FINAL REPORT

Funding and Rationale for Early Intervention Services
in Nebraska's *Early Development Network* in 2004

An Evaluation Study
for the Nebraska Departments of Education
and Health and Human Services

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Abstract

Anecdotal information has recently suggested that families of infants and toddlers with disabilities in Nebraska were seeking early intervention services from providers not affiliated with the free, state-sanctioned *Early Development Network* and children's *Individualized Family Service Plans* (IFSPs). This study collected and analyzed data from a variety of sources and populations to document the extent and reasons for such practices across the state. In particular, the incidence of duplicated services were examined for physical, occupational or speech therapy provided by public school employees and reimbursed by the state *Medicaid in the Public Schools* program (MIPS) and also Medicaid providers in the community clinics and hospitals.

The evaluation study analyzed data from four sources, including (a) families of infants and toddlers with disabilities who received early intervention services in 2004 (n = 121), (b) Service Coordinators for the *Early Development Network* across the state (n = 49), (c) experts in Nebraska's early intervention services (n = 6), and (d) the data for infants and toddlers in Nebraska who were on record with the state as referred to the *Early Development Network* and the services they received in 2004 (N = 3,939).

Results suggest that a small percentage of children in 2004 received early intervention services from outside the *Early Development Network* and documented IFSP. Less than half of the families surveyed reported use of non public school providers for PT, OT or SP; less than 10% of the state-wide data showed Medicaid billing from nonschool Medicaid providers for these services. Although as many as 50% of the families surveyed reported use of both school and nonschool services in 2004, less than 3% of all Medicaid-eligible children that year showed billing through both MIPS (schools) and community Medicaid Providers for PT, OT and SP services. Exclusive use of nonschool providers for PT, OT or SP services was reported by less than 7% of the families, and less than 10% of the Medicaid-eligible children in the state database. The majority of exclusive, non-school services reported by families were related to audiology and vision needs followed by psychology, occupational therapy, speech therapy and then physical therapy; payment for these services was most often private insurance.

Families and Service Coordinators delineated two primary reasons why families sought nonschool services for their children: (1) a desire for more or different services than those provided by the school-based IFSP team and (2) physician recommendations.

Funding and Rationale for Early Intervention Services in Nebraska's *Early Development Network* in 2004

Introduction

Nebraska infants and toddlers (birth to age 3 years) with disabilities are entitled under federal (IDEA, Part C) and state special education laws to a variety of health and developmental services through the Nebraska Departments of Education and Health and Human Services. These two departments jointly administer *Nebraska's Early Development Network* (EDN). Typically, a team composed of Network professionals and family members will write an *Individualized Family Service Plan* (IFSP) that specifies the needs of each child and family and describes the services to be provided. A Service Coordinator is assigned to each family to coordinate the team meetings and verify that IFSP plans are written and implemented in effective ways. The services are delivered by professionals who are employed through public schools, private clinics, hospitals and other social/health agencies in the local community. Services by public school employees are provided at no charge to families and can include developmentally-relevant speech, physical and occupational therapy; audiology, vision and psychological services, as well as developmental/educational (teachers) supports and some costs affiliated with transportation and evaluations. Also at no cost to the family is the support and guidance provided by a Services Coordinator contracted with the state Health and Human Services agency. Each of these services is available free of charge through the child's third birthday as long as the child meets state criteria for eligibility under special education rules and regulations and as long as the needs persist. Some medically-prescribed procedures or therapies, nursing support, family counseling, respite, medications and intensive clinical psychological services are not available through the public school-affiliated EDN providers and are often secured privately by families and may or may not be discussed as part of the IFSP.

Recently, anecdotal information has suggested that some families are securing what may appear to be similar therapeutic services for their child through non-public school service providers who may not have been affiliated with the EDN/IFSP team plan. In some cases, these services appear to be in addition to those provided through the EDN/IFSP team of Speech (SP), Physical (PT) or Occupational therapists (OT) while, in other cases, the services appear to be an alternative to those provided through the EDN-affiliated public school employees. Families may be funding these services through Medicaid, private health insurance, or by paying themselves.

Arranging these additional/alternative services is not a violation of any statute. In fact, the philosophy for the IFSP and EDN is to assure access to the most appropriate community services to meet the child's and family's needs. However, the practice is concerning on several levels. It could imply that families believe the services provided free by the EDN-affiliated public school employees are insufficient or of poor quality. Alternatively, it is possible that families are being recruited into these additional for-fee services by providers who seek to build their practices. Or, perhaps costs for these services are being inappropriately shifted onto Medicaid to free public school employee responsibilities/loads. It is possible that families are being overwhelmed with an expectation that they should coordinate with multiple service providers in addition to those already arranged through the *Early Development Network* and

IFSP team. Finally, it is possible that these services are not well coordinated with free, school-affiliated IFSP plans and may present conflicting suggestions for families to consider.

Purpose

The purpose of this evaluation was to describe the non-EDN services being provided by non-public school employees to infants and toddlers with disabilities in Nebraska. Specifically, this evaluation study asked three questions:

1. To what extent are families of infants and toddlers with disabilities securing alternative/additional services outside of the EDN/IFSP team?

2. How are these alternative/additional services being funded?

3. Why are the families arranging for these alternative/additional services?

Evaluation Procedures

There were four parts to this evaluation.

Part 1: An internet-administered survey about non-EDN/IFSP services sent to Service Coordinators in the state;

Part 2: Data analysis of the Nebraska state-wide databases to identify the proportion of infants and toddlers receiving alternative/additional services through state Medicaid programs;

Part 3: A paper survey mailed to a sample of families of infants and toddlers with disabilities who were receiving EDN/IFSP services in 2004; and

Part 4: Interviews conducted with six key stakeholders who were highly familiar with Nebraska's early intervention services.

Part 1: Service Coordinator Survey

All active Nebraska EDN Service Coordinators were notified in advance by the staff of the Nebraska Departments of Education and Health and Human Services that the evaluation was being conducted by evaluators from the University of Nebraska-Lincoln. Then, an email message with a web-link and a password for an online survey was sent to all Service Coordinators. As each Service Coordinator entered the website, they saw the University of Nebraska IRB-Approved 'Informed Consent' information. If they consented to participate in the survey by clicking on the 'yes' button, they were directed to the survey webpage, and then completed the survey online. A copy of the *Healthcare Coverage Service Coordinator Survey* is attached in **Appendix A.** This web-based administration protected the Service Coordinator's anonymity, since the evaluators could determine who signed onto the survey website, but could not determine which Service Coordinators ultimately participated or which survey belonged to

which Service Coordinator. After 2 weeks, Service Coordinators who had not yet signed onto the website were sent a reminder email with the weblink and password, asking them to consider completing the survey. Forty-nine Services Coordinators completed the online survey (70% return rate). These 49 participants represented every geographic region in the state.

Part 2: Database Analyses

Participants in Part 2 of this evaluation were 3,939 Nebraska infants and toddlers, represented in the state *CONNECT*, *Medicaid in the Pubic Schools* (MIPS), and *Medicaid Management Information System* (MMIS) databases as having received any EDN or Medicaid services in calendar year 2004. This included children under age 3 as of August 2004 referred to EDN and assigned a Service Coordinator but for some reason did not receive special education services, as well as those with IFSPs and documented school-sponsored intervention services that year. The Nebraska Departments of Health and Human Services and Education maintain these databases to track services provided to infants and young children with disabilities. These include the *CONNECT* database that describes and tracks the referral, eligibility and IFSP team services for each eligible child with disabilities; the MIPS database that tracks PT, OT and SP services provided by Nebraska's public school employees for Medicaid-eligible children and the Medicaid compensation to the schools for those billed services; and the MMIS database that documents any health and social services funded through Nebraska's Medicaid program. The information from these databases was analyzed to determine which services were provided (PT, OT, SP or other), and whether they were funded through the (free) IFSP public school services, MIPS, traditional Medicaid, some combination of these resources, or through some other means. Percentages were calculated on the total EDN database for 2004 as well as the subset of Medicaid–eligible children and services.

Database records were analyzed independently for six geographic regions of the state. Each region was titled with the name of its largest city or town; however, together the regions comprise the entire state of Nebraska. The six regions are: Omaha, Lincoln, Norfolk, Kearney, North Platte, and Scottsbluff.

Part 3: Family Survey

Participants in Part 3 of this study were parents or guardians of infants and toddlers with disabilities who received services through Nebraska's Early Development Network IFSP teams in 2004. The parent/guardian names and addresses were drawn from the *CONNECT* database by personnel employed at the Nebraska Department of Health and Human Services. To be selected, their children must have been special education verified, received services in 2004, and were birth to 3 years of age in that calendar year. The number of children who met these criteria was 2,648. A stratified random sample was drawn from this original list, with stratification by the six geographic regions used in the Part 2 database analysis. A sample size of 818 was determined to be necessary by assuming a desirable 55% return rate and a 10% margin of error (within each region) for proportions near 50%.

Families of these 818 children were mailed the *Healthcare Coverage Family Survey* with a consent information sheet stapled on top, and a postage-paid return envelope enclosed. A copy

of the *Family Survey* is attached in **Appendix B**. They were asked to read and remove the consent information sheet, complete the attached survey and return it in the enclosed postage-paid envelope. After 2 weeks, all families were sent a reminder postcard asking them to consider completion and return of the survey if they had not already done so.

Of the 818 surveys that were sent, 37% had inaccurate or outdated addresses. Of the 818 mailings, the post office forwarded 97 surveys to changed addresses and returned 202 surveys as undeliverable or with a forwarding time that had expired. When this problem occurred, the evaluators hired additional personnel and attempted to correct addresses (using forwarding addresses supplied by the US post office) or randomly replaced families with others from the same region. This additional mailing started another wave of undeliverable returns, which the evaluation staff found challenging to monitor/track. There were an additional 54 returned surveys which were not replaced or resent, often because the number of eligible families in a region had been exhausted. The final return rate of 15% fell far below the desired response but yielded 121 useable surveys and represented all regions of the state.

Since parts of the survey were intended only for families who had received non-IFSP services in 2004, inconsistencies in family responses sometimes occurred. An example would be a family who indicated that they did not receive any services from a non-IFSP provider but also indicated that they paid for non-IFSP services using private insurance. These responses are inconsistent; if the family received no services, they should have nothing to pay for. In cases where inconsistencies were found, the earliest response on the survey was considered to be the respondent's "true" response, and subsequent responses were adjusted accordingly. This process of correcting inconsistencies was completed before any percentages were calculated.

Part 4: Expert Interviews

Individual telephone interviews were conducted with six Nebraska residents who are experts in special services for infants and young children. The participants included: two Medicaid providers of SP, PT or OT services to infants or young children; two public school providers of SP, PT, OT services to infants or young children; one school administrator who contracts for SP, PT or OT services and supervises the IFSP team services of public school employees; and one administrator from the state EDN Services Coordination program. The interviewees represented service in urban and rural areas of the state and four of the six geographic regions established for this study. Recommendations for this pool of experts were solicited from the Nebraska Departments of Education and Health and Social Services, and also from university faculty members with expertise in early intervention services. Investigators then invited the interviewees from this larger group.

Prior to the interview, each interviewee was provided a fact sheet summarizing the major findings from Parts 1, 2, and 3 of the evaluation, including information from the Service Coordinators, families and state databases. Then they were asked the following nine questions:

1. What surprises you and what does not surprise you about the earlier results of this study?

2. What are the reasons why families would use other community-based PT, OT, or SP services as a replacement for or complement to the services available through the IFSP team?

3. What advantages are there to having services from providers outside the IFSP team; consider advantages to families, IFSP team members, children, and agencies?

4. What disadvantages are there to having services from providers outside the IFSP team? Again, consider disadvantages to families, IFSP team members, children, and agencies.

5. From your experience, who most often initiates the decision to seek PT, OT, or SP services from outside the IFSP team?

6. Over the past two years, do you think there has been an increase or decrease in the use of multi-agency providers of PT, OT, and SP by families with an IFSP?

7. What conflicts of interest do you anticipate if families seek services from the same discipline but more than one provider?

8. What are the cost issues associated with families' use of PT, OT, or SP providers who are outside the IFSP team?

9. Is there anything else that you think we should consider in evaluating these data?

Specific questions were followed, as appropriate, by requests for clarification, examples, or elaboration.

The telephone interviews were conducted by an advanced graduate student who was trained in consultation interviews. She took careful notes during the interview, and then emailed these notes back to each interviewee, so that the notes could be checked for accuracy and completeness. She also prepared a summary of common themes for each question, which is found in **Appendix C.**

Results

The results are organized around data collected in each part of the study to answer the following three questions.

Question 1: To what extent are families of infants and young children with disabilities securing additional or alternative services outside of the Early Development Network?

Question 2: How are these additional or alternative services being funded?

Question 3: What are the reasons why families are arranging for these additional or alternative services?

Additional information related to each question is provided as it contributes to an understanding of the study as a whole. The final section provides results of the qualitative analyses of key open-ended questions on the family and service coordinator surveys and phone interviews.

When regional comparisons are made in this report, they reflect a cluster of communities around a major city and represent the Early Childhood Planning Regions in that part of the state. Table 1 summarizes the planning regions associated with the six geographic regions used for this study.

Table 1. Geographic Representation

Geographic Regions for this Evaluation Study	Early Childhood Planning Regions Represented	No. Service Coordinators Participating (n = 49)	No. Families Participating (n = 121)
Omaha	3, 19, 20, 21, 22, 23, 24, 25	15	19
Lincoln	4, 5, 6, 18	8	25
Norfolk	1, 2, 7, 8, 29	11	17
Kearney	9, 10, 11, 26, 28	7	32
North Platte	15, 16, 17, 27	4	13
Scottsbluff	12, 13, 14	4	15

Question 1: To what extent are families of infants and young children with disabilities securing additional or alternative services outside of the *Early Development Network*?

Service Coordinator Response

Thirty-four (69%) of the Service Coordinators responding reported that some families they served with IFSPs in 2004 had sought PT, OT or SP services from service providers other than the public school employees. Service Coordinators estimated that an average of 7.5% of the families sought these services in addition to those offered by the IFSP-affiliated public school employees. The Service Coordinators estimated that less than 1% of the families in 2004 sought such services in lieu of those provided by the IFSP team.

Database Analyses

As of December 1, 2004, the Nebraska Department of Education reported that 1,303 children under age 3 were receiving free special education/IFSP services in Nebraska (*Special Education Student Information System* [*SESIS*]). The current study was interested in those children under age 3 that year who received early intervention services that could be provided by the public school (free) special education programs or through a community-based medical provider. The inability to interface the *SESIS* and *CONNECT* databases, however, required the present evaluation to consider all children referred to EDN in 2004 in calculating the percent of children receiving specific services. Analysis of the *CONNECT*, MIPS, and MMIS databases revealed that only 887 children (of the 3,939 referred to EDN) received one or more of the PT, OT, SP, Psych and/or Audiology services available from school or non-school providers. Only 15% to 22% of the children referred received any PT, OT or SP services (see Table 2); less than 4% received any Audiology services and less than 1.5% had Psychology services documented in *CONNECT*.

These data concurred with the service coordinator data estimating the number of families and showed that relatively few EDN children in 2004 were receiving services funded by both MIPS (by public school employees) and Community Medicaid (by non-public school providers). Databases were examined specifically for PT, OT and SP services since these are the only MIPS-reimbursed services (see Table 2). Analyses showed that 29% of Medicaid-eligible EDN children received PT services in 2004, but only 2% of all Medicaid-eligible children were receiving services funded by MIPS and also receiving additional services from community PT providers, funded by Medicaid. Similarly, 30% of Medicaid-eligible EDN children received OT services, but only 3% received services from both public school (MIPS) and community-based OT providers for Medicaid). While 32% of Medicaid-eligible EDN children received SP services, only 1.7% received services from both public school (MIPS) and additional community Medicaid providers. Analyses of the MMIS database showed that 23 EDN children received Psychology services that year from nonschool providers and a total of 187 children secured Medicaid-funded Audiology services. These numbers are different from those reported in the *CONNECT* database for these services but it can not be discerned whether they are additional or duplicated counts of children.

In contrast, the analyses of the state databases, also summarized in Table 2, show that 7 to 10% of the Medicaid-eligible infants and toddlers in 2004 were receiving PT, OT and SP services through Medicaid only and were not receiving MIPS-funded services from public school employees.

Table 2: Frequency and Percentage of EDN Services Provided Free or Funded through Medicaid

	EDN database	Physical Therapy	Occupational Therapy	Speech Therapy	Audiology	Psych
Children receiving EDN service	3,939	636 (16%)	598 (15%)	887 (22%)	139 (3.5%)	61 (1.5%)
Non-Medicaid-eligible children (% of all children receiving the service)	3345 (85%)	451 (71%)	421 (70%)	606 (68%)	*	*
Medicaid-eligible children (% of all children receiving the service)	594 (15%)	185 (29%)	177 (30%)	281 (32%)	187 (*)	23 (*)
Children receiving services funded only by MIPS (% of all Medicaid-eligible children) [a]		111 (19%)	105 (18%)	230 (39%)	0	0
Children receiving services funded by both MIPS and Community Medicaid (% of all Medicaid-eligible children)[a]		13 (2%)	18 (3%)	10 (1.7%)	0	0
Children receiving services funded only by Community Medicaid (non-school employees) (% of all Medicaid eligible children) [a]		61 (10%)	54 (9%)	41 (7%)	187 (31%)	23 (4%)

[a] *Percents calculated using 594 Medicaid-eligible children as the denominator*
**Discrepancies between CONNECT and MMIS databases prevent an accurate calculation of eligible children for these services*

Also of interest from these data analyses was the fact that the percentage of Medicaid-eligible EDN children who were receiving PT, OT and SP services from any provider in 2004 was greater than the percentage of non-Medicaid eligible EDN children receiving these same type of services. This pattern was consistently evident across all three service-types, and across all regions of the state (See Table 3). Specifically, Medicaid-eligible children were 2.4 times more likely to be receiving PT services than non-Medicaid-eligible children, 2.3 times more likely to be receiving OT services, and 2.6 times more likely to be receiving SP services. This discrepancy is not necessarily a sign of differential treatment planning for Medicaid-eligible and non-eligible EDN children. Children who are Medicaid-eligible are living in families with lower-incomes and higher rates of other demographic risks relative to non-Medicaid eligible children. These same demographic factors are often related to more frequent and more severe delays or disabilities.

Table 3. Number (%) of All EDN Children per Region in 2004 and Frequency of PT, OT and SP Services Provided to Non-Medicaid- and Medicaid-Eligible Children

	Kearney		Lincoln		Norfolk		North Platte		Omaha		Scottsbluff		Totals	
	No.		No.		No.		No.		No.		No.		No.	
Total children in EDN[a]	588		839		515		216		1599		182		3939	
Not Medicaid Eligible[b]	441		702		428		181		1441		152		3345	
Medicaid Eligible[c]	147		137		87		35		158		30		594	
Physical Therapy														
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Total Receiving PT	76		146		103		29		258		24		636	
Not Medicaid Eligible	31	7%	91	13%	79	18%	17	9%	215	15%	18	12%	451	13%
Medicaid eligible	45	31%	55	40%	24	28%	12	34%	43	27%	6	20%	185	31%
Occupational Therapy														
Total Receiving OT	60		121		94		32		250		41		598	
Not Medicaid Eligible	11	2%	78	11%	70	16%	25	14%	204	14%	33	22%	421	13%
Medicaid Eligible	49	33%	43	31%	24	28%	7	20%	46	29%	8	27%	177	30%
Speech Therapy														
Total Receiving SP	127		167		143		79		319		52		887	
Not Medicaid Eligible	25	6%	111	16%	106	25%	61	34%	266	18%	37	24%	606	18%
Medicaid Eligible	102	69%	56	41%	37	43%	18	51%	53	34%	15	50%	281	47%

[a] values in this row were used as the denominator in calculating the percents noted for each regions' *Total Receiving PT, OT, SP*
[b] values in this row were used as the denominator in calculating the percents noted for each regions' *Not Medicaid-Eligible for PT, OT, SP*
[c] values in this row were used as the denominator in calculating the percents noted for each regions' *Medicaid-Eligible for PT, OT, SP*

Family Response

The *Family Survey* included two items that directly addressed the question related to who provided them with services for their children in 2004. One question asked about any services which were received from BOTH an IFSP school employee and another provider, and a second asked about services received from a provider who was not on the IFSP team. Given the low response to the family survey, results are reported statewide as a range of estimated values (Figures 1 and 2) and not by regions. Since the results of the *Family Survey* are based on a relatively small sample of families, it is likely that the survey percentages do not exactly match the real percentages that would have been found from surveying all IFSP families in Nebraska. Therefore, instead of reporting the exact percentages estimated from the sample, we report a range of plausible percentages that are likely to contain the result we would have found had we surveyed all families. Researchers refer to this range as a 95% confidence interval. For example, we estimate that between 28% and 48% of Nebraska IFSP families in 2004 received PT services from both the IFSP team and another provider. As indicated previously, the sampling intent was to limit the margin of error to 10% within each region; this was not possible due to the lower than expected response rates. However, margins of error for statewide estimates were still generally less than 10% as can be evidenced by the width of the intervals on the Figure charts.

Examination of the figures show that it was more common for survey respondents to receive services from BOTH an IFSP school employee and another provider (Figure 1) than to receive services only from a provider who was not on the IFSP team (Figure 2). Results also show that PT, OT, and SP services were received more often than vision, audiology, and psychology from BOTH an IFSP school employee and another provider (Figure 1). It is estimated that no fewer than 24% of the families had early intervention services from two providers (school and nonschool) in 2004. A different pattern of results emerged for the services rendered from a single provider who was not on the IFSP team. In this case, vision and audiology services were received more often than PT, OT, and SP services (Figure 2). Estimates based on the responses of the 121 families suggest that no more than 7% of the families with IFSPs in 2004 had PT, OT or SP services from a single, nonschool provider.

Expert Stakeholder Responses

Expert stakeholders had mixed reactions to the data from families and service coordinators. The EDN-affiliated practitioners interviewed were surprised that so few families were accessing additional or alternative services in their communities; they had the perception that more families were seeking such services. Four participants reported that the family reports matched their expectations for the reported use of both free and for-fee services; it was their view that this trend has been increasing in recent years or at least in concert with increased populations in their respective communities. Three professionals interviewed commented on the disparity between family and service coordinator reports; suspected explanations were not provided for the service coordinators' lower estimates for duplicated services.

Figure 1. Family-reported services received from <u>both</u> the IFSP team and another provider (mark all the apply)

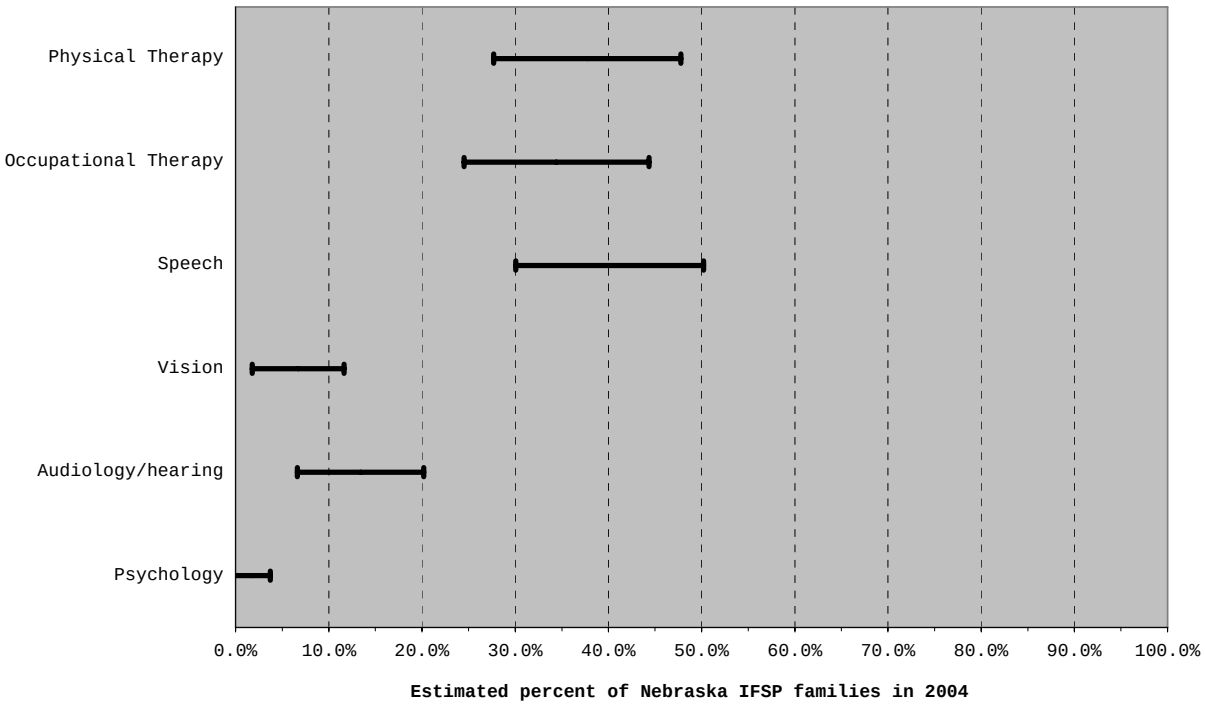
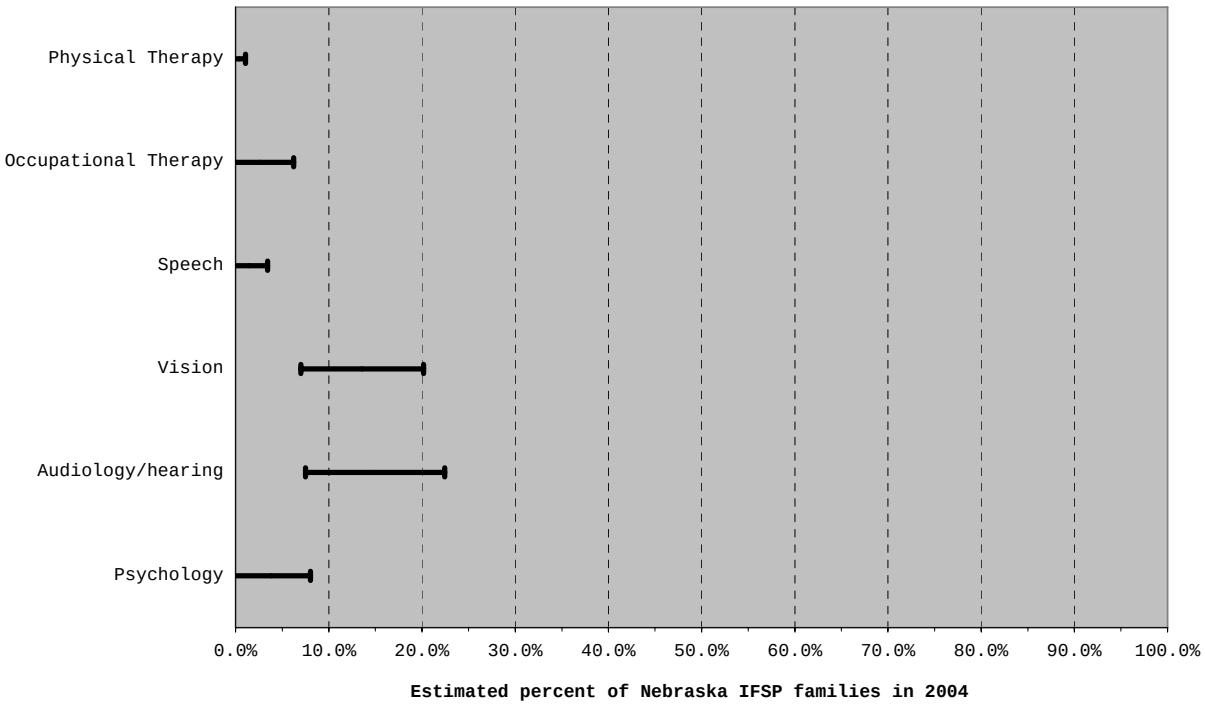


Figure 2. Family-reported services received from a provider who was <u>not</u> on the IFSP team (mark all that apply)



Question 2: How are these additional or alternative services being funded?

Service Coordinator Responses

Service Coordinators were asked how various services were funded. Although they could not provide valid counts of families per service, they could report whether *any* families funded PT, OT, SP or other services with Medicaid, Private Insurance or private pay and their estimates of the number of families using each provided a suggested profile of funding practices. Depending on the service, approximately half of the Service Coordinators (49 to 53%) reported having families in 2004 that used the free PT, OT or SP services of the EDN public school employees. Only about 30% (27 to 31%) reported knowing of families who used Medicaid to pay for non-school therapy services and less than one-fourth could recall families paying for these services with private insurance (12 to 22%).

The service coordinators' estimates of the numbers of families receiving services funded by private insurance was very small (between 1% and 5% of families). Their estimates of families receiving Medicaid funded OT and SP services was also quite small (between 1% and 2% of families). Estimates for the number of families receiving PT services funded by Medicaid were more substantial (approximately 14%).

Family Responses

Since IFSP services from public school employees are free to families in Nebraska, the *Family Survey* included a question about payment to providers who were not on the IFSP school team. Figure 3 presents interval estimates for these family-reported results, by each service provided. Despite what Service Coordinators assumed, results from *Family Survey* respondents who utilized non-IFSP services show that private insurance was the most common source of payment for all services and was used most often to pay for audiology/hearing and vision services, followed by OT and PT, then SP services.

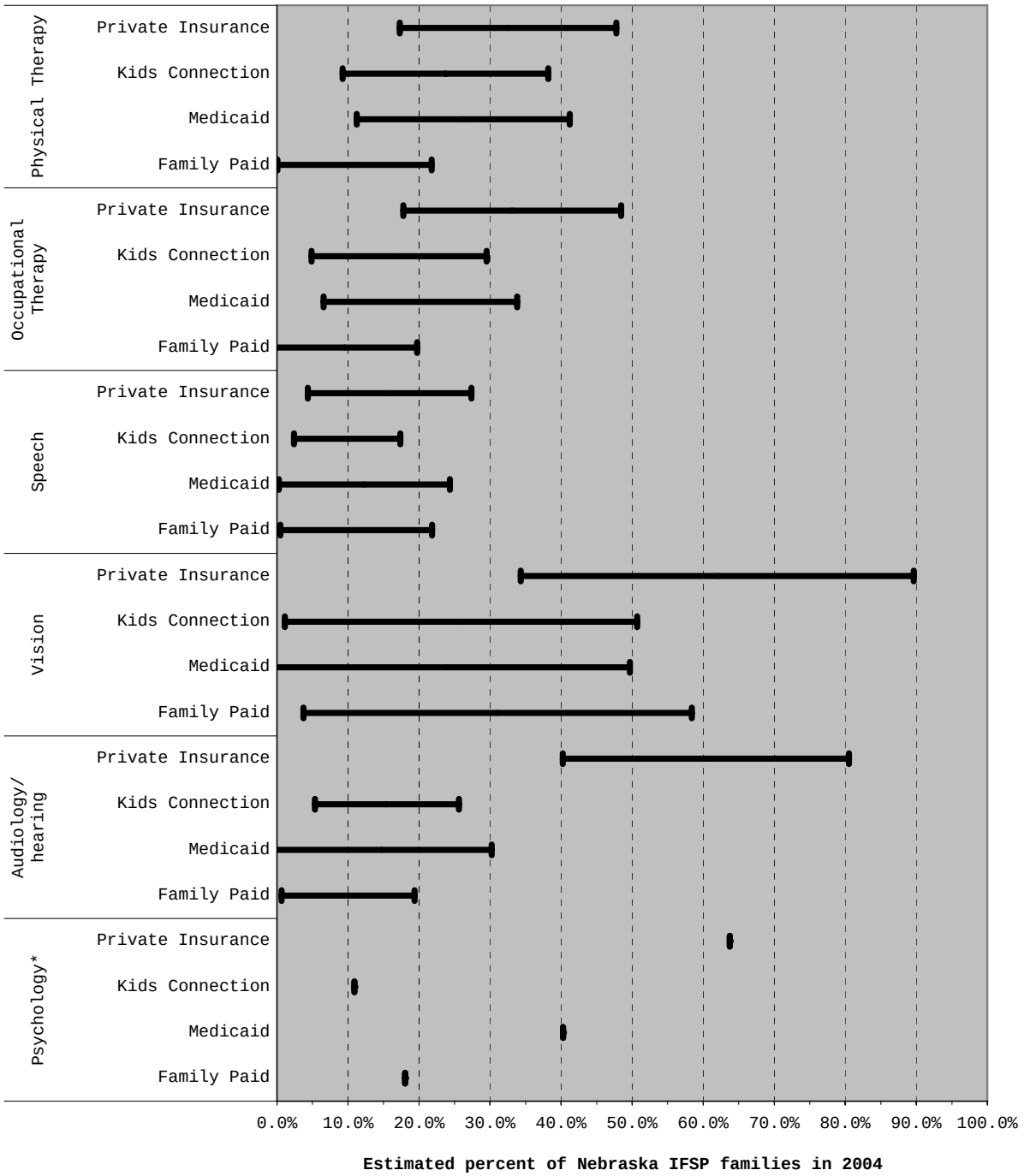
Parents and caregivers' answers to another question provide additional insight. Most families responding to the survey reported having private health insurance (61% $\pm$ 10%) but some did report the use of Medicaid (26% $\pm$ 9%) or Kids Connection (23% $\pm$8%).

Expert Stakeholder Responses

Although professional experts were not asked in their interviews how they thought these additional or alternative services were funded, a few commented on the cost implications of these early intervention services. One interviewee found the low numbers associated with dual billing across the state reassuring since it matched the infrequent practice in his/her own community. However, a recurring theme across the interviews was the concern that Medicaid may be paying twice if families seek or are encouraged to seek services in addition to those provided by EDN-affiliated school employees whose services are reimbursed through MIPS. One person said:

Medicaid and Kids Connection may be paying for the child's services outside the IFSP and reimbursing school districts for part of their services as well---- thus Medicaid ends up paying twice.

Figure 3. Family-reported payment source of services when the provider was <u>not</u> on the IFSP team (mark all that apply)



**Margin of error not available. There are planning regions in which no familiy answered this question*

One person, however, viewed MIPS as a funding source independent from Medicaid billing in the community and saw no duplication of service or charges when a child received therapy from both the school and private providers (i.e., PT from both).

> *We've been told by families that Service Coordinators say not to double-dip into Medicaid but MIPS and medical aid are two different [things]….they're not the same pool.*

Another commented that although payment for private services can be a concern and deterrent for some families, "*it's not a big issue because people frequently have Medicare, Medicaid or insurance.*"

> Finally, one administrator noted the lack of detail in the data since some families may have insurance but also be Medicaid-eligible for their child's services.
>
> *….how many of these families are paying primarily using insurance? Or are they maxed out on insurance and Medicaid is paying? Or are some families just on Medicaid?*

In addition to systems' costs, the cost to families was mentioned by more than one person interviewed.

> *If the family has insurance the family may pay 20% of a session…. they may end up paying lots of money.*
>
> *The parents have to get time off work and bring their child to a hospital or rehab center to receive services.*
>
> *If a child has multiple needs they have to go to multiple separate appointments.*
>
> *They spend a lot of time in the car traveling to sessions and have less family time. Families can get burned out with this and there may be disagreement among family members on the importance of going to all these places.*
>
> *I have heard parents talk about volunteering at private therapy clinics doing secretarial duties which helps to pay their therapy bill.*

Question 3: What are the reasons why families are arranging for these alternative services?

Service Coordinator Responses

Table 4 summarizes Service Coordinators' most frequently reported reasons why they thought families chose to pursue alternative/additional therapeutic service of PT, OT or SP. The majority of Service Coordinators (71%) reported that medical personnel

encouraged families to seek these services. The next most often reported (59%) was that the families wanted more or different services than what the school employees were offering. All other reasons listed in Table 4 were reported by less than one-half of the participating Service Coordinators.

Table 4. Reasons for Additional/Alternative Services as Reported by Service Coordinators

Service Coordinator Response	% of Service Coordinators n = 49
Physician, nurse, or other medical staff recommended it	71%
Family wanted more (*or different*) services than EDN was providing	59%
Family began services before they had IFSP and wanted to continue	35%
Specialty clinic recommended it	31%
Other parents recommended it	29%
IFSP team recommended it	29%
Other family members recommended it	22%
IFSP primary provider/home visitor recommended it	14%
Family withdrew from some EDN IFSP services	14%
Family withdrew from all EDN IFSP services	12%

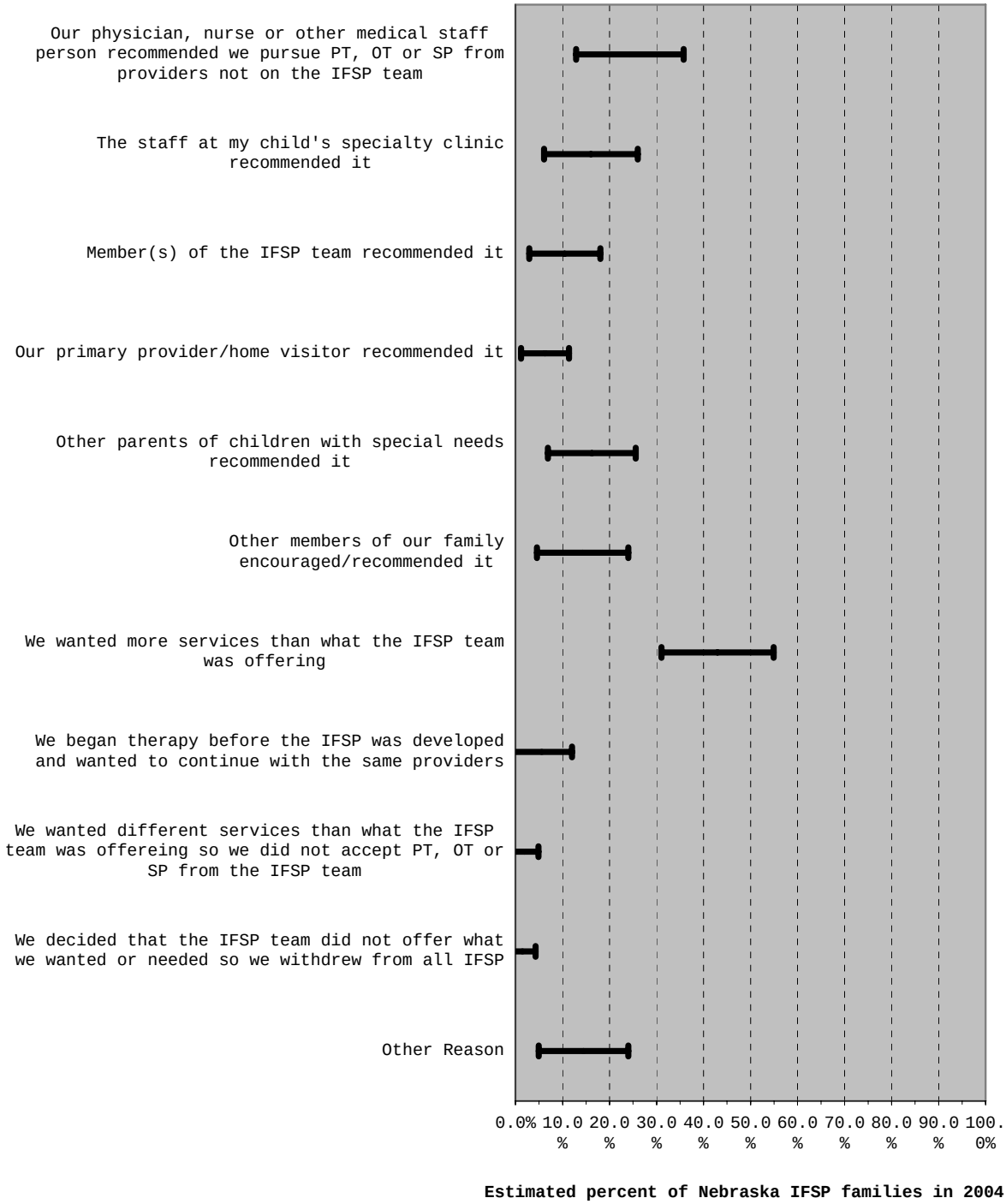
Family Responses

The *Family Survey* also inquired as to the reasons families sought services from a provider who was not on the IFSP school team. The list of possible reasons was constructed using information obtained from the *Service Coordinator Survey*, but allowed for families to add other reasons not included. Results are shown in Figure 4.

Results clearly show that the main reason families reported these alternative or additional services was that families wanted more services than the IFSP team was offering. As Service Coordinators assumed, however, the recommendation of medical

personnel and specialty clinic staff was another common reason families sought these services; but these were not the families' most frequent reasons.

Figure 4. Family-reported reasons a child received Physical (PT), Occupational (OT) or Speech (Sp) Therapy from a provider who was not on the IFSP team (mark all that apply)



Expert Stakeholder Responses

The professional experts interviewed for this study were generally struck by differences in the Service Coordinators' perceptions and families' reports of the primary reasons for additional services for their children.

> *I was surprised by the [data in the] Table----the Service Coordinator responses were higher than the family responses.*

> *I am surprised that Service Coordinators seem to be so out of touch with families.*

One participant offered a possible explanation for these differences:

> *I wasn't surprised that Service Coordinators perceived some of the reasons to be higher than the families reported. Services Coordinators have a different role and different interactions with families and tend to be more likely to hear if families are dissatisfied or uncomfortable with services. I think most of them would then see it to be their role to help the family seek out other services, and their perceptions of how often it actually happens would be elevated. What the Service Coordinator perceives to be "seeking out of other resources" is probably more based on what the family tells them or says they might do, than what the family actually does.*

Like the Service Coordinators, the practitioners interviewed thought medical referrals to private providers were most common. A number of persons interviewed commented on the recent increase in available providers in more communities across the state; the school personnel are no longer the only provider in town and families now have options and added supports. There was also mention of an increased effort on the part of private providers to advertise their services to families and physicians.

> *Two years ago the rehab center developed a marketing plan to let the physicians at the hospital know that they won't help [contract] through the schools [anymore] but that doctors could write prescriptions for their services.*

> *Families find out that there are additional services available . . . through marketing we've done or health fairs.*

> *They will be discussing their child with a physician and the physician will ask what they're getting from the educational system and they sometimes make referrals for additional services.*

> *There's been an increase because physicians are more apt to say that families need it, that the child isn't getting enough or right kind of services from the school team and because there are more outside services available. I've also seen a decrease in the number of referrals to the EDN. Now sometimes the*

physicians make referrals to the medical clinic as opposed to the EDN, whereas in the past, they would consistently make the referral to EDN.

…..the families usually follow doctor recommendations.

Not all practitioners, however, saw the increase to be related to physician dissatisfaction with EDN services.

Families are hooked up from the beginning with a medical provider and prescription before they come to [IFSP]. The majority are already hooked up. Other times the physicians provide a prescription and link families up to the schools at the same time. Some families will drop outside therapy after hooking up with [the schools].

I have heard from others in the state that there are some Service Coordinators who talk the families out of seeking additional services without any explanation. I have also heard that there are other Service Coordinators who will be the ones to initiate discussions with the family about seeking out additional services on their own, because they believe the family isn't getting enough service.

The Child Protection Service workers in our area will refer to a physician or call the rehab center because they can get the child in on a prescription for therapy. If they go through the EDN or IFSP [route], it's not as simple as getting a prescription and therapy.

None, however, were surprised that families reported wanting "more or different services" than those they received from the school employees. Some children, it was suggested, may in fact need more intensive or unique services that the school employees can not or will not provide. Children with high, medically-related needs were suggested as being most commonly enrolled in multiple services in the community.

It is more typical for medically involved children.

With some of the clinical therapy centers, the family has quick and easy access to fittings. They can try other equipment more quickly (if their child needs medical equipment)…. And they can try equipment before purchasing it.

…such as wheelchairs. It depends on how educated providers are in the EDN; some providers in the EDN assist families with a variety of needs and take care of everything; others dish it out to other alternative people/providers.

When a child has surgery, for example.

Some children need access to services like aquatic therapy.

Other reasons suggested for this pursuit of "more or different" service were related to the families' desire for more hands-on approaches than that offered by primary provider models used by some public school teams. But the explanations for this desired

approach were not universally similar. Some participants reported family dissatisfaction with the lack of hands-on approaches by school personnel, or lack of direct access to trained specialists on the school team or limited frequency of service, while others commented on a family's preference for "*the best of both worlds*" and a "*more is better'* philosophy.

> *Families say: "They don't touch my child, but you do; they just watch my child and give suggestions" which is what they should do in their model.*
>
> *Families don't think that the school is appropriately addressing the needs of their child. They don't view the services as intense enough. Most kids on an IFSP are on a consultation thing and may just see a teacher (not a speech pathologist).*
>
> *Families are not happy with what's going on in the schools, and just want more therapy.*
>
> *The model in schools around here is that although the child's primary need might be OT, the provider within the school is chosen on a round-robin basis ….whoever is next in line becomes the child's primary service provider. Thus the service providers within the schools are not as specialized and need to be trained.*
>
> *Parents may have a "more is better' mentality and think that one more resource will always be better.*

Qualitative Analyses

Service Coordinator Responses

Service Coordinators were asked to describe the challenges and/or benefits they experience when families on IFSPs seek to complement or substitute PT, OT or SP services with non-IFSP/public school employees. Although there were far more comments about challenges than advantages, the comments pro and con clustered around a few similar themes. Service Coordinators repeatedly mentioned that it was difficult for families when school and non-school providers had poor communication, coordination or collaboration. Parents could be confused by inconsistent messages or suggestions. Service Coordinators also found it difficult to explain to parents why some specialty equipment was only available in clinics but not homes, as well as to explain the occasional disparaging remarks from some providers about the quality of the EDN provider's approach.

The advantages described by Service Coordinators as being associated with a family's pursuit of alternative or additional therapy services for their child included children making "good progress" and the family feeling they were doing "more" and "all they could do" for their child. Other comments included reference to availability of new and different points of views, access to a therapy that the special education eligibility

criteria prevented the child from receiving for free from school employees; and families feeling pleased with services from a "specialist" in an area vs. a generalist or non-specialized primary provider on the IFSP team. One Service Coordinator implied that coordinated efforts do happen and can lead to "the best of both worlds" for the child and for medical professionals who may have encouraged one or both types of services. **Appendix D** provides a listing of all the Service Coordinator comments about perceived challenges and advantages to non-IFSP services.

Family Responses

An open-ended question on the *Family Survey* elicited comments about what parents/caregivers liked about the services their child received from providers who were and were not on the IFSP team. Comments were read and categorized by a special education graduate student and verified by the project's special education senior investigator. A table quantifying the responses for each service and sample responses can be found in **Appendix E**.

Representative responses of what families liked about the services their child received from a provider not on the IFSP team were generally (1) more frequent service ("*more time each week*"), (2) better equipment and (3) medical/hands-on treatments. Sample responses of what families liked about an IFSP provider were generally related to (1) helpful/practical suggestions ("*could apply ideas to home environment*"), (2) convenient schedule or location ("*She came to our house and school as needed.*"), and (3) quality of interactions ("*therapist is kind, insightful and very caring*"). Overall comments about the IFSP providers emphasized affective dimensions about professionals' interaction with the family and/or the child, i.e. "*the PT is very helpful, understanding,*" and "*She takes her time with my child"* and *"[child] has improved so much.*" Responses regarding providers who were not on the IFSP team focused more on medically-specific approaches and expertise and the frequency or availability of service, particularly in relation to PT, audiology and vision services.

Expert Stakeholder Responses

The professional experts interviewed about the family and service coordinator data also were asked questions that provided more insight to the advantages and disadvantages of services that were additional or alternative to the EDN/IFSP services provided by public school personnel. Similar themes were evident as were noted by the families' and service coordinators' comments. Four participants viewed the use of non-IFSP providers as increasing in their geographic areas and causing challenges for families relative to costs, scheduling, and understanding of the purpose and benefits of different approaches.

> *By differing philosophies, I mean that there's predominance of a hands-off approach with families who want alternative services, and the alternative providers provide the hands-on "therapy"[with the child] while the family sits in the waiting room or watches through one-way mirrors while their child receives*

> *services. This is different from what happens with EDN providers who coach the families and let the family be more involved in and participate in coming up with ideas/strategies to help their child participate and learn through their daily routines.*
>
> *There is more of an effort placed on making it family-centered within the schools.*

However, five of the six persons interviewed also spoke of advantages for families and children in having access to more or otherwise unavailable therapy and access to more professional perspectives.

> *With the new service delivery models [in the schools], kids get lots less therapy than they used to. I think it's all due to them having to follow certain guidelines.*
>
> *There's not a lot of direct intervention with EDN's.*
>
> *People who are in the community have to be licensed to practice and that's not true in schools.*
>
> *There is a greater pool of experience for the family to pull from for ideas, strategies.*
>
> *Also I think it may be possible to provide better services if the agencies are in frequent communication.*

Two persons interviewed for this study spoke of the advantage associated with families having choices and the right of families to seek all the services they believe to be beneficial for their child.

> *Some families have options available to them and they're exercising their right and have the backing of their pediatrician.*
>
> *It gives the family and providers a second opinion and the whole team learns from each other. The family is better able to make an educated decision that suits the family's needs. . . . I think it's good for parents to have choices.*
>
> .

One person spoke of the more family-centered services provided by school employees as a nice complement to the medically-oriented, child-focused services. Another indicated that families are encouraged to always keep the school-offered services even if they augment them with private providers because of the different perspective each can provide. Some commented on successful ventures between school and private providers to the benefit of families and children; distinct roles were outlined and communication with the family and medical community were apparently kept open and reciprocal.

In medically-involved children, I see them as complementing each other.

The school person worked on feeding and the outside person worked on sensory training. It's a coordination of services.

…..the child had reached their goal of full arm extension. It was achieved by a joint effort on the part of both the school and the outside aquatic therapy. Staff and families can both be pleased by the outcomes.

I know of and am involved in many situations where services from both work well, where it is helpful in meeting the child's and family's needs.

All of the persons interviewed, however, commented on the poor coordination of services that generally occurs when families seek PT, OT, or SP outside the IFSP team. Poor communication, and poor or limited efforts at coordination may contribute to possible misunderstanding of what each provider can and does provide. Missed opportunities for what would be optimal intervention for young children with disabilities were described as consequences of dual services in some communities.

Two different providers can be providing counter-productive or detrimental services.

Communication does not always occur between IFSP and non-IFSP providers.

It requires an extra level of coordination.

I think it can work well if you have a therapist that will attend the IFSP meetings. But outside therapists are so busy it's hard to get them to attend.

Usually the medical team is not part of the IFSP. Most often we're not invited to the IFSP; that would be nice to be able to coordinate services better.

We do not feel like the Service Coordinators here have ever given families information about the fact that there are additional services available. It relates back to feeling like there's a competitiveness between educational and medical models.

The main thing is educating the population and making sure all providers/clinics are educated.

Physicians are not educated on the recent EDN shift in their philosophy of providing a coaching model for families with emphasis on a primary provider for the family.

Summary

In order to appreciate the results of the many data sources used for this study, it is helpful to reconsider the size of each database, lest one erroneously compares percentages only. The state databases provided data on 3,939 infants or toddlers with disabilities who were active in the EDN program in 2004. Just 15%, or 594 of these children, were Medicaid eligible that year. In contrast, the family surveys represented only 121 families from across Nebraska who had infants or toddlers enrolled in the EDN program in 2004; a return rate of 15% and far below the desired 55% originally hoped for in this study. Of these 121 families, 26% reported being Medicaid-eligible for the services secured outside the EDN/IFSP team. Another 61% of these families reported using private insurance for the additional/alternative services.

Because we did not have a database on non-Medicaid-funded services outside the EDN/IFSP team, we could not compare state-wide data with family reports on all questions. However, we could look at patterns of reported services and Medicaid-eligible children's use, in particular, of specific services.

Extent of Services Outside EDN

There was mixed but complementary evidence about the use of EDN and non-EDN providers in 2004. Family-reported data suggested that 24% to 50% of the families had children receiving PT, OT or SP services from both IFSP and community providers. Analyses of information from state databases, however, showed Medicaid-eligible children had low rates of dual providers; less than 3% of these children in 2004 had PT, OT or SP services billed to both MIPS and Medicaid directly. Taken together, the data from these two sources would suggest that although dual services may be a practice some families pursue, it is not common for the families represented in state Medicaid databases for 2004. The larger percent of dual services reported by families in the study may reflect the small sample size and possible bias of the self-selected families who, in addition to taking an interest in this survey, may also be financially-capable of paying for nonschool services (51 – 71% had private insurance) and/or more likely to take advantage of all opportunities to help their children. Furthermore, the families may be reporting use of services other than PT, OT or SP, such as Audiology, Psychology or Vision specialists which are not eligible for MIPS reporting and therefore not available for comparison of school and nonschool provided services.

A range of 1 to 7% of the families responding to the survey reported having PT, OT or SP service for their child from only a community, non-public school provider. The family-reported data were not sorted by funding sources. When we looked at the state databases for information related to billing only to Medicaid directly (no MIPS-billed services from the schools) we found that a somewhat larger percentage of Medicaid-eligible children were receiving PT (10%), OT (9%) or SP services (7%) from the community providers. Furthermore, the PT, OT or SP services received from only private providers in 2004 were more common than dual services (school and community)

for Medicaid-eligible children. Reasons for this latter pattern are not clear but may be related to the increased need for any therapy service among Medicaid–eligible children.

Funding of Additional/Alternative Services Outside EDN

Although the family surveys represented a larger percent of Medicaid-eligible families than the state databases (26% vs. 15%), the family-reported data suggested that the majority of PT, OT and SP services received from outside the EDN/IFSP team were funded by private insurance and not Medicaid in 2004. Among the families responding to the survey, private insurance was reported by more than twice as many families than either Medicaid or Kids Connection for OT services, in particular. In terms of frequency of specific services, private insurance was reported most often for vision and audiology services and two times more often for PT and OT services than for SP services. A similar trend existed when Medicaid was the source of funding used, with more of the families reporting Medicaid-paid vision, PT and OT services than SP services. Kids Connection was reported as the payment source by more families for vision services than any other services, followed by PT, OT and audiology services.

Finally, when we reviewed the state databases for all EDN-referred children in 2004 (Table 3), we found that therapy services from any provider (schools or community) were notably more evident for Medicaid-eligible children than those not Medicaid-eligible. The rate of reported PT, OT and SP service was at least two times greater for Medicaid-eligible children; these patterns were noted across all six geographic regions in the state. In three communities, over one-half of the Medicaid-eligible children received SP services in 2004 compared to only 6 to 34% of the non-Medicaid-eligible children in those communities. The use of community-based services for Medicaid-eligible children, however, (dual or exclusively) appears to be infrequent (less than 10%) based on analyses of state-wide databases for 2004, and at lower frequencies than services funded by private insurance, based on family reports.

Reasons for Additional/Alternative Services

Data from the *Family Survey*, *Service Coordinator Survey* and expert interviews clearly show that in 2004 there were two primary reasons why families pursued for-fee services for their children. The *Family Survey* data suggest that families initiated and sought "more or different' services than those offered from the IFSP team. Vision and Audiology services were reported more often than PT, OT or SP services among families responding to the survey and were more often paid for by the family or private insurance. Family comments on the surveys mentioned the physician-prescribed need for treatments related to specific medical conditions not available through the school-sponsored programs as well as complementary services to augment what the schools were providing. It also appeared to be related to more hands-on approaches that comforted some families compared to the reported consultative coaching from school providers.

The family-reported data also shed light on what may be "different" about the PT, OT or SP services children and families received from school and private providers. It

was not clear that school-affiliated providers and non-IFSP providers always did "different" things; the concept of "medical therapies" and "educationally-oriented" services appeared to be blurred and often related to location and frequency of services delivered (i.e., clinic vs. home, twice weekly) as much as they were the specific practices and approaches used. The positive comments about unique equipment, more frequently scheduled sessions and expertise related to private providers were thematically different however, from the positive comments families made about public school providers. The providers associated with the public school IFSP team were more often described as sensitive, supportive, convenient and helpful. Hints at dissatisfaction with IFSP school providers were few in number and related most often to lack of intensity, indirect models of service and perceived lack of expertise. Overall, most families viewed both sets of providers has having something to offer them.

The families' report of physician/clinical staff referral to private providers was secondary to their desire for more and different services. Although families could check 'all that apply" on the survey form, and could have had both reasons driving their decisions to seek community services for their child, it does not appear that the medical community is solely responsible or dictating these practices. Furthermore, other parents, family members and IFSP team members appear to have influenced only a very small percentage of families in their decision to pursue private providers to address their children's needs. The survey did not explore family reasons by type of service/therapy.

The information from Service Coordinators and experts across the state provided supportive insights to the data analyzed from the state databases and family surveys. Both groups suggested a misunderstanding or misperception of how often and why families sought out private providers in 2004. Service coordinators and practitioners assumed a greater use of community services and a greater influence of the medical community than what parents reported. However, both groups did agree with parents that some conditions prompted need for more intensive or unique treatments not available from the school-sponsored providers. The experts interviewed suspected, in general, the use of community providers to be increasing across the state, possibly because of increased populations in Nebraska's communities and/or increased access to private providers in communities (rural) where previously the IFSP school providers were the only options. Also mentioned was perceived family dissatisfaction with school providers' quality or frequency of service as the reason for an increase in private services across the state.

Overall, the six experts called for increased efforts to engage ALL community providers in the development of IFSPs for families and children and not restrict IFSPs to be viewed as "school programs" in competition with "other providers" or as home (convenient) vs. clinic (expensive) services. Similarly, the professionals interviewed felt there was much to be done to educate physicians, families and private providers about possible misconceptions related to "medical" vs. "educational" therapies, the purpose of some treatments/approaches, the Primary Provider Model used in many school-affiliated IFSP teams and the real and perceived limits to both the private providers' and school employees' availability and their options and philosophy for design of services (i. e.,

frequency, focus). A number of interviewees commented on the challenges families face in paying for, scheduling and traveling to services provided outside the IFSP team. They also commented on the "caught in the middle" feeling some families may experience when they try and do all they are told, or believe to be, in their child's best interest but experience conflicting suggestions. Finally, one person commented that mixed messages are possibly conveyed to families when the IFSP Service Coordinator refers to their efforts to "coordinate services" and yet appears to coordinate only school services and makes no attempt to include private providers or consider them as part of the team.

Conclusions and Recommendations

The use of non-IFSP providers of PT, OT or SP services in 2004 was relatively minimal. Despite the fact that 69% of the Service Coordinators in the state reported knowledge of some families who had sought alternative or additional services in the community, and survey data from 121 families suggested that 24 to 50% had used both IFSP and non-IFSP providers for some services in 2004, fewer families (1 to 7%) reported the use of non-IFSP providers exclusively. These family-reported community services were more often vision, audiology and psychology services than PT, OT or SP services when only one provider was used; families reported PT, OT and SP services from both school and nonschool providers. Furthermore, analyses of state Medicaid databases, showed that only 1.7 to 3% of all Medicaid-eligible children with IFSPs in 2004 received services from both school and nonschool providers, while 7 to 10% of the Medicaid-eligible children only secured services from nonschool Medicaid providers. The lack of a comparable database for non-Medicaid-eligible families' use of non-IFSP providers makes it difficult to interpret the data on Medicaid-eligible children. State-wide data do show that Medicaid-eligible children were more than two times more likely than non-Medicaid-eligible children to receive PT, OT, SP services from school providers in 2004, but there may be justifiable demographic reasons for this difference. In addition, private pay and private insurance appear to be used more often (by family report) than either Medicaid or Kids Connection for coverage of costs associated with alternative or additional services.

Overall, non-IFSP providers and Medicaid appear to be responsible for only a small percentage of children's early intervention services in 2004. When children did receive non-IFSP services, the reasons for these services varied by family and child, but were most often associated with a family's desire for more or different services than what the IFSP team provided. Sometimes, but not always, the services were the result of recommendations from physicians. Other mentioned reasons were the need for specialized services and a family's desire to continue with providers involved in the child's treatment prior to the initial IFSP.

This evaluation study provided a preliminary quantitative and qualitative examination of the use of school and community resources to meet the needs of families who have young children with disabilities in Nebraska. The findings suggest that subsequent activity at the state level should include further, more focused analyses of

newer data, interagency training and education and reconsideration of current efforts to achieve interagency collaboration in local communities.

For example, further studies could address the following questions:

1. How do a child's diagnosis, age and severity of disability influence a family's and physician's decision to seek additional or alternative services from that offered by the IFSP team in a local community?

2. Do family reasons for accessing non-IFSP providers differ depending upon the specific service they seek?

3. What factors influence the frequency of services provided by school- and nonschool-affiliated personnel?

4. What guidelines are school employees using to determine whether PT, OT or SP services are needed to meet the developmentally-relevant needs of infants and toddlers with disabilities?

5. Are the trends in the 2004 data stable or is there an increase or decrease in use of Medicaid-billed services from non-IFSP providers in subsequent years?

6. What explains the large number of family surveys returned to the evaluators by the postal service for inaccurate addresses?

Results of the qualitative analyses of comments suggest that public school-employed AND non-school providers, physicians and families should be educated on the following topics:

1. Medicaid policy for payment of services from two providers of same discipline; required documentation of progress and ceiling limits related to maximum number of sessions; the relationship between MIPS and Medicaid billing from the community.

2. Cost implications to families, schools, and Medicaid for services from two providers of same discipline (PT, OT, SP) from different agencies.

3. Available, allowable and forbidden services at no cost to families whose infants and toddlers are eligible for special education programs through the public schools.

4. Perceived vs. actual differences between "medical" and "school" therapies for infants and toddlers.

5. Philosophy and design variations of the primary provider model and family-centered services for infants and toddlers served through school-employed PT, OT, and SP providers.

6. Intervention conflicts and benefits from use of two providers of same discipline (PT, OT, SP) from different agencies.

7. Perceived and actual challenges associated with true interagency representation on IFSP teams.

8. Service Coordinators' role and responsibility to promote, support or discourage the use of services from two providers of same discipline from different agencies. Service Coordinators' responsibility to public school special education personnel, families and medical providers in the community.

Local Early Childhood Planning Region Teams should be encouraged to include both school and non-school providers for PT, OT, and SP services and medical personnel (physician, nurses) in their discussions and activities in an attempt to educate and facilitate collaborative ventures. IFSP teams and Service Coordinators should assure both free, public school and for-fee, private–provider input and collaboration in development of IFSPs for children and families. The philosophy of family-centered, interagency, community based services for children with IFSPs can not be achieved if plans are viewed as dominated by one agency or set of providers, or if providers are viewed as "competitors" for the family's attention. Finally, the state should develop or clarify guidelines for developmentally-relevant practices related to the design and delivery of PT, OT, and SP services for infants and toddlers and share this information with both school-affiliated and non-school providers in the state. Attention might be given to the practices that differ from those considered for children 3 to 21 years of age with IEPs and to the difference between "developmentally-relevant" and "educationally-relevant" intervention services as defined under Parts B and C of IDEA, state Rule and the professional literature on evidenced-based practices in these three disciplines of physical, occupational and speech therapy.

-Respectfully submitted

June 30, 2004

Appendix A

Nebraska Early Development Network
Healthcare Coverage
Services Coordinators' Survey

1. Planning Region # in which you work as a Services Coordinator for the state Early Development Network (EDN):_____

2. When did you begin employment as a Services Coordinator in EDN? _____

3. How many children did you serve last year (January-Dec 2004) through a MDT process?_____

_____

4. Do you know of any children last year who received (PT OT or Speech) early intervention services other than those available through the EDN's IFSP team?

_____ Yes _____ No

If yes, estimate the number for each of the following:

Received PT OT Speech in addition to EDN's IFSP Services: _____ (#)
Received PT OT Speech in lieu of EDN's IFSP Services: _____ (#)

5. If Yes for #4, which of the following professionals worked directly with the children in the past year? Circle all that apply. Then in the columns to the right check all the programs that provided those services.

Service Provider	Free EDN's IFSP Services	Medicaid services	Other Covered Services (Insurance or Private Pay)	Unknown Funding Source
Services Coordinator				
Physical Therapist				
Occupational Therapist				
Speech Therapist				
Infant/Preschool Teacher				
Vision Specialist				
Nutritionist				
Nurse				
Personal Care Provider				
Deaf Educator				
Psychologist				
Motor Activity Aide				
Communication Specialist				
Audiologist				
Respite Care Provider				
Child Care Provider				
Primary Service Provider or "Home Visitor Write here the home-visitor's profession if you know it _____				
Other : ……..				

6. To your knowledge, how many children on your caseload last year (Jan-Dec 2004) received services from any of the following providers outside the EDN's IFSP program?

Service Provider	# of children Covered by Medicaid	# of children Covered by Insurance or Private Pay	# of children with Unknown Coverage
Services Coordinator			
Physical Therapist			
Occupational Therapist			
Speech Therapist			
Infant/Preschool Teacher			
Vision Specialist			
Nutritionist			
Nurse			
Personal Care Provider			
Deaf Educator			
Psychologist			
Communication Specialist			
Audiologist			
Respite Care Provider			
Child Care Provider			
Other : ……..			

7. To your knowledge, why did families in 2004 seek each of these services outside the EDN's IFSP program? Estimate the number of children whose families sought services for each reason below. (Record 0 if you know of no families seeking services for a particular reason. Record "X" if you don't know.)

_____physician, nurse or other medical staff recommended it
_____specialty clinic staff recommended it
_____EDN's IFSP team recommended it
_____EDN's IFSP Primary Provider/home visitor recommended it
_____other parents recommended it
_____other family members recommended it
_____family wanted more or different services for the child than EDN was providing
give example: _____
_____
_____family began such services before they had an IFSP and wanted to continue
_____family withdrew from all EDN's IFSP-covered services
_____family withdrew from some EDN's IFSP-covered services
Which services? _____
_____ Other reasons: _____

8. To your knowledge how many children on your caseload last year (Jan-Dec 20 were eligible for each of the following health-care programs? (Record 0 if you know of no children who were eligible for a particular health-care program. Record "X" if you don't know.)

_____Private Insurance
_____ Kids Connection
_____ Medicaid
_____Low-income eligible
_____ Income waiver eligible
Specify the waivers: _____

9. What challenges or advantages do you face when families seek to complement or substitute IFSP-sponsored services with PT OT or Speech services from other providers?

Nebraska Education Development Network - Healthcare Coverage Family Survey
Planning Region _____

Use an "X" to mark the appropriate box.

1. **Did your child have an IFSP for all of 2004?** ☐ *Yes* ☐ *No*

If no, how many months during 2004 did your child receive IFSP/EDN services?

Number of Months ☐☐

2. **Mark which health care programs you were enrolled in during 2004.**

Private health insurance ..... ☐

Kids Connection Nebraska Insurance ..... ☐

Medicaid ..... ☐

Is your child eligible for Medicaid because of:

Low family income? ..... ☐

Income was waived for the family? ☐

3. **In 2004, which of these services were part of your child's IFSP?**

Service Coordination ..... ☐	*Physical Therapy* ..... ☐	*Occupational Therapy* ..... ☐
Speech Therapy ..... ☐	*Vision* ..... ☐	*Nutrition* ..... ☐
Nursing ..... ☐	*Audiology/hearing* ..... ☐	*Deaf Education* ..... ☐
Psychology ..... ☐	*Respite Care* ..... ☐	

Other ..... ☐

4. **In 2004, which of the following services did your child receive from both the IFSP team and another provider?**

Physical Therapy ..... ☐	*Occupational Therapy* ..... ☐	*Speech* ..... ☐
Vision ..... ☐	*Audiology/hearing* ..... ☐	*Psychology* ..... ☐

5. **In 2004, which of the following services did your child only receive from a provider who was not on the IFSP team?**

Physical Therapy ..... ☐	*Occupational Therapy* ..... ☐	*Speech* ..... ☐
Vision ..... ☐	*Audiology/hearing* ..... ☐	*Psychology* ..... ☐

6. **In 2004, how were the services paid for when the provider was <u>not</u> on the IFSP team? Mark the appropriate boxes for each service.**

Service	**Funding Source**			
	Private Insurance	*Kids Connection*	*Medicaid*	*Family Paid*
Physical Therapy	☐	☐	☐	☐
Occupational Therapy	☐	☐	☐	☐
Speech	☐	☐	☐	☐
Vision	☐	☐	☐	☐
Audiology/hearing	☐	☐	☐	☐
Psychology	☐	☐	☐	☐

7. **In 2004, why did your child receive Physical (PT), Occupational (OT) or Speech (SP) Therapy from a provider who was <u>not</u> on the IFSP team? (mark all that apply)**

My child did not receive any PT, OT or SP therapy services in 2004. ..... ☐

My child only received PT, OT and/or SP therapy from providers on the IFSP team in 2004. ..... ☐

Our physician, nurse or other medical staff person recommended we pursue PT, OT or SP from providers not on the IFSP team. ..... ☐

The staff at my child's specialty clinic recommended it. ..... ☐

Member(s) of the IFSP team recommended it. ..... ☐

Our primary provider/home visitor recommended it. ..... ☐

Other parents of children with special needs recommended it ..... ☐

Other members of our family encouraged/recommended it. ..... ☐

We wanted more services than what the IFSP team was offering ..... ☐

We began therapy before the IFSP was developed and wanted to continue with the same providers. ..... ☐

We wanted different services than what the IFSP team was offering so we did not accept PT, OT or SP from the IFSP team. ..... ☐

We decided that the IFSP team did not offer what we wanted or needed so we withdrew from all IFSP ..... ☐

Other Reason ... ☐

8. **How many <u>miles</u> did you usually drive per session so that your child could receive any of the following services from a provider who was <u>not</u> on the IFSP team?**

Physical Therapy		*Audiology*	
Occupational Therapy		*Speech*.....	
Vision		*Psychology*	

9. **What did you like about the services that your child received from a provider who was <u>not</u> on the IFSP team?**

Physical therapy:

Occupational Therapy:

Speech:

Vision:

Audiology/hearing:

Psychology:

10. **What did you like about the services that your child received from a provider who <u>was</u> on the IFSP team?**

Physical therapy:

Occupational Therapy:

Speech:

Vision:

Audiology/hearing:

Psychology:

Appendix C
Common Themes from Expert Stakeholders Answers to Interview Questions

1. What surprises you and what does not surprise you about the earlier results of the study?

- most were surprised by the significantly different reports provided by families and service coordinators
- most were not surprised by the number of families who said they were receiving services from both outside and in-school providers; some said that they were not surprised that families wanted services in addition to those they receive in the school

2. What are the reasons why families would use community-based PT, OT, or Speech services as a replacement for or complement to the services available through the IFSP team?

- many said that some kids simply need more services (more intensive, or additional) than what the school is able to offer – pertains to more acute needs
- some rural people said that community-based services are more accessible now
- school-based personnel would say that physicians are recommending it, and families are following through on that recommendation
- community-based personnel were more apt to say that the families are seeking it out because they want more direct services, or a different kind of service, than what schools provide; some stated that families are unhappy with the services provided through the school
- many said that families perceive that "more is better"

3. What advantages are there to having services from providers outside the IFSP team; consider advantages to families, IFSP team members, children, and agencies?

- many said that second opinions, collaboration and more information in general are advantages
- community people said that they look at the bigger picture, and provide more comprehensive services; or that they help schools out with services they can't or are unable to provide
- some said that it provides the children with more time and more services

4. What disadvantages are there to having services from providers outside the IFSP team; again, consider disadvantages to families, IFSP team members, children, and agencies?

- Many said that there can be differing opinions, which can make it difficult for the families to know whom to trust, and that it can sometimes make one group look bad (most often it was the schools who "lost face")
- Most said that there are disadvantages to the families, in terms of having to go to appointments, instead of the providers coming to them – also translates to lost work time, having to find a baby-sitter for other kids, loss in work pay, etc.
- Almost all said that communication was difficult – although some community-based people said that it was a result of the IFSP team not inviting them to meetings, while

school-based people said it was because the community people didn't want to or were too busy to come
- A few said that payment was a disadvantage – that people have to pay out of their pocket if they don't qualify for Medicaid
- A few cited "differing philosophies" between the medical and school models as a disadvantage

5. From your experience, who most often initiates the decision to seek PT, OT, or Speech services from outside the IFSP team?
- there was a fairly clear split here, at least with people's initial response: community people mostly said that families were initiating services, whereas school people were more likely to say that physicians were initiating it

6. Over the past two years, do you think there has been an increase or decrease in the use of multiagency providers of PT, OT, and Speech from families with an IFSP?
- almost everyone said that there's been an increase, for a variety of reasons:
    - some rural folks said that it was due to increased accessibility and visibility
    - or because physicians recommend it (school people)
    - some didn't know why, but agreed there was an increase

7. What conflicts of interest do you anticipate if families seek services from the same discipline but more than one provider?
- some said that one conflict is when people "double-dip" in Medicaid – by using MIPS and community-based Medicaid – basically, a concern about a duplication of resources
- some mentioned communication, or conflicting philosophies/recommendations again

8. What are the cost issues associated with families' use of PT, OT, or Speech providers who are outside the IFSP team?
- a few cited an increase in costs to insurance companies/Medicaid
- a few seemed confused by the question or felt uncomfortable with their background knowledge in this area
- again, people mentioned communication, duplication of resources, conflicting philosophies and differing opinions among the two providers

9. Is there anything else that you think we should consider in evaluating these data?
- I got very different things here – some people reiterated earlier points (rural different than urban), some asked questions about the study (what is it trying to find out, what does X mean?), and some attempted to explain the conflict between schools and medical providers.

Overall, most people were optimistic that the two fields should be able to come together; only a few thought that their field was better off without the other. However, it was

usually quite clear to me early in our conversation as to who's "side" the interviewee was on, based on their responses to questions.

Appendix D

Service Coordinators' responses to the question:
What challenges or advantages do you face when families seek to complement or substitute EDN/IFSP-sponsored services with PT, OT or Speech services from other providers?

Challenges	Advantages
Lack of communication between providers and parents; medical versus educational model. Education seems to understand the medical model but it's more difficult the other way around. This can create mixed messages for the child and family if providers recommend different interventions	Coordinating services Medical vs. Educational. Families receive the best of both worlds and the medical professionals are content knowing the services they recommended are being provided
challenges = parents get medical & educational services confused	I happen to know a lot of private providers and also other resources available.
Those [Medical] providers are hesitant to participate in IFSP or general updates about the children's progress. They aren't interested in teaming up to serve the child.	Families feel like their concern is being addressed by someone who specializes in that area, as opposed to someone who is assigned as their PSP. Also, families feel like "more" equals better.
It undermines the biological parents' wishes for their child and they are unable to be involved with those services in a foster parent situation.	advantages= when high need children get double therapy you see very good progress with these kids
Sometimes families get conflicting information or have a hard time understanding the difference between education and medical therapies	Families felt that they were doing all they could for their child and that more equals better.
Families may not be understanding the difference between educational and medical therapy.	I know lots of private providers so I am able to guide the families.
Lack of communication between different providers, other providers saying that EDN services are not adequate and not really "therapy."	Many miles and much time to travel for such [medical treatments]; however children seem to make better progress
A difference in services from School-Medical. Medical has more actual hands on time and the parents are less involved than with school services	The child will usually (always) qualify for private OT and PT through the clinic and it is on-going indefinitely.
They want medical models, which schools do not provide.	The PT's worked together and shared goals to assist the family and child.
Equipment and assistive devices could not be transported between hospital and home therapy due to size or need for daily sessions.	. Advantages: Families have access to more information/suggestions/points of view. There are opportunities for providers.
The family feels guilty if they don't take their child because the professional recommends the service.	Family and EDN providers might get other information or different ways to work with the child.
The [Medical] visits are usually 2 to 3 times per week not in the natural environment.	Usually receive more services with other [Medical] providers (amount of times per month).
We receive no feedback [from medical providers] other than what the parent tells us.	Advantages: Increased services for some families who have more specialized or medically related

Challenges	Advantages
Communication does not always work well.	
Challenge - communication between all team members (this included non sponsored EDN providers)	
Lack of collaboration	
The family we worked with saw us as not doing our jobs when we expected them to be part of the solution for their daughters. They would rather have paid someone to do the therapy in a clinical setting. They seemed to think the services in the clinic were better.	
Challenge - communication between all team members (this included non sponsored EDN providers) It's hard to coordinate goals that two therapists are working on for a child. Often times the medical model PT's, etc. don't want to attend our IFSP meetings because they aren't in their town. Sometimes they send things with parents, but not very often. It depends on how persistent the parent is with the therapist.	
Communication gap between medical/specialty team and educational team, but I work (with some) to bridge that by sending reports.	
Challenges: Coordination of information across agencies	
Confusion of the difference between medical and educational services and why they do not do the same things.	
For the babies the services they are receiving are probably the same services as the schools; OT and PT give them	
Challenges: Getting information from the non-EDN/IFSP providers. Helping families understand the differences in the educational and medical services. Helping families sort out the information from the two providers when it seems contradictory.	
We are talking about two different issues. When we say "complement" then we have a bigger team that interacts with different perspectives on behalf of the child. At the end we all learn from each other and what the different models focus on. When we say "substitute" we refer to the fact that some families prefer a different model for the delivery of services.	

Appendix E: Open Ended Responses to Family Survey

In 2004
*What did you **like** about the services your child received from **NON-IFSP** providers?*

PT	
More frequent	7
Better equipment, available therapy, suggestions	7
Medical perspective/treatments	6
More child-focused/hands-on	5
It was extra therapy	2
More professional, sensitive, attentive	1
No happy (too expensive; not pediatric-focused)	2
OT	
More frequent	3
Better equipment, available therapy, suggestions	6
Medical perspective/treatments	4
More child-focused/hands-on	3
It was extra therapy	1
More professional, sensitive, attentive	4
SPEECH	
More frequent	5
Better equipment, available therapy, suggestions	3
Medical perspective/treatments	1
More child-focused/hands-on	5
It was extra therapy	0
More professional, sensitive, attentive	2
Not happy (not thorough)	1
VISION	
More frequent	0
Better equipment, available therapy, suggestions	2
Medical perspective/treatments	12
More child-focused/hands-on	0
It was extra therapy	0
More professional, sensitive, attentive	1
Not offered by IFSP team	2
AUDIOLOGY/HEARING	
For hearing testing	13
Better equipment, available therapy, suggestions	9
Medical perspective/treatments	4
More child-focused/hands-on	1
It was extra therapy	0
More professional, sensitive, attentive	1
Availability in summer months	1

PSYCHOLOGY

Physician Referral	1
Not offered by IFSP Team	2
Second Opinion	1

Sample Statements about NON-IFSP providers:

My child benefits most from water therapy.

Medical, had weekly sessions

Focused, more direct, child-centered

He needs more therapy than what was provided by "school therapy", "medical therapy" has a different goal and atmosphere

Able to provide custom-made splinting and support after surgeries

Specific to the nature of her tendon-transfer surgery.

OT delivered by certified/degree OT

The therapist performed "hands on" activities, not just giving us suggestions on therapy activities

More time each week

Actually provided therapy, not just coaching

More time spent with my child (90 min. opposed to 60 min./week from IFSP provider). Also the focus was more directed to my child, as opposed to mostly demonstrating/telling me how to interact with my child.

Was assessed for possible need for glasses.

Vision was never offered to be checked by IFSP team

No hearing test offered on IFSP.

Fitting him for new ear molds and fixing broken hearing aids.

History of recurring ear infections and tubes

Full service audiological center.

Specialist/medical info

Just not offered through IFSP

*What did you **like** about the services your child received from **IFSP Team providers**?*

PT

Convenient schedule or location (home)	17
Helpful/practical suggestions	20
Good interactions with child	16
Free	2
Competent Professional (knowledge, skill, dependable)	12
Child Improved!	3
Nice: understanding, comfortable interactions	14
Appreciated 1:1 time	2
Not Happy (didn't meet; not often enough, cancelled appts; appeared bored)	4

OT

Convenient schedule or location (home)	14
Helpful/practical suggestions	18
Good interactions with child	3
Free	1
Competent Professional (knowledge, skill, dependable)	12
Child Improved!	4
Nice: understanding, comfortable interactions	14
Appreciated 1:1 time	0
Not Happy (never met; not enough; cancelled appts; appeared bored; PT delivered OT service)	3

SPEECH

Convenient schedule or location (home)	17
Helpful/practical suggestions	24
Good interactions with child	17
Free	1
Competent Professional (knowledge, skill, dependable)	15
Child Improved!	11
Nice: understanding, comfortable interactions	18
Appreciated 1:1 time	0
Not Happy (cancelled appts; talks down to me; appeared bored; not helpful; not enough)	8

VISION

Convenient schedule or location (home)	1
Helpful/practical suggestions	2
Good interactions with child	0
Free	0
Competent Professional (knowledge, skill, dependable)	1
Child Improved!	0
Nice: understanding, comfortable interactions	0
Appreciated 1:1 time	0
Not Happy (not often enough)	1

AUDIOLOGY/HEARING

Convenient schedule or location (home)	1
Helpful/practical suggestions	1
Good interactions with child	0
Free	0
Competent Professional (knowledge, skill, dependable)	1
Child Improved!	6
Nice: understanding, comfortable interactions	2
Appreciated 1:1 time	0
Not Happy (provider appears uninterested, bored)	1

PSYCHOLOGY

Convenient schedule or location (home)	2
Helpful/practical suggestions	0
Good interactions with child	0
Free	0
Competent Professional (knowledge, skill, dependable)	0
Child Improved!	0
Nice: understanding, comfortable interactions	1
Appreciated 1:1 time	0
Not Happy (not often enough)	0

Sample Statements about IFSP providers:

Practice everyday modifications for high chair, seat, etc.

Could apply ideas to home environment.

Excellent rapport with child and family.

The PT is great, very helpful, understanding, always kept us informed of things we can do also.

Friendly, easy to work with.

I love that they do home visits, they ask me what my son needs. They are interested in who he is and his accomplishments. I like that my son's services are documented and people are held accountable for his services. I appreciate that bills are paid and we do not have any additional paperwork from Medicaid.

Mostly helped with modifying everyday things to better support/stabilize my child.

How she has improved so much.

Out therapist is kind, insightful and very caring. She helped us tailor exercises to increase our daughter's strength and agility.

Provider was knowledgeable, caring and unafraid to speak her mind. Gave advice into areas even the medical community wouldn't help with; consistent, observant and innovative.

She showed me lots of things that I could do a little differently that would help him progress that I never thought of. She really cared about how he was doing.

Provided sign language book for us. Helpful, patient and knowledgeable, etc.

She supplied us with many communicative devices and strategies as far a manipulative devices.

She came to our house and to school as needed.

I appreciated the time they took to develop a rapport with my son. I also noticed a tremendous amount of improvement on his speech and the articulation of his sounds.

Worked very well with my child on a personal level

Has sense of humor and loyal to the child. Gave specific activities, allowed parental input, considerate, observant of effectiveness and gave handouts.

She takes her time with my child, she helps me understand what I need to do. She cares about what happens with my family. She is a caring person.

She worked well with my child and gave great tips for us parents to work with him at home.

I didn't have to take time off from work to transport my child.

Very caring!