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EXECUTIVE SUMMARY

This evaluation of Iowa's Early Access services, contracted by the Department of Education, focuses on five priorities themes:

- interagency collaboration,
- family-centered-service delivery,
- child find effectiveness,
- the Individual Family Service Plan (IFSP) as a document reflecting and responding to child and family needs, and
- maximizing available resources.

These themes were identified as areas critical to meeting the goals for high quality service provision on the part of the state, and also took capitalized on the experience and expertise of the evaluators, the National Resource Center for Family Centered Practice at the University of Iowa.

Instrumentation

The evaluation was designed with a three-tiered approach to data collection—focusing on the state level, regional level, and consumer/client level. These three levels encompasses all of the major stakeholders in Early Access services—state administrators and personnel, regional administrators, service providers in the field, and the children and families receiving the services. By collecting data from each of these three levels with more than one data-collection instrument, the evaluators were able to triangulate the information gathered to compare the perceptions and priorities of the various groups.

The following were the primary data-collection instruments used, all written for the evaluation by the NRC/FCP. Each instrument is described more extensively in the introduction to the reporting of results from that instrument.

- parent survey: a 22-item written survey of parents (or other family members) focusing on their satisfaction with Early Access and their priorities for services for their family.
- provider survey: a 22-item written survey of professionals who work with the 0-3 age group, exploring their knowledge of and experience with Early Access.
- parent focus group: a 90-120 minute monitored discussion held in each region with a small group of parents, discussing in detail their experience with Early Access.
- regional council focus group: a 90-120 minute monitored discussion with selected members of each regional council discussing their experience with collaboration and service provision among Early Access providers.
- technical assistance team (TA team) interviews: a 17-item telephone interview conducted with each member of the state technical assistance team at the beginning of the evaluation and again at the end,

targeting their perceptions of change within the Early Access program.

- IFSP analysis: a content analysis of IFSPs focusing on family-centered language and the correlation between the IFSP and services received as reported elsewhere.

Sample Selection

The study sample for collection of data from families (the parent focus groups, parent surveys and IFSP analysis, all of which used the same sample group) was originally selected from the population of all families served by Early Intervention in the 1997 calendar year. Regional coordinators in the 15 EI regions provided lists of all the infants and toddlers served by their region in that year, along with demographic data about each participant. The original population provided for selection included 1385 infants and toddlers (including 533 children who were over three years old).

From this population a sample of 350 families—between 20 and 26 families per region—were invited to participate in the evaluation. This included taking part in the focus group in their region, completing the parent survey, and providing their child’s IFSP for analysis. The parents were carefully selected to be representative of their region in terms of all known demographic factors, as listed above.

Participants in the regional council focus group were selected from the lists of regional councils provided by each regional coordinator. Each council list included between 20-40 names of active members. From each list, 10-12 members were selected to participate, in order to reach the target of 8-10 participants with the goal of maximizing the professions and agencies involved, as well as maintaining geographic diversity.

The provider survey was pulled from the largest population of all the instruments. The sampling population was collected by gathering complete lists of providers or agencies in the state of Iowa in nineteen different categories: pediatricians, family practitioners, general practitioners, child psychiatrists, child psychologists, hospitals, Child Health Specialty Clinics, audiologists, Maternal-Child Health Agencies, WIC agencies, occupational therapists, physical therapists, Early Head Start programs, Public Health nurses and home care aides, physicians’ assistants, Department of Human Services social workers, Area Education Agency Early Childhood staff, childcare providers, and pediatric dentists. These complete lists provided a total of 16,124 names. Names were selected from each population list using systematic random sampling procedures, allowing for geographic distribution throughout the state.

Selected Key Findings

INTERAGENCY COLLABORATION

- Regional Council composition was dominated by the Area Education Association. Those who regularly attended meetings tended to be from the AEA, Child Health Specialty Clinics, and Community Service Agencies (WIC and Early Head Start in particular). Particularly underrepresented on the council were Department of Human Services staff, childcare providers, and private

practitioners.

- Almost all service coordination was done by AEA staff—most often by home intervention teachers, and less often by physical, occupational, and speech therapists. Of the other partner agencies, only Child Health Specialty clinics staff did any significant amount of service coordination.
- Providers found the a constant struggle to understand the system of rules and guidelines that each individual agency used to be a barrier to cooperation and collaboration. Providers felt that they received little support from the state level in helping them to negotiate other agencies' systems.
- Along with paperwork, providers and parents both saw too much continued duplication in testing, the individual family service plan (ifsp)
- Providers spoke of a determined effort made by service coordinators to keep the IFSP in lay language, accessible to parents. This seems to be succeeding—only 5.9% of the IFSPs analyzed contained professional jargon.
- Parents felt much more strongly than did providers that when the two disagreed on IFSP goals, the parents should make the final decision.
- Providers described the difficult process of preparing for the IFSP meeting by coming up with goals in advance, without cutting off the parents' opportunity to express their own goals. As a result, parents indicated on the parent survey that IFSPs regularly included goals that they had not come up with themselves.

MAXIMIZING AVAILABLE RESOURCES

- Providers uniformly value the work of the regional coordinator highly, and feel that she is largely responsible for whatever successes they may have as a council. They would like to see a full-time regional coordinator in every region, perhaps one with greater authority and autonomy than some of them currently have.
- The MR Waiver, while potential a valuable source of support for parents, is instead a recurring source of frustration for parents and providers. Parents asked for more help with the process, but providers said they themselves are overwhelmed and confused by the paperwork.

FAMILY-CENTERED-SERVICE DELIVERY

- Parents would like to have more parent-to-parent contact available. Providers expressed frustration that when they did organize parent support groups and other opportunities, parents were reluctant to take on the responsibility of continuing them.
- The gaps in service during the summer months was a major concern for both parents and providers. Providers from other agencies saw services from the AEA as slowing to a halt during the summer.

- Providers saw the obvious solution to the problem of summer services the hiring of additional staff. Ideally new staff could be hired to work evenings and weekends to accommodate the schedules of families with two working parents.
- Parents were very happy with the extent to which providers gave them techniques and tools to be able to provide their children with continued therapies on their own. However, they did not feel that to any significant extent they were given tools to help them negotiate systems and access resources on their own.
- Parents were enthusiastically appreciative of the effects that Early Access had on their children, as well as of the personal generosity of most of their service providers.
- Many parents were dissatisfied with the availability of speech and language therapy for their child. In contrast, providers rated this as one of the services most widely available to families, and made no reference to it as a potential problem.
- There was agreement, however, between parents and providers that respite and childcare were not uniformly available to parents.
- Transportation was mentioned by providers as a service gap for families, although families rarely mentioned this themselves.
- Parents were very satisfied with the efforts made by providers to adapt to their cultural, language, and religious differences. Providers, on the other hand, felt that language barriers in particular limited their ability to create close bonds with families, and recommended that agencies should make greater efforts to hire Spanish-speaking service providers.
- Parents felt very strongly that their opinions were solicited by providers and their input had a significant impact.
- Parents felt that they were actively included in the services provided for their child.
- Parents were not usually completely satisfied with the process of transitioning out of Early Access. They indicated that a gradual phasing out of in-home services and phasing in of preschool would have been easier for everyone.

CHILD FIND EFFECTIVENESS

- Medical professionals, particularly doctors, do not consistently refer potentially eligible families for Early Access services. Providers attributed this problem in part to public relations, and in part to the lack of a feedback loop—doctors rarely hear back from other providers about patients they had referred, and are rarely invited to take part in ongoing service coordination. Public Health agencies were much more likely to refer than private offices.

- The following demographic groups were seen by providers as potentially falling through the child-find net:
 - ♦ minorities
 - ♦ families new to the region or state
 - ♦ geographically or socially isolated families
 - ♦ children with slight or moderate delays
 - ♦ first-borne children
 - ♦ transient families and immigrant families

Recommendations

(executive summary recommendations summary here)

BACKGROUND

In 1975, Congress passed the Individuals with Disabilities Education Act (IDEA), legislating means and methods by which the states were to provide education and other services and opportunities for children with disabilities and delays. In 1986 IDEA was amended to include provisions for early childhood programs, serving children between birth and school age. Part H of IDEA. (changed to Part C in the reauthorization amendments of 1997) created funding for Early Intervention programs, specifying that states were to provide seventeen designated services, at a minimum, for infants and toddlers , ages 0-3, with disabilities or developmental delays.

In the state of Iowa, however, similar services were already being provided. As a “birth mandate” state, Iowa had passed state legislation guaranteeing educational services for children with disabilities or delays from the moment of their birth. With the passage of IDEA, federal funds became available for these services, and the challenge became how to continue supplying services for Iowa’s children and families while adapting to the requirements of the new federal legislation. Iowa’s Council for Early Intervention Services adopted a definition of children to be served in the state as those “experiencing developmental delay or those with a high probability of developmental delay.”¹

The federal legislation allowed for a fair amount flexibility for states as to how to administer their Early Intervention programs. Like most states, Iowa chose to have its Department of Education as the lead agency for Early Intervention, continuing in the role it had had prior to the federal legislation. In response to IDEA, the Department of Education drew in three partner agencies—the Department of Public Health, The Department of Human Services, and the Child Health Specialty Clinics. These four agencies were to work

¹ Iowa Department of Education Request for Proposals, Attachment A.

together to provide a network of service and programs to meet the diverse social, educational, financial, health, and other needs of children with disabilities or delays and their families.

Iowa continues to structure the administration of Early Intervention—now known as Early Access—around the state’s fifteen Area Education Agencies (AEAs). Within each of these fifteen regions an Early Access Regional Coordinator works with a Regional Council to coordinate services and programs in that region. The Council is usually composed of representatives from the four partner agencies along with service providers and administrators from a variety of other agencies that provide services for infants and toddlers, along with parent representatives. In most, but not all, regions the Regional Coordinator is an employee of the AEA, and is supervised by the AEA director of Early Childhood Special Education.

At the state level, a management team composed of departmental directors from the four partner agencies, along with the state Part C (Early Access) coordinator, have the final decision-making capacity for the program. Working with them are two other groups. The Iowa Council on Early Intervention Services (ICEIS), a larger group including parent representatives, service providers, experts in early childhood development from universities, et al., works with the management team and state administrators in an advisory capacity. The technical assistance team, a six-member work team including the state Part C coordinator, a technical assistant representing each of the four partner agencies, and a technical assistant representing parents and parent organizations. The TA team acts both as liaison between the state and the regional providers and as a resource for local providers in program implementation, federal compliance, and best-practice development.

Iowa’s Early Access program serves approximately 1000 infants and toddlers between 0-3 years of age with disabilities or delays in a given year. This represents approximately 1% of the total population in that age group. The population is unevenly scattered among the fifteen regions—the highly urban regions, such as AEA 11, including Polk and surrounding counties, may serve a few hundred children in a year, which the most rural regions may serve only a few dozen.

Children and families who use early access services receive any of a variety of services. Federally mandated services include assistive technology, audiology, service coordination, family training & counseling, health, medical, nursing, and nutrition services, occupational therapy, physical therapy, psychological services, social work, special instruction, speech language therapy, vision services, and transportation. Beyond these, each community provides a broad range of services and programs according to the individual needs of their families and the community’s resources, including respite care, childcare, toddler play groups, parent support groups, et al.

EVALUATION GOALS AND FRAMEWORK

In 1996, the Department of Education issued a Request for Proposals for an evaluation of Iowa’s system of

Early Intervention Services, in order to “ensure that Iowa infants and toddlers with developmental delays or at high probability of delay and their families have access to and receive high quality early intervention services.”² The contract for the evaluation was granted to the National Resource Center for Family Centered Practice (NRC/FCP) at the University of Iowa, in consultation with Susan McBride, Ph.D., of Iowa State University, Mary Jane Brotherson, Ph.D., Iowa State University, and Susan Maude, Ph.D., Lora College. The 27-month contract period began April 1, 1997.

The framework of the evaluation was developed first according to the guidelines of the RFP, and in greater detail through the cooperative efforts of the evaluators, the Iowa Council on Early Intervention Services, the Interim Director of Part C Services, and an advisory committee (including state personnel, local service providers, academic experts, and parents) put together to guide the evaluation process. Five key themes were identified as the evaluation’s focus:

- interagency collaboration,
- family-centered-service delivery,
- child find effectiveness,
- the Individual Family Service Plan (IFSP) as a document reflecting and responding to child and family needs, and
- maximizing available resources.

These themes were identified as areas critical to meeting the goals for high quality service provision on the part of the state, and also taking advantage of the NRC/FCP’s experience and expertise.

The evaluation, in accordance with the stipulations of the RFP, took place in three stages:

- Phase I: gathering knowledge about Iowa’s system of Early intervention services, meetings with key stakeholders, developing and piloting evaluation instruments;
- Phase II: administering evaluation instruments, collecting data, continued participation in meetings involving all stakeholders;
- Phase III: completing data collection, data analysis, writing and disseminating final reports.

DESIGN AND METHODOLOGY

Instrumentation

The evaluation was designed with a three-tiered approach to data collection—focusing on the state level, regional level, and consumer/client level. These three levels encompasses all of the major stakeholders in Early Access services—state administrators and personnel, regional administrators, service providers in the field, and the children and families receiving the services. By collecting data from each of these three levels

² RFP p. 4

with more than one data-collection instrument, the evaluators were able to triangulate the information gathered to compare the perceptions and priorities of the various groups.

The following were the primary data-collection instruments used, all written for the evaluation by the NRC/FCP. Each instrument is described more extensively in the introduction to the reporting of results from that instrument.

- parent survey: a 22-item written survey of parents (or other family members) focusing on their satisfaction with Early Access and their priorities for services for their family. Data is primarily Likert-scaled quantitative data, supplemented by open-ended questions with written responses.
- provider survey: a 22-item written survey of professionals who work with the 0-3 age group, exploring their knowledge of and experience with Early Access. Data is primarily Likert-scaled quantitative data, along with open-ended listings of services by respondents.
- parent focus group: a 90-120 minute monitored discussion held in each region with a small group of parents, discussing in detail their experience with Early Access. Data is entirely qualitative, summarized across regions to draw out major themes and provide for confidentiality of responses.
- regional council focus group: a 90-120 minute monitored discussion with selected members of each regional council discussing their experience with collaboration and service provision among Early Access providers. Data is entirely qualitative, summarized across regions to draw out major themes and provide for confidentiality of responses.
- technical assistance team (TA team) interviews: a 17-item telephone interview conducted with each member of the state technical assistance team at the beginning of the evaluation and again at the end, targeting their perceptions of change within the Early Access program. Data is entirely qualitative, summarized between respondents to highlight repeated issues and conflicts and protect confidentiality.
- IFSP analysis: a content analysis of IFSPs focusing on family-centered language and the correlation between the IFSP and services received as reported elsewhere. Data is quantitative, scored according to a content-analysis tool.

Each of the six major instruments (provided in Appendix 2) explores more than one of the five key themes of the evaluation. Each element being explored, therefore includes data from at least four sources, allowing for extremely robust findings. For example, data concerning interagency collaboration was collected from the regional council focus groups, the provider surveys, and the TA team interviews. Child-find effectiveness was explored in almost all of the instrumentation—the parent focus groups, parent surveys, provider surveys, and TA team interviews.

While some of the instrumentation provides primarily qualitative and discursive data (focus groups, TA team interviews), others provide more quantitative data (parent and provider surveys, IFSP analyses), thus allowing qualitative findings to be backed up by statistical results, and allowing quantitative findings to be explored more fully through qualitative correlations.

Sample Selection

The study sample for collection of data from families (the parent focus groups, parent surveys and IFSP analysis, all of which used the same sample group) was originally selected from the population of all families served by Early Intervention in the 1997 calendar year. Regional coordinators in the 15 EI regions provided lists of all the infants and toddlers served by their region in that year, along with the following data about each participant:

- date of birth
- date of referral for EI services
- services received (from a list of 15 services)
- whether the child suffered from a significant health impairment
- socio-economic status, as estimated by the regional coordinator and service coordinator
- racial/ethnic background
- urban/small town/rural residence of family

The original population provided for selection included 1385 infants and toddlers (including 533 children who were over three years old). The demographic breakdown of this population was as follows:

TABLE 1: DEMOGRAPHICS OF EARLY ACCESS POPULATION

	N	Mean or %	Std. Dev.
age of child (all children)	1378	2.62	0.95
age of child (children over three years old excluded)	845	2.03	0.68
age at referral for services (all children)	1296	1.29	0.83
age at referral for services (children over three years old excluded)	1284	1.27	0.80
Children with significant health impairment	396	30.2%	
socioeconomic status			
Lower	483	52.0%	
Middle	416	44.8%	
Upper	30	3.2%	
racial/ethnic background			
Caucasian/White/non-Hispanic	1050	85.0%	
Asian/Pacific Islander	13	1.1%	
Native American/Alaskan Native	8	0.6%	
Hispanic/Mexican/Latin American	46	3.7%	
Black/African American	64	5.2%	
Other	55	4.4%	
town population			
Rural (under 20,000)	691	50.6%	
small town (20,000 to 50,000)	206	15.1%	
urban (over 50,000)	468	34.3%	

The population of families being served by Early Access is fairly similar to, although not identical to, the population of Iowa as described by the 1990 census. Early Access families include more ethnic and racial

minorities than the state as a whole, particularly African American (5.2% served, compared to 1.7% statewide in 1990) and Hispanic/Latin Americans (3.7% served, compared to 1.1% statewide). The Early Access population is also more rural than the state as a whole—while 50.6% of Early Access families live in towns of under 20,000, in 1990 only 39.4% of all Iowans did so. While some of these differences may be attributable to demographic shifts in the state over the past nine years, to some extent they are likely to reflect actual discrepancies between those served and the population of the state as a whole.

From this population a sample of 350 families—between 20 and 26 families per region—were invited to participate in the evaluation. This included taking part in the focus group in their region, completing the parent survey, and providing their child’s IFSP for analysis (see page \$\$). The parents were carefully selected to be representative of their region in terms of all known demographic factors, as listed above. Twelve parents in each region were originally invited, and as responses came in from parents, additional parents were chosen to invite in order to maintain the demographic proportionality. Parents were offered a \$50 stipend for their participation, particularly to cover the costs of childcare and transportation for focus group attendance.

Participants in the regional council focus group (see page \$\$) were selected from the lists of regional councils provided by each regional coordinator. Each council list included between 20-40 names of active members. From each list, 10-12 members were selected to participate, with the goal of maximizing the professions and agencies involved, as well as maintaining geographic diversity. In regions where the council met as more than one group, members from the different sub-councils were pulled into one group. As with the parent sample, as responses came in, additional council members were selected in order to reach the target of 8-10 participants in each focus group while maximizing professional and geographic diversity. Although parents were members of every regional council, they were excluded from the sample for the regional council focus groups in order not to compromise the providers’ sense of confidentiality, and because parents were represented exclusively in the other focus groups.

The provider survey (see page \$\$) was pulled from the largest population of all the instruments. The sampling population was collected by gathering complete lists of providers or agencies in the state of Iowa in nineteen different categories: pediatricians, family practitioners, general practitioners, child psychiatrists, child psychologists, hospitals, Child Health Specialty Clinics, audiologists, Maternal-Child Health Agencies, WIC agencies, occupational therapists, physical therapists, Early Head Start programs, Public Health nurses and home care aides, physicians’ assistants, Department of Human Services social workers, Area Education Agency Early Childhood staff, childcare providers, and pediatric dentists. These complete lists provided a total of 16,124 names. From this population, a required stratified random sample size of 2700 was estimated. Population lists for each professional category were ordered geographically. Names were selected from each population list using systematic random sampling procedures, allowing for geographic distribution throughout the state.

PARENT SURVEY RESULTS AND ANALYSIS

OF INDIVIDUALIZED FAMILY SERVICE PLANS

This section presents findings from a survey of 141 parents³ of infants and toddlers with disabilities or developmental delays, completed during the spring and summer of 1998, along with a content analysis of each family's Individual Family Services Plan, collected from them at the same time. The purpose of the survey was to obtain primarily quantitative information about parents' perceptions of Iowa's system of Early Access services.⁴ This information, when triaged with qualitative data from the parent focus groups, would provide a well-rounded picture of Early Access services from parents' perspectives.

Content of the Survey

The survey itself was a seven-page questionnaire, organized into various sections which were fairly chronological in terms of consumer involvement with the system: identification of the disability or delay, referral to Early Access services, assessment/evaluation for services, the IFSP process, service coordination and specific services and supports received, transition out of Early Access, and several demographic items.

Most of the questions were closed-ended, requiring categorized responses or ratings on Likert-type scales. For many of the items, parents were asked to rate their level of agreement with specific statements about services, and to correspondingly rate the level of importance that they attributed to each particular aspect of services. There were a smaller number of open-ended questions dealing with such issues as difficulties in accessing services and ideas for improving services.

Profile of the Sample

The original sample for the parent survey was identified through the process described previously (see Methodology, p. \$\$). Through this method, the evaluators sought to achieve a sample that would be inclusive of the diversity of families receiving Early Access services across the state. In the initial sample, 73 parents who participated in focus groups also completed the survey, and another eleven parents completed the survey but for one reason or another did not attend focus groups. A second sample was identified in order to increase the number of respondents for the survey only, resulting in an additional 57 completed surveys. The analytic strategy began with testing for equivalence between the initial sample and the supplemental sample. Demographically the two were comparable, and on only a few items did the two samples demonstrate significant differences; therefore the survey results are presented for the group as a whole, with differences noted in the text when important.

³ "Parents" in this context is used to refer to biological parents, foster parents, or other legal guardians.

⁴ The name of Iowa's system of services changed from "Early Intervention" to "Early Access" over the course of the evaluation. Throughout this report, the program will be referred to as Early Access, unless specifically quoting from an instrument that was written before the name change, or from a parent, provider, or administrator who used the earlier name.

The response rate on these surveys was fairly high: among the 350 parents originally invited to attend the focus groups, the 84 who completed the survey represented a 24% response rate. Among the second set of parents, 57 parents were originally asked to complete the survey, thus the returned number of 57 represented a 57% response rate.

The total sample for the parent survey, 140 parents, was predominantly Caucasian (87%), comparable to the population of Iowa as a whole. Family income was fairly equally distributed between four income levels, as shown in Table 1. More than one-third of the parents had completed college, and 34% had either completed a vocational degree or had some college education. Twenty-two percent indicated high school as the highest degree completed, and few (7.6%) had not graduated from high school. The majority of parents were married (81%), while 13% were single/never married and a relatively small percentage, 6%, were divorced.

TABLE 2. DEMOGRAPHIC CATEGORIES

	N	Total N	%
<i>Race/ethnicity</i>			
White	122	140	87.1
Asian or Pacific Islander	1	140	0.7
Black	4	140	2.9
Native American	1	140	0.7
Hispanic	5	140	3.6
Other	7	140	5.0
<i>Annual Family Income</i>			
\$0-14,999	34	132	25.8
\$15,000-29,999	35	132	26.5
\$30,000-44,999	27	132	20.5
\$45,000 +	36	132	27.2
<i>Last year of education</i>			
Less than high school	10	133	7.6
Completed high school	29	133	21.8
Some post secondary	45	133	33.9
Completed college	37	133	27.8
Graduate school	12	133	9.0
<i>Marital status</i>			
Single, never married	18	141	12.9
Married	113	141	81.3
Divorced	8	141	5.8
Widowed	0	141	0
<i>First child with disability/delay</i>	98	141	87.5

Findings: Likert-Scale Items

REFERRAL INTO THE EARLY ACCESS SYSTEM

Parents were asked three questions about their referral into the Early Access system: who (other than themselves or their own family) first noticed their child's disability or delay, who first told them about Early Access services, and whether they were concerned about their child before a disability or delay was pointed out. Data about this entry point into the system was used, along with data from the provider survey, to assess weak points in the referral system, to discover whether some categories of providers were providing more information about Early Access than others, and to determine if parents had a more satisfactory experience being introduced to Early Access services by one type of provider than by another. These items directly addressed one of the priority themes of the evaluation: child find effectiveness.

For most parents, the person who first noticed their child's disability or delay was a medical professional (71.4%). (Medical professionals included doctors, public health nurses, and "other medical professionals.") Among these, 37 were identified at the hospital where the child was born, leaving 58 cases where the child was identified by medical professionals after birth (43.6%) and 38 cases (28.6%) where the child was identified by someone else, including a childcare worker, a sibling's teacher, a social worker, a babysitter, a friend, or someone else. Most of the parents (68.4%) were concerned about their child before an issue was pointed out.

Although 71.4% of the identifiers (above) were medical professionals, only 54.7% of the people who first informed parents about Early Access services were medical professionals. This suggests that in a substantial number of cases, medical professionals pointed out a problem's disability or delay but did not tell the parents about services. This may indicate either that medical professionals in Iowa are not all aware of Early Access services, or that those who did not refer families for services felt that the possible disability or delay could be best monitored outside the Early Access system.

Many parents heard about services through social workers (8.6%) friends (6.5%) and others, (22.3%). The other sources included having had other children receive services, being a teacher themselves and knowing about services through their school, co-workers, and neighbors.

Parents were given four statements about the experience of referral and signing up for Early Access services, and were asked to give their level of agreement with these statements on a scale of one to four and their judgment of the importance of that issue on a scale of one to four.⁵ The statements, which were intended to reflect family-centered practices, were:

TABLE 3: REFERRAL AND INTRODUCTION TO EARLY ACCESS SERVICES: ITEMS 4-7

⁵ For agreement, 1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree; for importance, 1=unimportant, 2=somewhat important, 3=important, 4=very important.

	Mean agreement	std. dev.	Mean importance	std. dev.
4. <i>When you first talked to someone about the services available for your child and family, they gave you enough information.</i>	3.20		3.66	
5. <i>The information that was first given to you about services was clear and understandable.</i>	3.14		3.68	
6. <i>When you first learned about early intervention, you were given adequate time and information to make your own decisions about participation.</i>	3.38		3.62	
7. <i>The person who told you about services explained that early intervention is a group of services provided by different agencies.</i>	2.74		3.07	
Overall mean	3.11		3.49	

Those parents whose children’s disabilities or delays were identified by a medical professional, or who were referred to services by a medical professional, expressed lower levels of agreement with these statements than did other parents.⁶ The differences between the two groups approached statistical significance in two cases: questions 4 and 7 (above), comparing those who identified the disability,⁷ and in two cases the differences were actually statistically significant: questions 4 and 5 comparing those who referred parents to Early Access services.⁸

The item receiving the lowest level of agreement (2.74) was “The person who told you about services explained that early intervention is a group of services provided by different agencies,” perhaps indicating that parents, from the beginning, do not perceive Early Access as a system of services.

The mean for the agreement sections for these four items, 3.11, was statistically significantly lower than the overall mean for *all* agreement items on the survey, indicating that this is an area in which parents were less satisfied than average.⁹

ASSESSMENT AND EVALUATION

Parents were asked eight questions about the process of their child’s assessment or evaluation, using the same agreement and importance scales. Many of the assessment and evaluation items addressed the basic assumptions of family-centered service delivery—the family as decision-makers, two-way communication between providers and parents, and accommodation of the families’ needs; along with the priority theme of collaboration in service provision—specifically non-duplication of testing. These questions were geared to

6 Specifically, the mean for all four items was 3.06 among parents with disabilities identified by medical staff, compared to 3.28 among others, and the mean for all four items was 3.01 among those told about services by medical staff, and 3.25 among others.

7 With p values of 0.061 and 0.067 respectively.

8 With p values of 0.004 and 0.007 respectively.

9 p=0.000

wards learning about parents’ feelings of empowerment as part of an Early Access team early on in their services.

TABLE 4: ASSESSMENT AND EVALUATION: ITEMS 9-16

	Mean agreement	std. dev.	Mean importance	std. dev.
9. <i>The providers who conducted the evaluation/ assessments were clear with you about what they were doing and why it was important.</i>	3.30		3.67	
10. <i>The providers explained each test in language you could understand before conducting it.</i>	3.38		3.60	
11. <i>The providers asked for your opinions and comments about your child's needs and abilities.</i>	3.53		3.74	
12. <i>The evaluation/ assessment took place at a time and place that was convenient for you.</i>	3.52		3.57	
13. <i>The providers told you what they were learning about your child as soon as possible.</i>	3.34		3.67	
14. <i>When the providers told you the results of their evaluations/ assessments, they did so in a sensitive and considerate manner.</i>	3.44		3.70	
15. <i>You and anyone involved with your child were actively included in the evaluation/ assessment.</i>	3.46		3.62	
16. <i>The same tests were given to your child more than once by different providers.¹⁰</i>	2.36		3.02	
Overall mean	3.30		3.58	

Parents consistently rate the importance of these behaviors higher than their perception that these behaviors are actually evidenced by Early Access providers. Item 16 has the lowest agreement score (2.36), indicating that many parents perceive a problem with their children receiving the same test multiple times during the assessment and evaluation process.

For this section of the survey, both the mean for agreement and the mean for importance for all items was higher than the overall mean for all items on the survey, indicating that evaluation and assessment was an area where parents felt they were receiving the services as described in the items, and that these items were among the most important ones to them. Only the difference in the importance scores, however, was statistically significant.¹¹

¹⁰ This was the only item on the survey that was phrased in such a way that strong agreement carried negative implications. Because on all other items 1 was the most negative response and 4 the most positive, the scoring was reversed on this item, (“strongly agree” was coded as 1...”strongly disagree” was coded as 4) in order to allow the mean scores to be interpreted in the same way as all the other items on the survey.

¹¹ P=0.000.

WRITING AND USING THE INDIVIDUAL FAMILY SERVICE PLAN (IFSP)

Parents were asked eleven questions about their experiences with writing and using the IFSP. This was especially important data in light of the fact that the parents who had participated in the focus groups had expressed strong dissatisfaction with the IFSP process, and had not found the IFSP to be a useful document for them (see page \$\$). The evaluation of theme of family-centered service delivery asks the question “does the IFSP reflect and respond to child and family needs?” and the items below address the specifics of this question. Because the IFSP form (and process) has gone through numerous transformations in recent years, and continues to evolve, parents’ feedback on how to make this document useful for them is particularly important.

TABLE 5: WRITING AND USING THE IFSP: ITEMS 17-27

	Mean agreement	std. dev.	Mean importance	std. dev.
17. <i>The time and place of the first IFSP meeting was chosen for your convenience.</i>	3.48		3.42	
18. <i>You were encouraged to bring along anyone who was involved with your child (family members, childcare providers, etc.)</i>	3.25		3.34	
19. <i>You were asked what priorities you had for your child.</i>	3.51		3.69	
20. <i>You were asked about priorities for your whole family, not only the child receiving services.</i>	2.99		3.24	
21. <i>The IFSP includes only priorities chosen by you and your family.</i>	2.85		3.16	
22. <i>When you disagreed with providers about priorities for your child and family, you made the final decision about what was written on the IFSP.</i>	3.24		3.51	
23. <i>For IFSP meetings after the first one, all the people who provide services to your family were encouraged to be there or provided information.</i>	3.47		3.52	
24. <i>You felt that everything you wanted for your child and family got written into the IFSP.</i>	3.33		3.57	
25. <i>If you needed help getting to the IFSP meeting (a ride, childcare, etc.), these were arranged.</i>	3.11		3.20	
26. <i>You were asked about other concerns in your family (childcare, housing, etc.), not only those about the child receiving services.</i>	2.95		3.08	
27. <i>The IFSP is a useful document for you.</i>	3.24		3.32	
Overall mean	3.23		3.37	

Item 21, “The IFSP includes only priorities chosen by you and your family,” had the lowest mean agreement score. Although parents ranked this item as less important than most of the others in this section, they clearly felt that the IFSP process did not meet this description to the extent that they felt it should.

The two other items with the low mean agreement scores, 20 and 26, both related to services for family

members other than the child with a disability or delay. While parents judged these items as being accurate descriptions of their services well below the mean for all items in this section, they also judged the importance of these items below the average importance for all items. This indicates that while parents may not feel that the IFSP process includes goals for other family members, they also do not strongly believe that it is important for it to do so.

The IFSP item means were statistically significantly below the overall means for the survey for both agreement and importance. These items were ones which parents felt they were not receiving the services as described as much as elsewhere, but they also felt that this was an area in which the services described were less important to them.¹²

PROVISION OF EARLY ACCESS SERVICES

Parents were given fifteen statements describing the provision of Early Access services for their families. Items 45-48 are not included in this section but are instead included below, in the section on ‘Cultural Awareness and Adaptations.’ The statements below were designed to reflect family-centered practices and collaborative techniques on the part of Early Access service providers. These items got to the heart of the priority theme of family-centered service delivery, addressing the three key questions:

- To what extent does the service system facilitate the family’s role in decision-making regarding services?
- To what extent do families perceive service providers to be family-centered in their service approaches?
- What can be done to make services more family centered?

The items included on the survey not only allowed parents to describe their experiences with family-centered service delivery as defined for the evaluation, but also allowed them to lay out their own priorities for family-centered practices. In this light, the parents’ importance ratings on the following items is particularly important.

TABLE 6: PROVISION OF EARLY ACCESS SERVICES: ITEMS 31-49

	Mean agreement	std. dev.	Mean importance	std. dev.
31. Most of the services for your child and family are provided in your	3.00		3.01	
32. When services are scheduled, your family’s needs are considered first.	3.43		3.51	
33. You and others involved with your child are encouraged to take an active role with your child’s activities.	3.56		3.74	
34. Providers explain what they are doing in language that is clear to you.	3.55		3.70	

¹² agreement p=0.005; importance p=0.000.

35. Providers teach you what they are doing with your child, so you can do it on your own.	3.48		3.75	
36. Providers are aware of services your child and family are getting from other people and agencies.	3.48		3.40	
37. Providers listen to your opinions and concerns about your child's	3.52		3.78	
38. Providers use the information you share with them about your child to help you better.	3.50		3.75	
39. Providers are positive and point out the strengths they see in your child and family.	3.53		3.65	
40. You feel you are the leading member of a team that is helping your	3.39		3.50	
41. If some of your child's services take place in a center or a classroom, you feel welcome there.	3.54		3.58	
42. You have enough opportunities to talk with other parents whose children receive services.	2.47		3.07	
43. Providers are flexible and understanding if you need to change the schedule of services.	3.47		3.60	
44. Providers tell you about other services and resources which may be useful to you and your family.	3.19		3.55	
49. If you or someone in your family has a disability and needs supports such as sign language translation, TTD, or more time with forms, providers are helpful and provide what is needed.	3.29		3.38	
Overall mean	3.37		3.54	

The overall means for both the agreement and importance for these “service” items were significantly higher than the average for all items on the survey, indicating that parents felt that these items were being provided as described on the survey more than others, and that they felt these items were more important than others.¹³

By far the lowest scoring item was “You have enough opportunities to talk with other parents whose children receive services.” This was one of very few items on the entire survey with a mean score of less than 2.5 on agreement.

A few items in this section received importance ratings of above 3.70. These items, which are particularly critical in the parents’ opinions, were 33, 34, 35, 37, and 38. All related to the providers’ involvement of the parents in the services provided for their children, and showing respect for the parents’ opinions. These two aspects of family-centered service delivery are to be noted as being particularly prioritized by parents.

TRANSITION OUT OF EARLY ACCESS SERVICES

¹³ agreement $p=0.000$; importance $p=0.002$.

Those parents whose children were at least two years old at the time they completed the survey were asked to complete four additional questions about preparing for transition to preschool programs. One hundred parents completed this last section of the survey. As above, with IFSPs (see page \$\$), this is an area that, according to other instruments, parents found particularly difficult or problematic. The parent survey responses to a certain extent quantify the dissatisfaction parents felt with this aspect of Early Access services.

TABLE 7: TRANSITION OUT OF EARLY ACCESS: ITEMS 60-63

	Mean agreement	std. dev.	Mean	std. dev.
60. Someone has talked to you about transition out of early intervention and explained how services for your child and family	3.08		3.62	
61. You have a written transition plan for your child and family.	2.91		3.40	
62. The transition plan includes your ideas and goals for your child.	3.15		3.63	
63. The transition plan made the change to preschool programs easier for you and your family.	3.05		3.54	
Overall mean	3.00		3.54	

The agreement rating mean for the transition section was significantly lower than for the entire survey, at 3.00, compared to 3.28.¹⁴ This reinforces the finding that this was an area where parents felt services fell short and their needs were higher.

The lowest ranked item in this section on the agreement scale was “You have a written transition plan for your child and family.” Of the 92 parents who responded to this item, 72.8% answered “agree” or “agree strongly,” implying that such a plan was written.

CULTURAL AWARENESS AND ADAPTATIONS

One of the key questions posed by the evaluation is an assessment of cultural responsiveness in service provision, and the parent survey addresses a number of the points raised in this key question. Specifically:

- To what extent do consumers feel that services are respectful of their cultures?
- Are supports (i.e., interpreters, translators) readily available for families as needed?
- What can be done to enhance the cultural responsiveness of Early Access services?

Five items on the survey addressed the issue of providers’ awareness of diversity (racial, ethnic, linguistic, cultural, religious, et al.) among the families they serve, and their adaptations to that diversity. As indicated above, the survey addresses the critical factor of the parents’ *perception* of cultural responsiveness, as opposed to institutional and procedural efforts to serve diverse population.

One item was in the section about referral, the other four were in the section about receiving services. Those

¹⁴ agreement p=0.001.

items which only non-native-English speakers answered were completed by only eight respondents.

TABLE 8: CULTURAL AWARENESS AND ADAPTATIONS: ITEMS 8, 45-48

	Mean agreement	std. dev.	Mean	std. dev.
8. (Please skip if English is your first language.) If English is not your first language, a translator was available for you when you first went to learn about early intervention.	3.75		2.75	
45. (Please skip if English is your first language.) If English is not your first language, there are translators available at all meetings and whenever you have questions.	2.83		3.38	
46. When your scheduled services conflict with your family's religious holidays, providers are aware of the issue and quick to	3.42		3.34	
47. When providers want to do something with your child or family that conflicts with your cultural or religious beliefs, they respect your	3.41		3.40	
48. Providers do not always assume that your family has the same values and beliefs that they do, and when your values and beliefs differ, yours are most important.	3.39		3.43	
Overall mean	3.41		3.38	

The overall mean agreement score was higher than for the survey as a whole (3.28) and the overall mean importance score was lower than for the survey as a whole (3.48). The area of cultural adaptation seems to be one where parents feel that providers are providing the services as described, and this is of lesser importance to them than other aspects of services.

Question 45, "If English is not your first language, there are translators available at all meetings and whenever you have questions," had the lowest agreement score in this section, but because of the low numbers involved this is less meaningful than the other averages. Only six parents responded to question 45a (agreement), and of them one parent disagreed with the statement, five agreed. On question 8b, "If English is not your first language, a translator was available for you when you first went to learn about early intervention," (importance), while again there were only eight respondents, it is interesting that two of them felt that having translators available was *not* important to them. On question 45b (importance), however, when asked again about the importance of the availability of translators, the eight parents who responded (only 4 of whom had responded to question 8b), gave it the much higher importance rating of 3.38. None of these eight parents felt that the availability of translators was unimportant.

OVERALL SURVEY HIGHS AND LOWS

Parents' responses to the Likert scored items on this survey were remarkably consistent, indicating a fairly high level of satisfaction with their Early Access services, according to the service descriptions given. There were, however, a number of items for which the mean score was well outside of the normal range of responses. The items below all differ from the overall means for the entire survey with statistical significance.

TABLE 9: LOWER THAN AVERAGE AGREEMENT ITEMS

<i>Item</i>	<i>mean</i>
7. The person who told you about services explained that early intervention is a group of services provided by different agencies.	2.74
16. The same tests were given to your child more than once by different providers.	2.36
21. The IFSP includes only priorities chosen by you and your family.	2.85
42. You have enough opportunities to talk with other parents whose children receive services.	2.47

Of these four seemingly unrelated areas, two are areas where the parents actually tend to disagree with the item given more than they agree. The responses to item (see note \$\$) indicates that parents feel that their children are, in fact given the same test more than once by different providers. Parents do, however, give this issue a relatively low importance rating of 3.02 as well. Item 42, about opportunities to meet with other parents, also drew more disagreement than agreement, but also has a low importance rating at 3.07.

TABLE 10: HIGHER THAN AVERAGE AGREEMENT ITEMS

<i>Item</i>	<i>Mean</i>
11. The providers asked for your opinions and comments about your child's needs and abilities.	3.53
12. The evaluation/assessment took place at a time and place that was convenient for you.	3.52
19. You were asked what priorities you had for your child.	3.51
33. You and others involved with your child are encouraged to take an active role with your child's activities.	3.56
34. Providers explain what they are doing in language that is clear to you.	3.55
37. Providers listen to your opinions and concerns about your child's progress.	3.52
38. Providers use the information you share with them about your child to help you	3.50
39. Providers are positive and point out the strengths they see in your child and family.	3.53
41. If some of your child's services take place in a center or a classroom, you feel	3.54

The majority of these items (33-41) were in the service section of the survey. Items 11, 19, 33, 37, and 38 all indicate that parents seem to feel strongly that providers are soliciting and listening to their input. This is a very important factor in the provision of family-centered services, and the consistently high rating by parents on these items speaks well to providers' training and abilities in this area.

TABLE 11: LOWER THAN AVERAGE IMPORTANCE ITEMS

<i>Item</i>	<i>mean</i>
7. The person who told you about services explained that early intervention is a group of services provided by different agencies.	3.07
16. The same tests were given to your child more than once by different providers.	3.02

26. <i>You were asked about other concerns in your family (childcare, housing, etc.), not only those about the child receiving services.</i>	3.08
31. Most of the services for your child and family are provided in your home.	3.01
42. <i>You have enough opportunities to talk with other parents whose children receive services.</i>	3.07

While these five items represented the lowest importance scores on the survey, it is necessary to note that they all show a mean importance of over 3.00, which is the “important” point on the scale. No items on the survey were deemed unimportant by the parents as a whole.

TABLE 12: HIGHER THAN AVERAGE IMPORTANCE ITEMS

<i>Item</i>	<i>Mean</i>
11. <i>The providers asked for your opinions and comments about your child’s needs and abilities.</i>	3.74
14. <i>When the providers told you the results of their evaluations/assessments, they did so in a sensitive and considerate manner.</i>	3.70
33. You and others involved with your child are encouraged to take an active role with your child’s activities.	3.74
34. Providers explain what they are doing in language that is clear to you.	3.70
35. Providers teach you what they are doing with your child, so you can do it on your	3.75
37. Providers listen to your opinions and concerns about your child’s progress.	3.78
38. Providers use the information you share with them about your child to help you	3.75

Most of the above items are from the service section of the survey. All of these items, with the exception of Question 33, describe open communication patterns between providers and parents. Clearly ongoing communication, and active use of the information communicated in both directions is very important to parents.

Parents’ responses on agreement items and on the corresponding importance items were consistently highly correlated. In general, as agreement levels increased, so did importance ratings—parents tended to rate those aspects of services that they felt they were receiving as the most important ones to them. Agreement and importance correlations were statistically significant in all but one category on the survey—the referral into Early Access services. While for this category the importance also went up with agreement, the relationship between the two was not statistically significant.¹⁵

DEMOGRAPHIC FACTORS AND THE LIKERT-SCALE ITEMS

There were a number of items for which parents’ demographic differences had significant relationships with

¹⁵ Referral: Pearson correlation=0.100, p=0.243; assessment/evaluation: Pearson correlation=0.478, p=0.000; IFSP: Pearson correlation=0.474, p=0.000; service provision: Pearson correlation=0.628, p-value=0.000; transition: Pearson correlation=0.337, p-value=0.001; cultural adaptation: Pearson correlation=0.546, p-value=0.000.

their responses the above items. The majority of the responses, however, were consistent throughout all the demographic factors measured.

Parents' income affected their agreement with the IFSP items and the culture items, tending to agree less with the items as described on the survey. Married parents agreed less with the items on the IFSP section of the survey than their single or divorced counterparts, and also found the IFSP and culture items to be less important. Parents who were of middle- and lower-socioeconomic class were also in less agreement with the culture items on the survey, and white parents found the transition items to be less important than did non-white parents. Overall, as indicated by those items where income made a statistically significant difference in responses, wealthier, married, white respondents were less in agreement with how services were described on the survey, but also considered the survey items less important.

Parents of children over three years old (those who had already transitioned out of Early Access) agreed less with the service delivery items and the transition items than parents of younger children. This could indicate either that services had improved since these parents had experienced them, or that they are conflating their experiences with Early Access with post-transition experiences (a regular problem in focus group discussions).

TABLE 13: DEMOGRAPHICS AND ITEM MEANS: SIGNIFICANT DIFFERENCES

<i>demographic factor</i>	<i>mean agreement</i>	<i>mean importance</i>	<i>std. dev.</i>	<i>p-value of difference</i>
<i>IFSP items</i>				
income over \$30,000	3.13			0.004
income under \$30,000	3.36			
married parents	3.18			0.013
single/divorced parents	3.43			
married parents		3.32		0.007
single/divorced parents		3.58		
<i>service delivery items</i>				
children under 3 years old	3.45			0.004
children over 3 years old	3.24			
<i>culture items</i>				
<i>married</i>		3.31		0.014
<i>single/divorced</i>		3.63		
income over \$30,000	3.24			0.030
income under \$30,000	3.51			
<i>lower socio-economic class</i>	3.54			0.040
<i>middle/upper socio-economic class</i>	3.35			
<i>children under 3 years old</i>	3.48			0.048
<i>children over 3 years old</i>	3.25			
<i>transition items</i>				
white parents		3.50		0.015

non-white parents		3.82		
income over \$30,000		3.30		0.048
income under \$30,000		3.61		

DIFFERENCES BETWEEN AREA EDUCATION ASSOCIATION REGIONS: LIKERT-SCALE ITEMS

The size of the AEA from which parents received services had a significant relationship with a number of categories of items on the survey. The size of the AEA was measured by the number of children being served by Early Access services in the December 1997 count. This varied from 26 to 280. Higher numbers served correlated negatively with agreement in both the writing of the IFSP items and the provision of services items. I.e., as the number of children and families served by a region increased, the families' agreement levels on those aspects of services declined.¹⁶ AEA populations also correlate negatively with the overall mean for agreement items, (parents from larger AEAs express lower agreement ratings), a finding which may be heavily weighted by data from one region.¹⁷

There was some significant variation in a number of items between the 15 Area Education Association regions around Iowa. All of the items which showed significant variation were agreement items. One region in particular had mean agreement scores which were significant lower than at least one other region on all but one of these items. There were significant differences between the regions on the following items

TABLE 14: ITEMS WHICH VARIED SIGNIFICANTLY BETWEEN REGIONS

Item	p-value
4. <i>When you first talked to someone about the services available for your child and family, they gave you enough information.</i>	0.009
6. <i>When you first learned about early intervention, you were given adequate time and information to make your own decisions about participation.</i>	0.000
9. <i>The providers who conducted the evaluation/assessments were clear with you about what they were doing and why it was important.</i>	0.005
11. The providers asked for your opinions and comments about your child's needs and abilities.	0.002
14. When the providers told you the results of their evaluations/assessments, they did so in a sensitive and considerate manner.	0.002
22. When you disagreed with providers about priorities for your child and family, you made the final decision about what was written on the IFSP.	0.035
25. If you needed help getting to the IFSP meeting (a ride, childcare, etc.), these were arranged.	0.016
38. Providers use the information you share with them about your child to help you	0.015

¹⁶ IFSP Pearson correlation=-0.224, p=0.008; service provision Pearson correlation=-0.188, p=0.026.

¹⁷ Pearson correlation=-0.187, p=0.027.

49. If you or someone in your family has a disability and needs supports such as sign language translation, TTD, or more time with forms, providers are helpful and provide what is needed.	0.003
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Seven of these nine items relate directly to the issue of providers’ communication with parents (items 4, 6, 9, 11, 14, 22 and 38), while the other two are concerned with accommodation of parents’ needs. The most consistent difference between regions was between one highly urban region and one mostly rural region. Because this is specific to these regions, and does not apply more broadly across types of region or the demographic variation within the sample, it is likely that the difference is due to the particular characteristics of the urban region.

Findings: Open-Ended Responses

SERVICE COORDINATION

Parents were asked two questions about service coordination, to discover whether they could readily identify someone as their service coordinator, and what their service coordinator’s professional was. The survey question used the language “main contact person” rather than “service coordinator,” to avoid confusing parents who may not use that particular phrase. These items address the issue of collaboration in Early Access services—to what extent does Early Access succeed as an interagency collaboration, and to what extent is it dominant by some agencies over others, from the perspective of those receiving services? The response categories were:

TABLE 15: DESCRIPTION OF MAIN CONTACT PERSON: ITEM 28

Main contact	N	%
<i>Teacher</i>	68	50.4
<i>Unspecified AEA staff</i>	6	4.4
<i>Physical therapist/ occupational therapist</i>	13	9.6
<i>Social worker</i>	6	4.4
<i>Doctor or nurse</i>	3	2.2
<i>Someone else</i>	12	8.9
<i>No main contact person</i>	24	17.8

With the “teacher” and unspecified AEA staff grouped together, 68.5% of those parents who had a main contact person considered the AEA the source of this person. Among those who responded with someone else, the examples given included a number of unspecified “coordinator” or “case manager,” one developmental therapist, one AEA psychologist, one interpreter, and one parent’s mother.

There was wide variation between the regions in the number of parents reporting “no main contact person.”

While five regions had all parents reporting that they had a main contact, other regions had up to 50% reporting no main contact. Because no region had more than 13 parents responding, however, these numbers are not large enough to reliably indicate differences between the regions.

Whether or not parents reported having a main contact person had some statistically significant repercussions on their responses elsewhere in the study. Parents without a main contact person tended to have lower satisfaction with their referral into the Early Access system, lower satisfaction with the process of writing their IFSP, and lower satisfaction with receiving services. They also tended to consider the evaluation & assessment procedures, as well as the transition out of Early Access services more important than parents with main contacts.

TABLE 16: DIFFERENCES BETWEEN PARENTS WITH AND WITHOUT MAIN CONTACT PERSON

Survey section	Parents with main contact	Parents without main contact	p-value of difference
<i>Referral into EI system (agreement)</i>	3.18	2.79	0.001
<i>Evaluation and Assessment (importance)</i>	3.55	3.73	0.023
<i>Writing the IFSP (agreement)</i>	3.28	2.98	0.036
<i>Receiving services (agreement)</i>	3.40	3.21	0.046
<i>Transition (importance)</i>	3.50	3.80	0.016

Very few parents actually referred to their main contact person as a “service coordinator.” In response to the question “Does this person call him or herself your service coordinator?” almost half of the parents didn’t know, another third said no, and only one-quarter said yes.¹⁸

SERVICES RECEIVED BY FAMILIES

The parents completing the survey were asked to list all the services their child and family have received since their last IFSP meeting. Parents were encouraged to think as broadly as possible about what constituted an Early Access service. They were also asked who provided each service they received, whether they paid for the service privately, and to rate that service’s importance to them on a scale of 1-4.

This item also followed up on a theme from the parent focus groups—what do parents define as Early Access services? Do they see them as only home teaching and physical therapy from their AEA, or a broader network of services including the health care providers, social services, and other supports? Earlier on the survey, parents had indicated that, in the process of signing up for Early Access services, they did not always feel that “the person who told [them] about services explained that early intervention is a group of services provided by different agencies.”

The survey questions about services received could also be compared to the parents’ IFSPs, in order to

¹⁸ don’t know: 44.4% (59), no: 26.3% (35), yes: 29.3% (39).

explore whether the IFSP in fact reflects the full spectrum of services received by the families.

Parents responded to this question with the following categories of services:

TABLE 17: IMPORTANCE OF VARIOUS SERVICES TO FAMILIES

service	N	%	importance rating
<i>physical therapy</i>	54	38.3	3.83
<i>speech/ language pathology</i>	46	32.6	3.79
<i>home intervention/ teaching</i>	44	31.2	3.78
<i>occupational therapy</i>	42	29.8	3.76
<i>preschool</i>	28	19.9	3.96
<i>acute medical care</i>	23	16.3	3.95
<i>audiology</i>	15	10.6	3.69
<i>nursing care</i>	14	9.9	3.85
<i>respite care</i>	12	8.5	3.91
<i>WIC nutrition</i>	12	8.5	3.91
<i>vision care</i>	6	4.3	3.67
<i>evaluation/ assessment</i>	6	4.3	3.25
<i>Title XIX</i>	5	3.5	4.0
<i>homemaker services</i>	5	3.5	3.5
<i>SSI</i>	4	2.8	3.75
<i>toddler group</i>	4	2.8	3.75
<i>food stamps</i>	3	2.1	3.67
<i>well clinic care</i>	3	2.1	3.5
<i>FIP</i>	2	1.4	4.0
<i>foster care</i>	2	1.4	4.0
<i>behavior therapy</i>	2	1.4	4.0
<i>childcare financial assistance</i>	2	1.4	4.0
<i>early head start</i>	1	0.7	4.0
<i>genetics counseling</i>	1	0.7	1.0
<i>other</i>	57	40.4	

The “other category” for the most part included broad references to Early Access services, such as “AEA,” “early childhood services,” “early intervention,” or “one-on-one help.” Other items which were mentioned in the “other” category included babysitting, emotional support, rides to school, DHS, social worker, child psychiatrist, transportation costs, medical supplies, help with insurance payments, and orthopedic/prosthetic equipment.

Twenty-five families (17.7%) pay for at least one of the services they listed in this section of the survey. The

services most commonly paid for by parents are:

TABLE 18: SERVICES PAID FOR BY FAMILIES PRIVATELY

service	N	% (of paid services)
<i>medical care</i>	20	80
<i>physical therapy</i>	6	24
<i>childcare</i>	5	20
<i>occupational therapy</i>	4	16
<i>speech/ language pathology</i>	3	12
<i>optometry</i>	3	12

One family paid for each of the following additional services privately: prosthetics, infant teaching, therapy (unspecified), and respite care. Five parents indicated that they paid privately for speech/language, physical therapy, occupational therapy, and infant teaching services, although they also indicated that these services were provided for them by the AEA.

Parents indicated *who* provided 325 specific services for them. The majority of services were listed as provided by the Area Education Agency. The chart below indicates the various service providers for the six most commonly mentioned services, along with these six, families listed providers for their Medicaid, respite care, WIC, audiology, food stamps, nursing, SSI, FIP, toddler group, genetics counseling, well childcare, foster care, and vision services. The total column in the table below is the total percentage off all services provided by that agency.

TABLE 19: SERVICE PROVIDERS FOR THE MOST FREQUENTLY USED SERVICES

agency providing service	service being provided / % of the time that service is provided by that agency												
	physical therapy	%	speech/ language therapy	%	occupational therapy	%	ECSE	%	pre-school	%	medical care	%	total (for all services)
<i>AEA</i>	43	70.5	37	80.4	35	83.3	41	87.2	11	40.7	1	3.7	56.8
<i>DHS</i>									1	3.7	2	7.4	4.0
<i>doctor</i>											6	22.2	3.0
<i>home health agency</i>	2	3.3											2.4
<i>hospital/ clinic</i>	8	13.1	6	13.0	5	11.9					12	44.4	10.9
<i>schools*</i>	1	1.6	2	4.3			2	4.3	7	25.9			3.6
<i>Title 19</i>									1	3.7	5	18.5	2.7
<i>total N</i>	61		46		42		47		27		27		

* By "school," these parents may be referring to the AEA, or may be referring to their child's preschool.

Aside from the major categories listed above, parents indicated that they received services from the following sources: babysitters, daycare, EDI, Headstart, ARC, Community Action agencies, their county, High Risk Infant Follow-up, Ill & Handicap Waiver Program (not specifically identified as DHS), Public Health, the state, Title XIX, and WIC.

INFORMAL SUPPORT SYSTEMS

In addition to providing information on the services they received as part of Early Access, parents were asked about informal sources of support. A total of 53 of the parents (37.6%) listed at least one such source of support. The primary responses of parents were:

TABLE 20: PRIMARY SOURCES OF INFORMAL SUPPORT FOR PARENTS

	<i>% of those with informal supports</i>	<i>% of all parents</i>	<i>N</i>
church	24.5	9.2	13
family	47.2	17.7	25
support groups	11.3	4.3	6
medical providers ¹⁹	15.1	5.7	8
friends	22.6	8.5	12
other	37.7	14.2	17

Within the “other: category, parents most frequently included supports which were usually considered formal supports: e.g. their AEA, an occupational therapist, Medicaid, DHS, and respite care. They also included tumbling classes, YMCA waterbabies classes, the internet, and their babysitter.

Interestingly, among the 53 parents who described their informal resources, the six who were involved in support groups had a statistically significant lower mean agreement rating on the survey’s Likert-scaled items (2.94, as compared to 3.37 among those not using support groups).²⁰ One interpretation of this finding might be that parents who receive input from other parents have more information with which to form critical judgments of the services they receive.

There were two statistically significant differences between parents who listed informal resources and those who did not. Parents whose children had significant health problems were more likely to describe use of informal resources (28.4%, compared to 48.4%) and white parents were more likely to do so than were non-white parents (16.7% compared to 40.8%).²¹ Parents of more severely disabled children may find they have a greater need for the supports offered outside of Early Access services.

¹⁹ While medical care may not be considered in many cases an informal support, 8 parents listed it as such, and they are included here.

²⁰ $p=0.004$, $t=-3.03$, $df=51$.

²¹ health: $\chi^2=5.763$, $df=1$, $p=0.016$; ethnicity $\chi^2=3.893$, $df=1$, $p=0.048$.

Parents' Open-Ended Comments

Parents were given six items on the survey to respond to in their own words, and most took advantage of this opportunity on at least one item. The questions parents were asked were:

WHAT HAVE YOU LIKED BEST ABOUT EARLY ACCESS SERVICES FOR YOUR CHILD?

Of the 136 parents who answered this first question, all but three had very positive things to say about the services they received. The responses usually focused around the following eight topic areas:

1. Appreciation of the flexibility of providers, accommodation of the family's schedule or desire to change services

At least 14 parents made some direct reference to this as an aspect of services they liked best. For example, "They came into our home and have done an A+ super job with my child. If we want to change something in his therapy they gladly jump in feet first to see if it will help him out."

2. Appreciation of specific things learned about their child's disability or techniques for working with their child

Twenty-seven parents mentioned this specifically. For example, "It was most helpful when therapists, social workers, nurses and teachers taught me how to understand the growth and development of my child. They listened to problem areas and were sensitive to my needs."

3. Understanding the needs of their child and family

Eleven parents mentioned this strength in their services specifically, and many more alluded to it. For example: "Care and understanding of my child's needs; willing to teach me how to help my child's development; no high fees."

4. Feedback from providers about their child's progress and their concerns

This was the primary strength that 23 parents saw in the services they received. For example: "What I have learned from everyone and their encouragement and praise. They answer all my questions. They are good listeners and give good advice."

5. Personal interactions between providers and themselves or their children

Twenty-two parents praised the way in which providers interact with them and their children, with words like caring, personal, one-on-one, empathetic, and genuine. For example: "Everyone has always been very "kid friendly" to our son. They all were down on his level--speaking to him in ways he could understand. They always made us feel very comfortable with all the tests they did."

6. Effects of services on their child's growth and development

Many parents were very pleased with the effects services had on their children, and were quick to give credit to providers for this progress. Twenty-seven parents mentioned this explicitly in their comments.

For example: “I like that I can see a change in my son, with all the work he had, from AEA teachers, he’s come so far. Compared to when he first started, I think the program really helps the children as well as parents.”

7. Provision of services in the home

Twenty-six parents commented that they appreciated that services were provided in their homes, sometimes because of the flexibility this allowed them, in some cases because they did not have to face transportation challenges, and in some cases because they felt it was the best environment for their child. For example: “That they come to my house and when they are here they take care of my questions and give me suggestions and bring different toys to help my child.”

8. The kindness of services providers

While closely related to number 5, above, (interaction with providers), it is notable that twenty-three parents specifically referred to the kindness of their service providers as one of the things they like best about services. For example: “From day one, they have all been very kind and knowledgeable. They respect my child and our family.”

Along with these eight major subject areas, repeated topics in this section of comments included appreciation of the fact that services were provided at no cost, acknowledgement that their input as parents was respected and utilized, the accessibility of their providers, and the continuity and consistency of service provision.

WHAT DIFFICULTIES HAVE YOU HAD GETTING SERVICES FOR YOUR CHILD AND FAMILY?

This comment question was completed by 103 parents. Almost half of these parents (51, or 49.5%), however, responded with “none,” or some other indication that they had never had any problems receiving services. The remaining 52 parents described difficulties which fell into the following six main categories:

1. Delays in beginning services

Eight parents said that there was an unsatisfactory amount of delay between when they first signed up for Early Access services and when services actually began. For example: “We have had to fight to get our program going and get other services we needed.”

2. Difficulties with finances or insurance

Five parents said that their primary difficulty involved their finances or receiving insurance coverage for services. For example: “At first money was a problem until Matthew received disability;” and “Private insurance denied for premature child.”

3. Not receiving requested services

The most common problem mentioned by parents was non-receipt of services they had requested or felt their child needed. This was mentioned by eleven parents (21.2% of parents with positive responses to this question, 7.8% of all parents responding to the survey). There were a broad variety of such problems,

as exemplified by the following comments:

“Denied access to classes and services.”

“. . . my child may require speech pathology and I was informed that the agency does not have one for the age of my child (2 years old). I do foresee this as a difficulty for my child’s sake.”

“My child qualified in one state. . . and did not in Iowa. I have a hard time with that. My child has a mild disability, but I don’t think he should be shoved aside because he is not disabled enough.”

“OT and PT was never offered. When I requested the services, I felt they were not being open about why she didn’t need the services. And, my requests were put to the side.”

“The occupational therapist through AEA isn’t enough. My son needed more than once a month therapy--speech therapy and PT. . .”

“We have not been getting occupational therapy and that is recommended by our child’s doctors.”

4. Lack of information about services

Six parents commented that they were not made aware of Early Access in a timely manner, in some cases referring to their ongoing service, in others referring to the commencement of services. For example:

“I’ve had problems finding out about services available to my and my family;” and “None--after I found out about the program. However, if I hadn’t been getting WIC--I would not have been hooked to the well clinic and never been informed on you services. I am sure there is others like me out there unaware of your services.”

5. Lack of summer services

Three parents mentioned that the lack of ongoing services in the summer was a problem for them. For example: “. . . I feel that AEA should keep helping the children through the summer.”

6. Understaffing of AEA providers

Five parents expressed concerns about inadequate staffing levels at AEAs, and how this was affecting the services they received. For example: “The therapist has such limited time. We try to schedule therapy with another provider and the AEA therapist is stretched for time available.”

Additional issues which were mentioned among these responses included: language barrier as a problem, excessive amounts of paperwork, inaccurate recording of test results, transportation to group services, lack of flexibility on rescheduling services, and unmet need for assistive technology.

WHAT HAVE YOU LIKE LEAST ABOUT SERVICES FOR YOUR CHILD AND FAMILY?

As with the previous question, a large number of the 104 responses here were along the lines of “nothing” or “no problems.” Thirty-seven parents (35.6%) gave this response. Among the remaining 67 parents who responded to this question, there were seven areas that were repeated at least three times.

1. Communication between providers and parents

Five parents felt that communication between themselves and their service providers, or the AEA, was inadequate. For example: “As my son grew older and needed to move on with other activities, such as crawling, the providers didn’t listen to my concerns and didn’t work on activities that encouraged more physical activities;” and “Sometimes (not always) things were not explained. I would have to ask, okay, now what are you doing? What will this show?”

2. Problems with specific providers

Eight parents described difficulties or conflicts they had had with specific service providers. Examples of these included “One particular worker is very negative. But that is a personal problem, not necessarily a professional problem;” and “. . . I felt that one team member really underestimated me....almost expected me to be sad and overwhelmed rather than strong, informed, confident and optimistic;” and “We have one professional working with our child who does not attend or provide input to the IFSP.”

3. Summer services

Four parents were unhappy that services are interrupted or change over the summer. (Note that an additional three parents mentioned this fact in response to the previous question.) For example: “Providers only saw my child once a month in summer, and saw him once a week otherwise.”

4. Providers canceling appointments

Three parents felt that providers too frequently cancel services or do not show up for services, and it is then difficult to reschedule that time. The three comments were: “His teacher seems to cancel and reschedule a lot;” “Not being able to keep certain appointments;” and “They are not reliable.”

5. Lack of flexibility in service provision

Four parents said that their providers are not flexible enough in the scheduling of appointments and parents’ needs. For example: “. . . when [my daughter] is ill and I cancel I feel hassled sometimes;” and “If you were a minute late with AEA they canceled or didn’t wait.”

6. Quality of services provided

Nine parents were dissatisfied with at least one aspect of the services provided to them or their child. This was most often a problem with the attitude of the providers. Some examples are: “The negativity [my son] received during physical therapy. Also, that they don’t take siblings into consideration;” “The times that the professionals come seemingly unprepared but in effect trying to ‘wing it.’ I think that each visit should have a main goal--something which has been thought about ahead of time;” and “The varied quality of services. Some providers are excellent and others are mediocre at best. However, something is better than nothing.”

7. Quantity of services provided

The eleven parents who were dissatisfied with the quantity of services provided fell into two categories—those who would want services more frequently, and those who would want additional services.

Examples from the first category are: “I feel our son needs speech therapy more than once a week. I feel 2-3 times a week would be more beneficial. He forgets to quickly;” and “There’s not enough PT, OT and speech therapy and they always say that my son receives more services than others in the program.”

Examples of the second category are: “I wish more services were offered for children under three such as a day care program for children with special needs;” and “I wish there were more toddler groups where the parents are able to get together.”

Additional topics which were mentioned by more than one parent in response to this question were: inadequate hygiene and infection control policies, too much turnover of staff, providers are too rushed, and difficulties with insurance and MR waivers.

IN WHAT WAYS DO YOU THINK PROVIDERS COULD IMPROVE THE WAY THEY WORK WITH FAMILIES?

Of the 109 parents who answered this question, 41 (37.6%) had no suggestion for improvement, but rather indicated that they were satisfied with services currently. Of the remaining 68 parents, there were eight main categories of comments.

1. Improved communication between providers and parents

This was a very broad category, about which 13 parents made some comment. These varied from the general: “I feel that better communication links need to be established;” to specific issues such as “[Don’t] assume that the parents don’t know anything about the child’s disability;” “Make sure it is always explained what the provider is doing and why and how the child responds and needs to improve;” and “Listen to what the parents say about what their kids are doing at home.”

2. Greater sensitivity to families’ needs and feelings

Nine parents felt that providers sometimes displayed a lack of sensitivity, either in the way they communicated, or in the way they worked with the child. For example: “Be more sensitive to our feelings and not so quick to stereotype our child;” and “Tell them when they are assessing your child. . . in a sensitive manner, rather than in a “cold, hard facts” attitude.”

3. More frequent and diverse services

Nine parents mentioned that they would like to receive more services, wither more frequently, or additional services (also see above, response ### to question \$\$). These responses included: “The more visits all year would be great, twice a week, instead of once a week;” and “Be allowed to come more often.”

4. Greater flexibility on the part of providers

Six parents felt that providers were not flexible enough in the scheduling of their services or in how services were provided. For example: “Be more flexible in their testing and be able to score with more

objectivity. A child's true abilities (or lack of) are not just a number on a piece of paper;" and "They could be a little more flexible. It seems that when you have to cancel a session, or if they do, your child is not rescheduled. You are just seen on the next scheduled appointment."

5. More information provided at the beginning of services

Five parents felt that when they began receiving Early Access services, the information they received was not clear or complete: "At the first meeting or testing it would have been nice to have in writing, job descriptions and credentials of those involved because I did not know what an occupational therapist was, etc." and "It would be nice if there was one person who upon referral to the system, would outline all services available and how to obtain them."

6. More service during the summer

Four parents felt that services need to be more consistent during the summer months (see also above, response \$\$, question \$\$). For example: "During the summer they've tended to scatter out and come at different times. That gets a little crazy;" and "She spends one hour a week with [my son] and having services in the summer would help."

7. Increase parent involvement

Four parents felt that they and other parents should be more involved with the services for their children, in a variety of ways: "Get parents more involved with their children, especially in the classroom. Parents are welcome anytime, but I know no one goes. They have to be asked to come in;" and "Educate the parents more. . . . Children with special needs would benefit more if [parents] were taught how to work with their children everyday and rely on the therapists and teachers less."

8. Be more up-front and honest with parents

In contrast with some of the responses given above in #2, three parents specifically requested that providers be more direct in describing their assessment of children's needs and abilities. For example; "I think they need to give parents realistic expectations, instead of being vague to save feelings;" and "Be brutally honest about the child if necessary. Give the parents all information available to providers about the child's condition, prognosis, and possible progress so that the parents are well-informed and can make better decisions concerning the child."

Additional topics which were mentioned by parents in response to this question included: more consistency in the providers who work with them, increasing the number of Early Access staff, more attention paid to siblings, decreasing paperwork or not doing it on parents' time, improved outreach about Early Access services, making reminder calls about appointments, and improving the sensitivity of medical personnel.

ARE THERE ANY SERVICES YOU WISH YOU HAD FOR YOUR CHILD OR FAMILY THAT YOU DID NOT RECEIVE?

Over half of the 109 parents (61, 56%) who responded to this question said there were no services they wanted but did not receive. The 48 remaining parents who responded had a number of categories of responses which a large number agreed upon.

1. Speech & language services

Ten parents mentioned that they wanted speech and language services for their child and did not receive them. In seven cases this was a request for any speech therapy at all that had not been met, in the other three cases, the parents wished for more speech therapy than they received, e.g. “Speech therapy during the summer months for our child because our child forgets some of what our child learned during the school year so the keystone AEA speech therapist has to backtrack so to speak when school begins again in the fall.”

2. More occupational and physical therapy services

Seven parents felt that their child would benefit from more occupational and physical therapy than they received. For example: “Actual physical therapy and occupational therapy. Someone to physically work with my child (like the PT/OT did in SD) not just monthly courtesy visits;” and “. . . I think all special needs children can benefit from OT/PT. I never did receive those services.” Four of the parents who wished for more occupational or physical therapy were also parents who would have like speech language therapy.

Two additional parents said they would like more services available, without specifying which services they received. These comments were: “Possibly the teacher working more frequently with child on a one on one basis. . .” and “What other agencies were/are available other than Area Education Agencies? I would have liked our child to be seen two times a week.”

3. More childcare and respite availability

Eight parents mentioned that they would have use for more childcare services and/or respite services. These ranged from ongoing daily care for their disabled child or siblings to just occasional help for evenings off. For example: “. . . time for my husband and I to have a night out 1 to 2 times a month where we aren’t afraid to go out of town or so we can play cards with friends at their place;” and “Occasional childcare! I can not hire the “average teenager” to watch this child. I pay \$3 -\$4 per hour because of child’s high needs. Plus, \$1 per hour for each of my other children. I cannot afford this but there are times I have no choice. I cannot take her everywhere I need to go, like some meetings or training sessions.”

4. More parent-to-parent support opportunities

Of the seven parents who indicated that they would have more opportunity to talk with other parents, four mentioned support groups and three mentioned direct one-and one contacts. For example: “Help locating information about the child’s disease and help getting in touch with other parents of children with the same disease/problem;” and “Support group opportunities on a regular basis. Someone to have

contacted us after our child's diagnosis to help us deal with the devastation.”

5. Mental health services

Along the same lines as the previous item, five parents said they would have liked some help dealing with the psychological repercussions of their child's disability for themselves or for their other children: “Counseling services to help family cope with chronically ill child. Sibling support!!” and “Mental health help, but I don't think AEA is involved with that.”

6. More services for siblings

In addition to the counseling parents requested for siblings, four parents requested that services pay greater attention to the needs of siblings, either through additional services, or through greater awareness by providers currently coming into their homes. For example: “Sibling support groups. . .” and “. . . Having respite through the same agency to include siblings.”

7. Financial and in-kind support

Five parents said they would benefit from increased financial supports, whether to cover additional services or to help pay for the services and supplies they currently used. For example: “Services for working toward “buying” equipment. More ways to access equipment;” “We would like more PT, OT and speech therapy and for a funding to help pay for these so he can get it 5 times a week. . .” and “I wish there was someone to help us get more financial services.”

8. More summer services

As mentioned in the previous two questions, three parents indicated that they would like more regular services over the summer. For example: “More frequent visits in the summer months or forget it. Two one-hour visits a month isn't worth scheduling.”

Additional themes and issues brought up in response to this question were: more help with assistive technology, more opportunity for children to interact with other children (toddler groups, etc.), greater knowledge about what services are available to them from the start, and starting services sooner.

WHAT HAS IT BEEN LIKE FOR YOU TO TRANSITION OUT OF EARLY ACCESS?

(for parents of children over the age of two)

There were 79 responses to this question, and 17 of these were along the lines of “Transition has not completely happened for us. So I can't comment on it.” An additional five parents said they no longer received any services. Among the remaining 57 responses were the following major themes:

1. Transition went smoothly

Many of the parents who responded to this question felt that the transition out of Early Access went smoothly (20 parents, or 35%). They described the process as: “It was very easy, the Early Intervention

people walked me through the process;” and “I could talk to my teachers about the classrooms and the teacher. We went to visit in the spring and again in the fall before Megan started school. The transition was quite smooth. Services are provided by same support staff except teacher--which is helpful for Megan.”

2. Transition was for the best for child

Nineteen parents (seven of whom were the same as those who described transition as “smooth”) said they felt that the transition was in the long run the best thing for their child, that they gained a lot from starting preschool services. Parents said things like: “I know it will take some time and will be hard for both of us, but I know it will be for the best! I feel confident that they will take good care and teach Samantha a lot of fun activities;” and “Best opportunity for our child. She now receives consistent, day to day help with the same, familiar providers. . .”

3. Less feedback than prior to transition

Eight parents, including two who were otherwise positive about transition, felt that they received less feedback about their child’s progress and activities than they had during Early Access. For example: “Most services are now provided at the preschool, so I no longer see first hand how they are working with my son or what exercises they are doing. I feel a little more cut off from ‘the team;” and “The changes have been not personally meeting with my child and the providers. I liked to the monthly feedback and discussion. The notes are nice but not the same.”

4. Transition was scary for parents and child

Five parents described sending their child off to school as scary or traumatic for them or for their child, yet they felt it was worthwhile: “It was scary for me and the teachers;” “Marshall being three, I felt like I was sending a baby to school, but I know this is best for Marshall.”

5. Would prefer to still receive home services

Four parents explicitly mentioned that they wished services could have continued longer in their homes: “I think they should have come to the house for two days;” “At the time I would have liked to still have someone come to the house, but things have worked out fine;” and “I home school and do not wish to see my son lose in home services that he has now.”

6. Services are not as good as before transition

Four parents said that they felt that the quality of services had, in one way or another, declined after transition out of Early Access. For example: “The transition meeting was pointless--no teachers or associates were present. This was just the beginning of a disappointing year in ECSE. Communication is difficult, IEP meetings have been horrible, and speech services are ineffective. I feel that [my son’s] potential is underestimated and that my requests/suggestions are ignored. It is like night and day. How I wish we could turn back the clock and go back to our old team in Early Intervention!

7. Have heard nothing about transition

Four of the parents who responded to this question (all of whom had children over two years old) said that they had not yet heard anything about transitioning out of Early Access. A few were grateful that the survey had informed them that this was impending. For example: “Child turns three next week. I have no clue what happens next;” and “This has not yet occurred--news to me!”

Additional issues which came up in response to this question were that parents felt pressured by providers to place their children into preschools, concern that class sizes are too large, desire for summer programs for children over three, and discomfort with bussing a three-year-old child.

Analysis of Individual Family Service Plans

Along with taking part in focus groups and completing the survey, parents who participated in the evaluation were asked to submit copies of their child’s IFSP for analysis. Seventy-four IFSPs were analyzed from the 15 Area Education Association regions. The IFSPs collected included both their original IFSP and any Periodic Review forms completed between the inception of their Early Intervention services and the date of the request.

PROFILE OF THE SAMPLE

Of the 74 families whose IFSPs were analyzed, demographic information was available for 70.

TABLE 21: DEMOGRAPHICS OF IFSP SURVEY SAMPLE

	N	Total N	%
Race/ethnicity			
White	58	70	82.9
Asian or Pacific Islander	0	0	0
Black	2	70	2.9
Native American	1	70	1.4
Hispanic	3	70	4.3
Other	8	70	8.6
Annual Family Income			
\$0-14,999	13	64	20.3
\$15,000-29,999	20	64	31.3
\$30,000-44,999	16	64	25.0
\$45,000 +	15	64	23.4
Last year of education			
Less than high school	3	67	4.5

Completed high school	15	67	22.4
Some post secondary	27	67	40.3
Completed college	14	67	20.9
Graduate school	8	67	11.9
Marital status			
Single, never married	12	70	17.1
Married	56	70	80.0
Divorced	2	70	2.9
Widowed	0	70	0
First child with disability/delay	49	56	87.5
mean age of child	17 months		

IFSP CONTENT ANALYSIS

The IFSP documents were analyzed for content according to the relevant priority themes and key questions of the evaluation: Collaboration among service providers and agencies, maximizing available resources, family-centered service delivery, cultural responsiveness, and the IFSP as a document reflecting and responding to child and family needs. The eighteen criteria by which IFSPs were analyzed were designed to gather as much information as possible from each IFSP, and associate the information included in the IFSPs as closely as possible with specific questions raised for the evaluation. Clearly the eighteen criteria do not include all the information contained in the IFSP—much of the document pertains to specifics of child development and health, which is less relevant to the evaluation. The eighteen criteria are listed below, roughly divided according to the evaluation theme they address (although there is overlap on many of the criteria).

Collaboration among service providers and agencies

- non-AEA resources used (providers or activities that do not stem directly from the Area Education Agency are included)
- coordination between providers (indication that providers are working together to achieve goals)
- coordination between agencies (indication that agencies are communicating and coordinating their efforts for the family)

Maximizing available resources

- informal resources used (community, church, friends, or other informal resources are included)
- financial needs included (the family's financial resources are considered)

Family-centered service delivery

- professional language used (jargon or technical language used without explanation)

- parents’ roles included (the role parents are to play in providing an intervention is explicit)
- effects of services on family (the effects of the interventions on other family members is considered)
- parent input indicated (parents’ input as to their child’s needs and accomplishments is indicated)
- parents taught to use systems (indication that parents are given tools to access resources and programs without the aid of Early Intervention providers)
- marked met by parent report (outcomes and goals are marked as “met” based on parents’ input, rather than solely according to providers’ assessment)

Cultural responsiveness

- cultural supports/adaptations (indication that providers have made adaptations to cultural, religious, or ethnic differences)

IFSP as a document reflecting and responding to child and family needs

- item requested by family (a particular outcome or goal is explicitly indicated to have been requested by the family)
- family needs included (the needs of family members other than the child are considered)
- health needs included (the child’s health needs are considered)
- social needs included (the child’s social needs are considered)
- indication of transition (for children over 2 years of age, some discussion of transition out of Early Intervention services has taken place)
- family needs on transition (the needs of other family members are considered on any transition plan that has been written)

Each IFSP analyzed was composed of a number of different sections—commonly an assessment page, a family information page, health information, a page or section for each identified outcome and annual goal, conference notes, and a transition plan. No two IFSPs consisted of exactly the same combination of components. There was also a wide variety in the forms used for the IFSP, both because they were filled out over the course of three years, and because the fifteen regions seemed to utilize slightly different forms.

Each of the above criterion was marked as ‘met’ or ‘unmet’ on *each* of these elements of the IFSP. For example, “parents’ roles included” may have been ‘unmet’ on any of the outcomes pages, if no mention was made of how parents were to participate, but then may have been marked ‘met’ for the transition page, which might have indicated how parents were to continue therapies on their own after the end of Early Access services. A mean score for each IFSP for each item was tallied, indicating the percent of all criteria that were marked “met” for that IFSP. When these were combined across all 74 IFSPs in the sample, there were a number of criteria which were not met on the majority of the forms. The total means were as follows:

TABLE 22: RESULTS OF IFSP CRITERIA ANALYSIS

<i>Criterion</i>	<i>mean % marked “met”</i>	<i>std. dev.</i>
------------------	----------------------------	------------------

social needs included	79.3	.18
Indication of transition	73.2	.25
coordination between	71.2	.24
parent input indicated	67.5	.26
health needs included	66.4	.24
parents' roles included	51.8	.28
non-AEA resources used	51.0	.28
informal resources used	41.3	.28
coordination between	30.1	.27
effects of services on family	28.2	.25
item requested by family	26.6	.24
marked met by parent report	21.8	.25
parents taught to use systems	21.4	.26
family needs included	17.0	.18
financial needs included	15.5	.19
professional language used	5.9	.11
cultural supports/adaptations	4.3	.20
family needs on transition	0.00	0
overall mean	36.7	.11

With the exception of the two transition items, all of the above means were of the sample of 74 IFSPs. 'Indication of transition' was the mean of only those 41 IFSPs where the children were at least two years old. The 'indication of family needs on transition' criterion was on an even smaller sample: only those IFSPs written for children over the age of two *and* who had a transition plan as part of the IFSP were marked for this item, creating a sample size of only six IFSPs (one of which was for a child who was only 11 months old at the time). None of these six transition plans included family needs.

Those areas where the IFSPs seemed to be the strongest were the inclusion of health needs and social needs (which included speech-language services), parent input included, indication of transition, and coordination between providers (as indicated by more than one provider being responsible for outcomes). Professional language was used on only 5.6% of the IFSPs, which is another positive indicator. Parents roles were indicated and non-AEA resources were used on more than half of the IFSPs as well.

The areas that were marked met the least often were: family needs included, financial needs included, and cultural support/adaptations.

The discrepancy between the inclusion of health/social needs and family/financial needs does seem to point to a child-centered approach to the IFSP, to the exclusion of other family concerns. The high levels for both 'parent input indicated' and 'parent roles indicated' points to a high level of parent involvement throughout the IFSP process.

Comparison between IFSPs and Responses to the Parent Survey

Parents agreement with the IFSP best-practices, as described on the survey, did not significantly correlate with the percentage of items marked “met” on the analysis of their IFSPs.

Scores on the IFSP content analysis did not vary statistically between the various demographic groups, nor did they vary significantly based upon other data collected on the parent survey (presence of one main contact person, first child with disability or delay, presence of major health concerns), with one important exception. The IFSPs of children over the age of three at the time of data collection (January 1998) tended to have lower percentages marked ‘met’ overall than those of children still receiving Early Intervention services (31.1% met for over three, 38.2% met for under three).²² This is in keeping with other findings from the parents survey (see page \$\$), indicating that parents satisfaction had improved over the three years precious to data collection.

SERVICE PROVISION AND THE IFSP

Sixty-five parents gave information about the services they received both on the survey and by providing researchers with a copy of their IFSP. The IFSP lists all the services provided to that family, as well as what agency is responsible for them. These parents received a total of 229 services as indicated on the IFSPs, and a total of 184 services as indicated on their surveys.

As indicated below, for the most part, there was agreement on what services were being provided between the surveys and IFSPs of the 65 parents providing service data from both.

TABLE 23: COMPARISON OF SERVICES AS REPORTED ON PARENT SURVEYS AND AS INDICATED ON IFSPS

service	parents indicating service received on survey	%	service indicated received on IFSP	%	parents indicating service received on survey (including only those also in IFSP sample)	%
<i>physical therapy</i>	54	38.3	31	13.5	22	12.0
<i>speech/ language pathology</i>	46	32.6	25	10.9	19	10.3
<i>home intervention/ teaching</i>	44	31.2	63	27.5	20	10.9
<i>occupational therapy</i>	42	29.8	25	10.9	18	9.8
<i>preschool</i>	28	19.9	9	3.9	13	7.1
<i>acute medical care</i>	23	16.3	6	2.6	5	2.7
<i>audiology</i>	15	10.6	15	6.6	9	4.9
<i>nursing care</i>	14	9.9	13	5.7	7	3.8
<i>respite care</i>	12	8.5	1	0.4	6	3.3

²² t=2.489, df=63, p=0.015

<i>WIC nutrition</i>	12	8.5	5	2.2	5	2.7
<i>vision care</i>	6	4.3	6	2.6	4	2.2
<i>evaluation/assessment</i>	6	4.3	0	0	1	0.5
<i>Title XIX</i>	5	3.5	4	1.7	3	1.6
<i>homemaker services</i>	5	3.5	0	0	2	1.1
<i>SSI</i>	4	2.8	0	0	1	0.5
<i>toddler group</i>	4	2.8	4	1.7	3	1.6
<i>food stamps</i>	3	2.1	2	0.9	1	0.5
<i>well clinic care</i>	3	2.1	1	0.4	3	1.6
<i>FIP</i>	2	1.4	2	0.9	0	0
<i>foster care</i>	2	1.4	2	0.9	0	0
<i>behavior therapy</i>	2	1.4	0	0	0	0
<i>childcare financial assistance</i>	2	1.4	0	0	1	0.5
<i>early head start</i>	1	0.7	3	1.3	0	0
<i>genetics counseling</i>	1	0.7	0	0	1	0.5
<i>other</i>	57	40.4	12	5.2	45	24.5

The only large discrepancy is between parents who indicated on their survey they receive home intervention/teaching, (10.9%, using the sample of those parents who had both surveys and IFSPs) and those whose IFSP indicated home intervention/teaching (27.5%) is probably accounted for in the large “other” category on the surveys, in which, as mentioned above, parents often referred to AEA services in very general terms.

Other smaller discrepancies between the two were:

Mentioned on the IFSPs more than on the surveys:

- physical therapy (difference of 9 cases)
- occupational therapy (difference of 7 cases)
- speech/language therapy (difference of 6 cases)
- audiology (difference of 6 cases)
- nursing care (difference of 6 cases)
- early head start (difference of 9 cases)

Mentioned on the surveys more than on the IFSPs:

- preschool (difference of 4 cases)
- respite care (difference of 5 cases)
- evaluation/assessment (difference of 1 case)
- SSI (difference of 1 case)
- homemaker services (difference of 2 cases)

- well-clinic care (difference of 2 cases)
- genetic counseling (difference of 1 case)
- childcare financial assistance (difference of 1 case)

In general, the IFSPs seem to be more inclusive than the surveys in listing major services, and those directly serving the child, while parents listed services that were more geared toward the entire family's needs. This reinforces the finding from the IFSP content analysis that IFSPs tend to cover health and social needs and not include family and financial needs (see page \$\$).

PROVIDER SURVEY RESULTS

In the spring of 1999, 2676 surveys were mailed to providers around the state of Iowa who, in their professional responsibilities, were likely to encounter infants and toddlers between the ages of 0-3 with developmental disabilities or delays. The primary goals of the survey was to discover the degree to which these providers were familiar with Early Access services in their regions, and whether, why or why not they referred children and families for these services. Secondly, the survey addressed their familiarity with the various aspects of Early Access services, their assessment of the availability of various related services in their communities, the degree of their involvement with service coordination and Individualized Family Service Plans (IFSPs), and some of their attitudes and beliefs about family-centered practices.

Sampling Methods

The sampling population was collected by gathering complete lists of providers or agencies in the state of Iowa in nineteen different categories: pediatricians, family practitioners, general practitioners, child psychiatrists, child psychologists, hospitals, Child Health Specialty Clinics, audiologists, Maternal-Child Health Agencies, WIC agencies, occupational therapists, physical therapists, Early Head Start programs, Public Health nurses and home care aides, physicians' assistants, Department of Human Services social workers, Area Education Agency Early Childhood staff, childcare providers, and pediatric dentists. These complete lists provided a total of 16,124 names.

Based on the total number of providers in each of these categories, a required stratified random sample size of 2700 was estimated. This sample size obtains reliability at a sufficiently high level to accurately reflect the statewide population for the categories selected. In fact, the sample size is relatively robust so that a less than optimal response rates, through analyses, might be controlled resulting in little compromise in reliability.

The various categories of providers were sampled proportionately to their size in order to develop a total mailing of 2700. Stratification by population size was as follows:

TABLE 25: PROPORTIONAL SAMPLING OF PROVIDER SURVEY GROUPS

group size	% selected
less than 100	100%
101-550	50%
551-3000	16.6%
3000 and above	5%

Population lists were ordered geographically. Names were selected from each population list using systematic random sampling procedures, allowing for geographic distribution throughout the state.

Response Rate

There were 736 surveys returned, of which 13 were eliminated because the provider indicated that they did not ever work with children between the ages of 0-3 or their families. A total of 723 surveys were used for analysis of the data, comprising a 27% response rate. The surveys were from all over the state, and from a wide variety of providers, and response rates varied widely depending on the category of providers.

TABLE 26: RESPONSE RATES FOR PROVIDER SURVEYS BY PROVIDERS

	returned	total sent	response rate
Early Head Start staff	18	29	62.1%
AEA (Early Childhood Special Education teachers, physical therapists, occupational therapists, social workers, speech-language pathologists, psychologists, and administrators)	87	187	46.5%
WIC (dietitians and other staff)	53	119	44.5%
MCH agencies (nurses, social workers, other staff)	60	139	43.2%
DHS (primarily social workers)	166	411	40.4%
hospitals (clinic staff, social workers, nurses, physicians' assistants)	36	90	40.0%
pediatric dentists	12	39	30.8%
Public Health /home care (includes public health nurses, aides, physicians' assistants, administrators, et al.)	51	167	30.5%
pediatricians	35	137	25.5%
physical therapists (AEA, hospital, and private offices)	21	101	20.8%
childcare workers	40	192	20.1%
physicians' assistant (private offices)	42	216	19.4%
audiologists (AEA, hospital, and private offices)	19	98	19.4%
CHSC (nurses, other staff)	15	90	16.7%
family practitioners	14	111	12.7%
speech-language pathologists (AEA, hospital, and private offices)	12	96	12.5%
child psychiatrists & psychologists	2	19	10.5%
occupational therapists (AEA, hospital, and private offices)	26	277	9.4%
general practitioners	14	158	8.9%
TOTAL	723	2676	27.0%

There were numerous surveys that were sent to one agency and returned by a provider working for a different agency, particularly when the agencies shared offices (for example, Early Head Start and WIC are commonly run from one Community Action Program office, and providers passed surveys between them). In addition, many providers who were sent surveys on an individual basis (such as physical therapists, who were sent surveys if they were licensed with the state) turned out to be employed by a surveyed agency, such as an AEA). Because of this frequent crossing of categories, the above response rates are only close, workable approximations.

Overall Sample Responses

The survey questions can be divided into four topics: familiarity with Early Access services, referral to services, availability of services in the community, involvement with service coordination and IFSPs, and family-centered practices.

Minimal background information was collected about the providers. They came from communities as small as a town of 92 to cities as large as Des Moines, in the following proportions:

- town population 20,000 and fewer: 352 (48.7%)
- town population 20,000-50,000: 156 (23.0%)
- town population 50,000 and more: 205 (28.4%).

Providers worked for various agencies and programs as follows:

TABLE 27: AGENCY AFFILIATIONS OF PROVIDERS SURVEY SAMPLE

	N	%
Public Health agencies	169	24.1
Department of Human Services	166	23.7
private providers (includes doctors, audiologists, therapists, et al.)	132	18.8
Area Education Agencies	122	17.4
private childcare providers	43	6.1
hospitals	36	5.1
Early Head Start	18	2.6
Child Health Specialty Clinics	15	2.1

Viewed according to their actual job responsibilities, the sample breaks down as follows:

TABLE 28: JOB DESCRIPTIONS OF PROVIDERS SURVEY SAMPLE

	N	%
social worker	199	27.5
non-hospital nurse or physician's assistant	151	20.9
doctor	67	9.3

childcare provider	61	8.4
ECSE home teacher	42	5.8
physical therapist	32	4.4
occupational therapist	32	4.4
administrator	25	3.5
speech-language pathologist	24	3.3
dietitian	22	3.0
audiologist	19	2.6
hospital nurse	15	2.1
dentist	12	1.7
psychologist	12	1.7
other	10	1.4

On average, providers had been working in their profession for 12.16 years (s.d. 9.38), with some working under one year, and one for as long as 63 years. They had been working in their specific community (within 100 miles of their current work) for an average of 12.8 years (s.d. 9.21), from as little as one year to as long as 63 years.

Providers estimated that they worked with children between the ages of 0-3 or their families 17.43 hours per week (s.d. 15.42), with some working with this population less than one hour per week, and others working with them as much as 100 hours a week.

FAMILIARITY WITH EARLY ACCESS SERVICES

Most providers were at least aware of Iowa’s Early Access services, at 76.5% (546). Of those who were aware of services, 407 (74.5%) had, in fact, referred children for services, and 139 (25.5%) had not. Providers who had heard of Early Access services tended to have worked in their professions and communities slightly longer, although the differences were not statistically significant.²³

There was, however, a statistically significant difference, among those who had heard of Early Access services, between providers who had referred for services and those who had not. Providers who had referred children and families for Early Access services had worked in their professions, on average, for 13.1 years, and had worked in their communities for 13.6 years. Those who had not referred any children and families for services had worked in their professions for an average of 11.0 years, and in their communities for 11.2 years.²⁴

Only 36.3% of the providers (258), however, were familiar with the Early Access Regional Council in their area. Of those who said they were familiar with it, only 160 (62%) could put a name to the group. Twenty-one providers attempted to put a name to the council, but identified either their local AEA (12 providers) or

²³ Providers who had heard of Early Access had worked in their professions an average of 12.5 years, and worked in their communities 13.0 years; those who had not heard of Early Access had worked in their professions 10.9 years and worked in their communities 12.2 years.

²⁴ difference in time in profession: $t=2.405$, $df=526$, $p=0.017$; difference in time in community: $t=2.686$, $df=535$, $p=0.007$.

some other agency. Once again, those who had worked in their professions and communities longer were statistically significantly more likely to be familiar with the council. Those who had heard of the council had worked in their professions, on average, for 13.6 years, and had worked in their communities for 14.4 years. Those who had not heard of the council had worked in their professions for an average of 11.2 years, and in their communities for 11.9 years.²⁵

Of those who were familiar with the council, 29.9%, or 79 providers, had actually served on the council. Longer tenure in one's profession and community increased the likelihood of a provider having served on the council, but only marginally and not significantly so.²⁶

[\$\$ ADD awareness of council activities!]

Providers were asked to give examples of activities sponsored by the regional councils, and 117 providers did so. Among those activities mentioned more than a few times were:

- workshops and trainings for parents and professionals
- starting and maintaining libraries of videos, books, and toys
- toddler groups
- development wheels
- health passports
- child find fairs and other screening activities
- support groups
- referrals to services
- grants for small projects
- funds for assistive technology and other equipment
- newborn packets

Of the 252 providers who had heard of their regional council, 40.9% (103) had participated in council activities. As above, those providers who had worked in their fields and communities longer were statistically significantly more likely to have taken part in council activities. Those who had participated had worked in their professions, on average, for 15.2 years, and had worked in their communities for 15.9 years. Those who had not participated in council activities had worked in their professions for an average of 12.4 years, and in their communities for 13.4 years.²⁷

As indicated above, providers' knowledge of and involvement with Early Access services increases as their tenure in their professions and in their communities goes up:

TABLE 29: KNOWLEDGE OF EARLY ACCESS BY JOB AND COMMUNITY TENURE

²⁵ difference in time in profession: $t=3.381$, $df=676$, $p=0.001$; difference in time in community: $t=3.448$, $df=688$, $p=0.001$.

²⁶ Providers who had served on the council had worked in their professions an average of 13.8 years, and worked in their communities 14.8 years; those who had not served on the council had worked in their professions 13.6 years and worked in their communities 14.4 years.

²⁷ difference in time in profession: $t=2.473$, $df=242$, $p=0.014$; difference in time in community: $t=2.169$, $df=245$, $p=0.031$.

	mean years in profession	mean years in community
Aware of Early Access services	12.5	13.0
Have referred for Early Access services	13.1	13.6
Familiar with regional council	13.6	14.4
Served on regional council	13.8	14.8
Participated in council activities	15.2	15.9

REFERRAL FOR EARLY ACCESS SERVICES

Almost all of the providers (647, or 90.5%) had, in the previous two years, seen children between the ages of 0-3 who they thought might have a developmental disability or delay. On average, providers had seen 19.16 such children in the previous two years (s.d. 51.35). They referred just over half of these children to another agency for assessment, evaluation, or services—on average, 11.77 (s.d. 38.39) in the previous two years, or 61.4% check this with provider breakdown, I think they differ! of those they had seen.

Providers made referrals to the following sources of services:

TABLE 30: REFERRALS BY AGENCY REFERRED TO

Area Education Agency	82%
Child Health Specialty Clinics	58%
Hospital	27%
Child Find Fair	8%
private provider	38%
other	14%

Among the 80 referrals to “other” were included WIC clinics, the Department of Human Services, Head Start, behavior clinics, daycare, community action agencies, the Department of Public Health, feeding clinic, Hopes program, home care services, hearing clinics, Iowa School for the Blind, and mental health services.

The private providers who were referred to included, among others: primarily medical doctors (including child psychiatrists), physical therapists, speech-language pathologists, childcare providers, orthotists, Lutheran Social Services, Visiting Nurses Association, and family therapists.

Only 58.4% of providers (422) felt that they could estimate the percentage of their referrals who received Early Access Services. Their estimates were:

TABLE 31: ESTIMATED RATE OF REFERRALS RECEIVING EARLY ACCESS SERVICES

<25% of referrals	11.6%
25-50% of referrals	14.5%
50-75% of referrals	23.9%
>75% of referrals	50.0%

From the above it can be determined that providers estimated that between 53.1% and 78.1% of referrals received Early Access services.

There were slight difference in the estimates of referrals receiving services depending on who the provider referred to, although these were not statistically significant. Referrals to Child Find fairs resulted in services between 58.5-83.5% of the time; to “other” providers between 58.2-83.2% of the time; to Child Health Specialty Clinics between 53.3-78.3% of the time; to AEAs between 52.3-77.3% of the time; and to hospitals between 51.2-76.2% of the time.

Of the providers who had seen at least one child with a potential disability or delay in the past two years, 17% (110) had not referred any children for assessment, evaluation, or Early Access services. Certainly the majority of the other 537 providers had, in at least one case, not referred the child on. Providers were asked their reasons for choosing not to refer children on for assessment, evaluation, or services:

TABLE 32: REASONS FOR NOT REFERRING FOR ASSESSMENT

	% of all providers responding	% of providers who had <i>not</i> referred children
not sure whether there was a disability or delay	9.1%	23%
didn't know where to refer the family	7.9%	21%
were concerned that the parent might react negatively	4.0%	16%
wanted to wait and see what happened	5.7%	11%
believed the needed services or supports were not available	1.5%	3%
other reason	21%	51%

Many of those who did not refer for an “other reason” did not do so because the child in question was already receiving services. Others did not refer because the parents did not want the services, because they were not aware of how to access services, because they felt the child would not qualify for services, because they had assessed that the child did not need services, or because someone else at their agency takes care of the referral process.

AVAILABILITY OF SERVICES

Providers were asked to rate the availability of seventeen services for children and their families in their communities. The services included the federally mandated Early Access services, as well as some services that had come up as issues on other evaluation instruments. The scale the used was 1=very available, 2=somewhat available, 3=little or no availability, 4=don't know. For the purposes of analysis, those responding “don't know” to a given item were counted as missing values. Therefore, the total number of responses for each item is an indicator of the number of providers who felt they did not have enough knowledge about a given service to judge its availability. The items below are listed from those considered most available to those considered least available.

TABLE 33: PROVIDERS' RATINGS OF AVAILABILITY OF RESOURCES FOR FAMILIES

	N	mean rating	std. dev.
public health nursing	659	1.21	0.44
special instruction/home instruction	622	1.34	0.55
audiology	618	1.34	0.56
social work services	653	1.37	0.56
speech-language pathology services	647	1.40	0.57
physical therapy	595	1.48	0.61
vision services	578	1.49	0.62
family counseling	630	1.49	0.60
nutrition counseling	609	1.50	0.61
occupational therapy	553	1.51	0.64
pediatric medicine	639	1.54	0.72
Child Health Specialty Clinics	598	1.59	0.69
assistive technology	427	1.72	0.69
child psychology/psychiatry	618	1.80	0.72
daycare/preschool open to children with developmental disabilities or delays	575	1.84	0.73
transportation for children with developmental disabilities or delays	472	2.00	0.76
respite care	540	2.01	0.72

INVOLVEMENT IN SERVICE COORDINATION AND IFSPS

On the 704 providers who responded to the question, 16.5% (116) had at some time served as service coordinators. Of these 116 providers, 103 went on to say how many children and their families they had coordinated services for over the previous two years: responses ranged from 0 to 100, with a mean of 12.72 (s.d. 15.89). Providers who had worked longer in their professions were statistically significantly more likely to have been service coordinators, at 13.78 years versus 11.50 years,²⁸ while time spent in their community also increased the likelihood of service coordination, but not significantly so (13.34 years, as compared to 12.45 years).

Providers who had been service coordinators tended to rate services in their community as more available than did those who had not served as service coordinators. This may indicate that, as service coordinators, they had the opportunity to learn about services and programs they had not known or earlier, or that those who were better informed about community services tended to become service coordinators. There were six statistically significant items which service coordinators rated as more available, and one (family counseling) with they rated as less available:

TABLE 34: PROVIDERS' RATINGS OF AVAILABILITY OF RESOURCES FOR FAMILIES: SERVICE COORDINATORS AND NON-SERVICE COORDINATORS

²⁸ t=2.477, df=671, p=0.014

	service coordinators	s.d.	non-service coordinators	s.d.
physical therapy ²⁹	1.38	.56	1.50	.63
occupational therapy ³⁰	1.30	.50	1.56	.66
special instruction ³¹	1.11	.31	1.40	.57
audiology ³²	1.18	.41	1.38	.58
assistive technology ³³	1.57	.61	1.78	.71
family counseling ³⁴	1.65	.64	1.46	.59
Child Health Specialty Clinics ³⁵	1.48	.69	1.62	.69

Providers were asked whether they saw themselves as “part of a team providing Early Intervention services to the children [they] refer for services.” Of the 686 providers who responded, 49% (336) saw themselves as such. Of these 336 providers, however, only 58.6% (178) said they were regularly contacted for periodic and annual IFSP reviews, and only 55.5% (156) regularly attended these review. Those who were listed on IFSPs over the last two years estimated that they were included on an average of 13.1 IFSPs (s.d. 21.5), and that they saw each child or family, on average, 22.1 times per year (s.d. 43.8).

Those providers who are invited to attend IFSP meetings, but do not regularly do so, gave varied reasons for doing so. Most often, they said they were not informed of IFSP meetings (43 providers): e.g. “Not invited or informed;” “Not aware of such meetings.” Others were not able to go because of scheduling or tie constraints, or because they felt that someone else took responsibility for these meetings: “School audiologist does that;” “In conflict with office practice;” “Conflicts or late notice.”

SERVICE PRIORITIES FOR FAMILIES

The final question asked of providers was limited to those who work directly with children 0-3 and their families. Providers were asked to rank, as unimportant, somewhat important, important, or very important, 15 items which were indicators of a family-centered approach to service. Wherever possible, these items were written to be comparable to items asked of parents on the survey of parents which was conducted as part of the evaluation.

Between 644 and 689 providers responded to each item; “responses of “don’t know” were coded as missing responses. The items are listed below from the one considered least important to the one considered most important.

²⁹ $t=-2.056$, $df=181.125$, $p=0.041$

³⁰ $t=-4.525$, $df=211.944$ $p=0.000$

³¹ $t=-7.45$, $df=303.031$, $p=0.000$

³² $t=-4.125$, $df=154.479$, $p=0.000$

³³ $t=-2.592$, $df=415$, $p=0.010$

³⁴ $t=2.873$, $df=616$, $p=0.004$

³⁵ $t=-1.997$, $df=584$, $p=0.046$

TABLE 35: PROVIDERS' RATINGS OF SERVICE PROVISION PRACTICES

<i>How important is it that. . .</i>	mean	st. dev.
When parents disagree with providers about priorities for their child and family, the parents make the final decision about what is written in the IFSP. ³⁶	3.25	0.75
Parents have enough opportunities to talk with other parents whose children receive services. ³⁷	3.39	0.67
When services are scheduled, the family's needs are considered first. ³⁸	3.52	0.63
At IFSP meetings, parents are asked about priorities for their whole family, not only the child receiving services. ³⁹	3.53	0.63
A transition plan is discussed with parents as early as possible before the child is three. ⁴⁰	3.60	0.57
Families evaluate the success of all intervention outcomes.	3.63	0.57
Parents feel like they are a leading member of a team that is helping their child.	3.65	0.53
Parents are given adequate time and information to make their own decisions about participation in Early Intervention services.	3.67	0.55
Providers help parents learn to negotiate systems and access services on their own.	3.68	0.53
Providers clearly understand the roles and resources of providers from other agencies ⁴¹	3.74	0.47
Parents and anyone involved with the child are actively included in the evaluation/assessment. ⁴²	3.77	0.46
Providers are positive and point out strengths they see in a child and family. ⁴³	3.78	0.45
If English is not the family's first language, a translator is available for them at all meetings. ⁴⁴	3.81	0.47
Providers who conduct an evaluation/assessment are clear with parents about what they are doing and why in is important. ⁴⁵	3.83	0.40
Parents are able to trust that the providers they work with will keep their confidences. ⁴⁶	3.88	0.37
Overall mean	3.65	

All of the footnoted items are statistically significantly different from the overall mean for these items of 3.65, indicating that providers' rated these items as significantly either more or less important than average.

Comparison of Provider and Parent Survey Items

A number of items included in this final section of the provider survey were written specifically to mirror questions asked on the Parent Survey, in order to compare provider and parent priorities on some aspects of service provision. Not surprisingly, providers and parents did not turn out to see eye-to-eye on all of these

³⁶ t=-13.438, df=643, p=0.000

³⁷ t=-10.176, df=675, p=0.000

³⁸ t=-5.317, df=683, p=0.000

³⁹ t=-4.938, df=663, p=0.000

⁴⁰ t=-2.392, df=678, p=0.017

⁴¹ t=5.402, df=685, p=0.000

⁴² t=6.706, df=679, p=0.000

⁴³ t=7.762, df=687, p=0.000

⁴⁴ t=8.872, df=680, p=0.000

⁴⁵ t=12.687, df=685, p=0.000

⁴⁶ t=16.422, df=688, p=0.000

items—there were quite a few aspects of service provision, and the family’s role in services, that displayed statistically significant differences in provider and parent responses. Those footnoted below showed statistically significant differences.

These items were scored identically for parents and providers: 1=unimportant, 2=somewhat important, 3=important, 4=very important.

TABLE 36: RATINGS OF SERVICE PROVISION PRACTICES: PROVIDER-PARENT COMPARISON

<i>How important is it that. . .</i>	Parent survey mean	Provider survey mean	Difference
[Parents are/You were] given adequate time and information to make [their/your] own decisions about participation in Early Intervention services.	3.62	3.67	0.05
[Parents/You] and anyone involved with the child are actively included in the evaluation/assessment.	3.62	3.77	0.15 ⁴⁷
Providers who conduct an evaluation/assessment are clear with [parents/you] about what they are doing and why in is important.	3.67	3.83	0.16 ⁴⁸
If English is not [the family’s/your] first language, a translator is available for them at all meetings. ⁴⁹	3.00	3.81	0.81 ⁵⁰
At IFSP meetings, [parents/you] are asked about priorities for [their/your] whole family, not only the child receiving services.	3.24	3.53	0.29 ⁵¹
When services are scheduled, [the/your] family’s needs are considered first.	3.51	3.52	0.01
When [parents/you] disagree with providers about priorities for [their/your] child and family, [the parents/you] make the final decision about what is written in the IFSP.	3.51	3.25	-0.26 ⁵²
Providers are positive and point out strengths they see in [a/your] child and family.	3.65	3.78	0.13 ⁵³
[Parents/you] have enough opportunities to talk with other parents whose children receive services.	3.07	3.39	0.32 ⁵⁴
[Parents/you] feel like they are a leading member of a team that is helping [their/your] child.	3.50	3.65	0.15 ⁵⁵

All of these items, however, were rated by both parents and providers as somewhere between “important” and “very important.” For the most part, providers’ higher importance ratings may indicate that their training

⁴⁷ $t=2.626$, $df=161.622$, $p=0.009$.

⁴⁸ $t=3.704$, $df=171.887$, $p=0.000$.

⁴⁹ On the parent survey this data was collected from two items, one regarding availability of translators and the original referral meeting, the other regarding all other meetings.

⁵⁰ $t=2.674$, $df=11.079$, $p=0.022$.

⁵¹ $t=3.897$, $df=170.145$, $p=0.000$.

⁵² $t=-3.655$, $df=767$, $p=0.000$.

⁵³ $t=2.864$, $df=178.557$, $p=0.005$.

⁵⁴ $t=3.936$, $df=161.579$, $p=0.000$.

⁵⁵ $t=2.573$, $df=170.129$, $p=0.011$.

may encourage them to theoretically prioritize behaviors that parents may take for granted or not care as much about. The one exception to this pattern is the item about disagreements between parents and providers—parents feel far more strongly than providers that the parents’ decision be reflected on the IFSP. The mean provider response to this item was lowered by the responses of private providers and DHS providers, while others responded with ratings more in line with the parents (see page 55).

Geographic Categories

The surveys were broken down geographically into three categories—providers who lived in small towns and rural areas (population under 20,000); those who lived in mid-sized towns (population 20,000 to 50,000) and those who lived in Iowa’s larger towns and cities (population over 50,000). The respondents came from towns with populations as small as 92, to cities as large as Des Moines. The breakdown in between the three categories was:

- 20,000 and fewer: 352 (48.7%)
- 20,000-50,000: 156 (23.0%)
- 50,000 and more: 205 (28.4%).

There were a number of items on the survey for which responses varied significantly depending upon whether the provider came from a small, mid-size, or large population area.

Overall, 76.5% of respondents were aware of Early Access services (including those who had and those who had not referred people to these services). This number was statistically significantly lower, however, in urban areas, where only 70.6% of providers had referred people for services. In rural areas the number was slightly higher than average, at 77.2%, and in mid-sized areas yet higher, at 82.2%.⁵⁶

This lower awareness of services in urban areas extended to the Early Access council and its activities. Overall, 36.3% of providers were familiar with the council in their area. In mid-sized areas, this number went up to 45.7%, but in rural areas it was only 34.5%, and in urban areas went down further, to 31.8%. Again, these discrepancies were statistically significant.⁵⁷

The other area in which population had a statistically significant result was in providers’ assessment of the availability of various services for infants and toddlers in their community. Specifically, pediatric medicine was seen as very available by 80.8% (147) of providers living in urban areas, while among those living in small and rural areas, pediatric medicine was seen as very available by only 42.9% (132). Along the same lines, while 13.5% of all providers felt there was little or no availability of pediatric medicine, the same was true of only 1.6% of urban providers (3), but 24% of providers in small and rural areas (74).⁵⁸

⁵⁶ chi-square=7.018, df=2, p=0.030.

⁵⁷ chi-square=8.521, df=2, p=0.014.

⁵⁸ chi-square=91.442, df=4, p=0.000.

There was a similar pattern concerning the availability of child psychology and psychiatry. Among all providers, 38.2% (236) felt these services were very available, yet among urban providers the percentage was 51.1% (92). In this case, rural/small town providers tended to see the services as somewhat available, at 45.6% (134). While the overall response to “little or no availability” was 18.1% (112), among urban providers it was only 8.3% (15), and among rural/small town providers it was up to 26.9% (79).⁵⁹

Child Health Specialty Clinics were also assessed by providers as being more available larger communities. Among all providers, 52.5% (314) felt CHSC were very available, but this number went up to 61.8% (107) in urban areas and down to 42.9% in rural/small town areas. As a whole, only 11.5% (69) of providers felt there was little or no availability of CHSC, but this went down to 6.9% (12) in urban areas, and up to 16% (47) among rural/small town providers⁶⁰

The final services that was statistically significantly different between the categories was the availability of transportation for children with developmental disabilities or delays. Among all providers, 28.6% (135) felt transportation was very available, yet in urban areas this went up to 39.4% (50) and in rural/small town areas it went down to 24.2% (59). Similarly, only 19.7% (25) of urban providers felt that there was little or no availability of transportation, as compared to 31.1% (76) or rural/small town providers and 29% (137) of all providers.⁶¹

The last area in which there were statistically significant differences between providers based on the population of their community was in their participation as service coordinators and with the IFSP (Individualized Family Service Plan) process. In this case, it was the mid-sized towns which seemed to have above-average levels of involvement.

Among all service providers, 16.5% (116) had served as a service coordinator, as listed on an IFSP. This was slightly lower among rural/small town providers (15.9%, 55) and urban providers (12.6%, 25), but higher among providers in mid-sized towns, among whom 22.4% (36) had served as service coordinators.⁶²

The pattern continued when providers were asked if they saw themselves “as part of a team providing Early Intervention services to the children [they] refer for services.” Overall, 49% (336) said they did so, while the number was slightly lower for rural and urban populations, and higher (57.1%, 89) for providers who lived in mid-sized towns.⁶³ Similarly, when asked if they were regularly contacted for periodic and annual IFSP reviews, 58% of all providers said yes (307), while a lower percentage of rural and urban providers said yes, and among mid-size town providers, the percentage went up to 64.1% (50).⁶⁴ When asked if they regularly attended IFSP meetings, again, providers from mid-sized towns said yes a higher percentage of the time than

⁵⁹ chi-square=42.839, df=4, p=0.000.

⁶⁰ chi-square=24.571, df=4, p=0.000.

⁶¹ chi-square=13.528, df=4, p=0.009.

⁶² chi-square=6.254, df=2, p=0.044.

⁶³ chi-square=6.217, df=2, p=0.045.

⁶⁴ chi-square=6.216, df=2, p=0.045.

rural or urban providers: the overall mean was 54.1% (166), and among the mid-sized town providers the percentage was 59.8% (49).⁶⁵

Agency Categories

As mentioned above in the description of sampling techniques, the 723 providers who responded to the survey fell roughly into 19 different categories, depending upon their profession and the agency for which they worked. These 19 categories were grouped into eight main agencies, which accounted for all but 22 of the providers:

TABLE 37: PROVIDERS BY AGENCY AFFILIATION

	N	%
private practitioners ⁶⁶	132	18.3
Iowa Department of Human Services	166	23.0
Area Education Agencies	122	16.9
Iowa Department of Public Health ⁶⁷	169	23.4
Child Health Specialty Clinics	15	2.1
Early Head Start	18	2.5
childcare providers	43	5.9
hospitals	36	5.0
unclassified	22	3.0

These categories provide perhaps the most interesting level of analysis of the provider survey. The responses of providers employed by the different agencies varied widely, and shed some important light on the successes and challenges of forging Early Access as a cooperative, inter-agency program.

There was a wide range of tenure in one's profession and community between the eight categories.

TABLE 38: PROVIDERS' TENURE IN FIELD AND COMMUNITY BY AGENCY AFFILIATION

	mean years in profession	st. dev.	mean years in community	st. dev.
Child Health Specialty Clinics	18.00	8.60	15.87	7.16
private practitioners	15.92	10.86	13.21	10.13
Area Education Agencies	14.18	8.64	14.08	8.33
hospitals	11.77	9.98	11.78	10.74
Iowa Department of Public Health	10.59	8.67	13.90	9.85
childcare providers	10.59	7.97	13.66	9.23
Iowa Department of Human Services	9.46	8.11	10.81	7.93

⁶⁵ chi-square=8.654, df=2, p=0.013.

⁶⁶ This category includes medical doctors, dentists, private physician's assistants, physical therapists, occupational therapists, speech-language pathologists and audiologists in private practice. Of these, 66 (50%) are doctors.

⁶⁷ This category includes Public Health clinic staff, WIC staff, and Maternal Child Health clinic staff.

Early Head Start	7.15	8.33	9.56	7.81
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FAMILIARITY WITH EARLY ACCESS SERVICES

All agency providers are not equally aware that Early Access services exist. Specifically, while overall 76.5% of all providers are aware of services, the breakdown by category is:

TABLE 39: PROVIDERS' AWARENESS OF EARLY ACCESS BY AGENCY AFFILIATION

	%
Child Health Specialty Clinics	100%
Area Education Agencies	98.4%
Early Head Start	88.9%
Iowa Department of Public Health	83.1%
hospitals	77.1%
Iowa Department of Human Services	75.5%
private practitioners	58.0%
childcare providers	31.0%

Notably, it is the private sector workers—doctors, other private practitioners, and childcare workers—who are least aware of Early Access services.⁶⁸

Of the 546 providers who were aware of Early Intervention services, providers from some agencies refer children and families for the services more than others. Compared to the 25.6% **[\$\$ check throughout that these overall numbers match up!]** of all providers who referred children and families, the various agencies referred as follows:

TABLE 40: PROVIDERS' REFERRAL RATES BY AGENCY AFFILIATION

	% who have referred children and families
Area Education Agencies	89.2%
Early Head Start	81.3%
Child Health Specialty Clinics	80.0%
Iowa Department of Public Health	72.5%
Iowa Department of Human Services	69.1%
hospitals	66.7%
private practitioners	65.8%
childcare providers	61.5%

Again, it is the private providers—doctors, physicians' assistants, hospitals, and childcare workers—who are the least likely to have referred children and families for Early Access services.⁶⁹

⁶⁸ chi-square=115.418 df=7 p=0.000

⁶⁹ chi-square=21.414 df=7 p=0.003

Awareness of the Early Access regional council also varied across agency groups with statistical significance. Compared to the 36.6% of all providers who were familiar with their regional council, a few agencies clearly had more familiarity than others:

TABLE 41: PROVIDERS' AWARENESS OF REGIONAL COUNCILS BY AGENCY AFFILIATION

	% familiar with regional council
Child Health Specialty Clinics	86.7
Area Education Agencies	69.5
Iowa Department of Public Health	41.9
Iowa Department of Human Services	29.3
Early Head Start	27.8
hospitals	22.9
private practitioners	17.1
childcare providers	14.3

Yet again, it is the private providers whose familiarity is farthest from the overall mean—yet in this case, the Department of Human Services respondents are also well below the mean.⁷⁰

The distinctions between the eight categories in terms of providers actually serving on regional councils were not statistically significant, in part due to the very small numbers of providers in some categories who had served on councils (e.g., no childcare workers, only three private practitioners, only one Early Head Start provider, only three hospital staff). However, if the categories are combined into slightly broader groups, the differences become statistically significant:

TABLE 42: PROVIDERS' SERVICE ON REGIONAL COUNCIL BY AGENCY AFFILIATION

	% who have served on regional councils
private practitioners/hospitals/childcare workers	16.7
Iowa Department of Human Services	14.0
Iowa Department of Education (includes AEAs and Early Head Start)	31.0
Iowa Department of Public Health/ Child Health Specialty Clinics	45.2

Compared to the survey-wide mean of 30.4% of all providers having served on their local councils, Public Health and Child Health Specialty Clinics seems over-represented, and private providers and DHS are underrepresented.⁷¹ Not surprisingly, in the Public Health category, it is the Child Health Specialty Clinic providers who bring the mean up, at 76.9% having served on their council, compared to only 39.4% for the rest of the Public Health providers.

⁷⁰ chi-square=110.324 df=7 p=0.000

⁷¹ chi-square=18.339 df=3 p=0.000

Awareness of council activities, with 249 valid cases, is also significant only for the broader set of four agency categories.⁷²

TABLE 43: PROVIDERS' AWARENESS OF COUNCIL ACTIVITIES BY AGENCY AFFILIATION

	% who are aware of council activities
private practitioners/hospitals/childcare workers	53.1%
Iowa Department of Human Services	48.0%
Iowa Department of Education (includes AEAs and Early Head Start)	65.9%
Iowa Department of Public Health/ Child Health Specialty Clinics	73.2%

For the survey as a whole, 63.1% of providers were aware of regional council activities. Consistent with the above results, private practitioners and DHS workers fall below the mean, and Education staff and Public Health staff fall above it.

Participation in council activities, to which 258 providers responded, is also statistically significant when broken into four broad categories:⁷³

TABLE 44: PROVIDERS' PARTICIPATING IN COUNCIL ACTIVITIES BY AGENCY AFFILIATION

	% who have participated in council activities
private practitioners/hospitals/childcare workers	25.0%
Iowa Department of Human Services	15.1%
Iowa Department of Education (includes AEAs and Early Head Start)	48.2%
Iowa Department of Public Health/ Child Health Specialty Clinics	52.4%

Once again, Department of Education employees, Public Health and CHSC clinic staff were significantly more likely to have taken part in council activities than their private or DHS colleagues, both of whom fell well under the overall mean for participation of 39.5%.

REFERRAL FOR EARLY ACCESS SERVICES

In the broader groupings, there were also statistically significant differences between agencies in whether or not providers had seen any children, in the past two years, between the ages of 0-3 who they thought might

⁷² chi-square=0.018, df=3

⁷³ chi-square=0.000, df=3

have had a disability or delay.⁷⁴

TABLE 45: PROVIDERS’ EXPOSURE TO POTENTIALLY ELIGIBLE CHILDREN BY AGENCY AFFILIATION

	% who had seen at least one child ages 0-3 (in the last two years) who they thought might have a disability or delay
private practitioners/hospitals/childcare workers	81.4%
Iowa Department of Human Services	95.8%
Iowa Department of Education (includes AEAs and Early Head Start)	98.5%
Iowa Department of Public Health/ Child Health Specialty Clinics	88.3%

In this case, it is only the private practitioners who are much under the overall mean response of 90.1%, and again the Education employees are well over the mean.

Providers who worked for the AEA had seen, on average, far more potentially eligible children in the previous two years than had providers from other agencies. Overall providers had seen an average of 19.16 such children. The differences were statistically significant for a few pairings of agencies—AEA providers had seen significantly more children than had DHS or Public Health providers.⁷⁵

Among the entire sample (with 524 valid responses), providers referred an average of 71.5% of the potentially eligible children they saw on to another agency for assessment, evaluation, or services. Not surprisingly, this percentage varied significantly between agencies.

TABLE 46: PROVIDERS’ ESTIMATE OF REFERRALS BY AGENCY AFFILIATION

	mean	st. dev.
Private practitioners	78.9	0.350
Iowa Department of Human Services	81.4	0.289
Area Education Agencies	48.6	0.336
Iowa Department of Public Health	78.2	0.320
Child Health Specialty Clinics	70.6	0.358
Early Head Start	85.3	0.249
childcare providers	49.6	0.448
hospitals	76.6	0.308

It is not incongruous with previous data that the referral rate from AEAs is lower than from other agencies—more often than not, children identified by AEA providers were probably referred on for services within the agency, rather than referred “to another agency” as the survey item specified.

⁷⁴ chi-square=0.000, df=3

⁷⁵ AEA mean=34.88; DHS mean=9.8; Public Health mean=12.98. DHS-AEA one-way ANOVA Bonferroni test significance=0.002; AEA-PH sig.=0.021.

A number of pairings show statistically significant differences between agencies in their referral rate. Private practitioners were significantly more likely to refer than were AEA providers or childcare providers. DHS employees were significantly more likely to refer than AEA providers or childcare providers. AEA providers were significantly less likely to refer than were Public Health, Early Head Start, or hospital providers. Public health providers were statistically more likely to refer than were childcare providers, as were Early Head Start providers.⁷⁶

There are also some significant differences between who providers eventually do refer children to, depending upon the agency they work for. These results are significant only within the broader grouping of agencies:

TABLE 47: AGENCIES REFERRED TO BY PROVIDERS BY AGENCY AFFILIATION

	<i>agency referred to:</i>	AEA	hospital	child find fair	CHSC	private provider
<i>provider's affiliation:</i>						
private/hospitals/childcare		75.5%	27.1%	3.6%	51.4%	37.0%
DHS		89.9%	32.9%	3.5%	57.9%	44.4%
education		67.8%	32.8%	16.1%	67.5%	38.5%
Public Health/CHSC		93.2%	16.0%	11.1%	59.6%	32.6%

For three of the agencies referred to: AEAs, hospitals, and child find fairs, the discrepancies in distribution among the agencies referring to them were statistically significant. I.e., it is statistically significant that only 3.5% of DHS workers referred to child find fairs, while 16.1% of education providers did so.⁷⁷ It is important to note, however, that the differences are probably exaggerated by lower numbers for self-referrals—AEA providers did not report continued AEA services as a referral, nor, probably, did hospital staff report referral to elsewhere in their hospital.

The differences between agencies is also significant when providers are asked what percentage of the families they referred they would estimate went on to receive Early Intervention services:

TABLE 48: PROVIDERS' ESTIMATES OF REERRALS THE RECEIVE SERVICES BY AGENCY AFFILIATION

	<i>Percent of referrals who received Early Intervention:</i>	>75%	50-75%	25-50%	<25%
<i>provider's affiliation:</i>					
private/hospitals/childcare		51.9%	22.8%	13.9%	11.4%
DHS		31.8%	25.2%	26.2%	16.8%
education		68.1%	21.8%	5.9%	4.2%
Public Health/CHSC		43.2%	24.2%	14.7%	17.9%

⁷⁶ One-way ANOVA Bonferroni test significances: private-AEA=0.000; private-childcare=0.02; DHS-AEA=0.000; DHS-childcare=0.000; AEA-Public Health=0.000; AEA-Early Head Start=0.001; AEA-hospitals=0.004; Public Health-childcare=0.001; Early Head Start-childcare=0.012.

⁷⁷ AEAs chi-square=39.773, df=3, p=0.000; hospitals chi-square=13.367, df=3, p=0.004; child find fairs chi-square=19.261, df=3, p=0.000.

These differences in referral completion rates are statistically significant.⁷⁸ The actual mean responses for each agency were as follows:

TABLE 49: PROVIDERS' ESTIMATE OF REFERRALS BY AGENCY AFFILIATION—DETAILED BREAKDOWN

	mean	st. dev.
Private practitioners	66.8%	26.5
Iowa Department of Human Services	55.5%	27.2
Area Education Agencies	78.2%	18.0
Iowa Department of Public Health	58.3%	29.2
Child Health Specialty Clinics	77.9%	16.3
Early Head Start	62.5%	25.0
childcare providers	72.1%	28.0
hospitals	65.2%	23.9
Overall	65.2%\$\$	26.5

On the low end of the spectrum of estimated completed referrals are DHS workers, Public Health workers, and Early Head Start providers. Hospitals and private practitioners fall near the overall mean, and AEAs, CHSC, and childcare providers estimate that their referrals receive Early Intervention services more than the average percent of the time.

When providers did not refer a child on for evaluation, assessment, or services, the reasons for making this choice did not vary significantly between agencies.

AVAILABILITY OF SERVICES

There were numerous statistically significant differences between the difference agencies in how providers rated the availability of various Early Access services. On a scale of 1-3 (1=very available, 2=somewhat available, 3=little or no availability) the mean ratings for each agency were as follows:

TABLE 50: PROVIDERS' RATINGS OF AVAILABILITY OF SERVICES BY AGENCY AFFILIATION

	private	DHS	AEA	Public Health	CHSC	Early Head Start	childcare	hospital
physical therapy**	1.31	1.67	1.41	1.46	1.67	1.60	1.64	1.50
occupational therapy*	1.37	1.87	1.27	1.50	1.60	1.62	1.57	1.59
special instruction/home instruction*	1.38	1.43	1.08	1.35	1.20	1.47	1.67	1.50
speech-language pathology services*	1.23	1.54	1.38	1.36	1.47	1.50	1.30	1.69
audiology*	1.25	1.56	1.13	1.38	1.20	1.35	1.36	1.57
vision services**	1.32	1.54	1.60	1.50	1.67	1.43	1.46	1.45
assistive technology*	1.65	2.05	1.48	1.73	1.87	1.60	2.10	2.05
nutrition counseling	1.44	1.59	1.58	1.41	1.64	1.29	1.57	1.42
public health nursing	1.20	1.22	1.24	1.14	1.40	1.28	1.28	1.23

⁷⁸ chi-square=42.526, df=9, p=0.000

pediatric medicine*	1.24	1.63	1.70	1.55	1.79	1.69	1.63	1.53
family counseling**	1.51	1.24	1.65	1.52	1.93	1.44	1.59	1.64
social work services*	1.36	1.20	1.46	1.44	1.67	1.35	1.42	1.43
child psychology/psychiatry**	1.70	1.77	1.74	1.93	2.20	1.79	1.81	1.89
daycare/preschool open to children with developmental disabilities or delays	1.71	1.89	1.80	1.98	2.00	1.63	1.83	1.85
respite care*	1.68	2.13	1.98	2.24	1.86	1.81	2.00	2.00
Child Health Specialty Clinics	1.54	1.67	1.44	1.59	1.33	1.67	1.67	1.89
transportation for children with developmental disabilities or delays*	1.74	2.22	1.89	2.10	2.29	1.94	1.69	2.08

** Differences between agencies are statistically significant with agencies divided into all eight categories.

* Differences between agencies are statistically significant if agencies are divided into four more-inclusive categories.

For almost all of the services listed, availability was judged differently by providers from different agencies, and the differences were statistically significant.⁷⁹ Some notable responses were:⁸⁰

- DHS providers rated occupational therapy as less available than other providers, while AEA staff rated it as more available;
- Childcare providers rated special instruction as less available than other providers, while AEA staff rated it as more available;
- Hospital staff rated speech language pathology services as less available than did other providers;
- AEA providers rated assistive technology as more available than other providers, while childcare workers rated it as less available;
- Private practitioners (including pediatricians) rated pediatric medicine as more available than did other providers;
- DHS workers rated family counseling as more available than did others, while CHSC providers rated it as less available;
- CHSC providers also rated social work services and child psychology/psychiatry as less available than did others;
- Private practitioners rated respite care as more available than average, while Public Health providers saw it as less available;
- CHSC rated their own services as more available than did others, while hospital personnel saw CHSC as less available than did others;
- Private providers saw transportation as more available than did other providers, while CHSC staff saw it as less available.

In a number of these examples (pediatricians, CHSC, et al.), providers rated their own services as more

⁷⁹ physical therapy: chi-square=34.536, df=14, p=0.002; occupational therapy: chi-square=56.599, df=6, p=0.000; special instruction: chi-square=38.945, df=6, p=0.000; speech/language: chi-square=15.545, df=6, p=0.017; audiology: chi-square=35.374, df=6, p=0.000; vision: chi-square=30.594, df=14, p=0.006; assistive technology: chi-square=36.854, df=6, p=0.000; pediatric medicine: chi-square=24.760, df=6, p=0.000; family counseling: chi-square=47.074, df=14, p=0.000; social work: chi-square=21.618, df=6, p=0.001; child psychology: chi-square=29.307, df=14, p=0.009; respite: chi-square=33.304, df=6, p=0.000; transportation: chi-square=22.368, df=6, p=0.001.

⁸⁰ The examples given were selected according to the criteria that the mean rating for that category was at least 0.25 points above or below the mean rating for all providers for that service. These examples are not specifically statistically significant.

available than did other providers, indicating either an internal bias or a lack of information on the part of other providers.

INVOLVEMENT IN SERVICE COORDINATION AND IFSPS

Providers from different agencies are not equally likely to have served as Early Access Service Coordinators, and the differences are statistically significant.⁸¹

TABLE 51: PROVIDERS SERVING AS SERVICE COORDINATORS BY AGENCY AFFILIATION

	Have been service coordinators	st. dev.
Private practitioners	1.6%	.13
Iowa Department of Human Services	6.7%	.25
Area Education Agencies	68.0%	.37
Iowa Department of Public Health	4.2%	.20
Child Health Specialty Clinics	40.0%	.51
Early Head Start	5.6%	.24
childcare providers	2.4%	.15
hospitals	6.1%	.24

While the differences are statistically significant, clearly it is the majority of AEA staff acting as service coordinators that weighs the data heavily. While a large percentage of Child Health Specialty Clinic staff have also been service coordinators, the total N for CHSC is only 15, while for AEAs it is 122.

In response to the question “Do you see yourself as part of a team providing Early Intervention services to the children you refer for services,” the responses varied statistically significantly by agency:⁸²

TABLE 52: PROVIDERS AS PART OF TEAM BY AGENCY AFFILIATION

	Sees self as part of a team providing services...	st. dev.
Private practitioners	29.7%	.46
Iowa Department of Human Services	39.0%	.49
Area Education Agencies	96.7%	.18
Iowa Department of Public Health	40.2%	.49
Child Health Specialty Clinics	80.0%	.41
Early Head Start	77.8%	.43
childcare providers	17.9%	.49
Hospitals	32.4%	.47

For those providers who had been part of at least one IFSP team in the previous two years, the number of families they have played that role for varied significantly between agencies. Specifically, AEA providers had

⁸¹ Chi-square=299.576, df=7, p=0.000.

⁸² chi-square=168.73, df=0, p=0.000

been on an average of 21.9 IFSP teams in the previous two years (std. dev. 25.63), while DHS workers had been on an average of 9.3 teams (std. dev. 23.29) and Public Health workers had been on an average of 5.23 teams (std. dev. 11.71).⁸³

Providers are not contacted for IFSP reviews on an equal basis among all agencies. Broken down into the broader categories of agencies, these differences are statistically significant:⁸⁴

TABLE 53: PROVIDERS CONTACTED FOR IFSP REVIEWS BY AGENCY AFFILIATION

	% regularly contacted for periodic and annual IFSP reviews	st. dev.
private/hospitals/childcare	29.3%	.46
DHS	44.2%	.50
education	87.1%	.34
Public Health/CHSC	35.7%	.48

There are also statistically significant differences between the number of times per year, on average, providers see the children whose IFSP teams they are part of, depending upon their agency affiliation. However, most of these differences seem to be inherent in the nature of the providers' work—e.g., childcare workers see children an average of 109 times per year, while public health workers see them an average of only 5.09 times per year.

How often providers attend IFSP meetings, however, is also statistically significant across agencies.⁸⁵ The following percentages, it should be noted, is not of all providers from that agency, but rather among only those who have been listed on IFSPs.

TABLE 54: PROVIDERS ATTENDING IFSP REVIEWS BY AGENCY AFFILIATION

	Regularly attends annual and periodic IFSP reviews	st. dev.
Private practitioners	15.4	.37
Iowa Department of Human Services	41.1	.50
Area Education Agencies	83.2	.38
Iowa Department of Public Health	31.0	.47
Child Health Specialty Clinics	66.7	.49
Early Head Start	69.2	.48
childcare providers	28.6	.49
Hospitals	45.5	.52

Private practitioners, Public Health providers, childcare providers and DHS workers are at the lower end of spectrum for attendance. It is particularly interesting to look at these discrepancies in IFSP meeting

⁸³ One-way ANOVA Bonferroni test significances: DHS-AEA=0.022; PH-AEA=0.000.

⁸⁴ chi-square=75.55, df=3, p=0.000.

⁸⁵ chi-square=74.731, df=3, p=0.000.

attendance in the context of the explanations given by some of the providers for choosing not to attend.. While the following statistics are not significant, they do shed some light on providers' choices not to attend these meetings:

TABLE 55: PROVIDERS REASONS FOR NOT ATTEND IFSP REVIEWS BY AGENCY AFFILIATION

	Not invited	Not enough time in schedule	Someone else attends in agency	Other reason
Private practitioners	58.3	23.1	0	23.1
Iowa Department of Human Services	52.6	21.1	0	26.3
Area Education Agencies	12.5	6.3	12.5	68.8
Iowa Department of Public Health	65.5	6.9	10.3	17.2
Child Health Specialty Clinics	25.0	25.0	25.0	25.0
Early Head Start	0	0	100.0	0
childcare providers	0	0	100.0	0
Hospitals	60.0	40.0	0	0

It is particularly interesting to note that although the common wisdom tends to be that DHS workers rarely attend IFSP meetings because of pressures on their time (see page \$\$), among the 19 providers who gave reasons for not attending, the majority said it was because they had not been invited to attend.

Among the other reasons given, Public Health providers all said that they were “not involved” with the IFSP. DHS workers indicated that they are not always continuing to work with the family (e.g., “case moved to new worker” and “not working with IFSP family”). Two of the three private providers who gave an “other” response said they did not know the program existed.

SERVICE PRIORITIES FOR FAMILIES

Providers' responses to the statements of service priorities varied according to the agency they represented, and for most of the items that variation was statistically significant. The following means are from a four-point scale (1=unimportant; 2=somewhat important; 3=important; 4=very important).

TABLE 56: PROVIDERS' RATINGS OF SERVICE PROVISION PRACTICES BY AGENCY AFFILIATION

<i>How important is it that. . .</i>	private	DHS	AEA	Public Health	CHSC	Early Head Start	childcare	hospital
Families evaluate the success of all intervention outcomes.	3.52	3.56	3.56	3.70	3.80	3.82	3.82	3.73
Providers clearly understand the roles and resources of providers from other agencies.*	3.62	3.73	3.75	3.81	3.87	3.82	3.79	3.82
Parents are able to trust that the providers they work with will keep their confidences.*	3.83	3.79	3.96	3.90	4.00	4.00	3.90	3.97
Parents are given adequate time and	3.50	3.50	3.91	3.70	3.87	3.94	3.67	3.65

information to make their own decisions about participation in Early Intervention services.*								
Parents and anyone involved with the child are actively included in the evaluation/assessment.	3.68	3.72	3.77	3.81	3.93	3.94	3.82	3.82
Providers who conduct an evaluation/assessment are clear with parents about what they are doing and why in is important.	3.76	3.81	3.85	3.85	3.93	3.95	3.88	3.83
If English is not the family's first language, a translator is available for them at all meetings.*	3.67	3.80	3.91	3.86	3.93	4.00	3.72	3.78
At IFSP meetings, parents are asked about priorities for their whole family, not only the child receiving services.	3.44	3.42	3.60	3.57	3.67	3.76	3.62	3.55
When services are scheduled, the family's needs are considered first.*	3.24	3.47	3.67	3.55	3.73	3.76	3.63	3.64
When parents disagree with providers about priorities for their child and family, the parents make the final decision about what is written in the IFSP.*	2.95	2.95	3.59	3.29	3.87	3.69	3.50	3.50
Providers are positive and point out strengths they see in a child and family.*	3.67	3.69	3.89	3.82	4.00	3.94	3.75	3.85
Parents have enough opportunities to talk with other parents whose children receive services.	3.33	3.28	3.43	3.38	3.47	3.47	3.58	3.48
Parents feel like they are a leading member of a team that is helping their child.	3.51	3.63	3.68	3.69	3.80	3.82	3.78	3.68
Providers help parents learn to negotiate systems and access services on their own.*	3.50	3.66	3.73	3.74	4.00	3.94	3.63	3.68
A transition plan is discussed with parents as early as possible before the child is three.*	3.42	3.59	3.61	3.65	3.53	3.76	3.70	3.71

* differences between at least one pair of agencies for this item are statistically significant, according to a one-way ANOVA Bonferroni test.

There are some differences in responses to these items that are particularly notable:⁸⁶

- “Parents are given adequate time and information to make their own decisions. . .” was considered less important by private providers and DHS personnel, and more important by Early Head Start providers.
- “When services are scheduled, the family’s needs are considered first” is considered less important by private providers than by the average of all providers.
- “When parents disagree with providers about priorities for their child and family, the parents make

⁸⁶ The examples given were selected according to the criteria that the mean rating for that category was at least 0.20 points above or below the mean rating for all providers for that service. These examples are not specifically statistically significant.

the final decision about what is written in the IFSP” was considered far less important by private providers and DHS providers (close to half a point), far more important by CHSC providers, and somewhat more important by Early Head Start providers.

- “Providers help parents learn to negotiate systems and access services on their own” was considered less important by private providers and more important by Early Head Start providers and CHSC staff.
- “A transition plan is discussed with parents as early as possible before the child is three” is considered less important by private providers than by providers overall.

FOCUS GROUPS: INTRODUCTION

Between February and April 1998, staff and consultants from the National Resource Center for Family Centered Practice (NRC/FCP) conducted 30 focus groups around Iowa with parents and providers involved in early intervention services. In each of the 15 Area Educational Association regions, one focus group was conducted with members of the Regional Council for early intervention, and one focus group was conducted with parents of children who were currently or had recently been receiving Early Intervention services.

Focus Group Selection & Demographics

Selection of the participants for these focus groups was by purposive random sampling. For the Regional Council focus groups, the National Resource Center was provided with a complete list of all members of the council, and a list of 10-12 participants was selected with the goals of creating a group representative of the various disciplines and agencies participating, as well as capturing the geographic distribution of the council within the region. Agencies represented included: Area Educational Association, Department of Human Services, Public Health Clinics; Maternal and Child Health Clinics, WIC, Childcare Resource and Referral, Head Start, Child Health Specialty Clinics, Community Action Agencies, and others. Parents who were members of the Regional Councils were not selected for this discussion, because of fears that providers might be less forthcoming with sensitive information of information which was unflattering to their agencies in the presence of consumers. The selected council members were invited to attend a special council meeting for the purposes of the conducting the focus group. Attendance at these focus groups, which were scheduled during the work day, varied widely, from 100% turnout to only a few council members attending. The average number of council members attending focus groups was 6.1, with a range of one to 12.

Parents were selected for the consumer focus groups from a list provided by regional coordinators in each region. This list included every child who had received early intervention services in that region from December 1996, up through December 1997. Thus the ages of the children were from newborn to over four years at the time of the focus groups. This range met the objective of including parents who had been through the process of transitioning from Early Intervention to preschool programming.

Consumer lists included information on each child’s age, age at referral to services, the number of diagnosed conditions the child had, whether or not the child suffered from severe health problems, an indicator of socioeconomic status, whether the family lived in an urban, small-town, or rural environment, and the child’s ethnicity. Ten families were randomly chosen from the consumer lists in order to achieve a balanced distribution of these factors to as great an extent as possible. (Six families were chosen by random sampling, and the additional four were selected to achieve a distribution of the other abovementioned variables that paralleled the early intervention population as a whole.) Regional coordinators then mailed letters to the selected families inviting them to participate in a focus group (to be held in the early evening), and asking them to complete a written questionnaire and allow the National Resource Center access to their Individual Family Service Plans (IFSPs). Parents received \$50 for their participation in these three components of the study. Attendance at parent focus groups also varied widely, from just two parents at one focus group to nine at two others. Ninety-four parents attended the 15 focus groups, an average of 6.3, with a range from 2 to 9 parents. More extensive demographic data were available for the 73 parents who completed surveys as well as attended focus groups. Table 155 presents some demographic characteristics of the parents in the sample:

TABLE 57: DEMOGRAPHICS OF PARENTS FOCUS GROUP PARTICIPANTS

	N	responses	%
<i>ethnicity</i>			
White	63	73	86.3%
Black	2	73	2.7%
Native American	1	73	1.4%
Hispanic	2	73	2.7%
other ethnicity	5	73	6.8%
<i>household income</i>			
\$0-14,000	12	68	17.6%
\$15,000-29,999	23	68	33.8%
\$30,000-44,999	16	68	23.5%
\$45,000-59,000	8	68	11.8%
\$60,000-74,999	4	68	5.9%
\$75,000 and above	5	68	7.4%
<i>marital status of parents</i>			
single	11	73	15.1%
married	61	73	83.6%
divorced	1	73	1.4%
<i>parents' education</i>			
some high school	3	70	4.3%
completed high school	13	70	18.6%
completed voc/tech school	10	70	14.3%
some college	19	70	27.1%
completed college	16	70	22.9%
graduate school	9	70	12.9%
<i>This is the first child with a disability or delay</i>	53	60	88.3%

As mentioned above, there was a great deal of variation between regions as to the number of parents and council members participating in the focus groups. Weather became a major factor in attendance at some focus groups, which were held during the March 1998 snowstorms. Others had to be rescheduled due to the weather. Multiple efforts were made to increase representation in low-turnout regions, including increasing the sample size invited, rescheduling focus groups after low response rates, and encouraging home intervention teachers to contact parents personally.

TABLE 58: TURNOUT FOR PARENT AND REGIONAL COUNCIL FOCUS GROUP

Region	parents	council members
1	5	6
2	6	6
3	4	4
4	2	5
5	8	7
6	8	7
7	8	3
9	8	12
10	9	7
11	8	4
12	7	4
13	3	1
14	4	5
15	5	7
16	9	13

The format of the focus groups was similar for both the parents and the Regional Council members. The group was lead by one or two facilitators from the National Resource Center for Family Centered Practice. The format included an introduction, a review of confidentiality of the information shared, a statement of participants' rights and responsibilities as research subjects, and an explanation of the purpose of the focus groups and the program evaluation. Facilitators then led the participants through a series of open-ended questions, and, to as great an extent as possible, allowed the conversation to follow its own course. The discussion lasted approximately two hours with each group.

Provider Focus Groups

The discussion questions asked of the regional council members centered around the four main evaluation themes:

- collaboration of providers and agencies;
- service coordination;
- family-centeredness of services;
- and the availability and maximization of resources.

The fifteen regions varied widely in specific program and approach details, but had common ground in many areas as well, particularly in valuing their council and approaches to family-centeredness. Clearly some regions had chosen very different foci for their attention in recent years than others, although most had seen common challenges, such as lack of information about early intervention among private family doctors and general practitioners. While many of the common foci seem to have stemmed from state leadership or availability of materials from the state, others seemed to arise from the individual regions in response to similar challenges, such as lack of transportation in rural area.

Parent Focus Groups

Discussion questions for parents were about the topics of their experiences with diagnoses and referral to early intervention services; the supports they receive, both personally and professionally, how they perceive service coordination, and advice they might offer for professionals about how best to work with families. Parents had very different experiences in the early stages of involvement with early intervention—a lot depended on whether their child had a diagnosable syndrome, whether their problem was identifiable at birth, and the region where they lived. Their support comes from the services they receive as well as from strong support systems in their communities, families, and churches. The perceptions of service coordination were very varied, from not being at all aware of the position to being very close with their service coordinator. Their advice to professionals was extremely varied, with some recurring themes being respect for families, sharing information, and a desire for more summer services. Parents were generally very happy with the early intervention services they received.

REGIONAL COUNCIL FOCUS GROUPS

Collaboration and Cooperation between Agencies and Providers

ACCOMPLISHMENTS AND INITIATIVES OF REGIONAL COUNCILS

Regional council members were asked to describe the achievements and practices of their council, particular initiatives which exemplify ways in which their council has been able to collaborate effectively. Uniformly, the council members stressed that the very fact of meeting as a council has been the most fruitful result—that by meeting face-to-face with representatives from other agencies, they have built relationships which have been professionally very important to them. Most of the councils ran informal informational meetings regularly, where members would speak to the group about their agency's programs, services, strengths, and frustrations. Many talked about now having a much greater awareness of the spectrum of services offered by other agencies—that a personal presentation of this information made it much more memorable than a newsletter of printed list which arrive on their desks every few months.

This enhanced communication was usually pointed to as the single most direct effect that their meeting as a council had on families involved in early intervention—that now, rather than giving them the front desk number of another agency, they could connect their families to individuals with whom they had personal relationships. Most providers felt that as a result families got quicker and more useful responses out of the agencies they had been referred to. In addition, providers felt that they had become, through the council, more aware of potential sources of aid or services for their clients, and the families benefited from this knowledge.

Concrete examples of council projects and accomplishments were fairly consistent between the regions. Most mentioned distribution of state-developed materials, such as the developmental milestones wheels. Many mentioned that they had adapted and distributed materials that were first developed by other regions, such as the Health Passports, common release of information forms, and Spanish-language informational materials. This indicated that some system is currently in place for sharing these innovations across regions, and that system is working well.

Most regions mentioned the development of a resource library for parents and providers, where toys, books, and videotapes were available. This was consistently one area in which councils had chosen to spend their available funds. There were also a number of references to directories that had been put together by the council of area agencies and programs, for use primarily by service providers (although some councils had made it available to parents as well). Many councils also pointed to in-service trainings and workshops they had coordinated as particularly valuable. Some regions described child find fairs as their councils largest regular activity, while other councils seemed to leave child find activities mostly in the hands of individual agencies.

Regions varied widely in the level of activity their council supported. Some regions quickly listed numerous activities for each year of their operation, including, in addition to those mentioned above, development of outreach materials, establishment of an interagency team for children with feeding concerns, establishment of newborn hearing screenings at area hospitals, fundraising for special equipment (such as the photo-screener purchased by the Lion's Club in Region 10), training for service coordination, and organizing parent-to-parent events. Others seem to be less proactive in their use of council funds, using the council as primarily a source of information and networking. In general, older councils seem to have a broader history of initiating projects, while younger councils seemed less aware of activities they might undertake as a group.

The vast majority of council members have sat on their councils for a long time—often since the council's inception, 5-10 years ago. When asked how meeting as a council had changed their ability to collaborate between agencies, many people indicated the prior to meeting as a council, other agency personnel were merely voices on a phone line, and the quality of their relationships was lower and exchanges were much more sporadic. Previous interagency meetings were held around specific topics or populations, not specifically the population targeted by early intervention services. Council members valued greatly the opportunity to spend time together regularly without having to focus on a specific situation or crisis, as in the past.

Larger regions, and those encompassing a greater number of counties, pointed to an additional advantage of meeting as a regional council. Because each of the involved agencies is divided into their own divisions along different boundaries, providers found that their relationships were often limited to other providers in their immediate geographic area. Early intervention regional councils brought together providers from a much broader geographic area, allowing providers a better sense of services and programs available in communities surrounding their own. Ironically, some of the larger regions (such as Region 1) eventually found it necessary to break into sub-councils in order to operate more efficiently, and cut down on travel time to meetings. Nonetheless, providers often mentioned some frustration with having to navigate the different divisions and geographic boundaries of the multiple agencies involved in a case—two children living ten miles apart may fall into the same DHS region, yet different public health regions, for example.

Attendance at council meetings is another indicator of the scope of collaboration in the regions. Notably, representatives from the Department of Human Services were present at only 3 of the 15 council focus groups. Almost all of the councils at which DHS was not present indicated that they have some difficulty in achieving steady participation from that agency on the council. Among the other participating agencies, Child Health Specialty Clinics, Maternal Child Health, and Public Health were consistently represented; AEAs were almost uniformly represented (13 out of 15 groups); Community Action agencies (including WIC and Head Start) were regularly present, and representatives from local home health agencies and local hospitals were frequently present. A few councils mentioned that they would like to see participation by members of the local private medical community, particularly family practitioners' offices and general practitioners' offices. One council had succeeded in including local pediatricians in their council.

ENHANCING COLLABORATION

Turf issues were still preventing some collaboration between agencies. Other councils, however, stressed that in recent years all of the agencies on the councils had made great strides in reducing territorialism. It was also mentioned in a number of councils that the rules of a particular agency often came into conflict with attempts to form interagency initiatives, and that they were not clear on the rules and regulations that guided each others' agencies. While the program was intended to be multi-agency, they felt there was little guidance as to how to navigate each agency's rules and guidelines to form one collaborative program.

Almost all of the councils praised the effect that the regional coordinator had had on their work and their ability to collaborate effectively. Most felt that this position was key to their being able to achieve what they had as a council. Some council members, however, expressed frustration that the position of regional coordinator could not be full time. Council members were not clear on the sources through which the position was funded, and the flexibility of the funding, but were annoyed that the position was not given the same amount of time in all fifteen regions. Most regions seemed as if they would have been grateful for and well-able to use a regional coordinator funded as a full-time position. A few councils were regretful that the role of regional coordinator had not been better-defined at the outset. Two regions in particular expressed the wish that their regional coordinator had been given more authority by the AEA, and could act more as a final

case reviewer and decision maker.

A number of councils mentioned that they had found it a challenge to keep parents involved in the regional council, and felt that this voice was a crucial one that was frequently missing from their collaboration. One council was exploring the idea of inviting parents of older children, rather than current clients, in the hopes that they might better be able to afford the time to participate in the council.

HOW CAN COLLABORATION HELP FAMILIES BETTER?

A number of providers expressed the concern that parents are given too much information at once, at the very beginning of their services—a time when they are probably overwhelmed as less able to absorb the information. It was suggested by more than one group that parents might benefit from a checklist of services and available resources, that providers could go back over with them on a regular basis, to determine whether their needs had changed. This seemed somewhat similar to the resource list a number of regions had put together for the use of providers, and a few had made available to parents as well.

Another source of ongoing frustration regularly mentioned was the inconsistency between agencies in terms of client eligibility. While a family may have their nursing needs met by a home visiting nurse for the first year of their child's life, another agency might have to be brought in when that agency no longer provides services, while another type of service the same child is receiving might drop off when the family's income level goes up. Providers felt that in order to work best as a team, they would need consistent eligibility standards for services across agencies, and not have their time and availability limited by differing rules about how their time is funded.

Along with this issue went some concern that the various providers had their time funded through differing mechanisms and with differing priorities. While some felt that the time needed to attend council meetings and events and take part in IFSP meetings was sufficiently supported by their agencies, other providers felt this was clearly not the case. Some providers indicated that lip-service was paid in their agency to their attendance at these meetings being fully supported, but in reality they felt that they were not given the extra time and leeway in their schedules to allow for full participation in early intervention activities. More often than not the lower levels of participation by some agencies (often DHS, but other local agencies as well) was excused by other agencies because they saw those caseworkers as overburdened to begin with. A simple request from many agencies was that their caseloads be reduced through new hires to allow them more time to take part in collaborative activities.

One region specifically recommended greater involvement by WIC—that across the state, WIC dietitians could and should be playing a greater role in services for children, especially those with feeding or nutritional problems. WIC has the resources and staff needed to be integrally involved in services, but other providers seem unaware of this fact, and do not often make referrals to WIC. One WIC provider specifically mentioned that she had inquired with the state about the possibility of WIC coordinators acting as service coordinators for children with major nutrition issues, and was told they could not do so [see page 11].

THE DEPARTMENT OF EDUCATION AS LEAD AGENCY

Given that the Department of Education has been the lead agency in early intervention services in Iowa since the program's inception, council members were asked how they felt this affected collaboration within the program, and whether they would consider changing the role the AEA plays in their region. With few exceptions, providers had difficulty even envisioning the program without AEA leadership. In some regions the AEA leadership seemed to be such a strong assumption that the question had to be put to the council members in a number of different ways before they fully understood what they were being asked. In more than one case the council members had to be reminded who the four partner agencies were. In many regions, the question, which was worded as "Do you think the AEA should continue to be the lead agency for this program?" met with a uniform nodding of heads. This was not necessarily passive acceptance of the status quo—most council members felt that the AEA is doing a very good job in their role as lead agency, and saw little reason to change that.

In those regions where providers did consider the question further, they generally agreed that they would like to see some aspects of the leadership shared more broadly, particularly service coordination. Many providers seemed unclear as to whether or not non-AEA staff could be funded to serve as service coordinators. In particular, it was mentioned in a number of regions that children with numerous medical needs, for whom educational needs were of lower priority, might more appropriately have their services housed with a medical agency, with the AEA acting as a consulting agency or perhaps service provider. Similarly, children with extensive involvement with DHS, such as children in the foster care system, might be better served by keeping that agency as their "service home." Documentation was seen as a barrier to this level of flexibility. Providers mentioned that as long as the IFSP was the primary required document for early intervention, and as long as the IFSP was primarily an AEA document, leadership in all cases would naturally fall back on the AEA (see page 77). One provider suggested that the AEA lead is predetermined by the scope of Iowa's early intervention services—because at-risk children are not served, almost all children have a home instruction component to their services, and thus AEA is involved in all cases.

Region 7 was an exceptional case in that the AEA currently takes a lesser role in the regional council than in other regions. This seems to be primarily due to the council's decision to house their regional coordinator in a private agency, Exceptional Persons, Inc. The impact of this decision has been significant, although it has not gone so far as to take the leadership of the program significantly away from the AEA. As with most other regions, the Region 7 council indicated that keeping the program housed within the AEA has its limitations, in terms of bureaucratic organization and vision, but they did not necessarily see how another agency would lead the program with fewer inherent limitations.

Child Find, Identification, and Referral

Council members were asked to describe the processes through which children were identified as possible early intervention recipients in their region, how referrals were made to the services, and which sources of referrals were particularly strong and weak.

Many councils expressed a frustration that when asked about referrals they could respond only with their personal impressions—that accurate records were not kept as to how many children were referred, from what source, the outcome of the referral and the assessment, etc. One region said that developing such a recording system had been a primary goal of theirs in recent years, but it had met with little success. One council meets in local groups on a monthly basis to discuss referrals, among other things.

Most councils were quick to mention child fairs as a source of referrals. As mentioned above, some of these child find fairs were the purview of the AEA, some were organized by the council as a whole. In either case, some concern was expressed that referrals through child find fairs were limited to families who had children already in the public schools, had some other contact with the AEA, and whose child was old enough for a developmental delay to be clearly observable. Many council members said they were reluctant to send younger toddlers and infants to child find fairs. Some providers mentioned that frequently a health professional would notice a potential concern with a child and send the parents to child find, rather than referring them directly to the AEA for services. Some providers saw this as a good thing—the health professional was, in a sense, requesting that the parents get a second opinion. Others saw this as an unnecessary step due to the fact the health practitioners were unclear on how the early intervention referral system worked.

The second most commonly mentioned source of referrals was the public health system, including Public Health clinics, Child Health Specialty clinics, Maternal Child Health clinics, and WIC offices. These offices were seen uniformly to be well-informed about early intervention services, and a steady source of referrals of children of all ages. In a few regions however, concern was expressed over the closing of a number of rural public health offices—that children would begin to fall through the cracks as they turned either to private practitioners or emergency room health care. Parents themselves (of parents with some prior knowledge of services), and preschools were also mentioned as fairly steady sources of referrals.

Private practitioners were the greatest concern to almost all of the councils. At least half of the councils mentioned that in recent years there had been an effort to reach out to doctors in the community with posters, flyers, trainings, meetings, etc., and that they felt that these efforts had paid off well in increased awareness of early intervention services. Nonetheless, most councils felt that private practitioners were far from ideally aware of the range of services available, or the range of children who should be referred to services. More than one council described the typical general practitioner response to a parent's concern to be “well, let's wait and see if he's talking when he turns three” Council members felt that lower-income children often received better preventative care and developmental monitoring than did middle-income children, because public health offices did far more extensive developmental screenings than did private professionals. Part of the blame in this case was laid upon insurers, who do not reimburse doctors for time spent administering Denver tests or other developmental screenings. A number of council members felt that part of the reason private practitioners do not consistently refer children was that there was little if any communication back to the doctor about the assessment, evaluation, and services being provided to their patient, so they did not become part of the early intervention loop.

Councils were mixed in their assessment of local hospitals as sources of referrals. Given that a significant proportion of early intervention cases are children with problems evident at birth (approximately 13% of cases on the client lists provided for focus groups were referred to early intervention services before they were three months old) hospital awareness of the program is key for truly early intervention in these cases. The larger hospitals seem to get better reviews as sources of referrals—there seems to be more difficulty in getting the referral process in place in smaller, local hospitals. The University of Iowa hospitals were mentioned by some councils as being an excellent source of referrals, and others as a problematic, uneven source. Regions where the closest hospital with tertiary neonatal services was out of state, such as Regions 2, 3, 12, and 13, found it more difficult to set up a steady relationship with those hospitals.

Providers across the state were concerned about many of the same populations slipping through the cracks in the referral and identification process. As mentioned above, low to middle income children were considered less likely to be given developmental screenings than were poor children. Minority children—whether Black, Hispanic, or some other locally prevalent minority—were seen as referred to services in numbers far lower than proportionate to their numbers in the region’s population. This was attributed primarily to cultural barriers, and in the case of Spanish-speaking families, difficulty in assessing language delays in non-English-speaking toddlers. One region pointed out that their council fell far short of reflecting the ethnic and racial diversity of their community, an observation that would probably have held true in any of the more urban regions.

Children in families new to the region, and especially those new to the state, were seen as difficult to identify—in part because they had less consistent health care provision, and in part because they were less connected to their communities and less aware of community resources. A related population were the geographically and socially isolated rural families, whom providers found it difficult to identify because they often resented any intrusion into their homes, especially by public agencies, frequently did not have telephones or reliable transportation, and might have less of a context in which to judge the physical and mental development of their children. Many providers expressed the concern that children with only slight or moderate delays, and without health concerns, were more likely not to get referred to early intervention—that their doctors, parents, and others were more likely to prefer to ‘wait and see’ about a questionable degree of development.

Service Coordination

WHO ACTS AS SERVICE COORDINATORS FOR FAMILIES?

The vast majority of the service coordination done statewide is done by AEA home intervention teachers. In some regions more than others, physical therapists, occupational therapists, and speech language pathologists take on a significant number of cases as well. Service coordination by a provider who is not an AEA employee is very uncommon statewide, although some regions manage to do more non-AEA coordination than others. Many council members were not aware that money was available to fund non-AEA employees to

do service coordination. AEA employees expressed the assumption that other providers, particularly DHS caseworkers, are not given the time to take on this extra responsibility.

In the regions where some non-AEA providers act as service coordinators, the most common agency to do so is Child Health Specialty Clinics (although one CHSC nurse indicated that the schedule requirements of working in a clinic all day do not fit well with the flexibility demanded of a service coordinator). In one region some service coordination is done by physical therapists at a local hospital clinic. Most councils seem to have done some piloting of non-AEA service coordination in the past, with Public Health nurses, DHS case workers, daycare workers, and even parents taking on the responsibility. Although for the most part reviews of these pilots were positive, the practice was not continued, but rather the default practice of AEA service coordination was returned to after the pilot year. It is a common practice for a non-AEA provider to act officially as service coordinator for the original referral and assessment period, and once services begin, an AEA employee would take over the role.

A number of providers mentioned being frustrated in their attempts to act as service coordinators because of reluctance on the part of AEA employees to let go of responsibilities they are used to having. A common example came from public health nurses, who would find the AEA teacher working with a child would call in the AEA nurse for a consultation, even though the service coordination was being done by the public health nurse. One Child Health Specialty clinic nurse mentioned that when she was acting as a service coordinator, she found that the AEA home teacher and the AEA physical therapist would meet to discuss the case without her, and that her efforts became superfluous. Non-AEA providers also mentioned that the learning curve required to comply with AEA paperwork was so steep that they felt everyone's time was best used leaving that responsibility to AEA employees.

In most regions, the fact that service coordination is primarily an AEA role seems to stem from the fact that all service providers, in all agencies, are overburdened, and the time and effort it would take to make a significant change in roles and responsibilities has been prohibitive. This is despite the fact that, as a number of council members indicated, there has been significant encouragement from the state level to broaden the base of service coordination. Providers acknowledge that they have received training and encouragement in this direction, but do not, for the most part, see follow-through from the state in terms of shuffling funding and job responsibilities at the partner agencies to allow multi-agency service coordination to actually happen.

In a few regions the struggle to make service coordination more broad based is a major goal of the regional council. Even in these regions, providers are just beginning to consider possibilities such as the IFSP being initiated by non-AEA employees, or providing services without including any educational component. One region mentioned that ideas they had put forward the possibility of sharing the service coordinators role, but had been told by state-level authorities that this was not possible, while another regional council made frequent mention of co-coordinators. Another mentioned that to a certain extent they feel their efforts are eventually frustrated, because while children may receive a broader focus of services between the ages of zero and three, once they turn three, their services will once again become entirely educationally-based.

WHAT ARE THE STRENGTHS OF SERVICE COORDINATION?

Most council members praise the hard work and dedication of the service coordinators in their region. These providers are described as being uniformly dedicated to their work and the families they serve, and often going above and beyond to meet the diverse needs of families. They sometimes struggle to bond with their families, and usually creating ongoing trusting relationships. The job of service coordination is often described as idealized and the multitude of its goals as unreachable, yet the current service coordinators do an excellent job of a very difficult and exhausting task.

At least half of the councils brought up the change in attitude in recent years toward IFSP meetings—that service coordinators now make extensive efforts to have all players at the table for IFSP reviews. This takes up a great deal of the service coordinators' time. Coordinators were also praised for making an effort to use accessible and straightforward language on IFSPs. Those council members who are also service coordinators mentioned that they are, in recent years, more aware of the range of programs and services available for families, and thus are better able to meet their needs.

HOW CAN SERVICE COORDINATION BETTER SERVE FAMILIES?

There was frequent mention of the duplication of forms and information that families are required to provide. Service providers indicated that shorter, non-duplicative forms among agencies would be very helpful to families. The most common example of this was health histories—frequently families are asked to provide the same health history information to two or three agencies within a few weeks of each other. Some providers also expressed the wish that various agencies could agree on tools and assessment instruments used to qualify children for services. Council members regularly mentioned that the paperwork burden involved in the IFSP could be further reduced. A number of service coordinators expressed the wish that they had more discretion to help families with their major barriers, such as transportation, telephones, etc.

A few councils mentioned the idea of parents serving as service coordinators. They felt that parents of older children, who had been through the experience of raising a disabled infant, were best prepared to guide other parents through the process. A few providers added to this the idea of parents of 2-3 year-olds acting as their own service coordinators, and receiving some form of payment for their time. Others mentioned that parents should be given more discretion in choosing their service coordinator—at present, it seemed parents are not aware that they have options in this regard, and tend to accept the person self-appointed to the role. There seems to be uneven focus among providers and certainly between providers and parents on how important the role of service coordinator is—not all providers on a case necessarily know who the coordinator is on that case, and not all parents even know who their coordinator is. Some parents might benefit from a clearer understanding of what is appropriate to expect and demand of their service coordinator.

SERVICE COORDINATION AND THE IFSP

In general, council members thought that the IFSP (particularly the family information sheet) was a

significant improvement over previous incarnations, and felt that it facilitated family-centered practice. One common frustration with the forms was that serving families with early intervention is such a dynamic process that goals and objectives change almost daily, and no form can truly capture the variability of the services provided. Some providers felt the language of the form included education-jargon, making it more difficult for medical professionals to take the lead on the paperwork. Even AEA staff sometimes asked for more specific guidance on IFSP completion.

As mentioned above, many providers indicated that the IFSP paperwork was burdensome and sometimes overwhelming to parents, especially at the very beginning. Some went so far as to say that some families drop out of services due to the IFSP process. A large number of providers said that in order to make the process of IFSP meetings easier on parents, and faster, they would do one of two things: talk to the parent ahead of time, and come up with a list of goals to bring to the meeting; or write their own list of goals first, and suggest those to the parent for approval. Providers seemed to be aware that they were walking a fine line between removing extraneous burdens from the family and removing the family's responsibility for and leadership of the process. Non-AEA service providers also see this procedure as cutting them out of the process, limiting the input they can have at the actual meeting. There was a general consensus that most of the goals on most IFSPs were written by AEA staff. One provider mentioned that the family information sheet needed to be updated more often than every six months.

Again, the frustration over differing forms between different agencies came up. Providers said that many different agencies require similar information on their forms, and it is a waste of time to have to transfer information from one document to another.

Family-Centered Services

When asked about how they practice family-centered service provision, council members uniformly indicated that it goes without saying that the families' wishes and priorities come first. Many people indicated that they had received a fair amount of training in this area in recent years, and gotten a strong sense that this was a major philosophical direction for their agency. Yet they felt that the most important thing agencies could do to become more family-centered they were not doing—that is, increasing staffing levels to allow greater time with families and greater flexibility in the hours when services were provided. They often related family-centeredness back to the IFSP, mentioning that there's little or no point in writing a goal on that document that the family did not agree with, as it was unlikely to be met and would be of little use to anyone.

Providers acknowledged that the services they provide may be construed by families as invasive, and they need to be very careful to respect families' privacy. Families' voices were heard by the agencies through family involvement on the regional councils, with which some regions seemed to be more successful than others; and through parent groups. Parent groups sometimes took the form of luncheons, sometimes play groups, sometimes advisory groups for providers. In all of these forms, encouraging ongoing participation by otherwise overburdened parents was always a challenge.

RESPECTING FAMILIES' BELIEFS, CULTURES, AND PRACTICES

Quite a few providers pointed out that the most frequent barrier between them and the families they serve is economic class—that it is very difficult for service providers to truly understand the needs, priorities, and issues of a family struggling with poverty. As primarily middle-class people, they often tend to project their own values about education, family life, etc. on their clients, rather than respecting the differences. Council members reminded each other frequently that their priorities—health and educational outcomes for the child and family—were not always the primary concerns of the family, which might be more immediately concerned about paying a heating bill or about a grandparent's illness. One council member pointed out that while having parent representation on the council has been very helpful in terms of hearing about families' issues, the parents who sit on the council are unlikely to be those in poverty and with related barriers.

Providers are more careful to respect differences in ethnicity, religion, et al. Most regions seemed to have relatively homogeneous religious make-ups, so providers felt that this was not an area where they had had to adapt much. In areas with significant minorities, such as those with Amish or Orthodox Jewish communities, providers have felt they have had to learn a lot about the community as they went, and tread very carefully in terms of offering educational services and not seeming too intrusive. A common issue for providers is accepting that a parent chooses to home school a three-year-old child or send them to a religious school when the provider feels strongly that an ECSE classroom would be the best environment for the child.

For the most part, however, providers seemed aware and comfortable about the idea of respecting the wishes of families when their customs were not in keeping with the service provider's wishes. They felt that in recent years people had become more sensitive to this possibility, and less judgmental about families' beliefs. A number of providers again brought up the challenges of working with non-English-speaking families—that language delays were much harder to diagnose, and that it takes much longer to create a bond with a parent through an interpreter. One region mentioned that they are making an effort to hire Spanish-speaking staff in order to improve services to their growing Hispanic population. In two regions providers mentioned the situation of providing all the relevant written materials to a mother in Spanish, thinking she was doing the culturally sensitive thing, only to discover months later that the woman was illiterate in Spanish, but had been embarrassed to say so.

RESPECTING FAMILIES' CHOICES ABOUT PARTICIPATION AND SERVICES

A number of providers described ways they get around parents who don't want all the services they, as providers, feel the child needs. One provider mentioned that the home intervention teacher can provide physical or occupational therapy in lieu of having a separate provider see the child. They talked about working the child's other needs into play time, etc.

More than one provider questioned whether parents always feel able to refuse services. They mentioned that providers come in as experts at a moment of crisis in parents' lives, and it is difficult at that moment for parents to know what they want for their child in the long term. It is a challenge for providers not to

overwhelm and bully parents into accepting services. A few providers felt this got easier farther along in their careers, as they acquired the experience they needed to learn to withhold judgment. Councils recognized that often when parents refuse a service it is because there is something else more pressing going on in their lives at that time. The most commonly described approach is to start with the minimal service that the parents are comfortable with, and gradually, as one provider works up trust with the family, revisit the idea of bringing other people into the home as well. Most councils indicated that it was most important that there be one trusted person in with the family regularly, in case any unmet needs became urgent. Many people stressed the need to keep resupplying parents with information, so they are offered what they need at the moment when they are ready to hear it.

One council mentioned that it is also important to continually ask the parents if they want to change to another service coordinator, especially as the focus of services changes. A few regions mentioned that families often don't fully understand what services they are entitled to, and don't push sufficiently for services their not getting, or changes in their service plan. In one region in particular this seems to have become a contentious issue, with the parent advocacy group encouraging parents to bring in lawyers to see that the AEA provided all the services the parent requested.

IS EARLY INTERVENTION REACHING ALL FAMILIES?

As mentioned above (see page \$\$) many providers fear that children with less severe disabilities or delays and without major medical issues are less likely to receive services. Providers also expressed concerns about reaching: first-borne children (whose parents may be less aware of the school system's facilities); children in transient families, (who may be new to the area, often do not have telephones, and are not tied in to any community resources); Black and Hispanic children; immigrant and working poor families, (in which parents may not have the time or resources to see to their children's educational needs); rural populations (especially those who live near the border of a region, and thus go outside of the region or the state for their medical care); and older children (for whom parents and medical professionals are more likely to chose to wait and see if school takes care of the problem or delay). Two councils suggested the possibility that the underrepresentation of Black and Hispanic children in their partly-urban regions may be connected to the fact that their councils do not have any ethnic minority representation. (It should be noted, however, that comparisons between the Early Access population statewide and the 1990 state census indicate that minority populations are not underrepresented. This may be due to changes in state demographics since 1990, or to disparate rates of minority populations in the fifteen regions. See page \$\$.) A few providers suggested that while they might see some children as being missed, their parents might not see a disability or delay as a problem needing attention.

Providers in most regions felt that this was an issue in which they had made some significant progress in recent years, yet there was still a great deal farther to go. Regions with rapidly changing populations—more urban regions, or those with significant immigrant populations—were more affected by this than others. As with family-centered practice in general, council members felt that in recent years their individual agencies

had been more directed towards reaching under-served populations as well. A few providers made the important point that they may not know what populations they are not reaching—for example, the transient homeless population in their region is not easily identifiable, and there may be other groups that the council is so unaware of that they do not even know they are not receiving services.

As might be expected, providers did not always feel that all families received the same quality and quantity of service. Parents better able to represent themselves and their needs got more out of early intervention than less-able parents. Parents with fewer barriers—without transportation problems, and with regular phone service—could take greater advantage of service offered. Families with only one working parent were more able to be part of their children’s services—while providers were as flexible as feasible in meeting parents’ scheduling needs, employers were not always as flexible, and services for many families are provided at a daycare or with a babysitter. Providers felt that non-English speaking families did not always receive the services they ideally would want, due to having to use translators.

SUPPORTS AND ADAPTATIONS FOR FAMILIES WITH DIVERSE NEEDS

All regions had some materials available in Spanish, which had been distributed by the state (although originally developed by a regional council). A few also used materials in Vietnamese. All regions had translators for Spanish, Vietnamese, and sign language available to providers as needed, but a few mentioned that for other languages (such as Laotian) interpreters were harder or impossible to get. One region with a very diverse population mentioned that parents were usually their best resource in solving this problem. Some providers felt this was a far from ideal way to communicate with parents, and would prefer to have teachers or therapists who spoke Spanish or other needed languages. Many providers expressed the wish for more materials beyond basic information in other languages—assessment tools, therapeutic tools, and information for parents on specific disabilities and syndromes. One region mentioned more pictorial tools would be useful to communicate with their growing Bosnian population. The initiative to react to changes in the demographic makeup of communities seemed to be up to the regions, some of which seemed more and less aware of population shifts in their communities. Councils did not refer to any specific leadership from state agencies on these issues.

More than one council mentioned that they have a growing problem with parents’ literacy levels. Many of the materials they have available for parents are written at a level that parents, especially those with mental disabilities themselves or for whom English is a second language, are not able to read.

HOW CAN SERVICES BE MORE FAMILY-CENTERED?

Providers felt that the best way for them to ensure more family-centered services would be for their agencies to free up more of their time to spend with families by increasing spending to hire more direct-service staff time. One council mentioned that new hires should be brought in to work off-hours, to provide services to families with two parents working all day. A number of providers also indicated a desire for more in-service training on family-centered practice and related topics.

One topic that came up frequently as a difficulty for parents was the waiver program. Providers found the process of applying for waivers very complex and confusing themselves, and had difficulties helping families apply for them. They would have the application process simplified, funding levels increased to reduce the significant waiting period for waiver eligibility, and have the applications remain consistent over time.

A number of councils also mentioned the need for more parent-to-parent interaction. While some regions seem to have regular, ongoing support of this kind, in others they seem to be a stop-and-go programs. Providers sometimes have a difficult time maintaining parent involvement, and shifting the burden for ongoing programming to the parents. One region mentioned that they had been considering developing a mentoring program for parents. Providers acknowledged that parents who might well benefit from a relationship with another, more experienced parent, might just not have the time and energy to go out in the evening with one more thing in their schedule. They struggle with this reality and the desire to continue providing some parent-to-parent support for parents who do want it, and when parents are ready for it. A few providers also mentioned that parent support groups are currently entirely a responsibility of the AEA, and they would like to see them as more of an interagency initiative.

Other recurring topics in this area included: increasing family representation (and the consistency of that representation) on the regional council; working with community businesses to encourage family-centered practices on their part (such as flexible scheduling); and greater efforts to involve fathers in services.

Funding and Other Resource Issues

Most council members indicated that there was no way they could possibly be fully informed about all the funding streams available, but it was more important that they had a general idea of what was out there, and a good idea of who to call to get help. Others felt that they had a good grasp of the funding options available for parents. As mentioned above (see page \$\$), many providers were very confused about the waiver process, and felt the confusion could only be worse for parents. More than one provider had to ask what the waiver program was when it came up in discussion. A few people mentioned that it was important to know the right buzzwords to be eligible for various streams of money, and if the parents applying or the provider working with them didn't happen to know the right language to use, the parent might well lose out. There was some concern expressed that families whose service coordinator was less experienced in the job would be less likely to receive extra funds or services because the provider would be less able to "work the system" on their behalf.

Some council members felt that their agencies did a good job of informing them about programs, services, and funding streams. Others felt just the opposite—that things change so much year to year that it was impossible to stay on top of necessary information. Council members expressed the concern that while they did get information from their state agencies, private providers—whether health care professionals, daycare centers, or others, had no such source of regular information that might be of use to their programs or the families they serve. Administrators felt in some cases that they received too much information from the state—sometimes it was impossible to weed out the important information from the pages and pages that

crossed their desks. One provider requested an annual newsletter describing all the changes in resources available for families across all the relevant agencies. A few councils mentioned that the technical assistance they had received from the state did not fit well with their needs and concerns.

Providers expressed needs for more funding for the position of regional coordinator, in order to make it full time, and more funding for non-AEA staff to do more service coordination.

Councils gave specific examples of ways in which they collaborate to maximize resources, such as the photoscreener purchased in one region, the use of Head Start funds to train daycare providers in another region, and holding in-service trainings that are open to multi-agency personnel. In general, however, there was a feeling that they do not have the time they need to think in financially creative ways, but that all their hours are taken up by service provision and the efforts they are currently making to collaborate.

MORE EFFICIENT USE OF FUNDS

Providers again expressed concern about duplication of services (see page \$\$) and forms. A shared set of assessment forms could save on time both for providers and for families, not only in filling out the forms, but in being able to use assessments and tests administered by other agencies.

Providers almost uniformly expressed the feeling of being overloaded with responsibilities, and the quality of their interactions with families suffering for it. They were looking for ways to decrease the amount of time they need to spend on paperwork, share the responsibilities of service coordination more between agencies, and free up more of their time, through additional hires, to work creatively and collaboratively with other agencies. A barrier to additional hires however, was also identified frequently—many regions indicated that they have had difficulties recently in recruiting and keeping new staff, and many positions sit open indefinitely. This seemed particularly acute in more rural regions, and in the areas of physical therapy, occupational therapy, and home intervention teachers. A few providers suggested that the state might want to address this issue by reassessing starting salaries to be more competitive with the private sector, and by building closer relationships with university programs training people in these fields.

Providers would like to see consistency between the participating agencies on how their time was funded. There was a great deal of confusion over which personnel were funded to come to regional council meetings, who was funded to act as service coordinators, whether any of the agencies reduced other responsibilities in order for personnel to perform these duties, etc. They would like to see a clear set of uniform guidelines on how their time with families is paid—some providers said they didn't like to insist on non-AEA staff attending IFSP meetings because they thought they had to do so on their own time.

Additional Themes and Issues

SUMMER SERVICE PROVISION

A number of councils talked about the way services are provided in the summer. AEA staff usually felt that

their time was stretched very thin in the summer. In order to continue seeing families during the summer, they had to skip some meetings with them during the rest of the year (this was a reference to most AEAs redistributing contract days over the full calendar year). Even doing that, they did not have the time in their contract to see families as much in the summer as they would have liked. Other agency personnel were under the impression that the AEA slowed almost to a halt during the summer months, and had been frustrated when they wanted to refer a new family during the late spring or summer. Often they felt the family had to wait too long for an assessment and for services to start. Many providers would like to see staffing levels that would allow early intervention services to continue uninterrupted year-round, at full intensity.

DAYCARE AND RESPITE CARE AVAILABILITY

Many providers expressed a concern that there was not enough quality childcare or respite care available for parents in their region. In most areas, the problem with respite care seemed to be a lack of people interested in doing the work, rather than a lack of funding. Many people saw daycare as a growing crisis as more and more parents are forced to work as part of Promise Jobs. Providers saw Promise Jobs as being particularly inflexible for parents with children with disabilities.

One region mentioned that they have outstanding childcare coordination set up specifically for special-needs children in their region, yet there was still a challenge to meet parents' needs—thus they imagined that the problem would be even more severe in other regions.

OTHER TOPICS

The following diverse issues came in up more than one focus group, or was particular concern to a specific council:

- Providers would like the freedom and resources to reach out to more at-risk children. They find the cut-off point of a 25% delay, below which children are not eligible for services, to be arbitrary, and feel they are missing some children who could definitely benefit from early intervention services.
- Providers are seeing more and more families with substance abuse issues, or other complex issues that lead to non-compliance with goals, and hostility on the part of families. They need more guidance from the state as to how best to deal with these issues.
- Regional councils seem to go through stages of energy and enthusiasm. Some felt their energy and participation was highest when they had specific tasks to accomplish, and as they have become more of an information-sharing body, participation has decreased. Councils would like some guidance from the state and from each other as to ways to maintain member participation and council energy.
- One council has explicitly made the decision to address issues for children ages zero to five, while the others continue to focus on the zero to three population. With the state-level focus on the zero to five population, some councils find it limiting to not include the three to five population in their

services and concerns.

- Council members also identified transportation as a major barrier for their families. Approaches to this issue vary widely between issues--from providing taxi vouchers to providing rides to Iowa City to leaving it in the hands of the service coordination. Almost all regions, however, felt that there were still families who received fewer services and took advantage of fewer program options due to a lack of reliable transportation.

PARENT FOCUS GROUPS

Diagnosis and Referral

CHILDREN DIAGNOSED AT BIRTH

The parents taking part in the focus groups introduced themselves by telling the group the story of their child's diagnosis and their referral to early intervention services. For many this was an difficult retelling, evoking strong emotional responses, anger, frustration, and sadness. Many parents seemed helped through this experience by hearing how others, many with children whose disabilities were more serious than their own, had found strength and encouragement.

For a large number of the parents, about 30%, the diagnosis of their child's disability had come shortly after birth. These were infants who were significantly premature, underweight, had severe complications during childbirth, or were born with a syndrome or illness. These parents had very varied experiences with hospital staff at this time. In many cases, parents said that their delivering doctors were very poorly informed about the situation—in one case a mother thought her obstetrician had never previously delivered a baby with any birth defects, and in another case the delivering doctor had no additional contact with the parents at all after the delivery. Frequently someone else at the hospital was the person from whom the parents first received any information and support. In a number of cases this was a specialist they were immediately referred to, in some cases it was a nurse or social worker, in one case it was the helicopter paramedics when the child was being flown to a tertiary care neonatal facility.

Parents also told stories of encounters with highly unsympathetic, unknowledgeable staff members at hospitals, including a social worker who left a mother in a room with a book on Down's Syndrome, and a nurse who told parents their child had cerebral palsy before any diagnosis was made. For the most part, larger, teaching hospitals (UIHC and the University of Nebraska) seemed to have better-informed staff, but this was not consistent—some parents reported being very upset by their treatment at UIHC, while others reported kind, knowledgeable professionals at small, regional hospitals. In general, for parents of disabled infants, treatment in the hospital seems to be very much the luck of the draw in terms of which physicians,

nurses, and social workers are working at the time. For longer-term care of their children, however, few if any parents continued using local hospitals, preferring instead to travel many hours to Iowa City, Omaha, or Minneapolis for treatment.

Many parents would have liked more information about their child's diagnosis to have been available at the hospital. They felt they were given only as much information as the professional they were talking to knew, or felt they should know. A few parents mentioned that they were given too much information too quickly, at a moment when they were still in shock, and were unable to absorb it all. They would have liked more resources, written information, or perhaps a tape recording of the conversation to be able to go back to later. There were mixed feelings about the way professionals communicated this difficult information to them—some parents wanted nothing held back, while others felt the diagnosis was given to them too abruptly. There was a general consensus, however, that there is no easy way to share this information, and professionals need to adapt to each parent's needs individually.

Many parents felt that professionals—particularly physicians—were too reluctant to state when they did not know the answer to a question. Instead, there was a tendency to make predictions and assumptions which could mislead parents. A number of parents complained that professionals seemed rarely to read their child's charts—instead, the parents would have to repeat the entire story again and again, often a painful process for them.

More often than not, when birth hospitals informed parents about early intervention services (which seemed to occur in most of the cases), it was not a physician who did so. Nurses, therapists, and social workers were far more likely to pass on the information about services.

REFERRALS OF OLDER INFANTS AND TODDLERS

Among children whose disability or delay was not apparent at birth, referral to the AEA came from a broad range of sources. About 40% of non-birth referrals came through medical personnel. Many were first noticed by a doctor or nurse at a Child Health Specialty Clinic. There were some particularly positive descriptions of parents' first meeting with CHSC staff—that the meeting was extremely thorough and informative. Others were referred by a nurse or dietitian at WIC, staff at the University of Iowa Hospital School, and friends. A significant number were self-referrals. These were most often parents who had a previous child who had received services or who knew about services through some personal connection to the school system. One parent was referred after approaching and questioning a woman who was leading a group of special needs children on a field trip through a shopping mall.

Among this group of parents a very large number had some level of frustration trying to get their child's situation properly diagnosed. Many heard varying diagnoses from different doctors, or heard again and again "let's wait and see..." when the parent knew without a doubt that there was a problem at hand. These parents felt anger, particularly at the medical community, for not listening to them, and not valuing their perceptions and opinions. They often felt that valuable time had been lost when their child could have been

getting treatment, but no one would clarify what they should be treated for.

A significant number of parents were dissatisfied with the amount of time that elapsed between their original referral to services and the commencement of services. One parent said the gap was 6 weeks, another said it was 4-5 months. The typical waiting period seemed to be somewhere between 3-4 weeks, although some parents praised the AEA for seeming to appear at their home instantly after their child was born. There was some consistency within a region on this—some regions seemed to be better than others at starting up services quickly. In a few cases, parents felt that their efforts to get services started were frustrated by lack of returned phone calls, having to argue about whether they qualified for services, etc. In quite a few cases, parents mentioned finding the beginning of services confusing. They felt that providers arrived at their home when they were unclear exactly what the program was, its scope or its purpose. They became comfortable with services fairly quickly, but would have preferred more information about early intervention services in general in advance.

Quite a few parents expressed concern that they had known nothing about early intervention services until they had a need to inquire. They encouraged further outreach into communities, and more visibility for the program with the general public.

Support Systems

SOURCES OF PERSONAL SUPPORT

By far the most common sources of support for parents are their families (many live near extended families), communities, and churches. A significant minority of parents felt their parents (and in a few cases their husbands) were sources of stress, rather than support, in that they were in denial about the child's disability, and hostile to the parents about treatment and care for the child. In most cases, however, parents were frequent babysitters, often took part in therapies, and provided emotional support for parents.

A few remarkable stories were told by parents about the support they received from their churches and communities that bear retelling. One mother, who lives in a small, rural community, was approached by a neighbor and told ““You can't say no. We're having a community fundraiser for your son” which proceeded to raise thousands of dollars to help pay medical expenses. Another mother said she has yet to buy any clothes for her daughter, because everyone around her has been so generous. On the other hand, one parents told a story of being run out of their church during services because their son was having seizures. For the most part, however, Iowa communities seem to have come through strongly for these parents.

There were very mixed reports about parent-to-parent support groups. For some parents, these were their primary source of support, and they had build close bonds with other mothers and fathers in their communities through them. These support groups were sometimes organized through the AEA, and sometimes organized through a parent advocacy group around a particular syndrome or disease. To some parents it was important that the other parents involved were dealing with the same syndrome or symptoms;

to others, it was enough that they could share the experience of taking care of a disabled infant or toddler. A number of parents were not aware of any such support groups available to them. Some regions seem to be more successful than others in putting together and sustaining such groups, with low-population regions having the most difficulty, particularly creating groups around a specific syndrome. A number of parents expressed interest in support groups, but had barriers such as lack of transportation, or need for childcare for their other children. Some parents were confused about the issue of confidentiality, and were under the impression that they were prevented from talking to other parents because of this issue. A few parents had attended the annual parent conference in Des Moines, and found it to be a wonderfully rewarding experience.

Many parents referred to early intervention services as major sources of support for them, not only in providing the services they did, but in also providing emotional and personal support for them as parents. Many mentioned specific teachers and therapists who were a great help to them in this way. Quite a few referred to WIC as a program they were particularly grateful for. While a number of parents talked about respite care, provided through the MR waiver program, as critical to their personal well-being, just as many or more parents were unaware that such services existed, or were unable to access them. A number of parents said they would like more information and support about how to apply for the waivers, and would like something done about the long waiting lists involved. As with parent support groups, for a number of parents, this focus group was the first they had heard about the availability of these programs.

OTHER SOURCES OF SERVICES

Many parents, when asked what services they received outside of their early intervention plan, responded by mentioning services from well-child clinics, WIC, DHS, and other early intervention providers. This was one of many indicators that most parents see early intervention as those services provided directly by the AEA only. Of the parents who mentioned receiving services from DHS, many indicated that they had been very frustrated in dealing with the agency, finding them unsympathetic, inflexible, and difficult to reach. This applied both to parents who were enrolled in Promise Jobs and other financial assistance programs and to foster parents.

A significant minority of parents received physical therapy, occupational therapy, or speech and language services from non-AEA providers. This was primarily because either they were unhappy with the person providing the services for the AEA, or because they wanted more services than the AEA was willing or able to provide. In a few of these cases the child did not qualify for any services under AEA guidelines, but parents and other professionals disagreed as to whether the services were needed. A few parents had moved between regions during the course of their early intervention services, and were struck by the dramatic differences in the amount of services they were able to get for their child in the two regions.

Service Coordination

While almost all of the parents involved said that there was one person who they would contact with questions or problems about their child's services, very few parents referred to this person as a "service

coordinator.” Some said they recalled this phrase being used at the very beginning of services, or seeing the phrase on their IFSP, but no one ever called themselves by that title. Often the person who had used that title at first was not the same person the parent would now refer to as their main contact. There was a small but consistent group of parents—approximately one in every other focus group—who expressed that they did not feel they had anyone coordinating services for them, but that they took care of that role primarily themselves.

ARE SERVICES WELL COORDINATED?

For the most part parents felt that the various services their family received were well coordinated with each other, and that providers communicated well with each other. They felt that communication with their providers was very open and a constant stream of information flowed both ways. Parents did not express any concern about this communication violating their privacy—rather, they often described their service providers as “part of the family.” There were exceptions to this, however, such as the parent who felt that her child’s speech pathologist was reluctant to share information about her son’s progress.

Parents were generally less satisfied with communication patterns when the medical community was involved. Many parents told stories about the dozens of phone calls it took to get the University Hospital and Hospital School to start sending copies of medical records to them and to the AEA. A few parents described it as two separate teams—one medical, housed at the hospital, and one therapeutic, housed at the AEA. While each team communicates well internally, it is up to her to carry information between the two. This seemed to become more of a problem in regions farther away from Iowa City.

In some regions, communication and coordination between agencies was sporadic. For instance, one parent felt that their home intervention teacher and their home-visiting nurse talked to each other regularly, but neither talked much to the physical therapist (a non-AEA provider). The broadness of coordination between agencies seemed to vary greatly between regions. One determining factor in this coordination might be the use of a common release form—some parents mentioned that at meetings with providers, they signed a form which allowed information to be shared with a whole list of providers.

Families tended to feel that this smooth coordination dropped off when their child turned three. Preschool services seemed to be more isolated from the parents and from other service providers. Parents communicate with their child’s teacher through occasional notes, and are rarely present for their child’s therapies. Services provided at the preschool are less likely to coincide with other medical or therapeutic services, and preschool teachers were less likely to be aware of the child’s other needs and services. Some parents shared their IFSP or IEP to inform preschool teachers about the other services their child was involved in.

PLANNING SERVICES AND GOALS

Parents felt, in general, that they were intimately involved in planning services for their child, and their

opinions were solicited and respected. The language they used to express this, however, belied a broad spectrum of actual decision-making power. In some cases this seemed to be because providers took varying levels of leadership in the process, in other cases it was because parents seemed to be more or less aggressive or confident in their knowledge of their child's needs. Parents frequently used language such as "I felt like they made the decisions—they offered what was available, but I took it, I accepted it," or "She asked my opinions, and if I couldn't think of something she would say "well, what do you think about this..." Their perspective on what was an acceptable level of leadership in decision-making varied widely. There also seemed to be clear variation between regions as to the degree to which parents felt part of the decision-making loop.

Parents and providers seem to work out between themselves a system of coming up with goals and making decisions about services that was acceptable to both parties. Most parents described the process as being part of a team, with the final decision-making authority in the parents' hands. The balance between parent and providers depended a great deal on the personalities involved. In one case, a mother lived with weekly visits from a physical therapists who she and her son actively disliked, and whom she felt was doing more harm than good for her son, for close to a year, because she was uncomfortable asking her to stop coming. Some parents are adamant that no one but they can really know the child and know what's best for him, while others feel that the providers have the knowledge and experience base to make better decisions about services. In all cases parents indicated that the final decisions were theirs—what varied was the process used to arrive at those decisions.

THE IFSP AND IFSP MEETINGS

Many parents said that they found the very first IFSP meeting particularly difficult. Frequently this was only weeks after their child's birth or diagnosis, and the parents were just beginning to learn about their child's condition and prognosis. They felt ill-prepared to come up with goals and plans for a set of services that was also completely new to them. A few parents suggested that they be provided with more information about what they should expect in advance of that first meeting. One parent suggested a regular seminar for parents new to the early intervention program.

There were mixed feelings about the amount of paperwork necessary—some parents complained that it was too much, others said they understood the need for all the information required. Parents did not seem to find the IFSP intrusively personal. Most parents found the process of writing the IFSP useful, but then rarely if ever referred back to the document. A few parents did use it for an occasional reference tool. When asked to bring copies of their IFSP to the focus group, over half were unable to locate a copy, and many who did bring a copy brought out-of-date or incomplete copies—indicating that this was not a document of much importance to most parents.

There was a recurring concern that providers required that the child demonstrate a completed goal in their presence; the parent's word that the child had done so was not considered sufficient. The parents often expressed a sense of pressure to perform surrounding the IFSP meeting because of this. Other parents,

however, were satisfied that providers regularly took their word for their child's achievements.

REQUESTING CHANGES IN SERVICES

Most parents stated that they had never had to request any changes to their services, but felt that if they did, providers would be receptive and accommodating. Parents who had had the experience of adjusting schedules or cutting down on a service felt that their decision was respected. A handful of parents expressed apprehension at their providers' potential responses to such a request.

When parents requested services that were not being provided, or requested an increase in the frequency of services, many found a much greater struggle. Many parents were unsure or confused about the availability of certain services from their AEA. Speech therapy in particular was often mentioned as not being available as much as parents wanted it. Many parents went other places for therapies that the AEA would not provide, and paid for services with their own insurance. Many parents described ongoing struggles with the AEA to provide a service which they, as parents, felt their child needed, or another professional felt their child needed, but the AEA did not feel was necessary. One parent had her child's doctor write an order for the maximum amount of physical and occupational therapy. In another case the parents threatened to sue the AEA to receive speech and language services. The ability to fight for a service, however, depended very much on the parents' personalities. Less confident or assertive parents described themselves as grateful and satisfied with whatever services were offered, and hesitant to push for more beyond those.

These struggles for additional services were uniformly between parents and the AEA. There were no mentions of such disagreements between parents and other service providers.

CHANGES IN SERVICE COORDINATORS

Almost without exception, parents were satisfied with their current service coordinator. Almost all of these service coordinators were AEA employees. Parents seemed unaware of the possibility of having a service coordinator from another agency, and seem to find such a scenario difficult to imagine.

Transitioning out of Early Access Services

Over half of the parents who took part in the focus groups had children over the age of two years and had at least begun the process of transitioning out of early intervention services. For some, this meant that they had only begun to talk to providers about changes in services in another year; for others, their child had been in preschool for a year already.

Many parents at the focus groups had children approaching three years of age and had not yet talked to their service coordinators about the transition to preschool services. Many parents of younger children were not aware that services would change when their child turned three. In many cases, parents took the opportunity of the focus group to inform each other about this change, often to the newly-informed parent's dismay. This was in keeping with the finding that at least half of those parents who had started preschool services had

found the transition to be an abrupt surprise. Many parents, however, were happy with the transition process, and felt they had been adequately informed and forewarned. Few parents could recall a specific transition plan being developed. The differences did not seem to break down along regional lines; instead, it seemed to depend on the parents' individual service providers.

Even for those parents who felt sufficiently prepared, it was a traumatic experience to send their child to preschool. Many expressed the wish that the transition to preschool could be more gradual, with in-home services tapering off while preschool attendance picked up. In many cases, parents were offered only one choice for a preschool in their area. When more than one school was available, most parents were encouraged to visit the various preschools and consider their options. A few parents felt that they had been pressured by the AEA to send their child to the AEA preschool when other options existed, and even when they were happy with those other options. In quite a few cases, parents felt that while the providers had to push them a bit into sending their child to school, they were glad they had done so, and were grateful for the gentle pressure.

Many parents were unhappy with the inflexible scheduling of preschool—their child had to start with full days, four or five days a week. Many parents felt this was too much separation for them or their child to handle all at once. There were a number of parents who were frustrated with the gap in services resulting from their child's turning three in the late spring or summer, and not being able to start preschool until the fall.

Many parents preferred the in-home services to the preschool program. A number of parents felt that the program shift at the age of three felt arbitrary, especially considering that for developmentally delayed children, a chronological age can mean anything in terms of development. Some preschools seemed to require that children be either walking or in a wheelchair, which many parents saw as an unwelcome obstacle to sending their child to school. Some parents felt that in-home services should continue until the age of five, or until the developmental age of three.

THE INDIVIDUAL EDUCATION PLAN (IEP)

As with the IFSP, most parents did not use the IEP much, and were not immediately aware of what the document was. But once reminded by the facilitator, most parents recalled having been dissatisfied with the IEP process and document. They felt their opinions and concerns were not considered, nor were those of other people involved with their child. They felt they were not kept as well informed about their child's progress, and often service providers were not very aware of their child's abilities and previous accomplishments. Many parents missed the personal relationships they had formed with the in-home service providers. In quite a few cases, these relationships continued informally.

Services Missed by Parents

Many parents expressed the wish that services could continue uninterrupted throughout the summer. Parents

who had not yet gone through a summer of services often expressed surprise and dismay that services slowed down or were discontinued. In cases where services were continued over the summer, parents were often upset to find that the staff would change, which they felt led to setbacks for their children. In a few cases, parents felt grateful for the break, and felt that the information and exercises provider had left was enough to tide them through the summer. Almost all of the parents felt that the drop in summer services was their most serious complaint about early intervention services.

A number of parents expressed the desire for more parent-to-parent support programs. Some asked for mentoring programs, others for play groups or support groups, and a few for a newsletter, listing all available programs and services.

Quite a few parents would have liked more help in applying for MR waivers. While some parents did not know what this program was (see page \$\$), others felt they had been left to find their way through the morass of paperwork on their own. Some had given up on the process, and regretted having done so. Other parents requested more general financial planning advice—what resources would be available as their child grew older, how to help plan for their child’s financial independence, etc. A handful of parents mentioned that information on assistive technology was particular difficult to access, and the wished that their providers had been more forthcoming information about these options and how to access them.

Providing Skills for Parents

Most parents praised providers on teaching them how to work with their children, showing them techniques, encouraging them to work on exercises between visits, and involving the entire family in the services. There were a significant number of exceptions—parents who felt they had to push to be included in their child’s therapy, or to have the providers leave instructions for activities during the week. This tended to vary between region, with parents in some regions being very enthusiastic about their services, and others very negative.

There was less enthusiasm about providers’ ability to teach parents how to navigate public administrations, access other resources, etc. A few parents felt that they learned more along these lines from other parents than they did from service providers. Some parents recalled having been given a great deal of information along these lines at the outset of services, but at the time the information was not useful to them, and they didn’t recall much of it years later, when the needs for it arose.

Advice to Professionals and New Parents

ADVICE TO PROFESSIONALS

Parents words of advice were often to medical professionals, who they saw as the most lacking in compassion and understanding. They asked repeatedly that professionals not prejudge them or their child’s abilities or future. In a number of cases parents felt that medical professionals tended to group all children with a single

syndrome together, not acknowledging the medical, developmental, and personality characteristics of each individual child. Parents ask that service providers remain as positive as possible about their children's achievements—asking “what is she doing now?” rather than “Is she rolling over yet?”

ADVICE TO NEW PARENTS

The most common recurrent advice to new parents was “Don't be afraid to ask any question.” Parents felt it was important to realize that you are your child's best advocate, and know your child best, and it is critical that parents stand up for what they want for their child. They also advised that parents not delay at all at contacting someone for an assessment as soon as they suspect there might be a problem with their child—the longer they can have the services, the better. They encouraged new parents to be forthright about their service providers—to insist on changing providers if they are not happy with one of them. They urged parents to dig for answers, not accept what providers tell them at face value, and to not be shy about expressing their needs.

Additional Themes and Issues

Many parents were very pleased with the way providers included their other children in activities and exercises. A few parents had been involved with early intervention with a number of children for as long as fifteen years, and these parents were very clear that services had become much more family-centered and compassionate over the years. They feel that providers are respectful of their families' priorities and beliefs, and that providers are increasing flexible about scheduling services when they can best fit it into their work lives. A few parents complained about turnover in staff, that they felt their child suffered setbacks from changes in providers. Most parents, however, when asked if they had any last thoughts or things to add, reiterated how grateful they were for services, and how strong a positive force early intervention had been for their child and family.

In more than one group parents were so enthusiastic about and grateful for services that they said they would do what was needed to help out, keep services funded, keep programs open, etc. Parents discussed writing to legislators, driving children to Head Start when funding was low, and wishing to be called on by the AEA as needed.

A few parents in almost every focus group felt that the discussion was very helpful to them, they had learned important information about services from other parents, and they might, in light of this, give more thought to finding time for parent-to-parent support groups.

TECHNICAL ASSISTANCE TEAM INTERVIEWS

The six members of the technical assistance team (the state Part C Coordinator, the Department of Human

Services technical assistant, the Department of Education technical assistant, the Department of Health technical assistant, the Child Health Specialty Clinics technical assistant, and the Parent Representative) were interviewed by telephone in November and December of 1997. At that time most of the team members were new to their positions, and had limited experience with Early Access, at least on a statewide basis. Interviews focused on their expectations for the program, and challenges that they saw in the years ahead. The interviews were repeated in August, 1999, with the same representatives from Public Health, Human Services, and parents, as well as the same state Part C Coordinator, but a different Education technical assistant. For the second round of interviews the position of CHSC technical assistance was in transition, and was not included.

Changes in Early Access over Time

In 1997, most of the TA team said that they had come to their jobs with the expectation that they would see a system ready for change, which in fact they did find. However, they felt that that change was much less far along than they had expected. They were surprised to find such a strong imbalance in the involvement of the partner agencies, and a high level of tension between agencies over funding resources. They were also struck by the lack of uniformity in program provision across the state, a lack of awareness of Early Access by many leaders at the state level. While in 1997 all six members of the TA team were eager to begin moving Early Access towards some vision of a program where families had dignity, respect, and power, they felt that there was a great deal to sort out on the state level before they could begin to disseminate a consistent message to the field.

In 1997, the TA team had not yet begun to see the impact that the recent changes in IDEA (see page \$\$) would have on Iowa's Early Access programs. There was general agreement at the time that any change would be minimal, with the exception of perhaps some impact from the "natural environment"⁸⁷ requirements and some positive repercussions from the increased requirements for state rules and regulations.

Aside from the reauthorization of IDEA, the TA team saw few other influences on Early Access. Increased use of managed care plans was seen by some to perhaps affect a small number of children. The development of a state task force on early childhood was seen to have the potential of increasing the visibility of Early Access.

Between 1997 and 1999, the most dramatic change in Early Access expressed by the TA team was the clarifying of the program's vision and mission. This allowed them to move, in the words of one team member, from "what are we doing" to "how are we going to do it?" The challenges to implementing this vision seemed to be communicating it thoroughly and profoundly to service providers, and implementing changes in the system in a truly collaborative manner. However, team members were encouraged by their

⁸⁷ add some brief explanation of natural environments in this note. \$\$

excellent relationships with staff in the regions as well as excitement and enthusiasm about the mission statewide.

Changes in legislation at the federal level were, by 1999, beginning to have an impact. While the requirements for services in “natural environments” was seen as a potential issue in 1997, by 1999 it had clearly become a major one. Most of the TA team felt that there had been little in the way of federal guidance as to how to implement “natural environments,” and as a result they were slow to provide the regions with much guidance. A major push towards natural environment compliance was seen as needed in order to prepare for the federal compliance visits expected in 2000. Other federal legislation and potential compliance issues that were seen as potentially affecting Early Access included:

- welfare-to-work incentives for people with disabilities, which might increase family stability and children’s access to health care;
- requirements that a transition plan be in place for all children leaving Early Access, not only those moving into Early Childhood Special Education;
- changes in parents’ rights regulations;

INCREASED USE OF MEDIATION WITH PARENTS; AND

- low rates of infants and toddlers served (1% of the state population).

Aside from implementing the new Early Access mission and federal requirements, specific challenges continued to be identified by A team members. A number of them said that, back in 1997, that had hoped to see change take place at a much faster pace than it has. They still struggle with the diversity of systems between regions, and with the different administrative requirements of each agency. A few TAs felt that there was still a distinct need for increased regulation and quality control at the regional level. Most of the TAs agreed that while Early Access is still viewed by many as primarily a Department of Education program, and that continues to be a barrier, real inroads had been made in communicating the message that Early Access encompasses a much broader array of services and agencies.

The Role of the Technical Assistance Team

In 1997, the TA team saw their roles as primarily provider support for the regional coordinators and other providers—specifically, helping to define best-practices, case consultation, developing procedures, and interpreting state and federal regulations. They had only just begun to travel around the state and meet people in each region, and felt that their relationship with providers was still becoming clear. They spent a great deal of their time on the phone answering questions, and reporting back to the management team and others about issues in the field.

Two years later, the vision the TA team had of their own role in Early Access had changed significantly. They had become much more comfortable with the broader goals of the system, and better able to see their place in that system. They were beginning to see themselves as a critical link in dissemination of Early Access’s vision and mission to providers and administrators in the field. They were beginning to see themselves as leaders, and working to be able to share that state’s vision for the future of Early Access not only with

providers within their own agency, but with all providers. They were spending more of their time actually visiting the regions, rather than troubleshooting specific issues over the phone.

At the same time, their relationship with the Management Team had changed. Most of the TA team felt that between 1997 and 1999 the Management Team developed a great deal of confidence in the TAs, and as a result they had far more decision-making credibility. It remained to be seen, however, how relationships would change and new ways of working together would have to be developed in the future, with three out of five members of the Management Team changing in 1999.

Barriers to Implementation of Early Access Services

In 1997, the TA's mentioned a diverse array of potential barriers to effective service provision. These included:

- turfism and continued personalization of agency issues;
- unclear decision-making role for TA's, occasionally found it difficult to have to regularly defer to the management team;
- a lack of an overall sense of direction and mission for Early Access as a whole;
- providers (and administrators) allowing the rules and regulations of an agency get in the way of problem-solving;
- the fact that IFSPs were still modeled on IEPs, creating a very education-centered sense of services;
- too many realms of responsibility for many players, such as providers who are also service coordinators or also regional coordinators; and
- lack of a cross-agency consensus on training and responsibilities for service coordinators.

In 1999, there was still a consensus among the TAs that turf remained a major issue, specifically competitiveness over which agency would provide a specific service for a family and therefore receive the funds that went with that service. This was seen as a particularly problem in the public health and medical communities, where providers had been long trained to think of their time in terms of billable hours. TAs also mentioned legislative initiatives as occasional barriers—specifically legislation passed for political purposes with little or no consideration for what is really needed by those involved day-to-day in service provision. And more than one TA mentioned that they had begun to have some difficulties with the structure of the TA team, expressing a desire to have a TA specifically oriented toward system-wide goals, public relations, training, or other non-agency-specific targets.

Nonetheless, clearly a number of the challenges that the TA team identified in 1997 had been significantly addressed—specifically their relationship with the Management Team and the lack of an overall sense of direction and mission for Early Access.

Collaboration and Cooperation between Agencies and Providers

EARLY ACCESS AND OTHER STATE INITIATIVES

In 1997, the TA team described the relationship between Early Access and other state initiatives as boding well, but not yet tested. Program directors and department heads were just beginning to become aware of Early Access, and seemed ready to start the process of working together. At the time, however, each program worked very independently, with little communication with external efforts. Some members of the TA team feared that the verbal interest expressed at the time in working collaboratively was merely “lip service,” and that the amount of federal and state money Early Access involved was not large enough to draw serious attention from other programs.

Two years later, TAs were able to provide a number of specific examples of Early Access working successfully with other initiatives, and other examples where inroads had been made. Within the partner agencies, they felt that real progress had been made towards the goal of bringing DHS up to the level of full partnership in Early Access. Connections and partnerships had been made with the Parent-Education Connection, parent education and information centers, the Birth Defects Registry (a project of the DPH and University of Iowa), and schools at the University of Iowa and Iowa State University. While some members of the team were excited about connections with HOPES and the High-Risk Infant Follow-Up program, others felt that these relationships, which needed to be strong, did not go sufficiently beyond sitting on boards.

Almost all of the team members mentioned Empowerment Areas as a key connection for Early Access. In many regions, regional coordinators sat on Empowerment Area boards and were part of the grant-writing process. It remained to be seen what the long-term impact of the relationship would be.

EARLY ACCESS AND OTHER LOCAL INITIATIVES

In many regions, as of 1997, TA team members saw local childcare providers adapting to serving children with disabilities and delays as a result of working with Early Access providers. Specific initiatives were partnering with Early Access in particular regions—one region had been successful in teaming up with local agencies to help chemically-affected families, and a few were working closely with local Decategorization programs. Aside from describing numerous additional examples of specific regional projects, there was little change in the TA team’s responses on this question two years later.

SUCCESSSES AND STRUGGLES WITH COLLABORATION AT THE STATE LEVEL

Most of the TA team felt, in 1997, that there was very little understanding between the four partner agencies about how each agency operated. They agreed that while some individual projects had succeeded as collaborative efforts, there was no system-wide collaboration happening. The barrier to this was primarily territorialism between agencies. The TA team did see some real discussion about system-wide collaboration happening at the level of division head and bureau chiefs, but were skeptical that without specific resources allocated towards moving this vision forward, anything would happen farther down the line.

Many of these same challenges remained two years later. The greatest challenge to collaboration between the four partner agencies remained DHS, where the TAs were beginning to see some movement toward more family-centered approaches to services. While collaboration between the TAs themselves occasionally remained a challenge, within the agencies they represented they felt they were just beginning to move people beyond the stage of awareness of Early Access. All of the TA team expressed some apprehension about the impact that the turnover on the Management Team would have on efforts to interagency collaboration.

SUCSESSES AND STRUGGLES WITH COLLABORATION AT THE LOCAL LEVEL

In 1997, the TA team saw a few regions doing excellent collaborative work on specific projects and programs. They described local collaboration as one of the major goals of the regional coordinators, but did not necessarily feel that the coordinators had been given enough follow-through and direction as to how to achieve true collaboration. Some members of the TA team felt that one of the biggest barriers to beginning collaboration at the local level was the Department of Education had not been clear with their staff that this was a significant goal, and had not made any efforts to combat the turfism they saw as rampant on the local level. In some regions, truly drastic changes remained to be made in order to even begin talking about collaboration, where providers were not even aware of who should be invited to meetings, and other called TA team members to complain that they were not invited to attend IFSP meetings.

By 1999, the TA team could point to examples of successful collaboration on a project basis in most of the fifteen regions. They saw much of the impetus for this as coming from the regional coordinators. They saw the regional coordinators still struggling, however, with the diversity in what they were hired to do, and still working to define their roles in their regions. Paperwork remained a particular barrier—each agency having its own forms, assessments, and requirements—and there seemed to be little progress towards agencies accepting each others' paperwork.

BROADER IMPACTS OF EARLY ACCESS

In 1997, a number of the TA team members indicated that, although there was no data available, they were confident that children who had been part of Early Access were less expensive as part of Early Childhood Special Education programs. They also expressed the hope that providers who worked with a broad range of children were able to take the skills which Early Access encouraged and apply them to their work with older children. They also hoped that the Early Access focus on family satisfaction might carry over into the work providers do with other families, as might the awareness of community resources that providers often gained as part of Early Access services.

In 1999 the team pointed to three specific examples of impacts that Early Access had had on other programs: Early Head Start was beginning to work more closely with Early Access and share resources; the Children at Home Program (a Family Support Subsidy program) pilot was developed with Early Access in mind, and at the state level, the Early Childhood work team was affected broadly by the priorities of Early Access.

Families and Early Access Services

GAPS AND UNMET NEEDS IN SERVICE PROVISION

In 1997, the six TAs concurred that the gaps in the network of services for families were as diverse as the families themselves, with little uniformity between regions. They described the “statewide” system as really fifteen different systems, with most regions believing that their way of providing services was the norm. TA’s saw the main problem in this diversity to be a lack of accountability, and a disparity in services received by two families who may live five miles from each other, but in different regions. They were also concerned by the great variety in the type of training that service coordinators and regional coordinators received, and in the level at which regions took advantage of local community resources. Transportation for isolate families was a specific issue that came up, and one which a few TA team members felt should have more financial resources focused on it.

Many of the same gaps remained two years later, and the TAs still pointed to the lack of system-wide accountability as an issue. Another major issue that was mentioned was eligibility guidelines--that inconsistent guidelines between agencies meant that some children and families were still falling through the cracks. This was mentioned as an area where the state was considering making changes, specifically, reassessing the cutoff of 25% delay for eligibility for services. Team member also listed a number of more specific gaps:

- While there have been real improvements, year-round services are not yet the norm;
- Childcare (for disabled and non-disabled children) has always been an issue and continues to be one;
- Parent-to-parent support is not routinely available;
- Respite care is sporadically available;
- and changes in Medicare eligibility has created some gaps for families.

INVOLVEMENT OF FAMILIES IN PLANNING AND IMPLEMENTING SERVICES

A number of the TAs felt, in 1997, that family involvement was only given lip service. While providers described themselves as giving options to families, these options were seen by the TAs as falling within parameters already strictly defined by the providers. TAs also expressed significant frustration with the IFSP as being particularly hard on families. As was described by the providers themselves, the TAs felt that the level of flexibility in services depended a great deal on the assertiveness of the family.

Much of the TA team saw many providers for whom the idea of being “nice to families” was enough of a commitment. While some training on family-centered service provision had taken place, the TAs felt that there was a distinct lack of follow-through on that training. Perhaps most importantly, many TAs pointed out that there was no system-wide consensus of what “family-centered services” meant in the context of Early Access, and felt it was unlikely that they would be able to implement family-centered practices in the absence of that definition.

Two years later, team members felt that while awareness of family-centered practices had increased, providers continued to deliver family-focused, provider-driven services. The team felt that they were themselves closer to a real understanding of what family-centered service meant in the context of Early Access. The training provided by Carol Trivet was widely considered to have been very effective, but there was concern from most of the team that without effective follow-through, much of its impact would be lost.

Some specific achievements over the two years were increased use of the family's language on the IFSPS (see page 88), significant efforts to increase parent involvement with councils, trainings, workgroups, et al., and the commitment of financial resources to help parents overcome barriers to participation in these.

Child-Find Effectiveness

The TA team agreed, in 1997, that the child-find system was weak, and there were many areas for improvement. They saw the system as at its strongest in its school-based portion, and at its weakest through hospitals and private physicians. The TAs saw follow-through as lacking as part of child-find—that providers who referred into Early Access did not get sufficient information back to them about the child and family. The team felt that the system had not been carefully studied in over 20 years, and needed a thorough review.

Specific gaps in child-find identified by the TA team were minority and non-English-speaking communities, children with “soft signs” or less clear evidence of disabilities or delays, and midwife and at-home births.

The big change in child-find activities since 1997 was the hiring of a public relations firm to design a statewide marketing plan for outreach to families and providers. This plan was seen by the TAs as an excellent step towards providing uniformity around the state in child-find activities. The 3-5 year plan will include billboards, television advertisements, and other plans to go beyond the typical reach of child-find efforts. Team members felt that with this plan in place, the true test would come a few years down the line, in whether or not referral numbers and the numbers of children enrolled in Early Access increase. In the short term, end-of-the-year count numbers had actually declined, as children who were on IEPs were taken off the Early Access count.

Two specific initiatives were seen as potentially boosting referrals in upcoming years—the Newborn Infant Hearing Screening project, which recognizes infants with hearing problems potentially years ahead of when they would otherwise be discovered, and the Iowa Review of Family Assets, given to all families at birth, which potentially could link families up with needed services as soon as a child is born.

KEY FINDINGS

Interagency Collaboration

Findings on interagency collaboration were gathered primarily from the regional council focus groups,

Technical Assistance team interviews, and provider survey, with additional data from parents as well. Notable findings include:

- Regional Council composition was dominated by the Area Education Association. While Regional Council mailing lists covered a broad spectrum of agencies and private providers, those who regularly attended meetings tended to be from the AEA, Child Health Specialty Clinics, and Community Service Agencies (WIC and Early Head Start in particular). Among all providers surveyed, only with AEA or CHSC staff of awareness that the regional council even existed at over 50%. Particularly underrepresented on the council were Department of Human Services staff, childcare providers, and private practitioners. While Regional Council participants tended to explain this unequal representation as due to time constraints, providers also attributed it to lack of support on the part of their agencies—not allowing them so spend time in non-billable activities, or structuring their work in such a way as to not allow for collaborative meetings.
- Almost all service coordination was done by AEA staff—most often by home intervention teachers, and less often by physical, occupational, and speech therapists. Of the other partner agencies, only Child Health Specialty clinics staff did any significant amount of service coordination. Parents were generally unaware of the possibility that their service coordinator could come from an agency other than the AEA. Parents were often even unaware that Early Access was defined any more broadly than the services provided by the AEA. Many providers did not seem to be aware that it was possible for non-AEA staff to serve as Early Access service coordinators.

A number of explanations were given for this. The IFSP process was seen as a real barrier to non-AEA service coordinator—the learning curve to process this paperwork was often seen as an obstacle for staff from other agencies. Providers were also not always clear about whether staff from other agencies would be reimbursed for the time spent as service coordinators. AEA providers in particular seemed to assume that providers from other agencies did not have the time to take on this added responsibility. In general, providers felt that while they knew that the state was encouraging broadening the role of service coordinator, they did not see much support of systematic change to make that a reality.

- Providers placed enormous value on the fact of their meeting as a regional council on a regular basis. They considered meeting each other face-to-face as critical in allowing them to truly understand what services other agencies offered, and it allowed them to refer the families they worked with to a specific person at any given agency. They continued to struggle to broaden the scope of regional council membership in the hopes that this participation would encourage broader referral into Early Access services.
- Providers found it a barrier to cooperation and collaboration that it was a constant struggle to understand the system of rules and guidelines that each individual agency used. The repercussions of this problem were numerous: it prevented them from understanding who could act as a service

coordinator; it was seen as a hindrance to even allowing some providers to attend regional council meetings; for parents, various eligibility guidelines for different agencies made it difficult to create a seamless service network; and it contributed to duplication in paperwork. Providers felt that they received little support from the state level in helping them to negotiate other agencies' systems.

- Providers felt that despite improvements in recent years, there was still too much duplication of paperwork for them as well as for parents. This was particularly the case with health histories, which families often had to complete three or four times.
- Along with paperwork, providers and parents both saw too much continued duplication in testing. Providers expressed the desire for agencies to standardize their assessment tools, so families would not have to go through unnecessary tests. Parents also indicated on the survey that they had regularly experienced the same test being given to their child more than once.
- Communication between providers was praised by parents to a certain extent. Within the AEA, or within the social service network, providers seemed to communicate well and frequently with each other about a family's needs and a child's progress. Between the social service and medical communities, however, a communication gap was seen, which parents felt they often had to bridge themselves through repeated phone calls and letters requesting that medical records be shared.

The Individual Family Service Plan (IFSP)

- Providers spoke of a determined effort made by service coordinators to keep the IFSP in lay language, accessible to parents. This seems to be succeeding—only 5.9% of the IFSPs analyzed contained professional jargon.
- In general, parents were slightly dissatisfied with the process of writing their IFSPs. While some found that the actual meeting was useful to them, most felt that the document itself was not. On the parents survey, parents considered the IFSP-related items less important than others, and also showed the lowest satisfaction with these items. Specifically, some parents felt that the IFSP was “finals time”—that their child would be expected to perform, and failure to meet the IFSP goals reflected poorly on them.
- Parents felt much more strongly than did providers that when the two disagreed on IFSP goals, the parents should make the final decision.
- Providers described the difficult process of preparing for the IFSP meeting by coming up with goals in advance, without cutting off the parents' opportunity to express their own goals. As a result, parents indicated on the parent survey that IFSPs regularly included goals that they had not come up with themselves. On only 26.6% of the IFSPs analyzed was there clear evidence that at least one goal had been devised by the family.
- Non-AEA providers also felt that the AEA tendency to arrive at IFSP meetings well-prepared with

goals made it difficult for them to include any other goals. This was also echoed in the IFSP analysis, where only 15.5% and 17% of the IFSPs analyzed, respectively, included any mention of financial or family goals. This IFSP analysis finding, however, also correlates with the fact the DHS personnel, childcare providers, and private practitioners were the least likely providers to attend IFSP meetings. This is a particular concern in light of the request from parents in focus groups for more help with financial and long-term planning for their child and family.

Maximizing Available Resources

- Providers uniformly value the work of the regional coordinator highly, and feel that she is largely responsible for whatever successes they may have as a council. However, they express frustration that the regional coordinator position is not funded or administered uniformly throughout the state. They would like to see a full-time regional coordinator in every region, perhaps one with greater authority and autonomy than some of them currently have.
- The MR Waiver, while potential a valuable source of support for parents, is instead a recurring source of frustration for parents and providers. Some parents who had applied for waivers had given up, either because they were intimidated by the paperwork or because they found the long waiting lists discouraging. Parents asked for more help with the process, but providers said they themselves are overwhelmed and confused by the paperwork.
- While many of the problems providers found in service delivery they attributed to low staffing levels (see page \$\$), aggravating this was a ongoing difficulty recruiting and retaining qualified new staff. Providers recommended that that state reevaluate its starting salaries for occupational therapists, physical therapists, and home intervention teachers to be more competitive with the private sector. They also recommended that the state strengthen its ties with universities for the purpose of recruitment.

Family-Centered-Service Delivery

- At the time when parents are first informed about their child's diagnosis, whether it be by a medical geneticist, at a child-find fair, or during an assessment in their home, parents ask that providers pay careful attention to their response to being given the information. Parents describe cases where providers burden them with enormous amounts of information when they are not emotionally prepared to process it, and other situations in which parents felt that no complete and honest information was forthcoming. Each parent reacts differently to this highly sensitive moment, and providers need to pay special attention to their particular needs. Doctors were seen by parents as often particularly insensitive at this time. Parent expressed overall dissatisfaction with the process of being referred into Early Access, rating these items among the lowest on their survey and reporting on referral in 11.5% of the open-ended questions about sources of dissatisfaction with services.

- Parents would like to have more parent-to-parent contact available. Many parents in the focused groups indicated that they were not aware that this was available for them. Other parents said that they had gone occasionally, but transportation, childcare, and time pressures limited their participation. Providers ranked this as one of the least important services for parents on their survey, in contrast to the parent survey response indicating that they did not have enough opportunities. Providers expressed frustration that when they did organize parent support groups and other opportunities, parents were reluctant to take on the responsibility of continuing them.
- Parents felt that there were often unnecessary delays between their referral for services and the commencement of those services. This accounted for 15.4% of the “difficulties you had getting services” that parents described on their surveys. Providers from other agencies connected this to the gap in summer services—they felt that when they referred children for services in the spring or summer, the slowdown at the AEA often meant that services did not commence until the fall.
- The gaps in service during the summer months was a major concern for both parents and providers. Parents felt that either they had very few visits from the providers during the summer, or new substitute worked with their child, which they usually considered unacceptable. AEA providers were frustrated that they had to cut back on visits to their families during the year in order to have enough contract hours to be able to see them at all during the summer. Providers from other agencies saw services from the AEA as slowing to a halt during the summer.
- Providers saw the obvious solution to the problem of summer services the hiring of additional staff, allowing each provider a slightly smaller caseload, so they might see each family at the same level of frequency year round. Providers saw increased staffing levels as critical to being better able to respond to family needs—it would allow them to spend more time with each family, and new staff could be hired to work evenings and weekends to accommodate the schedules of families with two working parents.
- Parents were very happy with the extent to which providers gave them techniques and tools to be able to provide their children with continued therapies on their own. However, they did not feel that to any significant extent they were given tools to help them negotiate systems and access resources on their own.
- Parents were enthusiastically appreciative of the effects that Early Access had on their children, as well as of the personal generosity of most of their service providers. Almost all parents felt that their service providers were almost part of their families, and a crucial emotional support for them. Regional council members praise service coordinators for working hard to create and sustain these bonds with their families. One impediment to this bonding is language—providers felt that their intimacy with Spanish-speaking families was impeded by the translation process, and that these families would be better served if more Spanish-speaking service providers were hired.
- Attempts to encourage parent involvement on regional councils was intermittently successful. Many

councils had a difficult time maintaining parent participation, in part because of the barriers of transportation, childcare, and time. Councils felt they would like more support from the state in addressing this problem.

- Many parents were dissatisfied with the availability of speech and language therapy for their child. In some cases parents had to fight with providers about whether or not their child qualified, in other cases they had to push to receive the frequency of therapy they felt was best for their child, and in other cases they resorted to private, paid providers to replace or supplement the services from the AEA. When asked in the parent survey about services they wished they had received, but had not, 21% of the replies were about speech and language therapy. In contrast, providers rated this as one of the services most widely available to families, and made no reference to it as a potential problem.
- There was agreement, however, between parents and providers that respite and childcare were not uniformly available to parents. Some parents in focus group discussions indicated that they had never been informed that respite care was even a potential service. This accounted for 17% of the services parents wished they had received. Parents in every region struggled with finding childcare for their disabled infants and toddlers that they could trust and afford. Providers attributed the dearth of respite care, in part, to a lack of people interested in work that was not particularly well-paid, sporadic, and challenging. Providers rated respite care as the service least available to families.
- Transportation was mentioned by providers as a service gap for families, although families rarely mentioned this themselves. This was considered by providers to be the second least available service for families. It was considered a barrier for parents' participation in regional councils and in support groups, and often made attending medical appointments challenging, according to providers. Regions had various approaches to the problem, from taxi tokens to relying on local public transportation. Parents may have failed to mention this in part because they did not see transportation as a part of the scope of Early Access services.
- In response to many of the open-ended survey questions (approximately 40% of the responses), parents expressed dissatisfaction with the quantity of services provided. Some parents turned to paid, private providers when they felt their struggles, primarily with the AEA, were not leading to increased levels of service. Providers agreed with this as a problem, mentioning that many parents don't fully understand what services they are entitled to, and do not therefore push sufficiently to receive everything they can for their child and family. This is in keeping with the finding that families with lower incomes, single parents, and non-white families were more satisfied with some aspects of services than were wealthier, married, white parents, who might have had more tools with which to push for more extensive services.
- Parents were very satisfied with the efforts made by providers to adapt to their cultural, language, and religious differences. While they felt that providers did well with these challenges, the parents did not consider cultural supports and adaptations particularly important. Providers, on the other hand, felt

that language barriers in particular limited their ability to create close bonds with families, and recommended that agencies should make greater efforts to hire Spanish-speaking service providers.

- Parents felt very strongly that their opinions were solicited by providers and their input had a significant impact. They felt that communication between themselves and most service providers was open and honest in both directions. They felt that they were intimately involved in the planning of services. While providers also say that parents' wishes and opinions are paramount, they acknowledge the fine line between helping parents make decisions and leading them in a particular direction (see page \$\$). IFSP analysis confirms this, in that evidence of parent input is clear on 68% of the IFSPs analyzed.
- Nonetheless, 19% of the parent suggestions regarding how best to improve services, they called for better communication with providers. This is probably due to the small, but significant group of parents who had had ongoing difficulties with one service provider in particular. Quite often, these difficulties were exacerbated by the parent's reluctance to make request a change in service provider, or lack of an alternative provider in their region.
- Parents felt that they were actively included in the services provided for their child. They felt providers made a significant effort to include them and other family members in all activities, and left parents well-equipped to work with their child alone. On 52% of the IFSPs analyzed, there was clear indication of parents' roles in the services planned.
- Parents were also greatly appreciative of having services provided in their homes. This accounted for 19% of the survey responses to what they liked best about Early Access, and was also one of their disappointments with the transition when their child turned three.
- Parents were not usually completely satisfied with the process of transitioning out of Early Access. During focus group discussions, many parents indicated that they had heard nothing about the fact that Early Access would phase out when their child turned three. Other parents felt that they had been informed about transition too suddenly, and the transition itself had been too abrupt. They indicated that a gradual phasing out of in-home services and phasing in of preschool would have been easier for everyone. They felt that the smooth communication and coordination they had been accustomed to with Early Access ended with the transition. On the parents survey, parents of children who had transitioned out of Early Access had lower satisfaction ratings, perhaps in part due to their experience with transition, in part due to changes in services in the previous three years. Nonetheless, a significant minority (35%) felt that transition went smoothly for them and their child, and most parents felt that the shift to preschool services, was, in the end, for the best for their child.
- Providers indicated that they were very comfortable respecting the wishes of parents when these differed from their own. Nonetheless, in focus groups providers regularly offered means they used to provide children with services that their parents had refused. This was in keeping with the finding that parents much more strongly than providers that when disagreements arose regarding the IFSP,

parents should make the final decision (see page \$\$).

Child Find Effectiveness

- Medical professionals, particularly doctors, do not consistently refer potentially eligible families for Early Access services. Only 58% of the private provider surveyed were even aware that Early Access existed. While many of the referrals of parents who took part in the focus groups happened in the hospital when their child was born, it was more likely a nurse, social worker, or therapist who made the referral than the delivering doctor or pediatrician. While 71% of those who informed parents about their child's delay or disability were medical personnel, only 55% of those who first referred them to Early Access were.

For older children, private doctors were more likely to encourage parents to “wait and see,” and approach which left many parents frustrated with having lost precious months of services. Providers attributed this problem in part to public relations, and in part to the lack of a feedback loop—doctors rarely hear back from other providers about patients they had referred, and are rarely invited to take part in ongoing service coordination.

Public Health agencies were much more likely to refer than private offices. Providers felt that this was one reason that middle-income children were likely to fall through the gap in child-find—while Public Health agencies (including CHSC clinics) routinely do Denver screenings and other developmental assessments, private doctors' offices rarely do these, for lack of time and insurance reimbursement.

- Only 31% of childcare providers (Early Head Start excluded) surveyed were aware the Early Access existed. They were also a negligible presence on regional councils.
- The following demographic groups were seen by providers as potentially falling through the child-find net:
 - ♦ minorities, whom some providers speculated might be better represented in Early Access if the Regional Councils were composed of a more representatively diverse group of providers;
 - ♦ families new to the region or state, who might be less connected to the community, and might receive less health care;
 - ♦ geographically or socially isolated families, who might have significant transportation and communication barriers;
 - ♦ children with slight or moderate delays, which might not be noticed until later in development, and whose doctors were more likely to prescribe “wait and see”;
 - ♦ first-borne children, whose parents did not have contact with the local school system;
 - ♦ transient families and immigrant families, who might have limited access to health care and be unaware of community resource
- Providers who worked in urban areas (populations of over 50,000) were significantly less likely to be

aware of Early Access than were providers in smaller towns and rural areas.

CONCLUSIONS AND RECOMMENDATIONS

The statewide evaluation of Iowa's Early Access service network was undertaken at a time of significant transition for the program and its stakeholders. Legislative changes in the 1997 reauthorization of IDEA indicated new directions the state would have to take in order to maintain compliance for continued federal funding. A new Director of Part C Services was hired by the Iowa Department of Education shortly after the evaluation began, and most of the members of the 6-person technical assistance team were also relatively new to positions. By the end of the evaluation, many of the members of the Management Team would be new as well. Perhaps most importantly, under the new leadership Early Access has not only taken on a new name, but has begun to define and disseminate a statement of mission and values to be shared by all the partner agencies and providers in the field.

In this context of change a statewide evaluation can seem awkwardly timed—it can perhaps be tempting to dismiss findings as “well, yes, that’s how things *used* to be...” But there is no more critical moment than one of radical and rapid changes to stop and capture a clear snapshot of the status quo, in order to be able, as change progresses, to have reference point to look back to and say “this has changed, and for the better;” or in some instances, “we’ve moved away from that, we need to get it back.”

The findings of this evaluation paint a portrait of a program that is extremely diverse, regionally and otherwise. Early Access in Iowa is currently full of strengths—there are countless areas in which families are so positively affected by their connection to Early Access that they were moved to tears in the recounting. In the transitions ahead, these strengths—the one-on-one intimacies between families and providers, the dedication of many regional staff, and more—must remain constants for the families. At the same time, the current climate for change must react to the needs of families and providers that this evaluation clarified, and incorporate them into the values and missions which are disseminated from statewide authorities.