. Use of the case method of instruction (McWilliam, 1992) and parents as trainers are potentially useful training strategies. As part of a more family-centered approach, better *training* models are needed to facilitate the development of more empowering relationships between families and service providers. Empowering relationships are dependent upon both parties being informed about best intervention practices and the available intervention resources within the community.

Perhaps the service provider styles and relationship typologies developed by Harbin, Shaw, McWilliam, Westheafer, and Frazier (1998) referred to earlier in this report might be useful in helping service providers learn how to develop more empowering and capacity building relationships with families. The

typologies also could be used by supervisors as part of their staff supervision and evaluation process. Research could be used to determine the effectiveness of various training strategies, such as the case method of instruction (McWilliam, 1992), role playing, mentoring, or coaching. Finally, *models* for providing easily accessible information to families about the array of specialized and natural resources and services within the community, using different formats and channels of communication would be beneficial to families. In addition, easily accessible information about best intervention practices in family-friendly language and formats are needed as well.

Improvements are needed in **service delivery systems**, making them more comprehensive and coordinated. *Models* are needed for a more comprehensive and coordinated child find process in order to find all eligible children at both age levels (i.e., birth to three and three through five years of age). In addition, models for developing and "mapping" a comprehensive and coordinated system of services along with models for evaluating the "system" of services instead of separate programs are also needed. This requires the identification of appropriate and measurable service outcomes. Guidance in *policy* and *training* is needed to assist local program administrators and LICC members in identifying a broader array of services and resources, knowing how to use those resources, and developing administrative, fiscal, and organizational structures and mechanisms to support an interagency system of services. Furthermore, models are needed to more systematically and accurately record the services being provided across agencies and programs, if we are to create a

baseline to determine needed changes in the system, as well as to determine the allocation of resources. Equally important are the creation of models to better determine the costs of various services and service delivery models. Also of importance are training programs to improve the skills and abilities of community program leaders. Current training programs ignore training in critical leadership skills, focusing instead on direct services. Many program coordinators need long-term, on-going training that prepares them to be the educational leader within their program (Garland & Linder, 1994), much like the principal is the educational leader of the school. In addition, they also must gain competence working as leaders at the *system* level, another skill for which they often are unprepared.

The ecological theory of development also recognizes the importance of the **community context**. Findings from this Institute reveal that a cluster of contextual factors interacted in unique ways in each of the nine communities. However, two contextual factors were seen as having an instrumental influence on service delivery across communities. These include: 1) support from the community for service delivery to children; and 2) the consequences of community growth and economic development initiatives. Community development *models* are needed which both foster support for, and ownership of, service delivery to <u>all</u> young children in the community by gaining the participation of all relevant stakeholders. In addition, *training* of community leaders is needed so that they will have a better understanding of the impact of their economic development decisions on the service systems within their

community. Equally important is the training of human service system providers from all agencies in the importance of having representatives "at the table" when these important community decisions are being made. Community leaders possibly could be aided in their efforts to better understand the consequences of their decisions if an impact analysis model existed. This model could be used to examine the effects of community decisions on the lives of children and their families, much the same as environmental impact analysis is required prior to finalizing decisions about land use and development. Finally, state policy makers can recognize that the community context will likely influence the success or failure of the implementation of state policies in diverse communities. State policy makers can assist local leaders in identifying potential community contextual barriers and provide suggestions for addressing and overcoming barriers.

IMPLICATIONS

Prior to the implementation of federal policy at the community level, Shonkoff and Meisels (1990) identified four broad challenges in meeting the intent, as well as the letter of the law: 1) matching service goals and recipients; 2) re-thinking traditional disciplinary boundaries; 3) reconsidering parent-professional relationships; and 4) re-designing service delivery systems. Results of the studies from this Institute indicate that local program developers and implementors continue to struggle with these as well as other challenges, well into the process of implementing the law. The programs participating in

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these studies were considered exemplary by state representatives. It is possible that less exemplary community systems may face even more substantial challenges. Although professionals and advocates may seek to initiate the recommendations proposed in this report in order to improve service delivery, they may encounter a variety of barriers. According to Gallagher (1995) there are several types of barriers to implementation: institutional, psychological, sociological, economic, political and geographic. There are few system changes that do not have any barriers standing in the way. Successful implementation often depends upon identifying which barriers are likely to interfere. One must assess and understand the nature of these barriers so that effective strategies can be designed in order to overcome these various barriers.

Despite these barriers, if the promises of IDEA are to be realized, continued improvement is needed in both service delivery and the creation of service delivery models for young children with disabilities. Currently, there is variability in service provision, with children and families in some communities being better served than children and families in other communities, raising important issues of equity. Review of the various findings in this paper indicate that improvements can be made only by addressing several *interacting factors*: no single factor is responsible for service provision. Though development of comprehensive, coordinated service delivery systems is a complex and challenging endeavor, results from the studies within this Institute indicate that it is possible to accomplish with knowledgeable and resourceful leadership, even in those communities with a poor economy. Meeting the various challenges

inherent in implementation is essential if the hopes and dreams of families and the potential of our nations' youngest citizens are to be realized.

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