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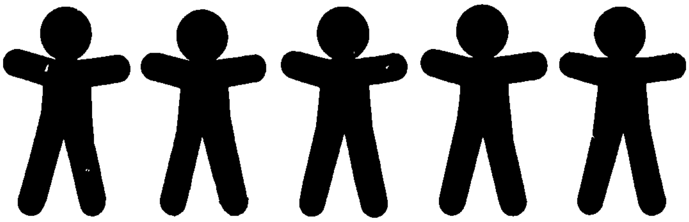
ABSTRACT

The report and an accompanying executive summary of a statewide needs assessment on young handicapped children in Iowa examine services available, effectiveness of services, and needed changes. The introduction provides an overview of State Planning Grants, Iowa's history of early childhood special education, and this project's approach to planning. The methods section outlines the purpose of the State Planning Grant, the needs assessment process, and the involvement of the State Plan Advisory Council for Early Services. Descriptions of the needs assessment sample population, analysis techniques, and a problem solving approach are also included in the methods section. The results section provides a thorough discussion of the descriptive and inferential data analyses for the professional and parent needs assessments and an analysis of the parent forums. The recommendations list proposed changes based on the data collection. Recommendations center on the need to: improve access to and receipt of services; explore case management issues; increase communication and coordination among service providers and agencies; increase the quality of parent participation; and offer an array of training options to parents and service providers. Twenty-four figures and 18 tables illustrate the data, and 6 appendices comprising the greater part of the report include detailed analyses of the questionnaire items and responses for both the professional and the parent needs assessments, a summary of state plan suggestions, and the parent forum questions. (DB)

Young Children with Special Needs in Iowa



Report of Professional and Parent Responses

State Planning Grant Needs Assessment

Iowa Department of Education

December, 1988

State of Iowa
DEPARTMENT OF EDUCATION
Grimes State Office Building
Des Moines, Iowa 50319

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PROJECT STAFF

Summary Authors
Peggy A. Cvach, Ed.D.
Program Consultant
Mountain Plains Regional Resource Center
Drake University

S. Pike Hall, Ph.D.
Associate Professor Special Education
Graduate School of Education
Drake University

Project Research Analyst
S. Pike Hall, Ph.D.
Associate Professor Special Education
Graduate School of Education
Drake University

Project Director & Summary Editor
Joan Turner Clary
Early Childhood Special Education Consultant
Iowa Department of Education
Bureau of Special Education

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PREFACE

The purpose of this summary is to provide concise information about the current status of comprehensive services for young children with special needs and their families. This information is based on a 3-phase, statewide needs assessment process.

The summary has been organized into four sections. The introduction provides an overview of State Planning Grants, Iowa's history of early childhood special education, and this project's approach to planning. The methods section outlines the purpose of the State Planning Grant, the needs assessment process, and the involvement of the State Plan Advisory Council for Early Services (SPACES). Descriptions of the Needs Assessment sample population, analysis techniques, and a problem solving approach are also included in the methods section. The results section provides a thorough description of the descriptive and inferential data analyses for the professional and parent Needs Assessments and a summary of the parent forums. The summary section outlines five major areas and findings within the areas. The recommendations section lists proposed changes based on the data collection. Readers may choose to (a) read only the summary, (b) scan the report and read the summary, or (c) read the entire report.

This summary does not attempt to provide all of the answers or ideas to improve comprehensive services for young children with special needs. The intent of this summary is to offer ideas from which to build and creatively use the numerous financial and human resources within Iowa.

INTRODUCTION

Planning Grants for Early Childhood

Public Law (P. L.) 98-199, which was passed in 1983, revised and extended the Education of the Handicapped Act. One of the revisions included in this law was the authorization of the Secretary of the U.S. Office of Special Education Programs to make available a grant to each state to assist the State in planning, developing, and implementing a comprehensive delivery system for the provision of special education and related services to handicapped children from birth through five years of age. The following grants were authorized: (a) a 2-year planning grant to assess needs within the State and establish a procedure and design for the development of a State Plan; (b) a 3-year development grant to develop a comprehensive State Plan; and (c) a 3-year implementation grant to implement and evaluate the comprehensive State Plan. The timelines for the State Planning Grants were changed with the passage of P. L. 99-457 in October, 1986. The funding for these grants was discontinued under P. L. 99-457; many of the State Planning Grant activities will be continued, however, under Part H of the new law as encouraged by the legislation.

The Iowa Department of Education was awarded a State Planning Grant for Young Handicapped Children in October, 1985. Two years were used to assess needs within the State through a 3-phase process — written needs assessment for service providers, written needs assessment for parents, and forums for parents. Iowa has attempted to determine needs across agencies as a basis for interagency planning, training, coordination, and funding.

Iowa's Early Childhood Special Education History

Iowa is known throughout the nation for its strong educational structure. In 1974, the Iowa legislature passed Senate File (S. F.) 1163 which mandated education and related services from birth to 21 years of age for persons with handicapping conditions. As a follow up to this legislation, the Bureau of Special Education, Department of Education, declared the preschool handicapped population as the largest unserved special education population in the State. With this designation, the flow-through portion of Education for the Handicapped Act — P. L. 94-142, Part B funds were designated for children from birth to seven years of age.

These two state level events provided the foundation which made possible the development of a comprehensive structure of services for all young children with special needs. The Area Education Agencies (AEAs) serve as the major providers for support services while local education agencies (LEAs) act as service providers for direct instructional services. Through this union of agencies, a refined service delivery model emerged.

Prior to the passage of Education for the Handicapped Act — P. L. 94-142 and the passage of S. F. 1163 in Iowa, there were few programs for young children with special needs within the State. There had been a few model demonstration programs which were funded through the Handicapped Children's Early Education Program and some agency-funded programs through the Easter Seals Society and the Association for Retarded Citizens. These programs had limited access and were generally located in urban areas.

During the past decade, there has been a documented increase in availability of services and programs for young children with special needs. As legal observers have noted, "By accepting the challenge of providing needed instructional and support services for young children, Iowa has become one of the leaders in the nation in moving toward provision of full services for all children with special needs" (*Iowa Law Review*, June, 1977).

In attempting to provide equal opportunities for all young children with special needs, a joint effort involving numerous agencies has emerged. By using a variety of human and financial resources available from the federal and state levels, every attempt is being made to identify and serve those children in need of special education and related services. Health, education, and social services are involved in a child's comprehensive program. The medical community, educators, and human services providers have worked together to make services available to all families with children who have special needs, regardless of their individual situations. Interagency coordination is an absolute necessity when working with the preschool population because of the level of needs within this group. The goals and objectives of the State Planning Grant promote interagency communication, cooperation, and coordination.

The Project's Approach to Planning

The planning grant process has provided decision makers with the opportunity to take an indepth look at how well Iowa's services for young children with special needs are currently working. The project's director and consultants decided to look at the involvement of the major agencies currently providing services to young children with special needs. Since Iowa's system for serving young children with special needs appears to be organized, cost effective, and comprehensive, the project planners asked the following questions: "Why is the system working?" "How can it be improved?" "What is really working?" The planners anticipate changes but want those changes to be data based.

Preliminary contacts and meetings were held to determine key agencies that provide direct and indirect services to young children with special needs and their families. Representatives from these agencies and parents comprise the State Plan Advisory Council for Early Services (SPACES) which has advised the project director and consultants throughout the assessment process. Two written needs assessments were developed to pinpoint gaps, overlaps, and frustration points in the service delivery system. Service delivery, case management, interagency communication and coordination, and personnel preparation were some of the issues addressed in the Needs Assessments. Parent forums were held to get more indepth information concerning several response patterns that resulted from the parents' written responses.

METHODS

Goals and Objectives of the State Planning Grant

The State Planning Grant was funded to give the Department of Education, Bureau of Special Education an opportunity to look to the past, assess the present, and plan for the future. Persons representing agencies and groups who have not previously worked together met for the purpose of planning, developing, and implementing changes in the service delivery for young children with special needs and their families. All aspects of the State Planning Grant include procedures for making informed decisions in order to (a) develop a more coordinated and cost effective continuum of services, (b) ensure that all young children with special needs receive the services they need, and (c) maximize the creative use of existing resources. The State Planning Grant Needs Assessment is the first step in this process.

The purpose of the Needs Assessments is to gather accurate and comprehensive data regarding services for young children with special needs from appropriate agencies, institutions, and parents. The objectives for developing and using the data from the Needs Assessment are to identify (a) what services are available, (b) which of these services are working, and (c) what can be changed to make the service delivery system more effective.

Questionnaire Design

Objective 1.1 in the Department of Education's grant proposal to the Office of Special Education Programs is "to identify the agency with professional expertise and resources to complete the activities necessary to the needs assessment process." A contract was developed with Drake University and the Department of Education for planning, developing, and distributing the Needs Assessments. The planning team, including Joan Turner Clary, Project Director, and Drs. Peggy Cvach and S. Pike Hall, used the following basic steps in designing the questionnaire: (a) developing a needs assessment process; (b) identifying and reviewing other needs assessments that had been done by other states; and (c) drafting the assessment design for data collection, data analysis, and reporting.

The process for gathering information included three phases: (a) a needs assessment for service providers of young children with special needs (Phase I), (b) a needs assessment for parents of young children with special needs (Phase II), and (c) parent forums to confirm the findings in Phases I and II.

State Plan Advisory Council for Early Services (SPACES) Participation

The State Plan Advisory Council for Early Services (SPACES) played a key role in the State Planning Grant. The Council consisted of individuals representing agencies or professions that serve young children with special needs and their families. The following agencies or professions were represented: Area Education Agency (AEA) Special Education Director, AEA Supervisor of Early Childhood Special Education, Child Health Specialty Clinics (CHSC), Day Care for Exceptional Children, Department of Health (DH), Department of Human Services (DHS), educators, Head Start (HS), institutions of higher education, occupational therapists, parents, and University of Iowa Hospitals (UIH). SPACES assisted the planning team with five tasks: (a) identification of the key agencies involved, (b) verification of the items to be included on the Needs Assessments, (c) identification of the population to be surveyed, (d) review of the findings, and (e) recommendations for changes based on the assessment findings. (See Appendix A for a list of SPACES members.)

Selection of Sample

Professional Needs Assessment

The planning team and SPACES decided to sample agencies and professional groups that contribute to the comprehensive service system. It was hoped that participating agencies and professionals would gain a greater awareness of the total scope of the service system, how they fit into it, and how the system fits together. Additionally, a thorough analysis of the total picture would provide the documentation needed to make sound recommendations for change.

Six hundred respondents were randomly selected from a pool of 2,192 names. The names were provided by many agencies serving Iowa families. Personnel from most agencies were asked to complete a survey. The following agencies were surveyed: Area Comprehensive Evaluation Services (ACES), AEAs, Day Care for Exceptional Children, Department of Health — Public Health Nursing Section, DHS, Des Moines Child Guidance Center, Iowa Braille and Sight Saving School, Iowa School for the Deaf, Mental Health Centers, Public School Districts, regional Child Health Specialty Clinics, regional Head Start units, University of Iowa Hospitals, and Visiting Nurses Association.

Within these agencies, a variety of professionals were surveyed. These professional groups were: administrators, audiologists, nurses, pediatricians, physical therapists/ occupational therapists, psychologists, social workers, speech clinicians, and teachers.

Table 1 shows what percent of the total sample each professional group represented.

Table 1

Number and Percent of Sample Population by Role Group (N=2192)

Role Group	#	%
Social Workers	635	28.9
Teachers	482	21.9
Psychologists	132	6.0
Occupational/Physical Therapists	65	2.9
Speech Clinicians/Audiologists	251	11.5
Nurses	201	9.2
Physicians	272	12.4
Administrators	154	7.0

Parent Needs Assessment

Parents with young special needs children were identified anonymously from Department of Education coded identification numbers. To maintain absolute confidentiality, AEA personnel distributed the Needs Assessments to 800 parents across the state. Due to the maintenance of confidentiality, it was not possible to make additional requests for parents to return surveys, send "thank yous," or distribute a copy of this report to the participants.

Sampling Technique

Both professionals and parents were sampled randomly. Professionals were first organized by professional groups (e.g., speech clinicians, social workers, teachers, etc.) and then drawn randomly from within the groups. The number of professionals surveyed within a role group was proportionate to the total number of that role group estimated to be working with young children with special needs. For example, Table 1 shows that 482 teachers is 22% of 2,192 (the total population); therefore, 132 teachers, or 22% of 600 (the total sample), were surveyed.

Parents were first classified by the age of their child and then drawn randomly until a proportionate share was secured. It was intended that both sample groups match the total population they were designed to represent.

Descriptive and Inferential Statistical Analyses

Responses of parents and professionals were subjected to descriptive analyses (e.g., averages, standard deviations, frequency counts, cross tabulations, etc.) prior to an inferential analysis. If descriptive analyses led to the possibility of group divergences (i.e., a difference between physicians and other groups, a difference between AEA staff and LEA staff), a 2-way analysis of variance was conducted on the item. When chances of alpha (saying two groups are different when they are, in fact, the same) was at or below the .05 level, group differences were stated and, when appropriate, interpreted.

Prose Analysis

Parents and professionals were given several items in which they were to write a response rather than select an answer from a number of possibilities. These prose responses were analyzed differently than multiple choice responses. Several steps were involved in the analysis. Responses were first scanned to determine the general variation in the answers. A trial category system (i.e., one which was coherent and contained few empty cells) was then constructed. Roughly five to ten percent of the responses were then selected from among all returns. If the category system appeared to work for the five to ten percent, that particular category system was used for the remainder of the responses. If, however, unanticipated types of responses were found, new categories were possibly added and old categories regrouped. Once the final category system was constructed, all responses were classified. Results from prose questions were reported in terms of frequency within the categories. A hypothetical example illustrates this process.

> Suppose that parents returned 100 questionnaires in which they were asked to, "Describe your concerns and feelings about AEA services." A scan of that item on all 100 questionnaires might, at first glance, show that 'happy, unhappy, and no response' were the best categories. Five to ten (or five to ten percent) of the questionnaires would then be thoroughly reviewed and, perhaps, it would become evident that the categories needed to be changed. Thus, if after very careful reading, some parents were found to be neither happy nor unhappy but indifferent to the services that AEAs provided them, a category would be added. Once the category was added, all questionnaires would be read and the responses to this item tallied into one of four (rather than three) categories. Finally, the number of people choosing each category would be provided in the results section and interpreted further if any meaningful pattern within the categorical responses appeared.

(See Appendices B and C for complete prose answers from both Needs Assessments.)

Priority Selection and Problem Solving

In an effort to pinpoint particular problem areas or issues, the planning team requested that SPACES members review a preliminary draft of this summary report and generate (a) problem areas, (b) specific problems within the targeted problem area, (c) ideas for solving the problem, (d) cost and effort required to solve the problem, and (e) expected results. A 2-day meeting was held for this purpose. The summary and many of the recommendations are taken from this 2-day planning session. (See Appendix D for a copy of the planning form and a summary of ideas generated during the session.)

RESULTS

Phase I: Professional Descriptive Information

The professional survey (Phase I) includes numerous items. Descriptive statistical information from these items is discussed in this section. Appendix B includes (a) the Needs Assessment questions, (b) frequency and percent results, (c) prose answers, and (d) professional comments. (See Appendix B for a further study of questions and responses.)

Return Rates

Fifty-two and one-half percent of the 600 professionals who were sent questionnaires returned an appropriately completed questionnaire. Response rates differed considerably among the professional groups, as Table 2 demonstrates.

Table 2

Distribution and Return Rate of Professional Questionnaires

Professional Group	# Sent	% Sent	# Returned	% Returned
Administrators	50	8.3	50	100.0
Teachers	132	22.0	88	66.6
Psychologists	50	8.3	32	64.0
Social Workers	99	16.5	61	61.6
Occupational/Physical Therapists	50	8.3	21	42.0
Nurses	55	9.2	23	41.8
Speech Clinicians/Audiologists	90	15.0	30	33.3
Physicians	74	12.3	10	13.5
TOTAL	600	99.9	315	52.5

Response rate differences encourage the formation of four separate clusters, each of which may be indicative of distinct underlying patterns. Administrators are the only group in the top cluster with a 100% response rate; the next cluster, containing teachers, psychologists, and social workers, has an average response rate of 64%. A third cluster, formed from therapists, nurses, speech clinicians, and audiologists, has response rates between 33 and 42%. Finally, with a response rate of 13%, the lowest cluster consists solely of physicians.

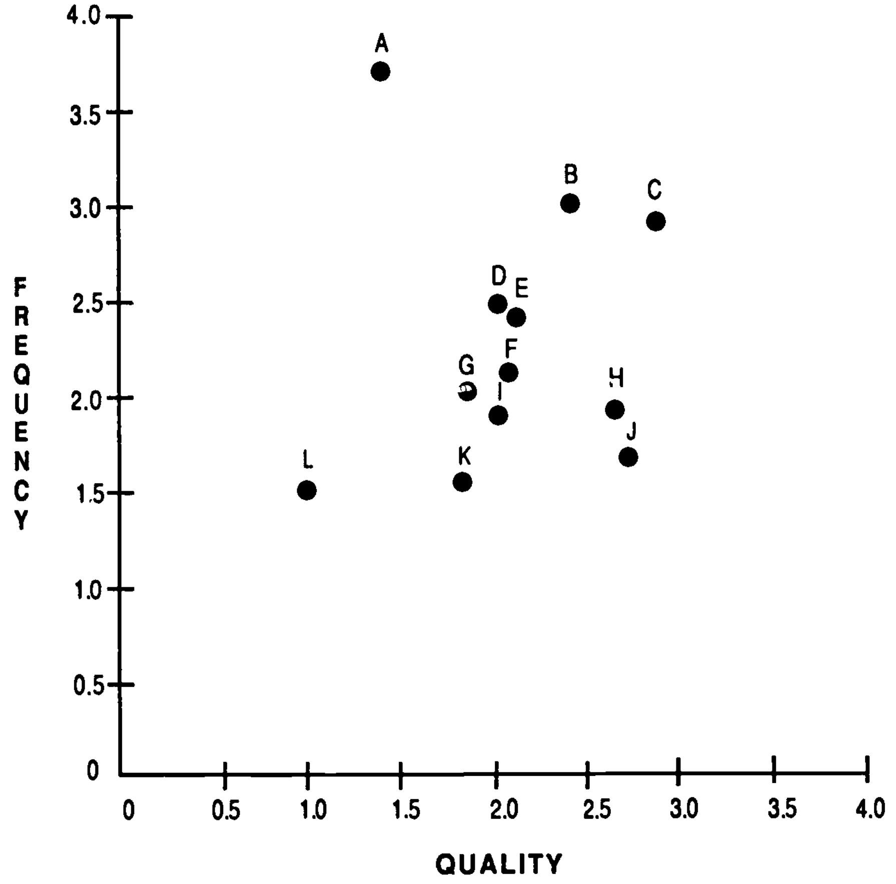
Frequency and Quality of Interagency Activity

Respondents perceive their agency's frequency and quality of collaboration with other agencies quite differently. For example, respondents indicated that the Early Periodic Screening Diagnosis and Treatment (EPSDT) Program, Maternal and Child Health (MCH), and University of Iowa Hospitals (UIH) were, on the average, used several times a year (somewhere between monthly and annually), whereas Area Education Agencies (AEAs) were used daily (somewhere between several times per day and several times per week). Average quality responses varied from very effective (1.0) to satisfactory (2.8). Figure 1 presents these results.

Overall, respondents indicated that specific coordination activities such as telephone calls and problem solving or planning meetings were conducted at least monthly and were generally effective.

Figure 1

Frequency and Quality of Activities with Other Agencies



Frequency: 1 = annually, 2 = monthly, 3 = weekly,
4 = several times per week,
5 = several times per day

Quality: 1 = very effective, 2 = effective, 3 = satisfactory,
4 = unsatisfactory, 5 = very unsatisfactory

A = Area Education Agency
B = Physicians
C = Department of Human Services
D = Head Start
E = Hospitals
F = Residential facilities
G = Public health nurses
H = Private diagnostic agencies
I = University of Iowa Hospitals
J = Advocacy groups
K = Maternal & Child Health
L = Early Periodic Screening Diagnosis & Treatment

Case Management

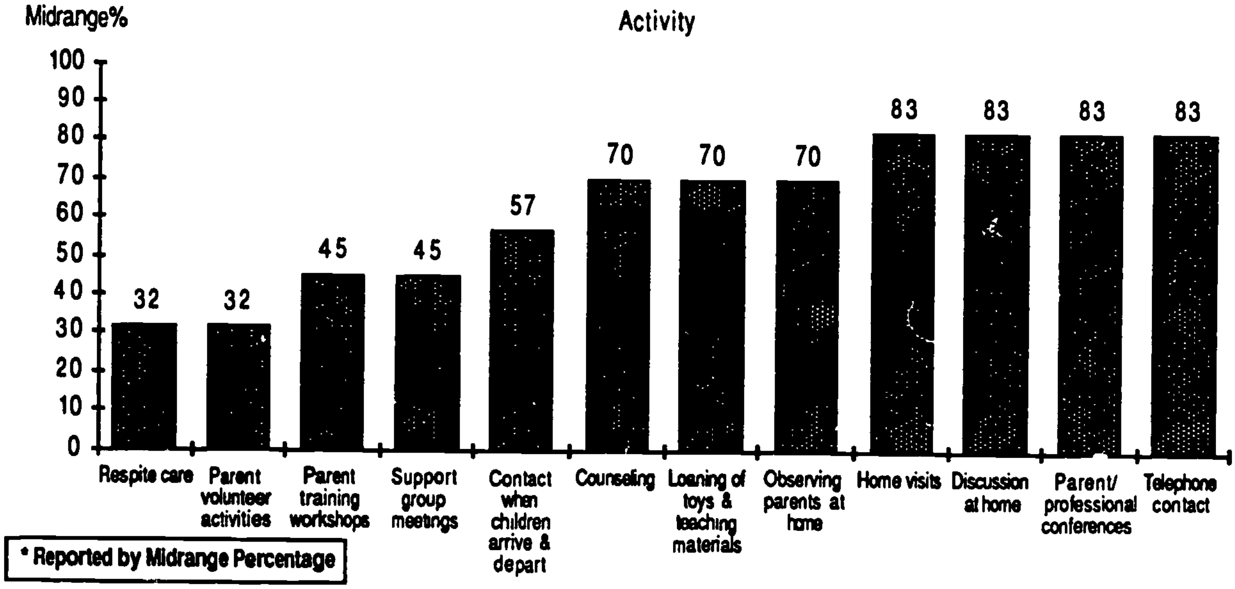
Most respondents indicated that their agency assigns case managers for young children with special needs and their families. The definition of *case manager* which was provided to respondents was, ". . . person in charge of assisting families of young children with special needs in most interactions with agencies." Respondents listed case manager duties as: (a) being the parents' initial contact and continuing source of general support, (b) providing legal information to and advocacy for parents (including monitoring the progress of service to assure that parent and child rights are being observed) and (c) coordinating staffings, annual reviews, and Individual Education Plan (IEP) development.

Parent Participation Activities

Professionals were, in general, 'satisfied' if not 'very satisfied' with their agency's parent participation activities. Specific activities which make up agency parent participation activities vary considerably in the frequency with which they were mentioned. Figure 2 lists specific activities and their frequency.

Figure 2

Parent Participation Activities*



* Reported by Midrange Percentage

Eighty-three percent of the professionals indicated that parents are 'frequently' to 'very frequently' involved in the decision-making process of the agency. Approximately four percent indicated that parents are involved infrequently; while, two percent of the respondents reported that parents are 'not at all' involved in decision making in their agency.

Professionals listed numerous strengths and weaknesses of their agency's parent participation activities. Three hundred forty-six respondents noted problems with agency parent programs. Problems most often identified were low numbers of staff, insufficient funding, inadequate facilities, and the fact that parent participation was not an agency goal or priority.

The most frequently mentioned strength of an agency's parent participation program was the availability of counseling and other support for parents. Good communication between parents and staff was also cited frequently as an agency strength.

Professionals were asked how they might improve the parent participation program. The respondents suggested various qualitative and quantitative changes in activities. The most frequently suggested qualitative changes were to provide more relevant activities and pertinent contact with parents. The most prevalent quantitative suggestion was to increase the number of (a) staff, (b) support groups, or (c) parent activities.

Screening and Identification

Respondents were asked to identify agencies that screen young children. *Screen* is defined: "to test a large population in order to identify individuals who are most likely to have a handicap." The data show that professionals believe major agencies in Iowa [e.g., AEAs, Department of Human Services (DHS), EPSDT, Head Start (HS)] offer screening programs to young children. While professionals noted that screening was available for all children birth through 71 months, they also noted systematic agency differences, particularly between age groups. These differences are explained by agency charter. For example, Head Start offers screening to children who are 36 months or older; Maternal and Child Health tends to screen children who are younger than 36 months.

Respondents demonstrated their concern with identification based on two factors: (a) handicapping condition and (b) age (birth through 35 months and 36 months through 71 months). When given a list of handicapping conditions, respondents reported that children with behavior disorders and children with learning disabilities need to be better identified within both age groups. Professionals were least concerned with identifying older (36 through 71 months) children with hearing impairments, physical handicaps, or visual impairments. Table 3 lists, in descending order, handicapping conditions and age ranges identified as in need of improved identification.

It is extremely difficult to identify very young children who have classic learning or behavior disorders due to variations in developmental patterns of children. It is worth noting that areas of least concern are those conditions most easily identified through mass or individual screening.

Table 3

Handicapping Conditions and Age Ranked
According to Need for Improved Identification Procedures
(Duplicated Count N=315)

	Child Age	
Handicapping Condition	**0-35 mo.**	**36-71 mo.**
Behaviorally Disordered	3 (139)*	1 (200)
Learning Disabilities	4 (86)	2 (188)
Mental Disabilities	5 (68)	7 (56)
Multi-handicapped	6 (58)	8 (47)
Speech/Language Problems	9 (46)	10 (43)
Hearing Impaired	10 (43)	13 (20)
Physically Handicapped	11 (36)	13 (20)
Visually Impaired	12 (34)	14 (18)

* Rank with frequency of respondent response in parentheses

Services Provided to Young Children with Special Needs

Respondents were asked to identify their agency's services and the quality of these services for children birth through 35 months and for children 36 through 71 months. The accumulated responses are presented in Figures 3a, 3b, and 3c and Figures 4a, 4b, and 4c.

Frequency of services. A first analysis involved grouping services according to (a) the type of service (medical, educational, other) and (b) whether or not the service is direct or indirect. Within each service group (medical, educational, other), services were rank ordered according to the percent of respondents who stated that their agency offered the service. This pattern of analysis was used twice: (a) for services to children birth through 35 months and (b) for services to children 36 through 72 months. These analyses are summarized in Figures 3a, 3b, and 3c.

Figure 3a

Summary of Respondents Who Stated Their Agency has Services (Educational)

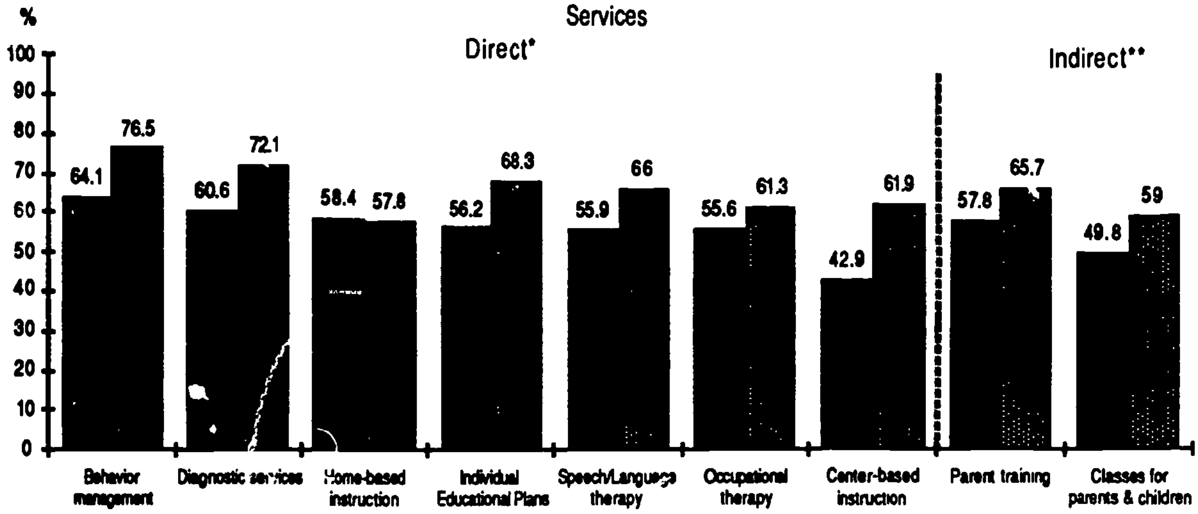


Figure 3b

Summary of Respondents Who Stated Their Agency has Services (Medical)

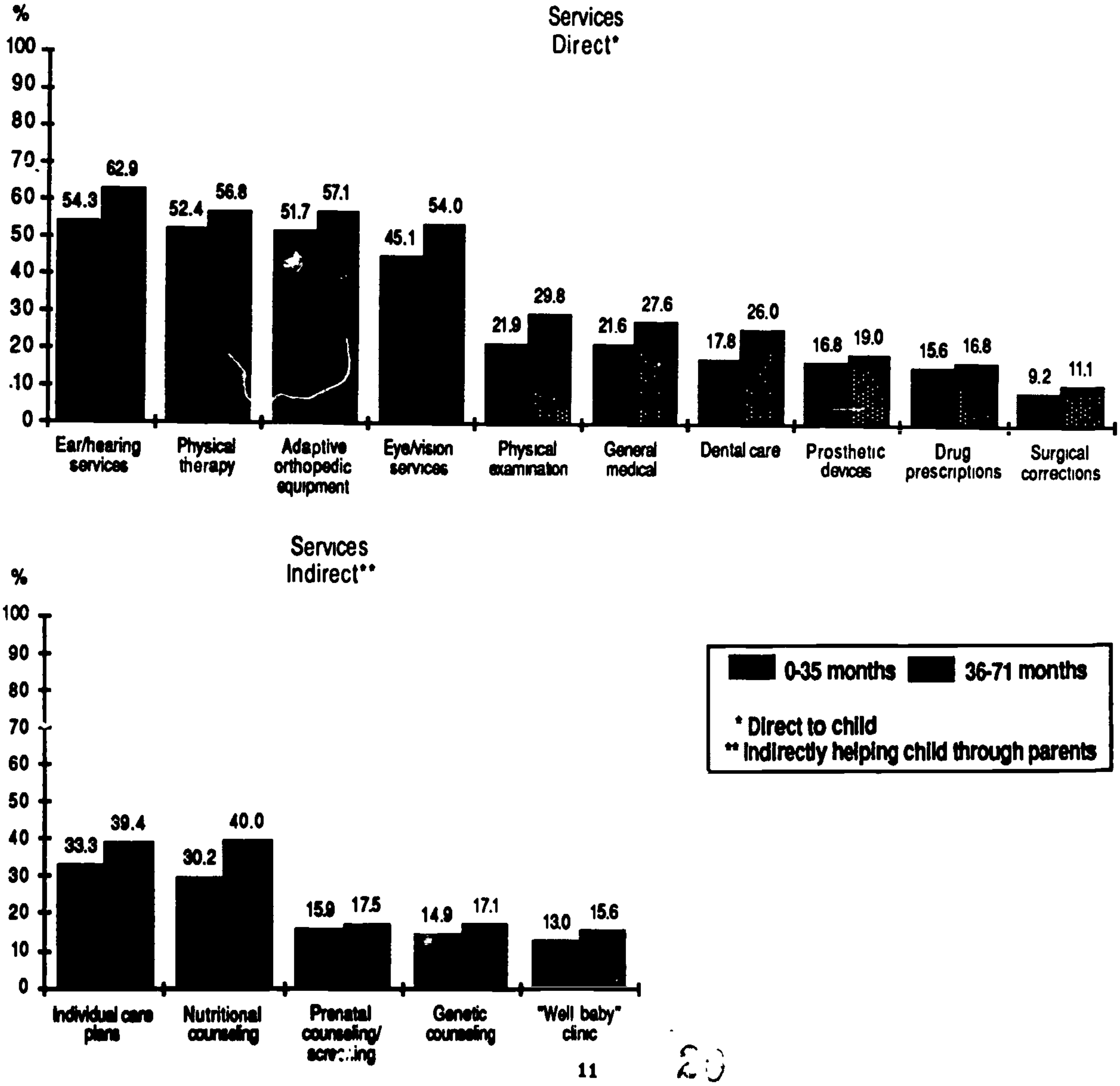
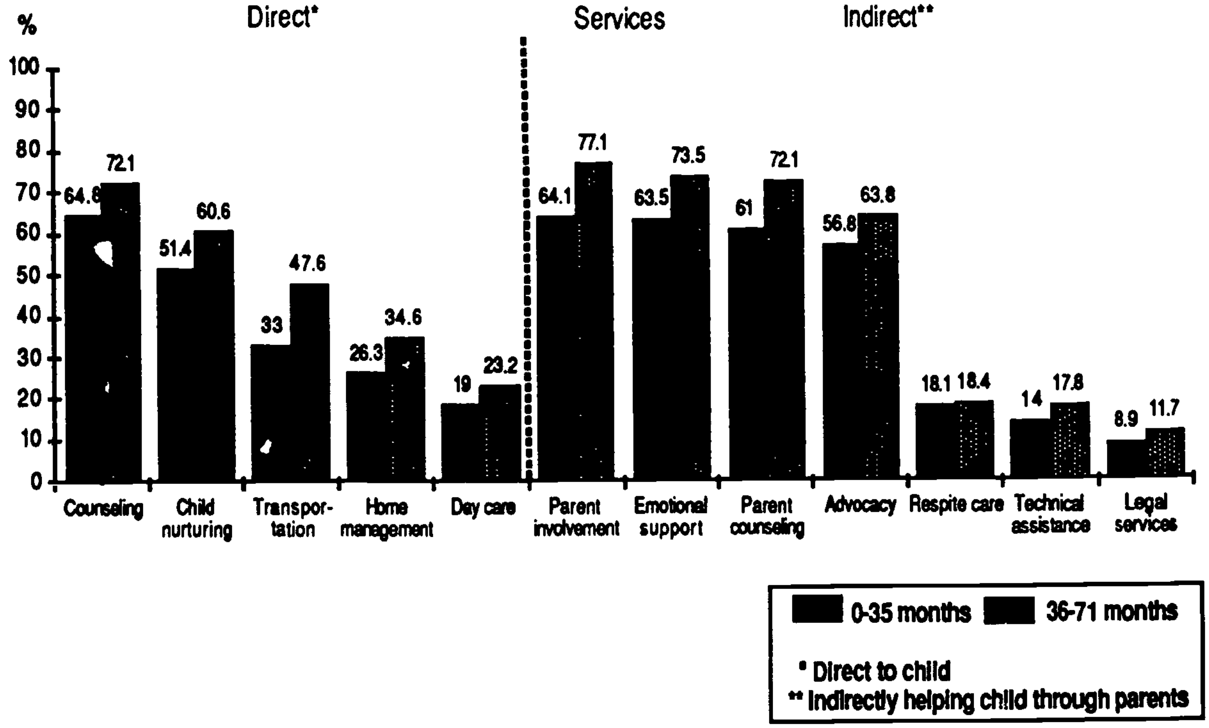


Figure 3c

Summary of Respondents Who Stated Their Agency has Services (Other)



When examining the range of services offered within each age group, a considerable range is shown in the direct and indirect medical categories and in the direct and indirect other categories. Certain medical and other services are offered least often to both age groups. For both age groups, the two least offered medical services are surgical corrections (9.2% and 11.1%) and well baby clinics (13% and 15.6%). Other services offered least often for both age groups are day care (19% and 23.2%) and legal services (8.9% and 11.7%).

A similar age-related pattern was found when looking at services that are offered most frequently. Ear/hearing medical services are offered most often to both age levels (54.3% and 62.9%). The other service that is offered most frequently to both age groups is counseling (64.8% and 72.1%).

Adequacy of services. Analysis of respondents' reports shows that agencies vary considerably in the frequency with which they offer the various categories of service. Respondents from agencies which offer a service also rated the adequacy of that service. Figures 4a, 4b, and 4c show the percentage of adequacy of the various services. Specific services are rank ordered within the service categories described in the "Frequency of services" section. Categories of service between top and bottom ranks are the same regardless of age.

Figure 4a

Summary of Respondents Who Stated Their Agency's Services are Adequate (Educational)

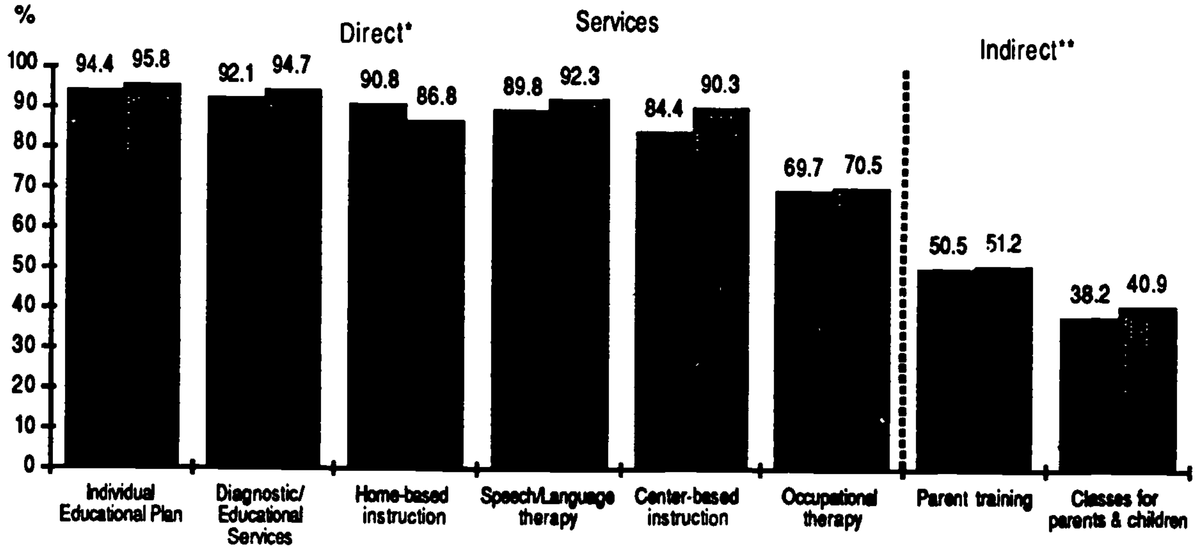
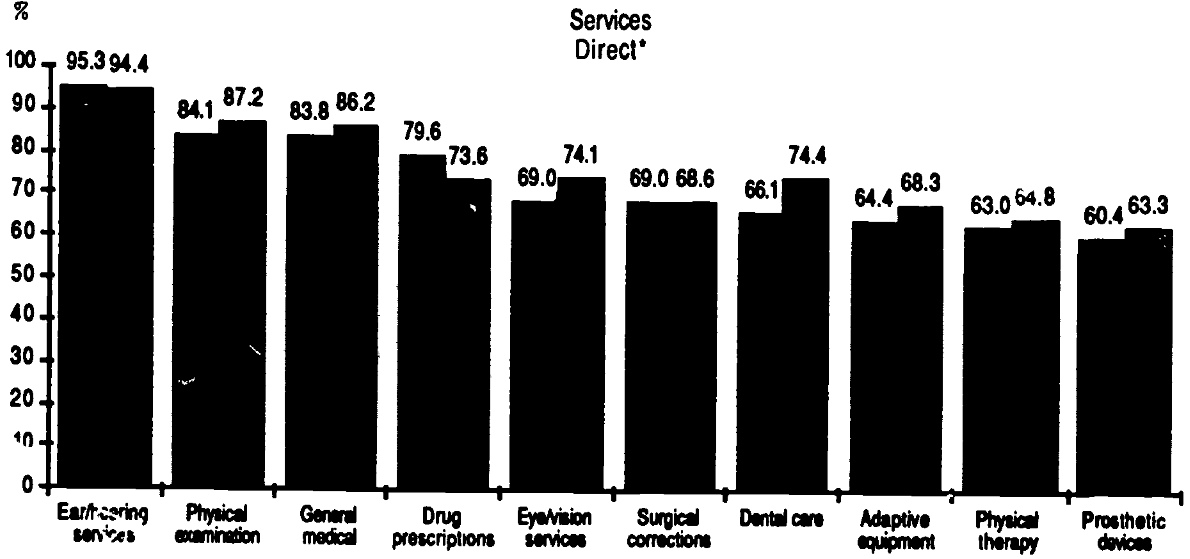


Figure 4b

Summary of Respondents Who Stated Their Agency's Services are Adequate (Medical)



■ 0-35 months ■ 36-71 months

* Direct to child

** Indirectly helping child through parents

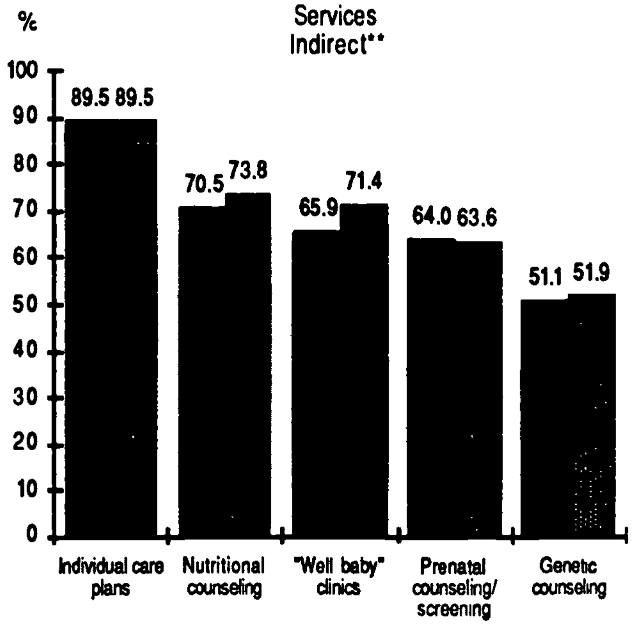
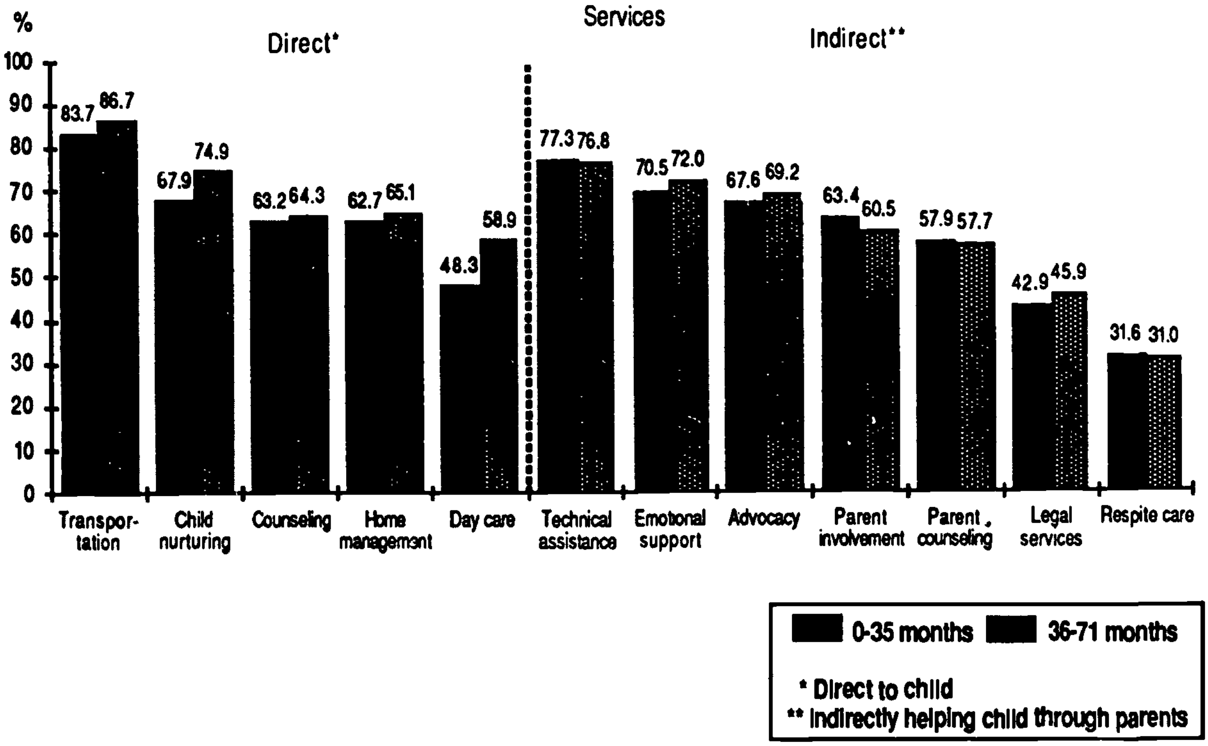


Figure 4c

Summary of Respondents Who Stated Their Agency's Services are Adequate (Other)



Several services were perceived by less than 50% of the respondents as adequate. They are day care for children less than 36 months; and for both age groups, classes for parents and children, legal services, and respite care. For both age groups, genetic counseling, parent training, and parent counseling were reported as adequate by 50 to 60% of the respondents and are also appropriate targets for concerned scrutiny.

Frequency and adequacy differences between age groups. Two statistics were used to estimate average respondent feelings about the differences between services for children younger than 36 months and services for children older than 35 months. The first statistic, offering differential, is the difference between the percent of respondents for each age group that indicated that their agency offers a particular service. The second statistic, the adequacy differential, is the difference between adequacy percentages for the two age groups. Table 4 shows whether the differences between availability and adequacy of each service for the younger age group is more, the same, or less than for the older age group.

Table 4

Adequacy and Availability Differences Between Services for Children Birth through 35 Months and for Children 36 through 72 Months

	ADEQUACY		
AVAILABILITY	Less	Same	More
More		Adaptive equipment, Nutritional, Physical exam, Transportation*, Classes for parents & children, Diagnostic educational*, Speech/language, Home management, General medical, Behavior management*, Advocacy, Emotional support*, Individual Education Plan*, Counseling, Occupational therapy, Parent training, Parent counseling*, Ear/hearing, Individual care plans, Parent involvement*	Dental care Child nurturing Center-based instruction* Eye/vision
Same	Drug prescriptions	Legal services Prosthetic device Physical therapy Genetic counseling Prenatal counseling & screening Surgical corrections Respite care Home-based instruction Technical assistance	Day care** Well-baby clinic
Less			

* Greater than 10-point availability difference for children more than 36 months

** Greater than 10-point adequacy difference for children more than 36 months

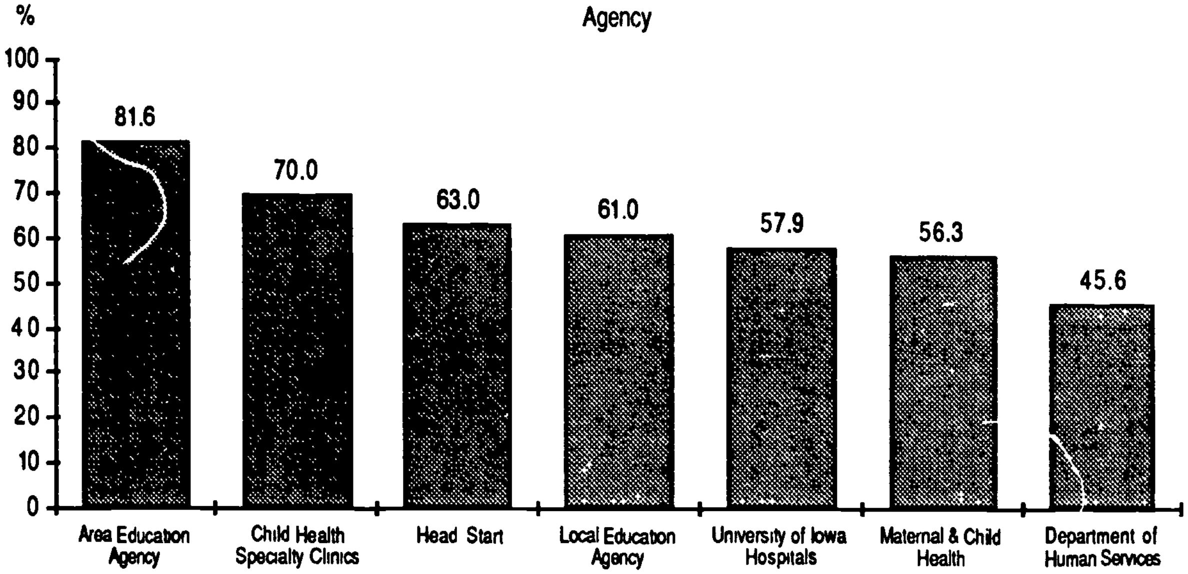
Regardless of the statistic used, one thing is clear: the older child with special needs is perceived to be better served. A considerably lower percent of respondents noted that their agency offers services to the younger child; a considerably lower percent of respondents reported adequacy of services offered to the younger child. This trend is reversed for only two services — drug prescriptions and respite care — and the difference is minor.

Tracking Systems

Respondents were asked to indicate which of seven major agencies have tracking systems and to rank the functioning of the tracking system. *Tracking system* was defined as "the means of following the progress of a young child with special needs within an agency, from agency to agency, and over time." The percentage of respondents who rated tracking systems either 'very effective' or 'effective' is shown in Figure 5.

Figure 5

Percentage of Respondents Who Rate Tracking Systems "Very Effective" to "Effective"



In general, respondents did not know about the existence of tracking systems in Iowa. For six of the seven agencies, the most frequent response was 'do not know.' (A nonresponse for either the agency's existence or the quality of the tracking system was also considered as 'do not know.') It appears that information about tracking systems is not used and/or not widely disseminated within the State.

The responses from professionals who did feel they knew something about agency tracking systems led to the placement of the seven agencies in one of three groups: (a) highest perceived effectiveness (82% of respondents), (b) medium perceived effectiveness (58 to 70% of respondents), and (c) lowest perceived effectiveness (46% of respondents). Percent was determined by combining percentage of respondents in the two top categories for each agency. AEAs are in the top group with the only rating in the effective range; DHS is in the bottom group; and the other five agencies are in the middle group.

Eighty-five respondents made suggestions for improving tracking systems. One-third of the suggestions relate to improvements in efficiency (e.g., eliminate duplication and inconsistency). Almost one-half of the suggestions call for increases in the quantity and quality of interagency communications (e.g., quicker communication, ongoing communication). The remaining responses fall in the other category. Among the specific actions mentioned were: (a) "assuring ongoing communication between sending and receiving teams during a case transfer between agencies" and (b) "maintaining a master data base of all children with special needs." Five respondents suggested that tracking systems would improve if one agency were in charge of records and evaluation of services.

Professional Training Needs

To find out what professionals know about topics pertaining to young children with special needs and how much they want to learn, respondents were asked to assign a score (from 1 to 5) to (a) their present knowledge of a given topic and (b) their desire to learn more about that same topic or area.

Table 5

Training Areas Listed by Descending Discrepancy Between Knowledge and Desire to Learn

Category	Content	Knowledge	Desire to Learn	Discrepancy
Teaching	Working with visually impaired children	2.4	3.6	1.2
Development	Funding & legislation for handicapped	2.5	3.6	1.1
Teaching	Managing behaviorally disordered children	3.1	4.0	0.9
Medical	Understanding genetic influences & handicaps	3.0	3.9	0.9
Support Service	Locating services for medically fragile children	3.0	3.9	0.9
Teaching	Working with hearing impaired children	2.7	3.6	0.9
Support Service	Knowing research in early childhood	3.0	3.8	0.8
Support Service	Finding & coordinating services of professionals & agencies	3.0	3.8	0.8
Medical	Adapting equipment to meet special needs	2.7	3.5	0.8
Medical	Feeding & positioning young children with special needs	2.7	3.4	0.7
Medical	Identifying dental & nutritional needs of young children with special needs	2.7	3	0.7
Support Service	Understanding single parent & step parent issues	3.2	3.8	0.6
Support Service	Knowing which services are available in community	3.5	4.0	0.5
Support Service	Working with parent groups	3.2	3.7	0.5
Support Service	Planning family involvement activities	3.1	3.6	0.5
Medical	Using first aid & CPR techniques	3.2	3.6	0.4
Management	Conducting program evaluation	3.0	3.4	0.4
Development	Knowing how language develops & how to help	3.4	3.7	0.3
Teaching	Managing & organizing learning environment	3.3	3.6	0.3
Teaching	Setting limits, discipline & behavior management	3.6	3.9	0.3
Development	Understanding methods aiding social development	3.5	3.8	0.3
Development	Assessing young children with special needs	3.5	3.8	0.3
Teaching	Collecting & analyzing progress data	3.2	3.5	0.3
Support Service	Getting the most out of professional conferences	3.5	3.7	0.2
Teaching	Developing & adapting curricula for individual needs	3.4	3.6	0.2
Development	Understanding intelligence tests & evaluation	3.4	3.6	0.2
Support Service	Teaching parents to work with own child	3.7	3.9	0.2
Management	Leading & managing groups	3.2	3.4	0.2
Management	Explaining handicaps to children, relatives & others	3.6	3.7	0.1
Management	Meeting with team members & families concerning infants	3.4	3.5	0.1
Management	Working with aides & volunteers to develop their skills	3.3	3.4	0.1
Management	Being a case manager	3.1	3.2	0.1
Management	Working & cooperating with other agencies	3.7	3.7	0.0
Teaching	Identifying functional & age-appropriate activities	3.7	3.7	0.0
Development	Screening young children	3.6	3.6	0.0
Teaching	Providing the least restrictive environment for young children with special needs	3.6	3.6	0.0
Teaching	Implementing learning activities with individual children	3.5	3.5	0.0
Support Service	Communicating with family members about their own needs	3.4	3.4	0.0
Development	Understanding the effects of stimulation on young children	3.8	3.7	-0.1
Development	Knowing how infants develop normally	3.8	3.7	-0.1

Areas were categorized as follows: teaching, development, medical, support services, management, and case manager. (See Table 5 for specific training topics within each area.) The information was analyzed in two ways: (a) difference between 'how much know' and 'desire to learn' and (b) level of 'desire to learn.' Table 5 lists the areas in descending order of the difference between the average rating of 'how much know' and average rating of 'desire to learn.' A high level of difference can be interpreted as, on the average, a respondent need for training in that area. For example, respondents have some knowledge (2.4 on a scale of 1 to 5) in working with children with visual impairments and want to learn more (3.6 on a scale of 1 to 5); therefore, since knowledge is somewhat low and desire to learn is relatively high, respondents need training in the area of working with children with visual impairments.

A comparison of the top and bottom areas on the list in Table 5 shows that two of the bottom topical areas are areas that have been addressed within the last few years. For example, least restrictive environment and screening are pertinent ongoing issues in services for young children with special needs. Management items dominate the bottom third of the list, while medical items are the top third. Teaching items are dispersed evenly throughout the list.

Desire to learn is important when planning adult training. Table 6 lists the areas in order of decreasing desire to learn. Areas with checks are not only needed, but are also areas about which respondents showed a high (in the upper third) desire to learn.

Table 6

Training Areas Listed in Descending Order of Desire to Learn

Category	Content	Knowledge	Desire to Learn	Discrepancy
Teaching	Managing behaviorally disordered children	3.1	**4.0**	0.9 √
Support Service	Knowing which services are available in community	3.5	**4.0**	0.5 √
Support Service	Locating services for medically fragile children	3.0	**3.9**	0.9 √
Medical	Understanding genetic influences & handicaps	3.0	**3.9**	0.9 √
Teaching	Setting limits, discipline & behavior management	3.6	**3.9**	0.3
Support Service	Teaching parents to work with own child	3.7	**3.9**	0.2
Support Service	Finding & coordinating services of professionals & agencies	3.0	**3.8**	0.8 √
Support Service	Knowing research in early childhood	3.0	**3.8**	0.8 √
Support Service	Understanding single parent and step parent issues	3.2	**3.8**	0.6 √
Development	Understanding methods aiding social development	3.5	**3.8**	0.3
Development	Assessing young children with special needs	3.5	**3.8**	0.3
Support Service	Working with parent groups	3.2	**3.7**	0.5
Development	Knowing how language develops & how to help	3.4	**3.7**	0.3
Support Service	Getting the most out of professional conferences	3.5	**3.7**	0.2
Management	Explaining handicaps to children, relatives & others	3.6	**3.7**	0.1
Management	Working & cooperating with other agencies	3.7	**3.7**	0.0
Teaching	Identifying functional & age-appropriate activities	3.7	**3.7**	0.0
Development	Understanding the effects of stimulation on young children	3.8	**3.7**	-0.1
Development	Knowing how infants develop normally	3.8	**3.7**	-0.1
Teaching	Working with visually impaired children	2.4	**3.6**	1.2 √
Development	Funding & legislation for handicapped	2.5	**3.6**	1.1
Teaching	Working with hearing impaired children	2.7	**3.6**	0.9 √
Support Service	Planning family involvement activities	3.1	**3.6**	0.5
Medical	Using first aid & CPR techniques	3.2	**3.6**	0.4
Teaching	Managing & organizing learning environment	3.3	**3.6**	0.3
Development	Understanding intelligence tests & evaluation	3.4	**3.6**	0.2
Teaching	Developing & adapting curricula for individual needs	3.4	**3.6**	0.2
Development	Screening young children	3.6	**3.6**	0.0
Teaching	Providing the least restrictive environment for young children with special needs	3.6	**3.6**	0.0
Medical	Adapting equipment to meet child's needs	2.7	**3.5**	0.8
Teaching	Collecting & analyzing progress data	3.2	**3.5**	0.3
Management	Meeting with team members & families regarding infants	3.4	**3.5**	0.0
Teaching	Implementing learning activities with individual children	3.5	**3.5**	0.0
Medical	Identifying dental & nutritional needs of young children with special needs	2.7	**3.4**	0.7
Medical	Feeding & positioning young children with special needs	2.7	**3.4**	0.7
Management	Conducting program evaluation	3.0	**3.4**	0.4
Management	Leading & managing groups	3.2	**3.4**	0.2
Management	Working with aides & volunteers to develop their skills	3.3	**3.4**	0.1
Support Service	Communicating with family members about their own needs	3.4	**3.4**	0.0
Management	Being a case manager	3.1	**3.2**	0.1

√ High combined desire AND discrepancy (>4.4).

Table 7 presents the general categories (medical, support, teaching, etc.) in three ways: (a) knowledge of categories in descending order (development is greatest; medical is least); (b) desire to learn about each category (respondents desire more training in support services; minimal training in management); and (c) discrepancy between desire to learn (Column B) and present knowledge (Column A). The medical category has the greatest discrepancy; management has the least.

Table 7

Rank Order* of Training Categories by Knowledge (A), Desire to Learn (B), and Need (C=B-A)

Knowledge			Desire to Learn			Need (Desire - Knowledge)		
Category	Rank	Average**	Category	Rank	Average**	Category	Rank	Difference Average**
Development	1	3.44	Support	1	3.76	Medical	1	.72
Management	2	3.31	Development	2	3.70	Support	2	.49
Case Manager	2	3.31	Teaching	2	3.66	Teaching	2	.44
Support	2	3.27	Case Manager	3	3.59	Development	3	.31
Teaching	2	3.23	Medical	3	3.58	Case Manager	3	.29
Medical	3	2.87	Management	4	3.45	Management	4	.20

* Ranked according to >.05 difference
**Average on a scale from 1 to 5

If the categorical values for knowledge (Column A) and desire to learn (Column B) are both inspected, the support and teaching categories would be chosen as training topics because of high desire coupled with relatively low knowledge. The medical category has the greatest discrepancy but received a low ranking in desire for training, as shown in Column B. Management, development, and case manager categories are the least acceptable to professional respondents, as is indicated by inspecting Column C.

Inferential Analyses of Professional Responses

Inferential statistical procedures were applied to the professional survey data very selectively Because the number of potential analyses was greater than time would allow, the planning team (Clary, Cvach, & Hall) chose each analysis based upon its potential use in planning. Members of SPACES were encouraged, collectively and individually, to suggest changes in the analyses that the planning team chose to carry out.

Three questionnaire sections were chosen for further analysis: (a) parent participation, (b) services, and (c) personnel preparation. SPACES and the planning team decided to explore the possibility of significant differences among (a) agencies (DHS, AEA, DH, UIH), (b) occupational groups (teacher, social worker, etc.), and (c) occupational groups within agencies.

Further Analysis of Parent Participation

An overall evaluation of the breadth and responsiveness of an agency's parent program was derived by combining questions C1 and C2 of the professional survey. (See Appendix B for the complete questions.) In C1, the respondent checked the particular activities which are part of a respondent's agency's program. In C2, the respondent judged the degree to which parents are involved in agency decision making. These two items were combined so that more services and more parental input into decision making resulted in a high score. A combined score was derived for each respondent.

Scores varied from 0 to 150, with 0 being no services and no participation in decision making and 150 indicating that all services listed in C1 are offered and that there is very frequent parent participation in decision making. A one-way Analysis of Variance (ANOVA) of scores was computed for agency differences. Agency scores were found to be different at the .01 level. This conclusion allowed rank assignments. Table 8 summarizes the respondents' average scores and rank. Head Start and AEAs received the highest composite rankings. Agencies whose primary function is health achieved the lowest scores and rank.

Table 8

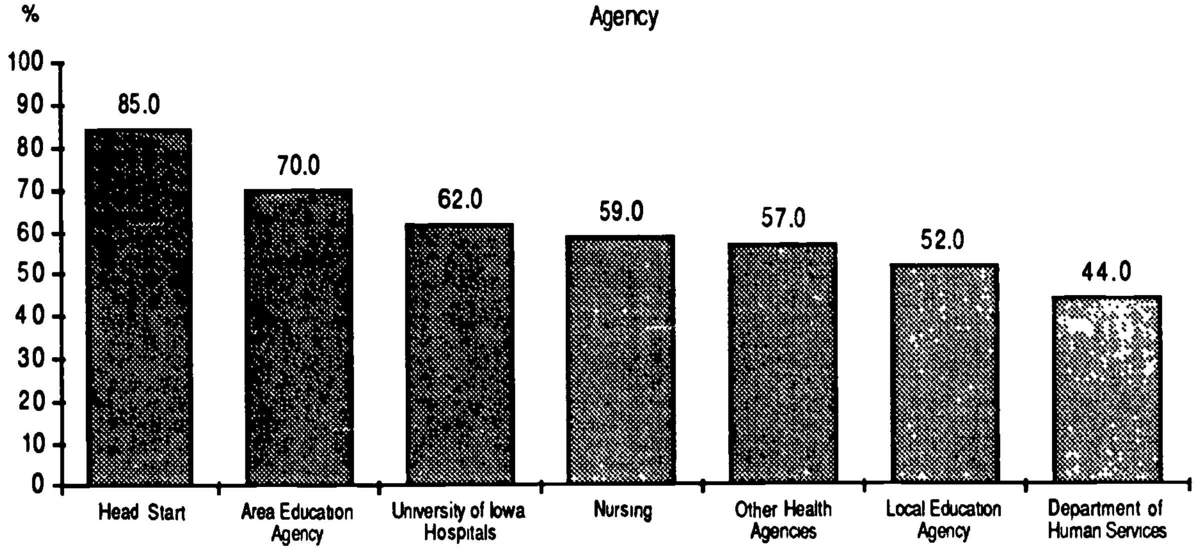
Rating and Ranking of Parent Agency Activities and Degree of Decision Making by Parents
(N=278)

Agency	# of Respondents	Average Score (0 to 150)	Rank
Head Start	33	107.3	1
Area Education Agency	138	98.2	2
Local Education Agency	31	75.4	3
Department of Human Services	39	71.1	3
Other Health Agencies	7	60.7	4
University of Iowa Hospital Schools	13	58.7	4
Nursing Agencies	17	57.6	4

Respondents were also asked to evaluate their agency's parent program by indicating their satisfaction with their agency's program. Respondents' answers varied considerably, depending upon their employing agency. The percentage of respondents who are 'very satisfied' or 'satisfied' with their agency's parent program is indicated in Figure 6. Satisfaction with an agency's parent program varies from 44% (DHS) to 85% (Head Start).

Figure 6

Percentage of Respondents Who are "Very Satisfied" or "Satisfied" with Their Agency's Parent Program



The results shown in Table 8 and Figure 6 probably reflect both the differing philosophies and differing service delivery systems of the agencies and groups which respondents represent. For example, the high priority given to parent participation by Head Start programs is suggested by its high ranking.

Further Analysis of Services

Items were grouped into three clusters: (a) parent services, (b) direct educational services, and (c) direct medical services. Cluster averages (0 = no service, 1 = service but needs improvement, 2 = adequate service) were compared among agencies. Respondents perceive four agencies (DHS, other health, LEA, HS) as having less frequent and less adequate services for children of any age. Self-rating showed University of Iowa Hospitals and AEA respondents to be most satisfied with their own agency's service.

The difference between perceptions of services offered to the two age groups was divided into three components. Discrepancies were calculated by determining the difference between a respondent's age level scores in each of three areas: (a) direct educational, (b) direct medical, and (c) parent. These statistics were calculated for each respondent and further analyzed using Multivariate Analysis of Variance (MANOVA) procedures. Table 9 presents the discrepancy figures.

Table 9

Average Agency Discrepancies
Between Services for Children Birth through 35 Months
and for Children 36 through 72 Months

Service	Agency						
	Head Start	Local Education Agency	University of Iowa Hospitals	Area Education Agency	Department of Services	Other Health Agencies	Nursing Agencies
Parent	18.40	4.36	.05	-.35	-.53	-.30	-.58
Educational	11.39	4.00	-.05	-.19	-.02	-.10	-.58
Medical	7.42	2.30	.05	-.15	-.11	.00	.00
ALL	37.21	10.64	.05	-.70	-.67	-.40	-1.15

Attention was next focused upon a respondent's perception of discrepancy between his/her agency's services to children younger than 36 months and children older than 35 months. For each respondent, items were classified in two ways: by age and by type of service (parent, educational, medical). A total score was derived for each age group and each type of service. The 'younger than 36 months' total was subtracted from the 'older than 35 months' total. This difference serves as the measure of respondent perception of discrepancy between services to the two age groups. The data demonstrate that respondents perceive agencies as differing strongly in services to children younger than 36 months and in services to children older than 35 months. Most notable are the discrepancies that exist in parent and educational services within LEAs and Head Start.

The high Head Start discrepancy can be attributed to regulations under which Head Start functions. Head Start may not serve children who are younger than 36 months. The extensive movement of AEAs into the delivery of services to children younger than 36 months is reflected in its low total discrepancy score, while LEAs serve children older than 36 months. Health-related agencies have not normally discriminated between these two age groups, with health services being available to all ages.

Further Analysis of Personnel Preparation

In order that professional training needs could be determined, respondents were asked to consider training topics (e.g., counseling parents) in two ways. First, respondents were asked to assess (5 being a high score) their present knowledge of the topic. Second, they were to determine their desire for further training in that area (again, 5 being a high score). Finally, a third score was created from the first two responses. A respondent's 'know' score was subtracted from the respondent's 'want' score for each item. This score was seen as a measure of readiness for training. The higher the difference, the more the respondent would be ready to accept training while still having a high need for training in the skill.

Six clusters (categories) were created to simplify analysis of the responses to the forty skill items. Those clusters were: development, management, medical, support, teaching, and case management. Items from the first five groups created the case management cluster. Table 5 identifies specific training topics within each category. The averages of group responses, by agency and by role group, are presented in Figures 7a, 7b, 8a, 8b, 9a, 9b, 10a, 10b, 11a, 11b, 12a, and 12b.

Figure 7a

Knowledge of and Desire for Training in Development Issues (Agencies)*

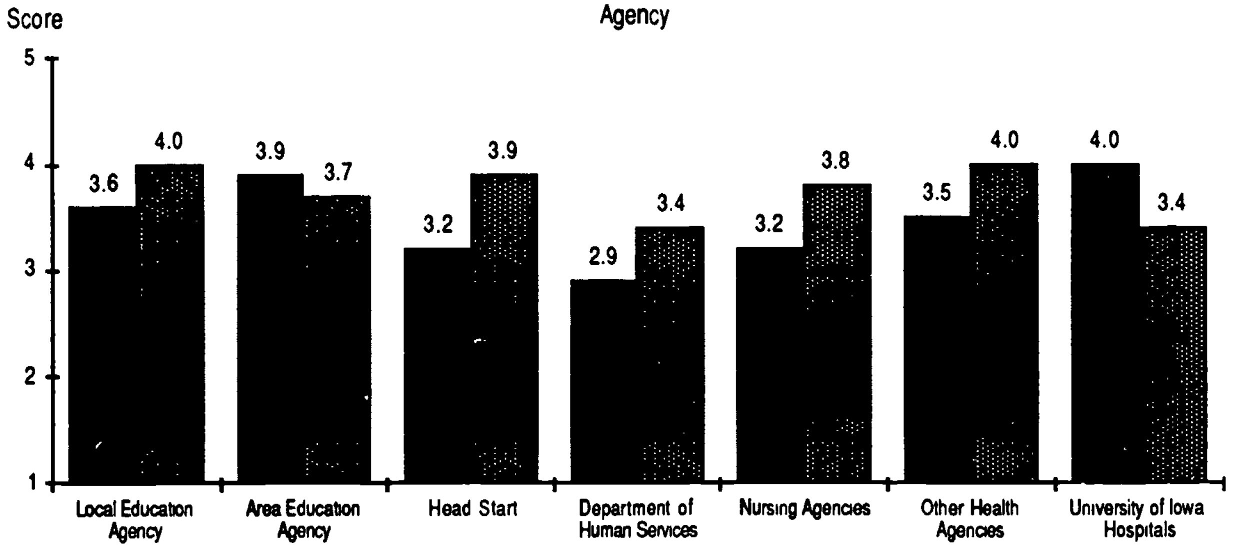


Figure 7b

Knowledge of and Desire for Training in Development Issues (Role Groups)*

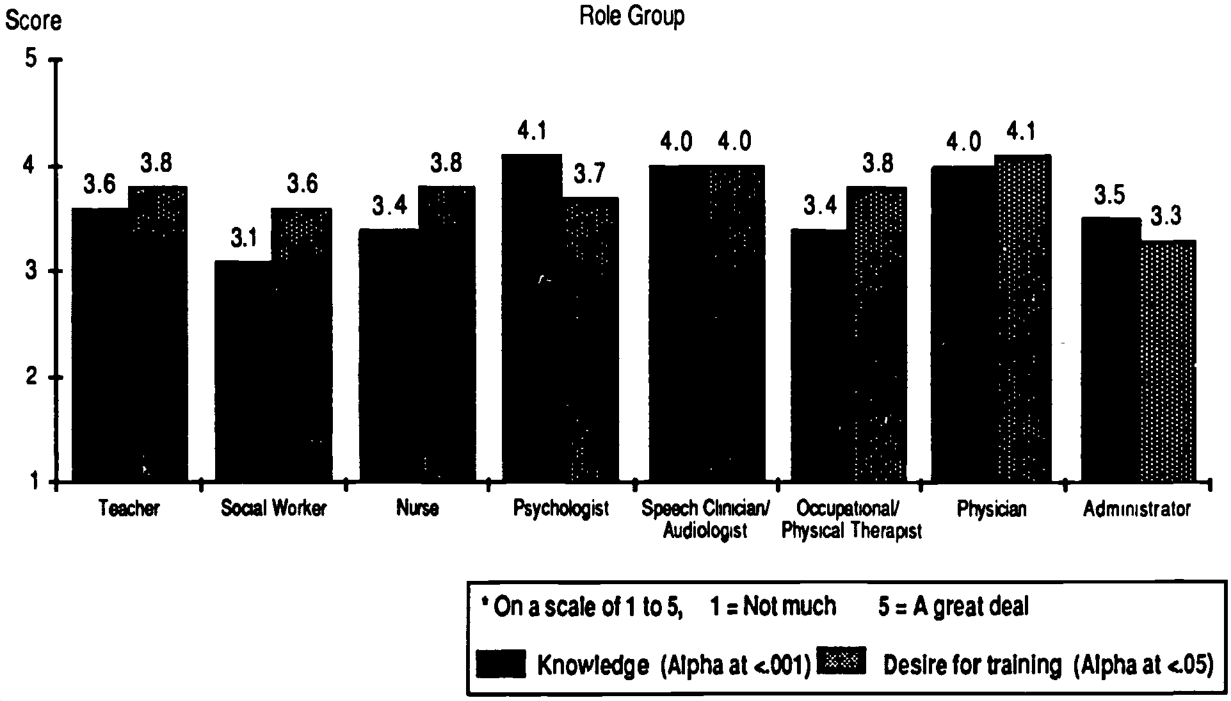


Figure 8a

Knowledge of and Desire for Training in Management Issues (Agencies)*

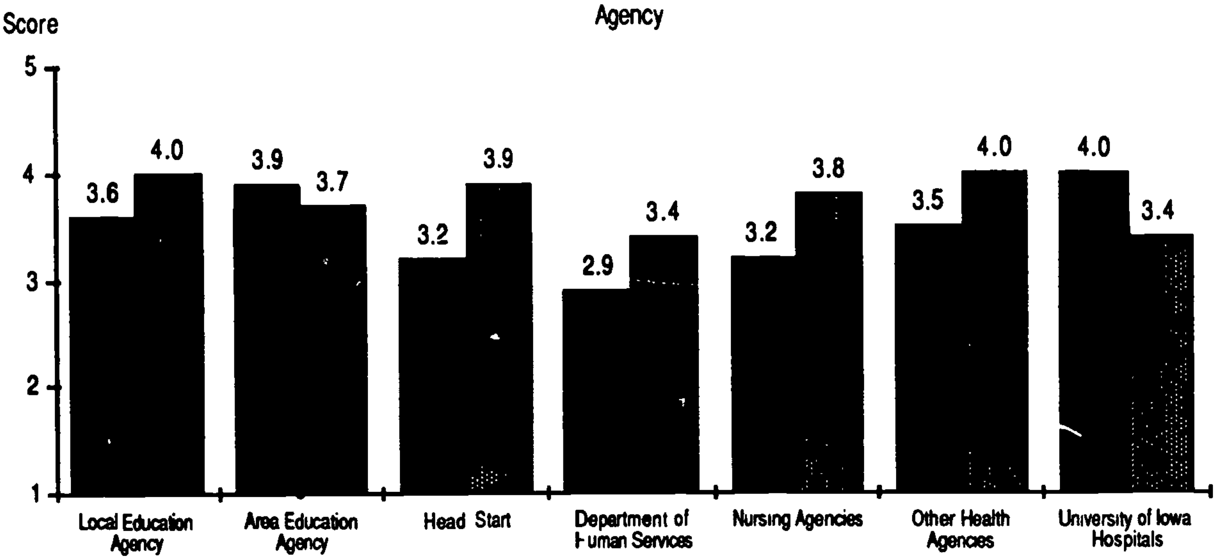
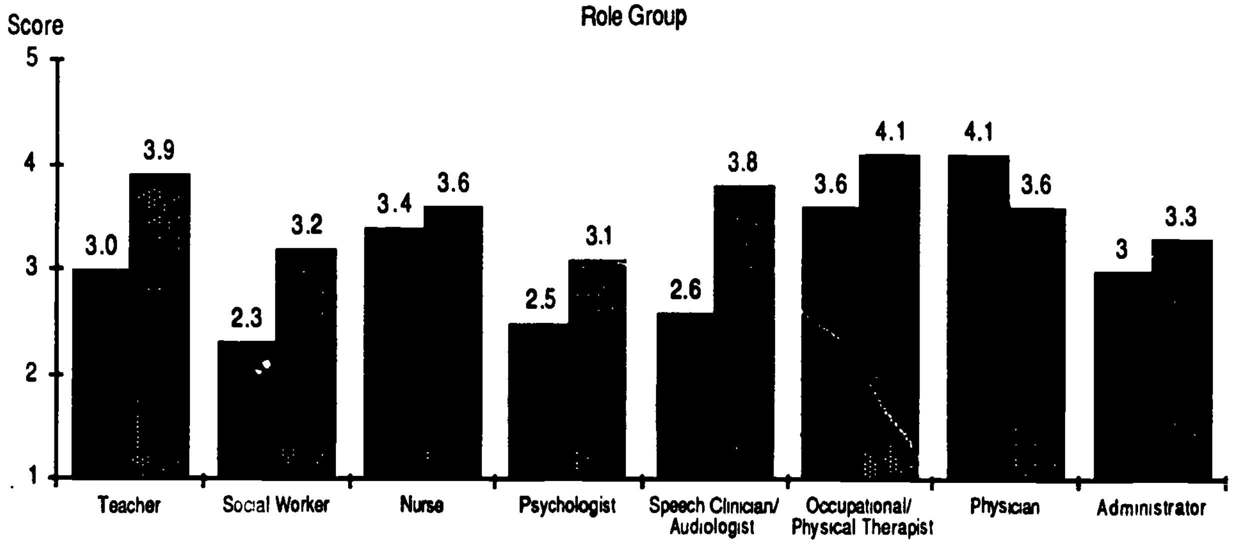


Figure 8b

Knowledge of and Desire for Training in Management Issues (Role Groups)*



* On a scale of 1 to 5, 1 = Not much 5 = A great deal

■ Knowledge (Alpha at <.01) ■ Desire for training (Alpha at <.05)

Figure 9a

Knowledge of and Desire for Training in Medical Issues (Agencies)*

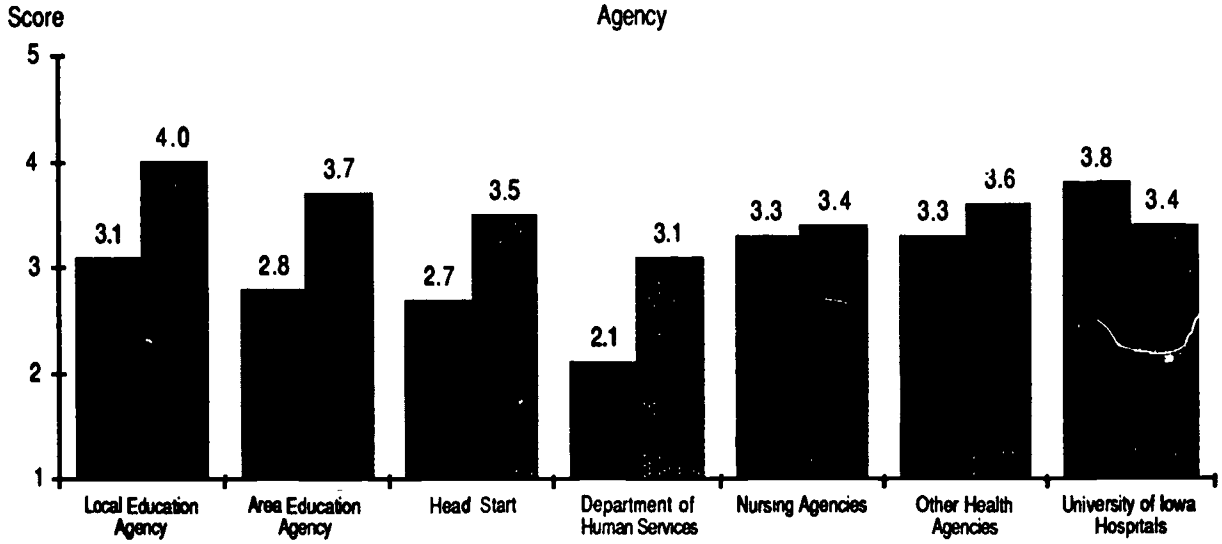
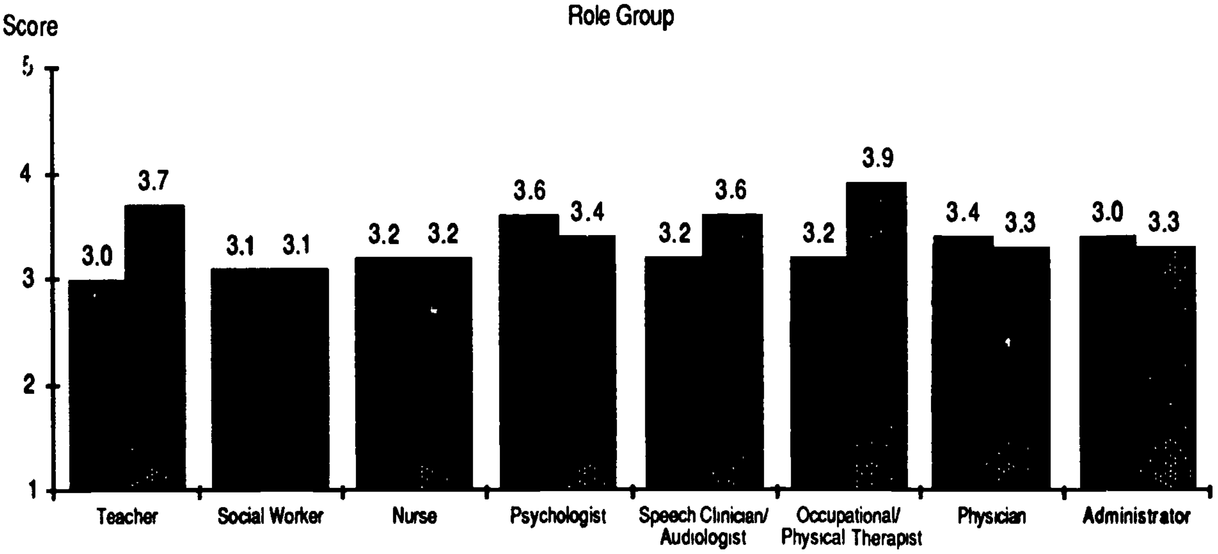


Figure 9b

Knowledge of and Desire for Training in Medical Issues (Role Groups)*



* On a scale of 1 to 5, 1 = Not much 5 = A great deal

■ Knowledge (Alpha at <.001) ■ Desire for training (Alpha at <.05)

Figure 10a

Knowledge of and Desire for Training in Support Issues (Agencies)*

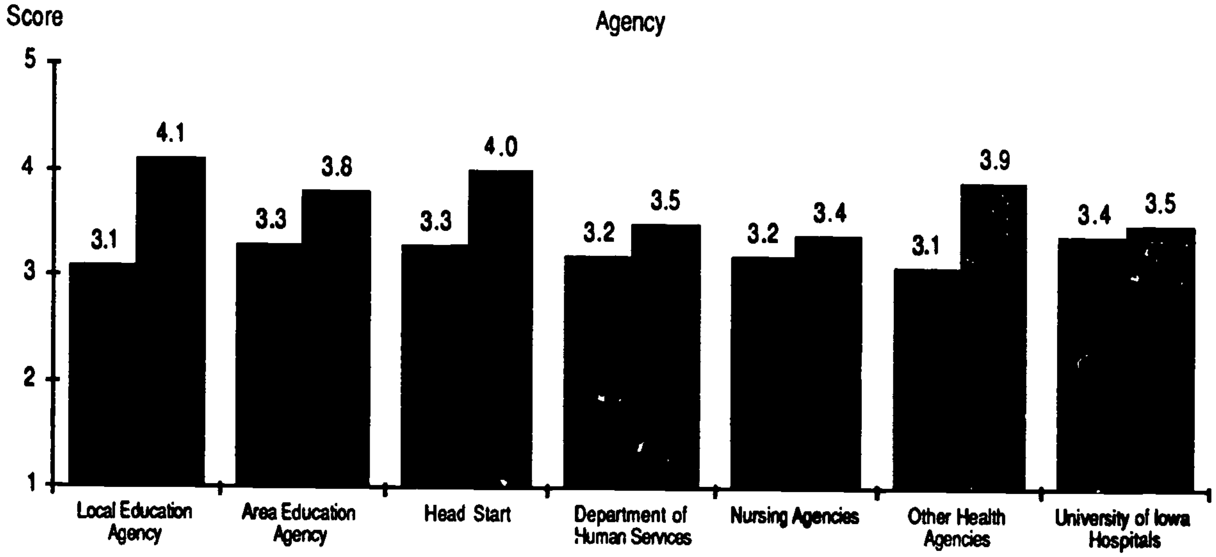
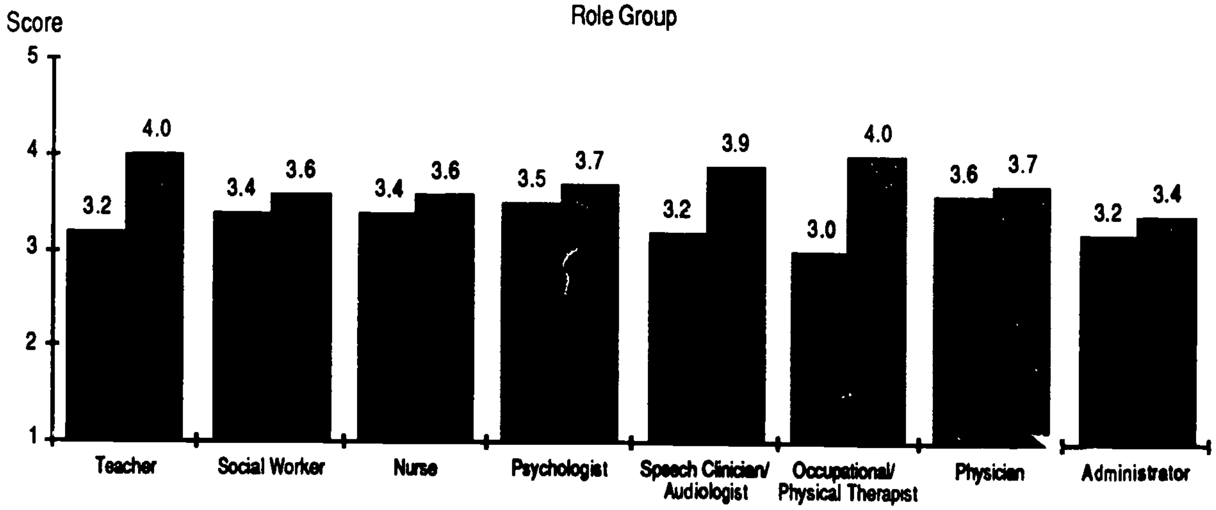


Figure 10b

Knowledge of and Desire for Training in Support Issues (Role Groups)*



* On a scale of 1 to 5, 1 = Not much 5 = A great deal

■ Knowledge (Alpha at >.05) ■ Desire for training (Alpha at <.05)

Figure 11a

Knowledge of and Desire for Training in Teaching Issues (Agencies)*

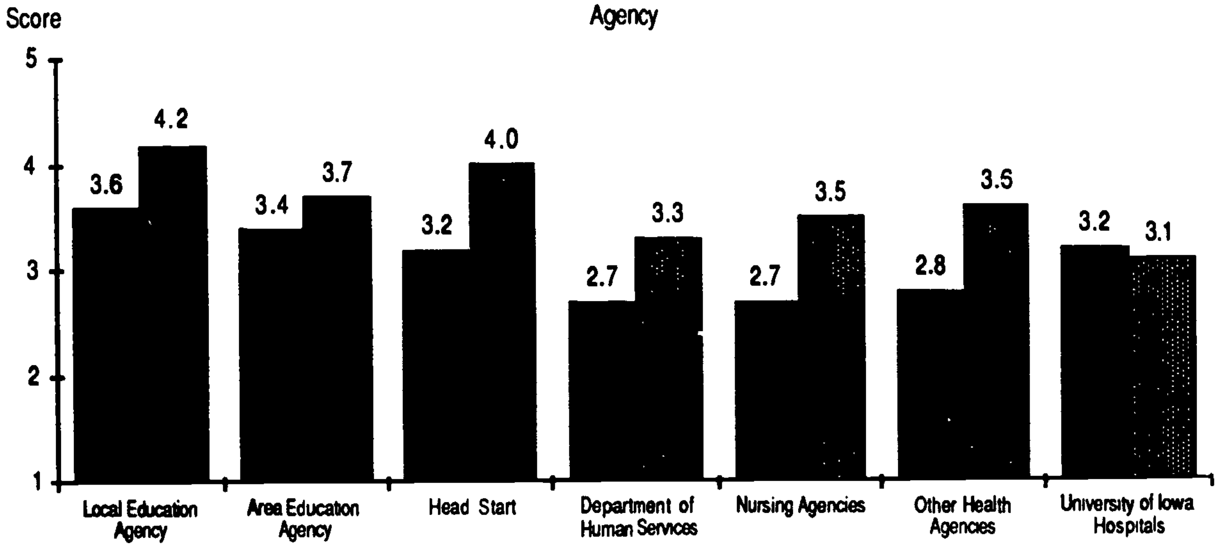
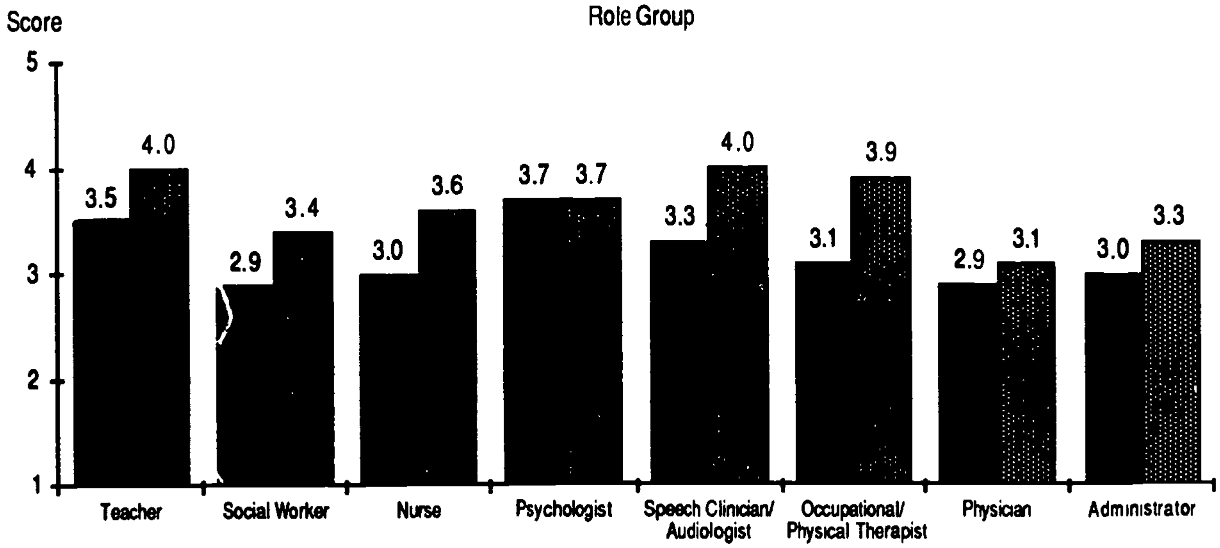


Figure 11b

Knowledge of and Desire for Training in Teaching Issues (Role Groups)*



* On a scale of 1 to 5, 1 = Not much 5 = A great deal

■ Knowledge (Alpha at >.001) ■ Desire for training (Alpha at <.001)

Figure 12a

Knowledge of and Desire for Training in Case Management Issues (Agencies)*

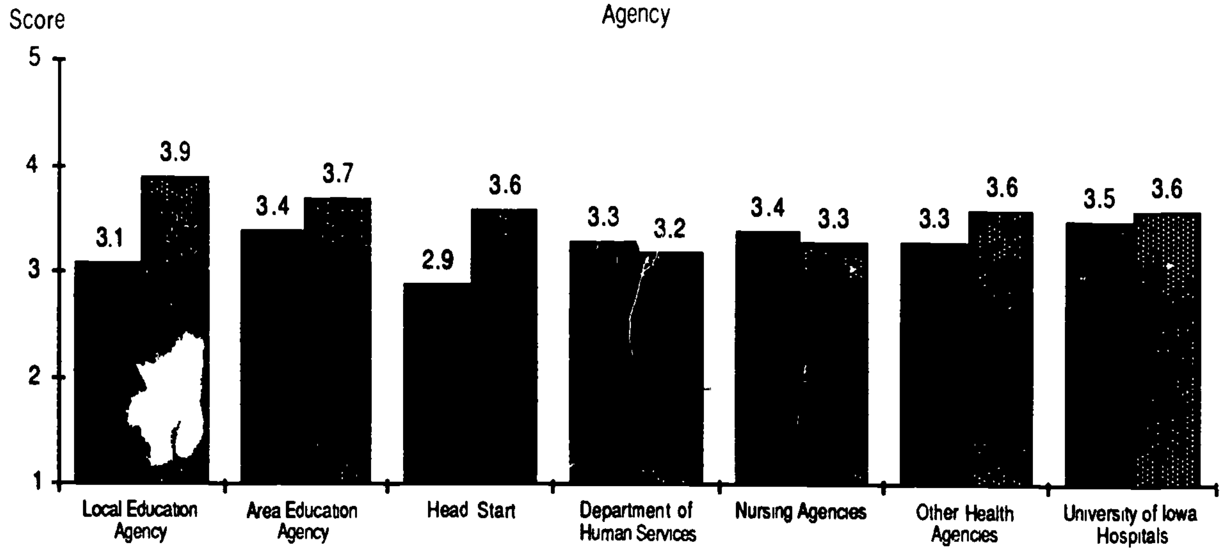
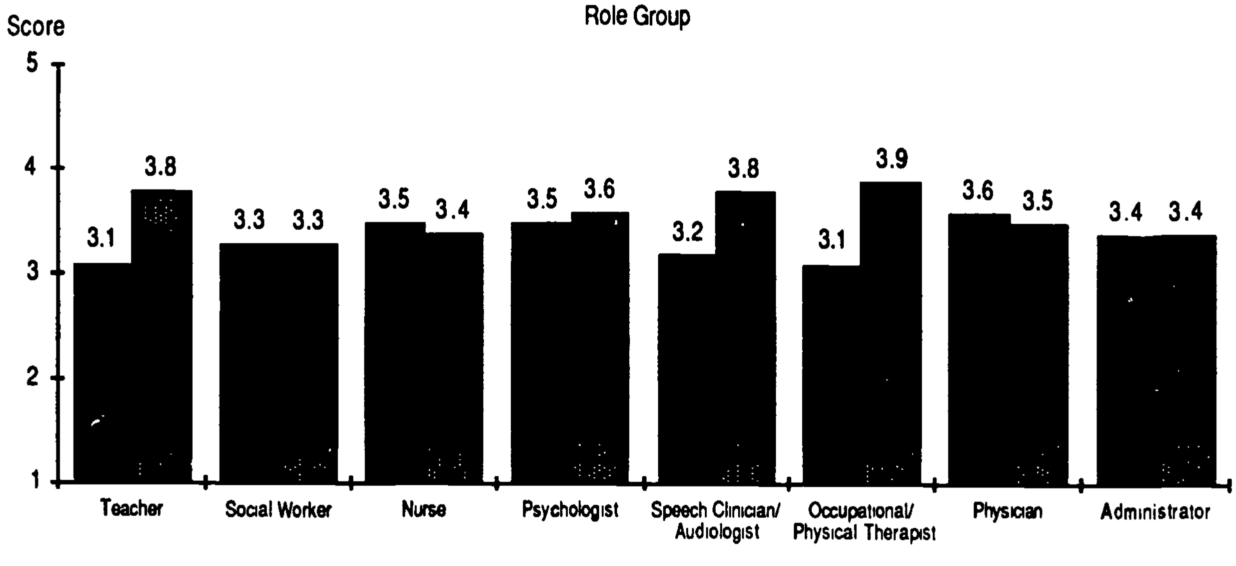


Figure 12b

Knowledge of and Desire for Training in Case Management Issues (Role Groups)*



* On a scale of 1 to 5, 1 = Not much 5 = A great deal

■ Knowledge (Alpha at <.01) ■ Desire for training (Alpha at >.05)

Occupational groups (i.e., teachers, occupational therapists, doctors, etc.) and agencies (i.e., AEAs, Head Start, DHS, etc.) clearly differ on the three aspects of training. More specifically, respondents differ on an agency-by-agency and occupation-by-occupation basis in their knowledge, desire for further training, and need for training. Tables 10 and 11 list the rank order of need for training according to agencies and professional groups.

Table 10

Training Needs Ranked Within Agencies*

Category	Agency						
	Local Education Agency	Area Education Agency	Head Start	Department of Human Services	Nursing Agencies	Other Health Agencies	University of Iowa Hospitals
Development	2	4	1	2	2	1	2
Management	1	3	1	4	3	3	1
Medical	1	1	1	1	3	3	2
Support	1	2	1	3	3	1	1
Teaching	2	3	1	2	1	1	1
Case Management	1	3	1	4	4	2	1

1 = high 4 = low
* Ranking level changes when more than .1 discrepancy among categories is found.

Table 11

Training Needs Ranked Within Professional Groups*

Category	Professional Group							
	Teacher	Social Worker	Nurse	Psychologist	Speech Clinician/ Audiologist	Occupational/ Physical Therapist	Physician	Administrator
Development	4	2	1	4	4	4	2	3
Management	2	3	3	3	3	3	2	2
Medical	1	1	3	1	1	3	3	1
Support	2	3	2	2	2	1	2	2
Teaching	3	2	1	3	2	2	1	1
Case Management	2	3	4	3	3	2	2	2

1 = high 4 = low
* Ranking level changes when more than .1 discrepancy among categories is found.

Inspection of Table 10 (agency ranking) allows several observations. First, among professionals in educational agencies (LEAs, AEAs) knowledge of development or teaching is least needed; while knowledge of medical, support, management. and case management skills seem most needed. Head Start personnel indicate a uniformly high need for training, regardless of area. While there is more divergence among health service agencies, it is clear that teaching and development are the most needed training areas among those agencies. Among those working for DHS or in public health satellite offices, management and case management skills are least needed. Among DHS employees, development, medical, and teaching are most needed areas.

In Table 11, comparison of professional groups' rankings also leads to some interesting observations. Nurses and social workers rank training in development areas highly. Medical skills are most needed by teachers, social workers, psychologists, speech clinicians/audiologists, and administrators. Nurses, physicians, and occupational and physical therapists need medical skills the least. Support skill training is most needed by occupational and physical therapists as well as teachers, nurses, psychologists, speech clinicians/audiologists, physicians, and administrators. Support skills are least needed by social workers. The teaching cluster is most needed by nurses, physicians, administrators, social workers, psychologists, and speech clinicians/audiologists. Teaching skills are least needed by teachers and psychologists. Case management skills are needed by teachers, occupational and physical therapists, physicians, and administrators. Social workers, nurses, psychologists, and speech clinicians/ audiologists need case management training the least.

Members of professional groups diagnose themselves as needing little training in their own core skill area and more training in other skill areas. The high need for training skills expressed by occupational and physical therapists and speech clinicians could be viewed as an exception since theirs is an instructional role, even if specialized and distinct. Tables 12 and 13 show, at a glance, what type of training agencies and groups desire. A '+' shows the highest ranking as given in Tables 10 and 11.

Table 12

Highest Category of Training Desired by Agencies

Category	Agency						
	Local Education Agency	Area Education Agency	Head Start	Department of Human Services	Nursing Agencies	Other Health Agencies	University of Iowa Hospitals
Development			+			+	
Management	+		+				+
Medical	+	+	+	+			
Support	+		+			+	+
Teaching			+		+	+	+
Case Management	+		+				+

Table 13

Highest Category of Training Desired by Professional Groups*

Category	Professional Group							
	Teacher	Social Worker	Nurse	Psychologist	Speech Clinician/ Audiologist	Occupational/ Physical Therapist	Physician	Administrator
Development			+					
Management								
Medical	+	+		+	+			+
Support						+		
Teaching			+				+	+
Case Management								

Phase II: Parent Descriptive Information

Of the 800 questionnaires sent out to parents, 229 were returned in time for inclusion in this report. Parent responses to the Needs Assessment questions are discussed in this section. Appendix C contains (a) the Needs Assessment questions, (b) frequency and percent results, (c) prose answers, and (d) parent comments. (See Appendix C for a further study of questions and responses.)

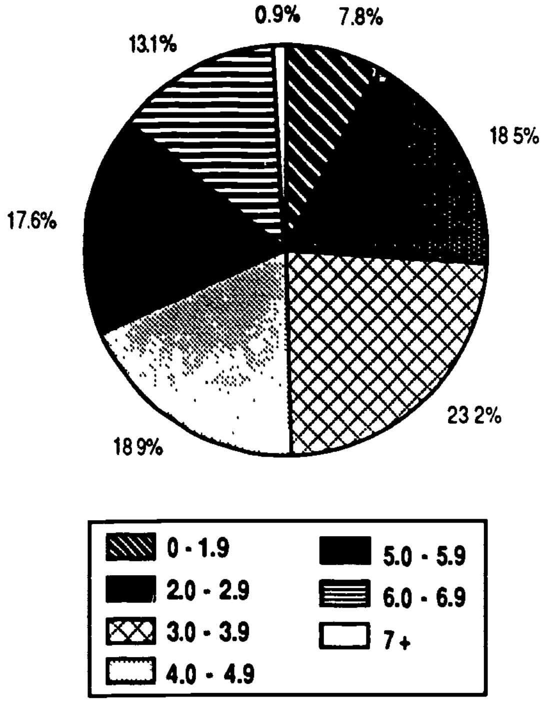
Characteristics of Those Who Responded

Two hundred sixteen mothers and sixty-one fathers responded. A survey returned by both mother and father of a child with special needs was counted only once. In these families, the mother's average age is 30.2 years and the father's average age is 33.2 years.

As shown in Figure 13, ages of the children whose parents participated in the survey are evenly distributed among the age ranges between one and 6.9 years.

Figure 13

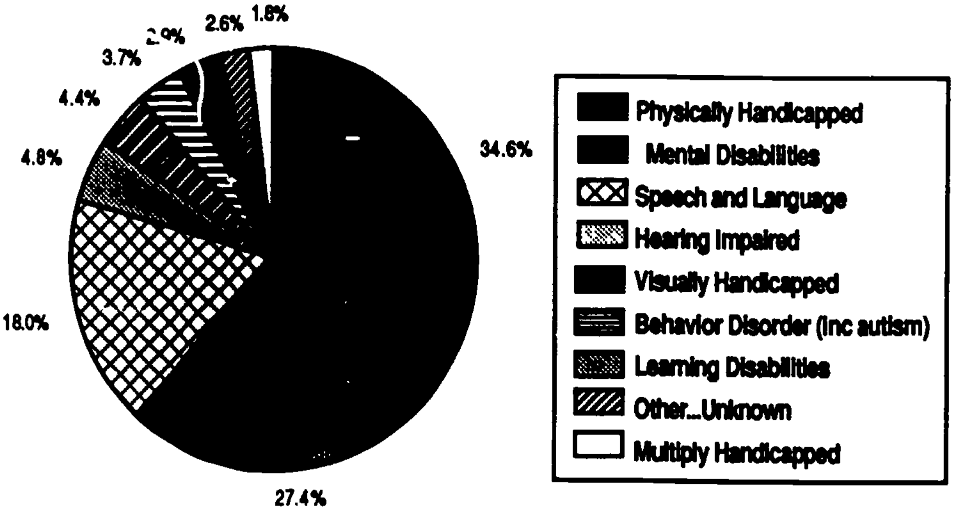
Children's Age Distribution by Percent (June/July 1986)
(N=228)



The distribution of handicaps indicated in Figure 14 shows a relatively high concentration of physical and mental disabilities with serious speech and language problems also showing significant concentration. The total of noted disabilities is greater than the total of children because 43 parents noted multiple handicaps. Of those parents, five noted more than two handicaps. The number of parents noting more than two disabilities is the number that is recorded for multiply handicapped in Figure 14.

Figure 14

Percentage of Child's Primary Handicap
(N=272)

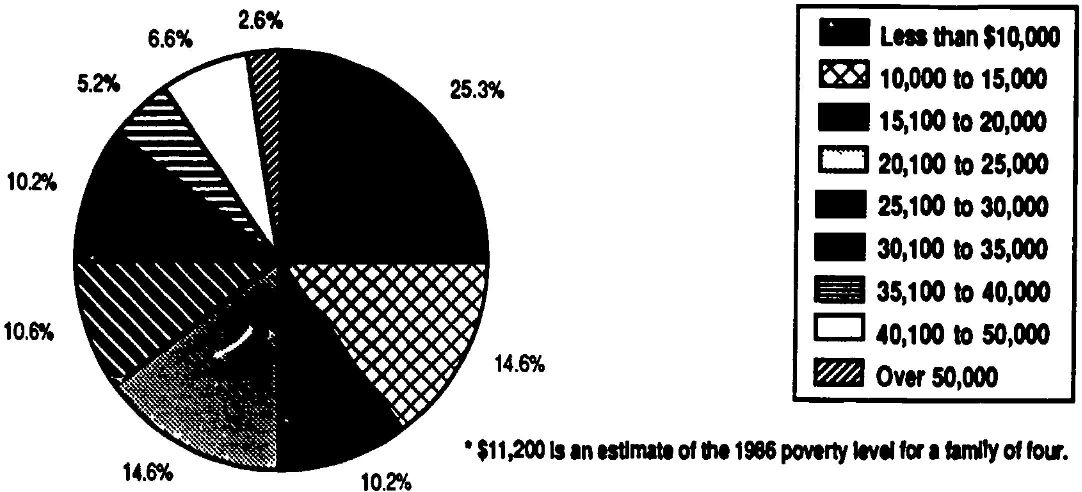


The onset of parental concern. More than twice as many parents worry that their child has a disability prior to some expert confirmation of its presence as parents who do not worry. The time between suspicion of problems and the actual receipt of services is roughly seven months. Presumably this time is divided between deciding to act and attempting to secure services. How the time is divided cannot be directly derived from the survey results.

Income distribution. Figure 15 details the income levels reported by the parents. One-fourth of the parents reported a family income of less than $10,000 dollars and one-half of the parents reported a family income of less than $20,000. $11,200 is an estimate of the 1986 poverty level for a family of four. These figures (one-fourth of the parents and one-half of the parents) are five and ten percent higher than national statistics of 1983. Inflation should have decreased the number of families at this income level since 1983.

Figure 15

Percentage of Income Distribution of Families Who Responded
(N=226)



* $11,200 is an estimate of the 1986 poverty level for a family of four.

** These figures (one quarter and one half) are five and ten per cent higher than national statistics of 1983. (Inflation should have decreased the number of families at this income level since that time.)

Access to Services

When parents first learn that their child has special needs they seek help from medical personnel, educators, physical therapists, occupational therapists, speech clinicians, or audiologists. Given the significant number of physical disabilities and speech and language problems, it is not surprising that one-third of the responding parents initially turned to physical and occupational therapists and speech clinicians. Regardless of whom they contacted, parent efforts did not always succeed. A significant percent (from 7 to 17) of their efforts met with failure. Table 14 shows both who was contacted and the percent of successful contacts.

Table 14

Percentage of Success When Services were First Sought
(Duplicated Count N=261)

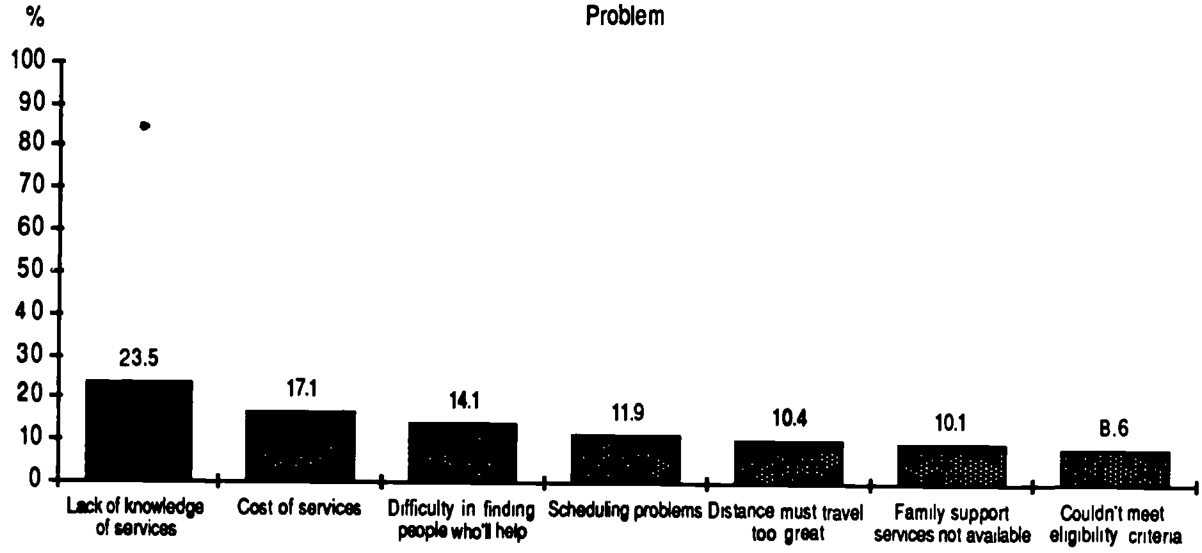
Role Group/Institution	# Looking	% Successful
Medical		
Home Nurse	57	79
Specialist	46	91
Family Doctor	30	80
Home Support		
Help with Care	8	63
Respite Care	3	0
Educational*		
Teacher	45	78
Home Intervention Teacher	39	90
Multi-categorical Preschool	33	94
Special Education Teacher	27	85
Child Development Program	16	94
Psychologist	12	100
Fiscal Support		
Supplemental Security Income	15	80
General	11	64
Support Services		
Physical Therapist	184	90
Speech Clinician	85	91
Occupational Therapist	51	86
Audiologist	27	100
Social Worker	10	90
Play Therapist	8	100
Behavioral Consultant	3	67
Parent Support		
Parent Support Groups	142	79
Family Counseling	12	75
Other Parent Groups	5	100
Mothers Groups	3	100
Pilot Parents	2	100
Psychiatrist	1	100

*Taken from unedited list provided by parents

Responses from the question, "What are the three most serious problems you have faced in trying to get services for your child and family?" suggested why parents might be unable to secure the services they sought. The most frequently mentioned cause of trouble is a lack of information about services for their child. Among other problems receiving most frequent mention are the cost of services and difficulty in finding people who can help. Figure 16 gives a more complete picture of the problems parents face in getting services for their child.

Figure 16

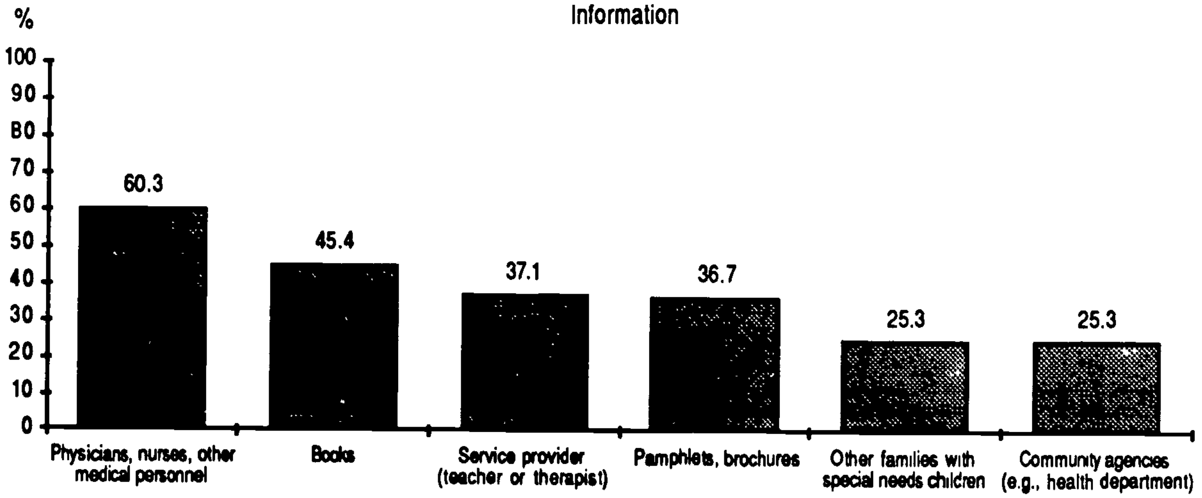
Percentage of Parents Who Have Problems Securing Services (Duplicated Count N=261)



How do parents receive information about their child's disability or services available for their child? Figure 17 shows that parents talk primarily with physicians and/or nurses. Teachers and therapists also share information with parents. Parents look to community agencies such as the health department and other families for information. Printed material (books, pamphlets, brochures) are also used. Visual resources such as movies, videotapes, or television do not play a large part in getting crucial information to parents. Obviously, well-written and timely national and local television spots could have an impact. The data indicate only that, based upon parent habits and present delivery of information, videotapes and television are not serving a vital role in information dissemination.

Figure 17

Percentage of Parents Who Use Specific Information Sources about Their Child's Particular Disability* (N=229)



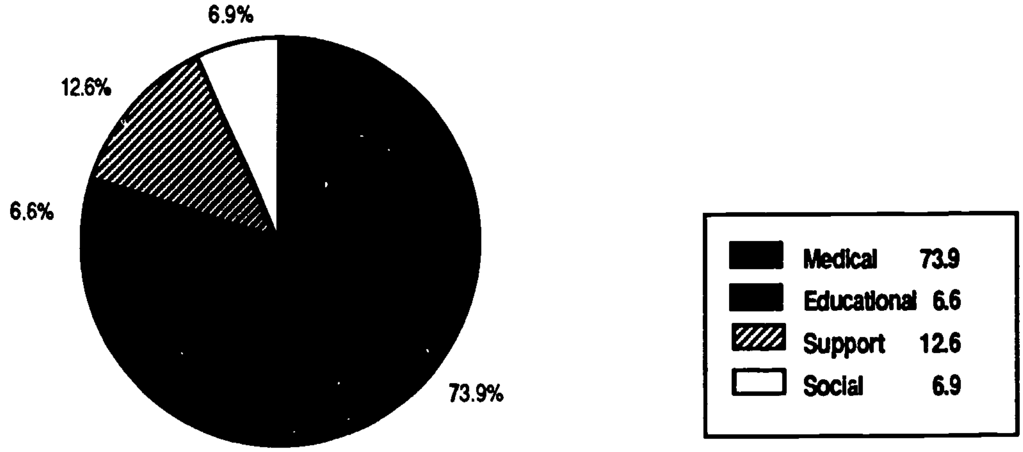
* Top 6 responses from percentage of total respondents (229)

When parents were asked about the services that are available for siblings, one-third of the parents responded. They feel that sibling support is incidental, probably unintentional. Sibling services are typically seen as 'involvement in their sister's or brother's special program.'

Travel is an issue in a rural state like Iowa. Parents listed 297 services for which extensive travel is involved. The vast majority of this travel is for medical services. Figure 18 shows a comparison of the services related to travel.

Figure 18

Percentage of Services for Which Travel is Involved
(N=261)

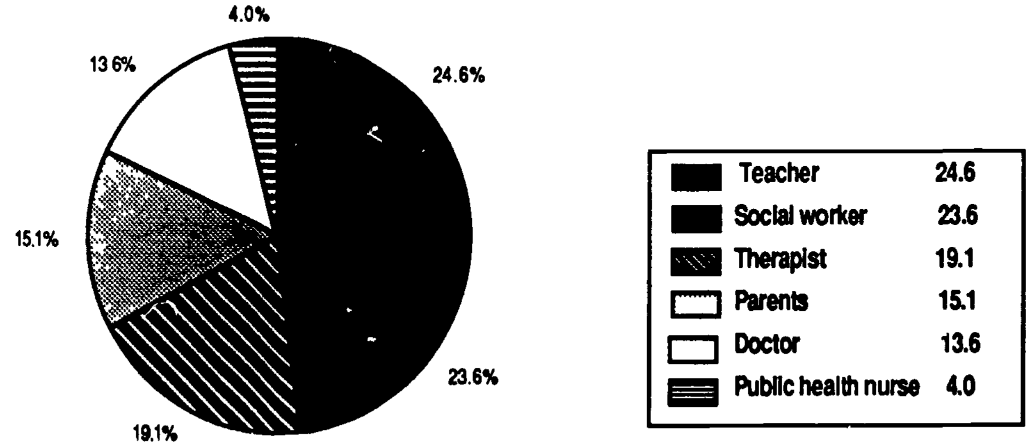


There are a number of possible explanations for the dominance of medical services over the others: (a) the relatively centralized medical service system for young children with special needs in Iowa; (b) the high proportion of parents who reported that their child has a physical disability which requires more medical attention than other disabilities like hearing, speech, or behavior; and (c) the age of the children.

Parents were asked to choose one person who they would like to see coordinate services for their young child with special needs. Figure 19 lists the parents' responses. They chose teachers and social workers most frequently; public health nurses least frequently. Occupational and physical therapists are in top-middle position; parents and physicians are in bottom-middle position.

Figure 19

Percentage of Professionals Who Parents Choose as Case Managers
(N=199)

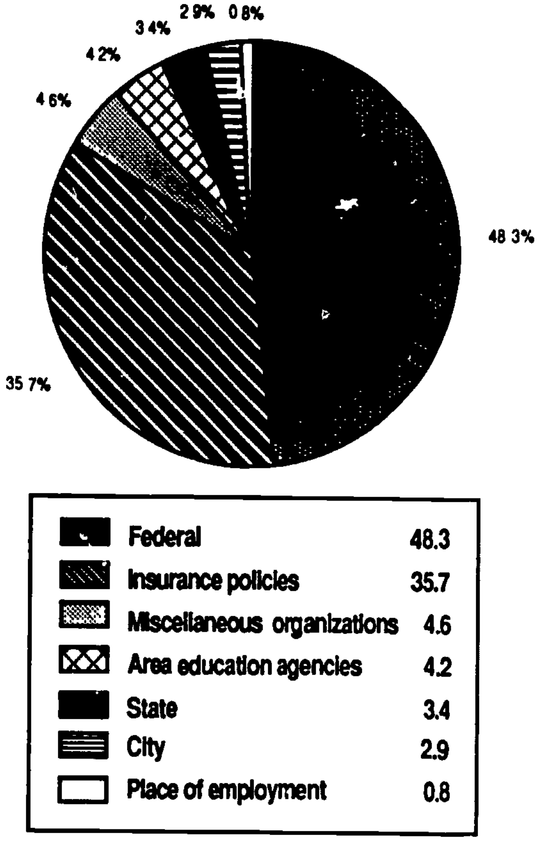


Cost of Services

Parents are financially stressed by the cost of treatment for their child with special needs. Outside sources of support are an absolute necessity for most parents. When asked to list the sources which provide financial assistance for their child's care, the most frequently cited sources are federal assistance and insurance. Only a small percentage of parents cited other organizations, AEAs, or state or city resources as sources for financial support. Sources for financial support are displayed in Figure 20.

Figure 20

Percentage of Sources Families Use for Financial Support (N=238)



Costs for a child's basic care can be prohibitive. When supplied with a list of optional services, parents reported that they would participate in several services if cost were not a factor. Approximately 40% would participate in counseling, 31% would use respite care services, and 20% would get occupational therapy for their child with special needs.

Parent Participation

Parents were asked two questions about their participation: "What activities are available to you?" and "In what activities are you involved?" The results of the two questions were combined and are shown in Figures 21a and 21b. Parents noted that conferences and Individual Educational Plan (IEP) meetings are the most available and most used services. Training workshops and respite care are the least available and least used services. Even though counseling is available and parents would pay for it if cost were not a factor, it is used by less than ten percent of the parents who responded.

Figure 21a

Group Percentage of Services (Available)*

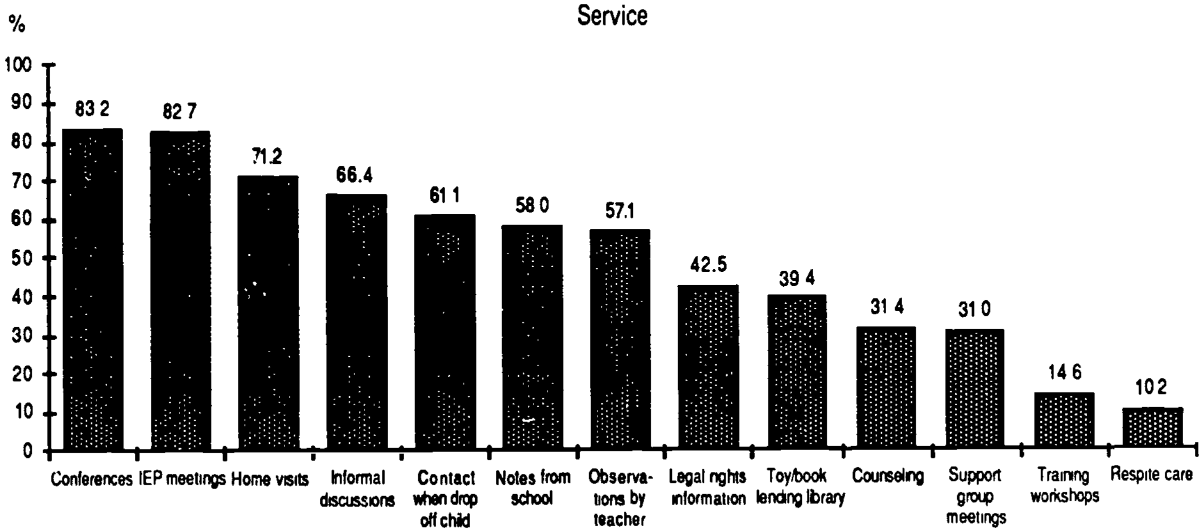
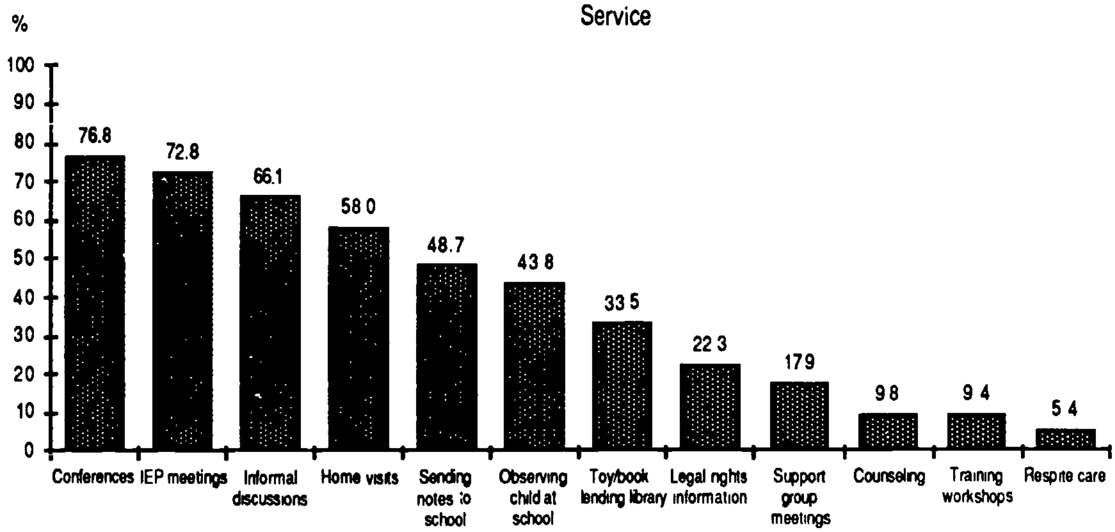


Figure 21b

Group Percentage of Services (Used)*



* Averages include only those who responded at least once to both questions

Because group averages (shown in Figures 21a and 21b) may differ somewhat from individual responses, each response to services available and services in which the parent was involved was compared. Figures 22a and 22b are the result of those comparisons. These figures show the percent of individuals who have each service available and the percent of individuals who use the services, given availability. These percentages are arrived at by combining 'Available, Not Used' information with the 'Available, Used' information and dividing the total by 'Available, Used.' The higher this index, the more likely that parents would use the service. Conferences with service providers and IEP meetings and staffings have the highest ratios, whereas counseling has by far the lowest. While respite care has low availability, it shows a middle index of use.

Figure 22a

Individual Percentage of Services (Available)

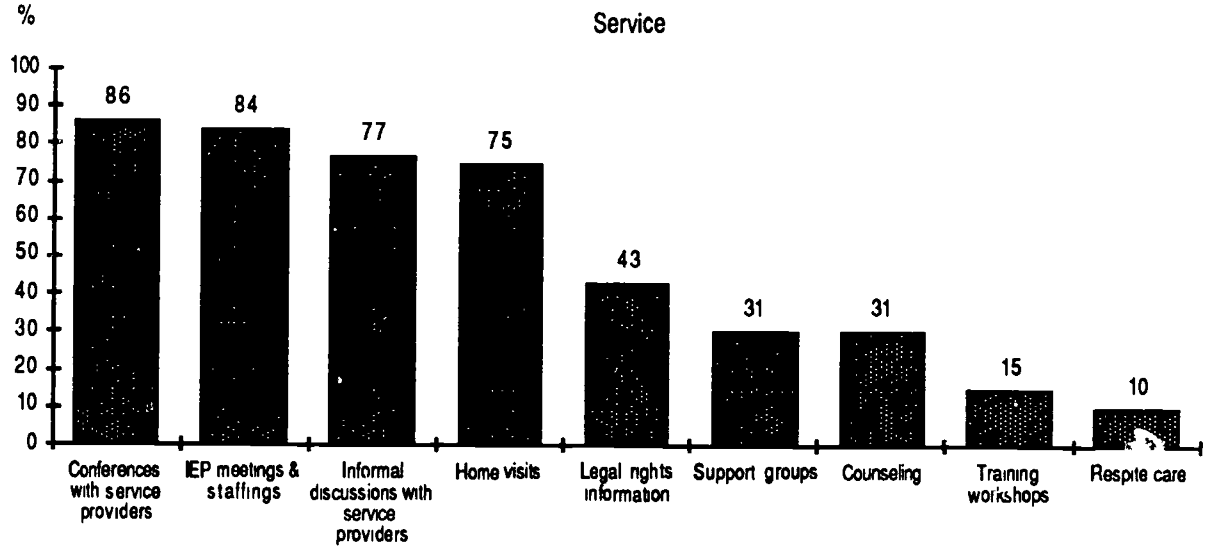
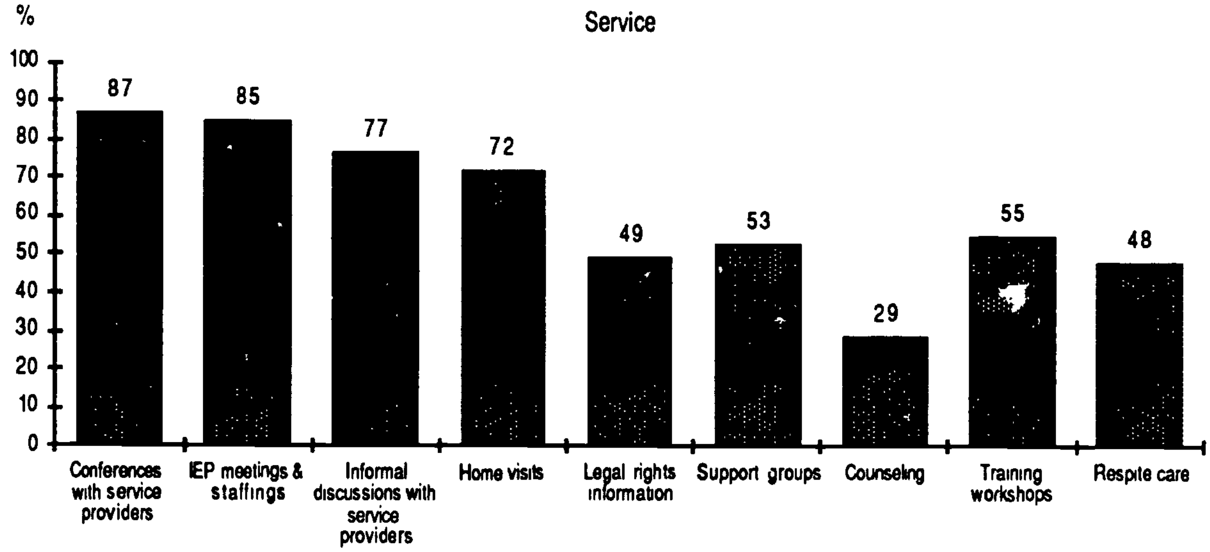


Figure 22b

Individual Percentage of Services (Used, Given Availability)



It is important to emphasize that, while services may not have been used in the past, future uses may not be well predicted by the indices. Figures 22a and 22b do not provide a summary of parent need for the service. They do provide a summary of usage after present factors have been accounted for. For example, a parent's need for counseling and awareness of that service may still not be sufficient to cause that parent to use the service. The parent might believe the service is too expensive or that it may be personally ineffective.

The prior tables show that approximately three-fourths of the parents attend staff meetings or conferences. Parents provided positive evaluation about these meetings. Professionals received high marks from parents when asked about how they (parents) feel about their participation in meetings organized by professionals. Parents feel comfortable, feel that they have a role in decision making, feel that enough time is provided for meetings, and feel they can be open and honest about what they want for their child with special needs. Parents did, however, differentiate among health, social, and educational service agencies on the basis of their satisfaction with opportunities to be involved in their child's program. Social services received the lowest score, medical services a middle score, and educational services the highest score.

Parents were asked which two aspects of AEA services would, if provided, enhance parent participation in agency parent activities. The two highest frequency responses (38% and 47% of respondents) indicated that (a) offering activities that directly benefit an individual child and family and (b) providing child care would be preferred and would, presumably, have a positive effect upon attendance. An overwhelming majority (161 or about 76%) of the parents noted that meetings which teach them about their child's disability are far more needed than either emotional support or workshops on educational legislation.

Services

Parents were asked to rate the overall effectiveness of professional groups and agencies from which they have received services. Tables 15a and 15b show how the overall effectiveness of professional groups and agencies was rated. All groups and agencies received a satisfactory or above rating.

Table 15a

Parents' Rating of Overall Effectiveness of Services (Professional Groups)

Professional Group	Average Score*
Teacher	1.4
Physical Therapist	1.7
Speech Clinician	1.9
Occupational Therapist	2.0
Family Doctor	2.1
Public Health Nurse	2.2
Counselor	2.4
Social Worker	2.5

* 1 = highest, 5 = lowest

Table 15b

Parents' Rating of Overall Effectiveness of Services (Agencies)

Agency	Average Score*
Area Educational Agency	1.6
Public School	1.7
Head Start	1.8
Child Health Specialty Clinic	2.0
Women Infants & Children	2.0
University of Iowa Hospitals	2.1
Local Hospital	2.2
Homemaker Services	2.3
Department of Human Services	2.8

* 1 = highest, 5 = lowest

The data show the same pattern: two or three agencies or professional groups are rated highly, while the rest show a .1 difference among adjacent scores. Within professional groups, teachers and physical therapists received the highest scores; social workers the lowest score.

Agencies follow the same pattern. The highs and lows are, however, more distinguishable. Educational agencies receive high scores and medically-related agencies receive middle scores. The Department of Human Services received an average score that fell considerably below the lowest of the scores achieved by other agencies.

Educators and educational agencies were rated highly. Similarly, the least favored professional group is contained in the agency that received the lowest agency rating. This leads to the hypothesis that either the professional group or the agency received ratings which were affected by the other. If the hypothesis were true, educators received scores that were derived in part from their association with educational agencies; educational agencies received scores related to their staff. Parents' ratings were interactive, not independent; parents may have had trouble giving ratings to one without being influenced by the other.

Coordination of Services

Parents were asked to list the frequency of their child's contacts with agencies and individuals. Table 16 summarizes the frequency of the contacts. The table lists the number of parents who checked one of two time periods: (a) daily-weekly or (b) monthly-yearly. Some agencies were mentioned in one time slot more than the other. This leads to the isolation of two major groups: (a) those that primarily occupy the monthly-yearly time niche and (b) those that primarily occupy the daily-weekly niche. A *niche* is defined as when the frequency of one is more than 2.5 times the other. Those in the monthly-yearly niche tend to be medically related; those in the daily-weekly niche tend to be educational. Some cross-over does appear between the categories, however. Hospitals and private clinics are members of the monthly-yearly service niche while generating significant activity at the daily-weekly level as well.

Table 16

Frequency and Percentage of Contacts with Agencies and Individuals*

Agency/Individual	Contacts		
	Combined frequency	% Used daily/weekly	% Used monthly/yearly
Hospital	249		90.0
Area Education Agency	187	84.5	
Private Clinic	134		74.6
Physician	111		95.5
Social Service	42		90.5
Public Health Nurse	38		60.5
Child Health Specialty Clinic	36		94.4
Head Start	31	81.0	
Day Care	30	96.7	
School	18	100.0	

* Figures are placed in primary niche column.

When given the opportunity to share their opinions on the effectiveness of communication and joint work of professional staff, 65% of the parents gave a favorable response. This response and the generally favorable response to each of the services and professional groups led to the conclusion that parents have a generally positive assessment of the service system with which they are dealing. This feeling did not inhibit parents when they were asked to list problems with or suggested changes in the system, however.

Parents found that specialization, red-tape, and extended travel for services constitute problems. They were more-or-less evenly divided over communication. Table 17 summarizes the positive and negative comments concerning communication. Interestingly, coordination received both the most positive and the most negative comments. Parents see coordination as a pivotal issue which determines whether or not the services they receive are satisfactory.

Table 17

Parent Comments about Communication

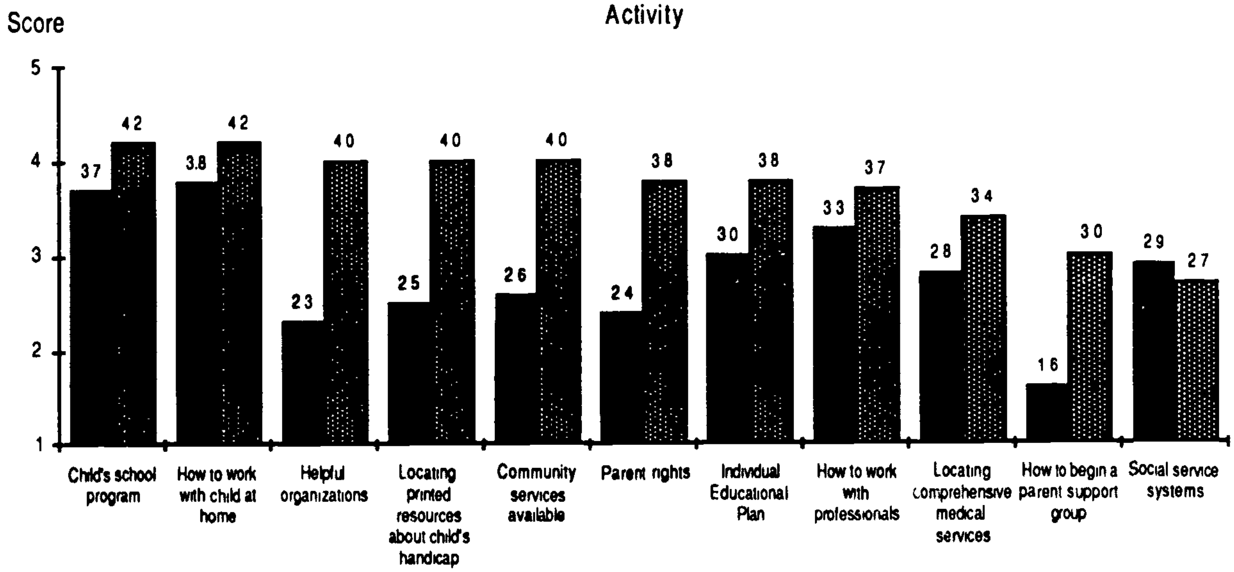
Comments			
Positive	#	Negative	#
They send reports back and forth to one another.	22	Don't share information well; no one assumes role of coordinator.	17
They are accessible to one another.	6	Discrepancies and contradictions between them. One tells you one thing and another tells you another.	9
Doctors contact AEA after visits to keep them up to date.	3	No communication between medical staff and school, except through parent.	7
Educational agency always sends reports back to our doctor's office.	1	The doctor gets written reports but never responds to the information.	3
They communicate their findings in a language we can understand.	1	Written reports to doctors from University of Iowa take too long; 4 to 6 weeks.	2
Positive but not specific.	24	Agencies are reluctant to send my child's records to other agencies.	1
		Negative but not specific.	9

Parent Training

Parents were asked to state their personal knowledge of and their desire to learn more about possible training topics. Their responses, summarized in Figure 23, show that parents have clear preferences and needs.

Figure 23

Parent Knowledge and Desire for Training*
Activity



A *need for training* is defined as a positive discrepancy between self-assessed knowledge and desire for training. Preference is simply desire for training. On the basis of preference or desire to learn, parents indicated high preference (4.2 on a 5-point scale) for knowing more about their child's school program and about working with their child at home. Next, parents selected other preferred areas for training: knowledge of (a) helpful organizations, (b) community services, and (c) techniques for locating print resources relevant to their child's handicap. Knowing about their rights, IEPs, and knowing how to work with professionals show average preference. Locating comprehensive medical services, knowing how to start a parent support group, and knowing about social service systems were least preferred training topics. After comparing the top and bottom clusters one might conclude that parents prefer training which has immediate bearing on, or support for, their own child and are less concerned about issues that may only indirectly benefit their child.

Need for training (desire to learn more about a topic minus knowledge of that topic) yields slightly different clusters. The highest need for training includes high preference items such as (a) knowledge of helpful organizations, (b) knowledge of community services, (c) knowledge of techniques for locating printed resources concerning their child's handicap, (d) knowledge of their rights, and (e) knowledge about starting a parent support group. Knowing about IEPs and their child's school program, locating comprehensive medical services, and working with their child at home, as well as working with professionals appeared to be middle level needs for training. Knowing about the social service system was not only least preferred training but least needed as well.

Need for training does not duplicate what is measured by separate categories. For example, even though parents do not prefer learning about starting a support group, the existence of little knowledge (1.6 on a 5-point scale) in the area and the presence of a relatively high desire for training (3 on a 5-point scale) suggest 'starting a support group' as a training topic.

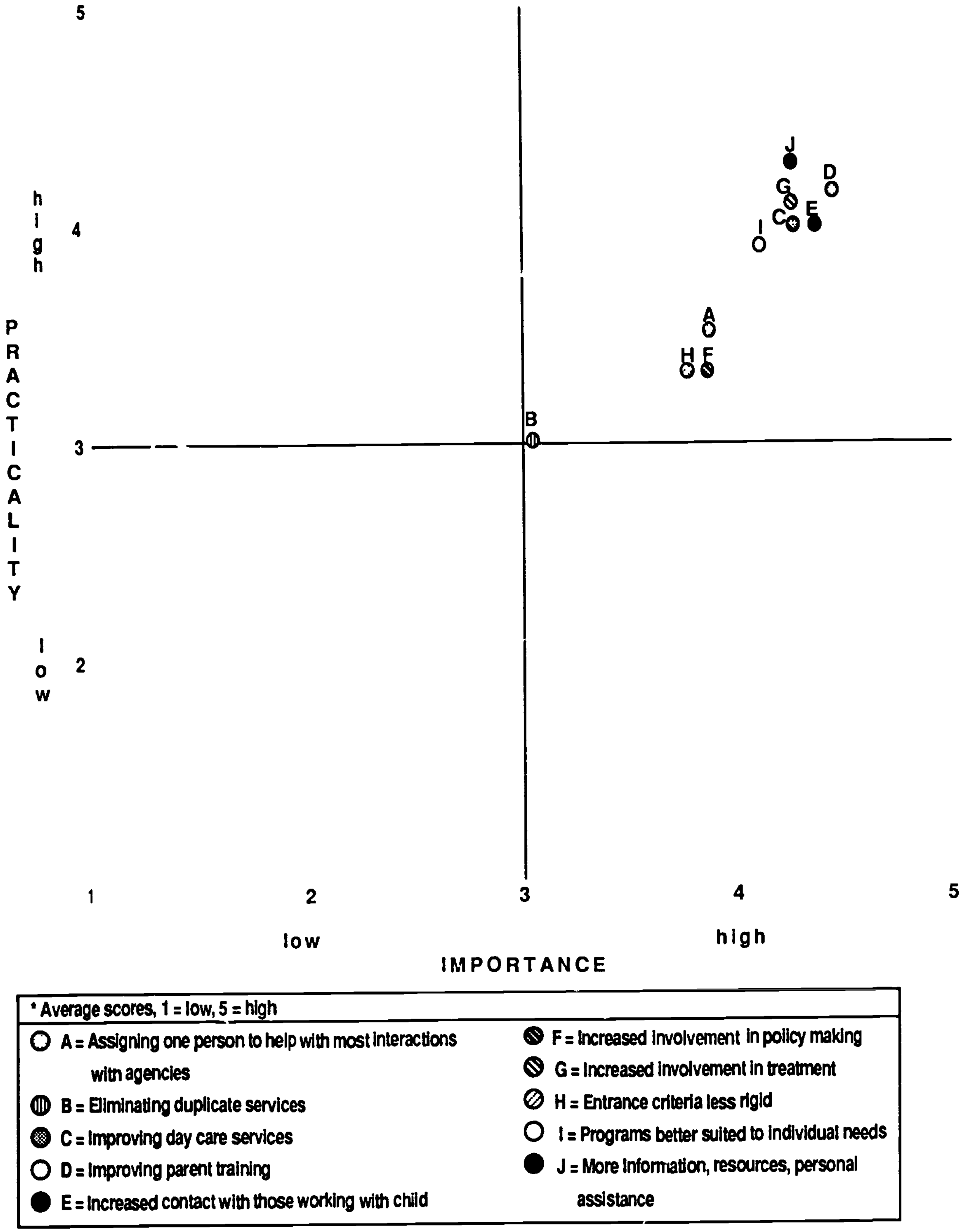
Using 'high desire' for training as a sole criterion for selecting training topics would have its failings also. 'Working with one's child at home' and 'knowledge of child's school program' have high preference ratings (4.2 on a 5-point scale) and high knowledge ratings (3.7 and 3.8 respectively) as well. Thus, these areas are not critical training topics.

Changes

Parents were asked to assess the importance and practicality of several possible changes in the service system for young children with special needs. Figure 24 shows the plots of average parent assessment of the importance (x-axis) and practicality (y-axis) of suggested changes. [Note that all items fell in the highly important (x greater than 2.5) and highly practical (y greater than 2.5) sectors of the graph.] Thus, parents stated that, in their opinion, each of these changes should and could be made. Scores fall into three clusters within the 'high high' (highly important and highly practical) quadrant. These highest clusters refer to six changes: (a) improved training for parents of young children with special needs; (b) more information, resources, and assistance; (c) increased parent participation in the child's treatment; (d) improved day care for young children with special needs; (e) increased contact between parents and individuals who work with their children; and (f) improved programs to better suit individual needs. Among these practical and important changes, parents gave least importance and practicality to the elimination of duplicate services between agencies.

Figure 24

Importance and Practicality of Changes Suggested by Parents



Parents were also asked to list other changes they would like to see in the system. Their responses were placed in categories and subcategories. The categories mentioned most frequently were: (a) alterations in services, (b) enhanced education for parents, and (c) altered relationships with professionals. Other general categories that were mentioned ere: (a) more financial support, (b) alterations in educational services, (c) community inservice, (d) alterations in laws, and (e) better emotional support for parents of young children with special needs. Table 18 presents all items which were nominated by more than five parents. These responses support, in a general way, the more specific changes which are depicted in Figure 24. In this section, parents have shown their concern for the education of and communication with the general public concerning the nature of handicaps.

Table 18

Changes Nominated by More Than Five Parents

Category	Change	# of Nominations
Financial Support	More financial support for families which don't qualify for aid under present system.	7
Parent Education	Parents better informed of all options so that they can make better informed decisions.	9
	Parents want more information on their child's disability.	9
	Parents want to know more about how to help their own child.	5
	Parents want someone to explain forms and paperwork.	5
Educational Services	Parents want less labeling and a recognition and responsiveness to ability rather than disability.	5
Community Education	Increase community's understanding of special needs children so that they can participate better in the child's experience (be less put off by handicaps and their symptoms).	6
Professional Actions	Professionals shouldn't "make [parents] feel stupid" when they are trying to explain their child's problem. They should use simpler terminology in their reports.	5
	Need better communication between the professionals who work with a child and the child's parents. [In that respect the relationship needs] more one-to-one communication, more genuine caring, more openness.	14
Services	Better public communication procedures used by agencies so that there is better awareness of the services available that they provide. Have list of services available in one place. (Doctor's office specifically mentioned as a desirable spot).	23
	Provide more daycare services for young children with special needs.	5
	Increase local programs.	8
	Increase availability of summer therapy.	5
Emotional Support	More support groups. More support groups with others outside immediate community.	12

Analysis of Parent Forums

Another section of the needs assessment process consisted of clarifying and verifying data found in the written Needs Assessments. Parent concerns about the needs of their child with a disability was examined in an objective, yet practical fashion during four forums conducted in four sites across Iowa. In order to maintain confidentiality, the sites are discussed as Site A, Site B, Site C, and Site D. Parents were invited to participate in the forums for one or more of the following reasons: (a) the parent was known to be articulate in his/her representation of child and/or parent need; (b) the parent represented a particular socioeconomic status; (c) the parent represented one of the handicapping conditions typical to young children with special needs; or (d) the parent could voice concerns about one of the age groups birth through 35 months or 36 months through 71 months. The number of parents attending each forum was limited to eight or nine so that each would have an opportunity to participate and make his/her views

known. Each forum's proceedings was videotaped for later analysis. (See Appendix E for a list of questions addressed during the forums.)
The forums' proceedings were analyzed by a trainer/facilitator and four observers/ developers who were divided into two teams. A categorical observation system was used to objectively scrutinize two of the four forums. The categorical observation system resulted from (a) an initial scan of each of the forums and (b) exhaustive and repeated application of the category system to one of the other forums. This process was used to assure both the workability of the categories and the reliability of the observers' use of those categories in viewing and independently analyzing the videotaped interactions. Each team of observers worked to a level of better than .80 correlation between category scores on 20-minute segments of Site A. Final analyses of Sites B and D were also as reliable (i.e., each team produced correlations of .80 or better for the team's assigned forum). The final analysis consisted of observing and categorizing each parent comment by two trained observers.

Positive comments in Site D concerned AEA direct services and coordination activities. The negative concerns about availability and quality focused on the following needs: (a) availability of child care (which needs to be both affordable and sufficiently staffed to deal with the unique needs of young children with special needs) and (b) availability of family counseling.

In Site B, the most frequent positive remarks were made about (a) the initial referral and explanation provided by medical personnel and (b) the level of services provided by the AEA (both direct and coordination services). Parents were concerned about the inaccessibility of physical therapy services, specifically, and with the general problem of accessibility of services for rural parents of children with special needs. Site B parents were also concerned with child care, most particularly with the absence of child care personnel who are adequately trained. Parents from Site B also noted a need for training about (a) nature of handicaps, (b) financial planning, (c) parents rights, and (d) family and individual counseling.

The concerns from the two forums which were intensely sampled were more alike than different. The average category scores were used to create rankings for the categories in each of the cities and for both positive and negative remarks. Correlation of positive remarks for the two cities was .80. Correlation of negative remarks between the two forums was .63. Thus, it could be suggested that parents have an underlying concern for (a) child care, (b) support groups, and (c) counseling. They appreciate (a) initial medical support, (b) AEA direct services, and (c) coordination among service providers. Appendix F contains more specific information regarding the parent forums.

SUMMARY

The purpose of the State Planning Grant needs assessments was to gather accurate and comprehensive data regarding services for young children with special needs from ppropriate agencies, service providers, and parents. The objectives underlying the Needs Assessments were to identify (a) what services are available, (b) which of these services are working, and (c) what could be changed to make the service system even better.

The process for gathering information included three phases: (a) a needs assessment for service providers of young children with special needs (Phase I), (b) a needs assessment for parents of young children with special needs (Phase II), and (c) parent forums to confirm the findings in Phases I and II.

The key information gathered through this process is addressed under five categories: (a) accessing and receiving services, (b) case management, (c) communication and coordination, (d) parent participation, and (e) training issues.

Accessing and Receiving Services

Accessing and receiving services within a reasonable time frame appear to be a concern to professionals and parents. The data show that, on an average, the time between the onset of suspicion that a problem might exist and the receipt of service is seven months. While parents may suspect that their child has a problem, they often have serious problems in finding someone who can help them confirm or deny their troubling concerns.

Parents most frequently turn to the medical community for information and guidance when first entering the service system. The majority of parents are successful in obtaining assistance when they talk to either physicians or physical or occupational therapists. A few parents first seek assistance from parent support groups; however, parents do not always find a parent support group when they want one. This is even more true when it comes to respite care, child care, financial support [except Supplemental Security Income (SSI)], and direct training on child behavior.

Case Management

With the implementation of Public Law 99-457, case management has become an important national topic for young children with special needs and their families. Within the parent and professional Needs Assessments, a *case manager* is defined as a person in charge of assisting families of young children with special needs in most interactions with agencies. The data show service providers and parents have various perspectives about case management.

Professionals feel that their agencies have case managers. It appears, however, that each agency defines the role of its case managers differently. This lack of a consistent role description for case managers and/or case management systems affects the quality of services for young children with special needs and their families, particularly when parents have to deal with several agencies at the same time (or one after the other). Even with the lack of a formal case management system, parents frequently report that professionals work well together and communicate to the degree that hectic schedules permit.

Parents offer differing opinions about who should have case management responsibilities. Some feel that their child's teacher could fulfill the role or that a social worker or therapist could be relied upon. Others see themselves as their own best case manager. Doctors and public health nurses were mentioned as possible coordinators of the many services that families require.

Communication and Coordination

All of the data gathered in the Needs Assessments point to a critical need for increased communication and coordination among service providers and parents. Communication among agencies, within agencies, and between agencies and the public are all concerns.

Professionals note that interagency communication exists. The most common interagency activities include providing referrals and transferring records. Service providers rarely meet to solve problems or plan services for families that they have in common. The parents' view that service providers could communicate more often and do more than exchange reports reinforces the professional responses.

Intra-agency communication appears deficient. Information gleamed from a number of data sources, none of which is individually conclusive, leads to the impression that people within the same agency communicate infrequently and often do not know what the other is doing. This lack of communication negatively affects both the amount and quality of information provided to families about their specific child.

Parents request that agencies develop improved public communication procedures so that they and professionals have a better awareness of available services.

Parent Participation

Overall, service providers and parents feel that adequate opportunities are given to parents for input into services the families receive. Professionals are satisfied with their agency's parent program. Many providers view parents as being highly involved in the decision making process. Parents confirm this by sharing that they feel they have a role in making decisions most of the time. Both groups, however, feel that the collaboration between parent and agency staff should be improved.

Professionals want to do more with parents but note that over worked staffs, inadequate funding, and the resulting lack of energy prevent the development and delivery of quality parent participation programs. They also observe that they do not know what parents want and thus feel that they are unable to assess families' needs accurately.

The most prevalent level of parent participation is seen in activities which meet the requirements of P. L. 94-142 for Individual Educational Plan (IEP) staffings or conferences. Parents do feel that they have ample time to share at these meetings and that they are comfortable attending them. Data show that in addition to staffing attendance, parents frequently communicate with service providers via notes and telephone calls. A few parents participate in training and support groups that are available to them; more would participate if the training and support activities were better suited to their individual needs.

Training Issues

Professional training which seems most needed includes the following topics: (a) managing children with behavior disorders, (b) understanding genetic influences, (c) locating services for children with special health care needs, (d) knowing about early childhood special education research, (e) finding and coordinating services, (f) knowing about various services, and (g) understanding single- and step-parent issues.

Agency training issues are: (a) Area Education Agency (AEA) personnel want training in medical and support areas; (b) Department of Human Services (DHS) staff want training in medical and development areas; (c) nursing agency staff prefer training in teaching and development; and (d) other health agencies request support, teaching, and development training. See Table 5 for specific training topics included within each area.

Parents want more knowledge of (a) helpful organizations, (b) community services, (c) their rights, (d) how to get material that will help them understand their child and his/her disability, and (e) how to start a parent support group.

RECOMMENDATIONS

The State Planning Grant Needs Assessments were designed to gather useful information. In particular, the information was to support: (a) developing a more coordinated and cost effective continuum of services, (b) ensuring that all young children with special needs receive services, and (c) maximizing the creative use of existing state and local resources. Results from the Needs Assessments should enable state agencies, specialized services, and the State Plan Advisory Council for Early Services (SPACES) to make recommendations which are directly formed by parent and professional input that went into survey responses.

This section presents a summary of the recommendations made by SPACES members. The SPACES recommendations are a response to the data and distinct from it. Each of the SPACES members brings diverse and profound experience to bear upon the data while making conclusions that are not strictly supported by it. SPACES input was obtained in a systematic manner through the use of a form which specified the *problem* as defined in the Needs Assessments, the *solution* proposed by the Council member, the *cost* and *effort* projected and the *expected results* from the proposed action. In most cases, it can be assumed that these recommendations will have a statewide focus. Specific agencies and role groups may wish to look further at the data contained in this document in order to make more specific recommendations for their disciplines or agencies. Some issues indicate a need for further study of the exact problem before any corrective action can be taken. The recommendations made by SPACES are presented in five categories: (a) accessing and receiving services, (b) case management, (c) communication and coordination, (d) parent participation, and (e) training.

Recommendations for Accessing and Receiving Services

1. A central referral agency should be established.
2. Information on available resources and eligibility criteria for receiving services should be maintained in a logical and easily accessible location in conjunction with the referral service.
3. Duplicate services should be eliminated.
4. Home instruction and related services should be made available to families throughout the calendar year as opposed to "a school year."
5. A system of matching "seasoned" parents with "new" parents should be implemented.
6. The tracking of young at-risk children needs to be expanded.
7. Confidentiality issues of one tracking system which necessitates the sharing of information across agencies should be explored.
8. Agency staff should receive inservice on the tracking efforts which are currently underway in the State and on how to input and access those systems.
9. Provision should be made for parents to have access to counseling at little or no cost. A multi-agency plan for counseling services should be developed based upon the resources available within the region and the intensity of the family's needs.

10. Careful review should be given to the availability of medical follow-up services for Iowans residing in rural and Western portions of the State.

Recommendation for Case Management

1. A task force should be established to explore case management issues, develop a philosophy, and recommend procedures which could be implemented in Iowa.

Recommendations for Communication and Coordination

1. The importance of interagency coordination and the increased levels of communication required to effectively serve young special needs children and their families must be recognized by agencies, administrators, and other staff involved with this population.
2. An acknowledgement of the extra time required for proper coordination of services must be reflected in the case loads of staff assigned to this population.
3. A regional structure which reflects the community needs and resources should be formulated for the State. Within these structures, community-based interagency planning groups should be formed with representation from Area Education Agencies (AEAs), Department of Human Services (DHS), Child Health Specialty Clinics (CHSC), Maternal and Child Health (MCH), and private providers (to include pediatricians or family practitioners).
4. Exemplary interagency models should be identified and examined for replication throughout the State. Pilot sites should be established for developing and adapting models which are new to Iowa.
5. Staff awareness should be promoted by offering ongoing inservice training to staff (including secretaries, receptionists, etc.) to acquaint them with functions and personnel from other agencies that provide services to young special needs children and their families.

Recommendations for Parent Participation

1. A "Guide to Services" should be developed and routinely updated for Iowa parents and professionals.
2. Vouchers or other incentives should be made available to parents who participate in projects and/or training which are beneficial to other parents or professionals.
3. Greater efforts should be made for the State Special Education Conference to include parent participants and presenters.
4. Parents should be provided the opportunity to participate in inservice training for respite care providers who have been chosen by the parents.

Recommendations for Training

1. Regional workshops for parents and service providers about community resources, case management issues, networking, communication, and transition need to be offered on an ongoing basis.

2. Concise, informative "packets" (e.g., pamphlets, videos, and bibliographies) about specific disabilities should be developed.
3. Community colleges should be used as training sites for family day care providers.
4. Genetics training should be more easily accessible to service providers and parents.
5. Joint training efforts should be promoted between agencies and groups whenever possible and feasible. The specific data within this report should prove helpful in determining the focus for training.
6. Resource personnel (e.g., CHSC regional pediatric consultants) should be trained to provide information on community resources to primary care physicians.
7. A task force should be formed to address personnel preparation procedures for the training of staff who are to serve children birth to three and their families. Further clarification should be sought regarding (a) content, (b) level of training (graduate or undergraduate), and (c) the competencies required to serve this population.
8. Paying partial costs for out-of-state training in return for a commitment of "X" number of years of service in Iowa should be explored. This concept could be used for pediatric physical therapy since there is no in-state program.
9. The data supplied in this report should be closely scrutinized to determine specialized training needs of the various professional groups surveyed.

Appendices

Appendix A

STATE PLAN ADVISORY COUNCIL FOR EARLY SERVICES (SPACES)

Julie Beckett
2420 "D" Avenue NE
Cedar Rapids, IA 52402

James A. Blackburn, M.D.
Assistant Professor, Pediatrics
Division of Developmental Disabilities
University Hospital School
University of Iowa
Iowa City, IA 52242

Joyce Borgmeyer
Program Administrator
Maternal & Child Health
Iowa Department of Health
Des Moines, IA 50319

Marge Corkery
Adoption Program Specialist
Iowa Department of Human Services
Des Moines, IA 50319

Donna Ehrhart
Mental Health Specialist
Iowa Department of Human Services
Des Moines, IA 50319

Linda Gleissner
Incentive Preschool Program
Education Center
University of Northern Iowa
Cedar Falls, IA 50613

Kay Grothers
Maternal & Child Health
Iowa Department of Health
Des Moines, IA 50319

Marcia Huemoeller, Director
Head Start
Operation New View
Box 152
Peosta, IA 52068

Jean Hume
Arrowhead AEA 5
1235 5th Avenue S.
P.O. Box 1399
Fort Dodge, IA 50501

Larry Keele
Southern Prairie AEA #15
R.R. 5, Bldg. 40, Box 55
Ottumwa, IA 52501

Jean Linder
3217 34th Place
Des Moines, IA 50310

Kathleen McCartan, Ph.D.
Child Development Department
Iowa State University
Ames, IA 50010

Richard P. Nelson, M.D.
Child Health Speciality Clinics
University of Iowa
Iowa City, IA 52242

Jule Reynolds
1922 E. 12th
Des Moines, IA 50316

Carolyn Wissler, Director
Day Care for Exceptional Children
2217 Beaver Avenue
Des Moines, IA 50310

Appendix B

Bold type indicates responses

ASSESSMENT OF SERVICES

The following list contains agencies and their abbreviations which are used frequently in this survey.

AEA = Area Education Agency
CHSC = Child Health Specialty Clinic
DHS = Department of Human Services
HS = Head Start
LEA = Local Education Agency
MCH = Maternal and Child Health
UIH = University of Iowa Hospitals

A. INTERAGENCY COORDINATION

1. Check the local agencies or groups with whom your agency collaborates and rate both the frequency and quality of the collaboration. Also, check if your agency has a formal agreement with the other agency.

Frequency:
1 = Annually
2 = Monthly
3 = Weekly
4 = Several times per week
5 = Several times per day

Quality:
1 = Very effective
2 = Effective
3 = Satisfactory
4 = Unsatisfactory
5 = Very unsatisfactory

	Frequency		Quality		Formal Agreement
	$\bar{x}$	SD	$\bar{x}$	SD	
Advocacy groups	1.7	.9	2.7	.7	5
AEA	3.7	1.4	1.4	1.0	65
Day care groups	2.4	1.6	2.1	1.5	32
DHS	2.9	1.7	2.8	1.6	49
HS	2.5	1.6	2.0	1.6	51
Hospitals	2.4	1.7	2.1	1.6	25
MCH	1.6	1.3	1.8	1.4	30
Public health nurses	2.0	1.6	1.8	1.4	17
Physicians	3.0	1.8	2.4	1.5	22
Private diagnostic/tutoring/ therapy agencies	1.9	1.6	2.7	1.5	15
Residential facilities	2.2	1.6	2.1	1.5	32
Early Periodic Screening, Diagnosis and Treatment Program (EPSDT)	1.5	1.1	1.0	0.0	23
UIH	1.9	1.5	2.0	1.5	23
OTHER________________					

ASSESSMENT OF SERVICES

AEA = Area Education Agency
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2a. Check and rate the interagency activities which take place between your agency and others while serving the needs of young children with special needs. RATE BOTH FREQUENCY AND QUALITY.

Frequency:
1 = Annually
2 = Monthly
3 = Weekly
4 = Several times per week
5 = Several times per day

Quality:
1 = Very effective
2 = Effective
3 = Satisfactory
4 = Unsatisfactory
5 = Very unsatisfactory

	Frequency		Quality	
	$\bar{x}$	SD	$\bar{x}$	SD
Planning meetings	2.0	.9	2.4	.8
Problem solving meetings	2.0	.8	2.4	.8
Records transfer	2.4	1.1	2.4	.8
Referrals	2.7	1.0	2.3	.8
Staffings	2.2	1.0	2.2	.8
Telephone calls	3.4	1.1	2.2	.7
OTHER__________				

b. These activities are:
CHECK ONE.
14.3% Very adequate
64.1% Adequate
21.6% In need of improvement
8.9% Missing

c. Offer suggestions for improving interagency processes.

3a. An interagency council specifically concerning young children with special needs exists in your community.
25.9% Yes
35.0% No
39.2% Do not know

b. If yes, indicate agencies or groups which are included in the council.

23.4% AEA
10.7% CHSC
20.4% DHS
12.7% HS
13.4% LEA
10.0% MCH
9.4% UIH
_____ OTHER ______________

ASSESSMENT OF SERVICES

4a. An interagency resource directory is available which assists with the location of services for young children with special needs and their families.

44.7% Yes
18.1% No
32.2% Do not know

b. Which directories do you use most frequently to locate programs or services for young children with special needs and their families?

B. CASE MANAGEMENT

1a. Does your agency have case managers?
(A case manager is a person in charge of assisting families of young children with special needs in most interactions with agencies.)

64.5% Yes
29.9% No
5.6% Do not know

b. Does your agency have a formal procedure for selecting a case manager?

42.3% Yes
29.9% No
5.6% Do not know

c. List specific duties of your agency's case managers.

1. ________________
2. ________________
3. ________________

d. If your agency has NO specified case manager, do you view this as a problem?

21.7% Yes
53.5% No
24.8% Do not know

e. If yes, elaborate.

2. The "case manager" structure for young children with special needs currently in place in Iowa is viewed as adequate.

25.9% Yes
17.1% No
57.0% Do not know

ASSESSMENT OF SERVICES

C. PARENT INVOLVEMENT

Check any activity which is a part of parental involvement in your program.

# %	
235/75.3	Counseling
276/88.5	Home visits/instruction/therapy
269/66.2	Individualized planning meeting and/or placement staffing
246/78.8	Informal discussions at home
87/27.9	Legal rights training
201/64.4	Loaning of toys and/or teaching materials to parents
207/ 7.2	Notes and/or newsletters sent home
204/ 7.1	Observations of parents at home
254/ 8.9	Parent-professional conferences
187/ 6.5	Parent-professional contact when children arrive or depart
142/ 5.0	Parent training workshops
85/ 3.0	Parents working as volunteers in the center
38/ 1.3	Respite care
153/ 5.3	Support group meetings for parents
277/ 9.7	Telephone conversations
______	OTHER ______________________________
______	OTHER ______________________________

2. How involved are parents in the decision making process at your agency? CHECK ONE ONLY.

43.3% Very frequently
39.7% Frequently
11.1% Occasionally
3.9% Infrequently
2.0% Not at all

3. Indicate your satisfaction with your agency's parent program.

15.2% Very satisfied
49.5% Satisfied
21.2% Neutral/Indifferent
12.4% Dissatisfied
1.8% Very dissatisfied

4. Describe the problems of your agency's parent program.

a. ______________________________
____

b. ______________________________
____

c. ______________________________
____

ASSESSMENT OF SERVICES

5. List strengths of your agency's present parent participation activities.
   a. ______________________________
   ____
   b. ______________________________
   ____
   c. ______________________________
   ____

6. Describe any ideas you have for improving parental participation in the program.
   a. ______________________________
   ____
   b. ______________________________
   ____
   c. ______________________________
   ____

7. List the services for which parents of handicapped children are currently paying at your agency.

____
____
____
____

ASSESSMENT OF SERVICES

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D. SCREENING

Screening is testing a large population in order to identify those individuals who are most likely to have a handicap. Assessment/evaluation is pinpointing an individual's skills and weaknesses.

1. Screening programs for young children are available from the following sources: CHECK THE BOX(ES) WHICH APPLY.

EPSDT = Early Periodic Screening, Diagnosis and Treatment Program

	0-35 mos.	36-71 mos.
AEA	3.5%	18.0%
DHS	9.1%	18.2%
EPSDT	6.1%	11.0%
HS	5.1%	68.8%
MCH	17.4%	9.6%
OTHER________		
OTHER________		

2. The screening process at your agency includes:

# / %	
224/19.0	Developmental (checking developmental milestones)
210/17.8	Hearing (checking for hearing problems)
101/ 8.6	Income level (noting fiscal resources of family)
179/15.2	Medical (noting general health of child)
212/18.0	Speech and Language (checking for any problems in communication)
186/15.7	Vision (checking for visual impairment)
69/ 5.8	All of the above
_____	OTHER ________________

3. Your agency:

	Yes	No	Do not know	NA
a. has criteria for eligibility to access screening services	53.7%	27.8%	12.0%	5.9%
b. has referral criteria for additional evaluation or services after screening.	84.7%	7.7%	4.7%	2.9%
c. provides an evaluation after screening.	82.9%	8.4%	5.7%	3.0%
d. refers for evaluation after screening.	84.8%	5.3%	4.1%	5.7%

4. Parents are provided the results of your agency's screening activities through:

71.1% Conferences
41.9% Form letters
41.0% Telephone calls
_____ OTHER ________________
_____ Parents are NOT provided results of my agency's screening activities.

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5. The boxes below show age ranges and handicapping conditions. Place a check in a total of FOUR boxes which represent the ages and handicapping conditions which are most in need of improved identification processes.

BD = Behaviorally disordered
HI = Hearing impaired
LD = Learning disabled
MD = Mentally disabled
MH = Multi-handicapped
PH = Physically handicapped
SL = Speech/language
VI = Visally impaired

	AGE	BD	HI	LD	MD	MH	PH	SL	VI	OTHER
#/%	0-35 mos.	139/12.6	43/3.9	86/7.8	68/6.2	58/5.3	36/3.3	46/4.2	34/3.1	
	36-71 mos.	200/18.1	20/1.8	188/17.1	56/5.1	47/4.3	20/1.8	43/3.9	18/1.6	

E. SERVICES

1a. In general, agencies require various entrance criteria which create barriers.

30.1% Yes
38.8% No
30.8% Do not know

b. If yes, where and when does this occur?

Where	When

ASSESSMENT OF SERVICES

2. Indicate social, health and educational services which are available from YOUR agency.

	0-35 mos.		36-71 mos.	
	Adequate # %	Needs improvement # %	Adequate # %	Needs improvement # %
Adaptive equipment/orthopedic	105/33.3	58/18.4	123/39.0	57/18.1
Advocacy	121/38.4	58/18.4	139/44.1	62/19.7
Behavior management	136/43.2	66/21.0	168/53.3	73/23.2
Child nurturing	110/34.9	52/16.5	143/45.4	48/15.2
Classes for parents and children	60/19.0	97/30.8	76/24.1	110/34.9
Center-based instruction	114/36.2	21/ 6.7	176/55.9	19/ 6.0
Counseling	129/41.0	75/23.8	146/46.3	81/25.7
Day care	29/ 9.2	31/ 9.8	43/13.7	30/ 9.5
Dental care	37/11.7	19/ 6.0	61/19.4	21/ 6.7
Diagnostic/educational services	176/55.9	15/ 4.8	215/68.3	12/ 3.8
Drug prescriptions	39/12.4	10/ 3.2	39/12.4	14/ 4.4
Ear/hearing services	163/51.7	8/ 2.5	187/59.4	11/ 3.5
Emotional support	141/44.8	59/18.7	167/53.0	65/20.6
Eye/vision services	98/31.1	44/14.0	126/40.0	44/14.0
General medical	57/18.1	11/ 3.5	75/23.8	12/ 3.8
Genetic counseling	24/ 7.6	23/ 7.3	28/ 8.9	26/ 8.3
Home management (budgeting, use of resources, meal planning)	52/16.5	31/ 9.8	71/22.5	38/12.1
Home-based instruction	167/53.0	17/ 5.4	158/50.2	24/ 7.6
Individual care plans	94/29.8	11/ 3.5	111/35.2	13/ 4.1
Individual Educational Plans (IEPs)	167/53.0	10/ 3.2	206/65.4	9/ 2.9
Legal services	12/ 3.8	16/ 5.1	17/ 5.4	20/ 6.3
Nutritional counseling	67/21.8	28/ 8.9	93/29.5	33/10.5
Occupational therapy	122/38.7	53/16.8	136/43.2	57/18.1
Parent counseling	133/35.9	82/26.0	131/41.6	96/30.5
Parent involvement	128/40.6	74/23.5	147/46.7	96/30.5
Parent training	92/29.2	90/28.6	106/33.7	101/32.1
Physical examination	58/18.4	11/ 3.5	82/26.0	12/ 3.8
Physical therapy	104/33.0	61/19.4	116/36.8	63/20.0
Prenatal counseling/screening	32/10.2	18/ 5.7	35/11.1	20/ 6.3
Prosthetic devices	32/10.2	21/ 6.7	38/12.1	22/ 7.0
Respite care	18/ 5.7	39/12.4	18/ 5.7	40/12.7
Speech/Language therapy	158/50.2	18/ 5.7	192/61.0	16/ 5.1
Surgical corrections	20/ 6.3	9/ 2.9	24/ 7.6	11/ 3.5
Technical assistance	34/10.8	10/ 3.2	43/ 3.7	13/ 4.1
Transportation	87/27.6	17/ 5.4	130/41.3	20/ 6.3
"Well baby" clinic	27/ 8.6	14/ 4.4	35/11.1	14/ 4.4
OTHER ______				
OTHER ______				

ASSESSMENT OF SERVICES

AEA = Area Education Agency
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3a. Effective tracking systems are being used by the following agencies:
(A tracking system is a means of following the progress of a young child with special needs within an agency, from agency to agency and over time.)
RATE EACH SOURCE.

1 = Very effective
2 = Effective
3 = Neutral/indifferent
4 = Ineffective
5 = Very ineffective/nonexistent
N = Do not know

		1	2	3	4	5	N
AEA	#/%	70/22.2	138/43.8	27/ 8.6	12/3.8	8/2.5	60/19.1
CHSC		28/ 8.9	77/24.4	29/ 9.2	10/3.2	6/1.9	165/52.4
DHS		17/ 5.4	67/21.3	54/17.1	31/9.8	15/4.8	131/41.5
HS		20/ 6.3	72/22.9	35/11.1	12/3.8	7/2.2	169/53.6
LEA		26/ 8.3	82/26.0	41/13.0	13/4.1	15/4.8	138/43.8
MCH		12/ 3.8	42/13.3	29/ 9.2	8/2.5	5/1.6	214/69.5
UIH		28/ 8.9	74/23.5	51/16.2	16/5.1	7/2.2	139/44.1
OTHER ______							

b. Offer suggestions for improving tracking systems.

____
____
____

4. Which of the listed agencies provide services for the following at-risk categories?
NAME "OTHER" AGENCY.

		AEA	CHSC	DHS	HS	OTHER
Environmental (child's surroundings)	#/%	109/7.8	28/ 2.0	208/14.9	124/8.9	
Medical (child's health)		73/5.2	178/12.8	87/ 6.2	64/4.6	
Psycho-Social (child's emotional/social condition)		193/13.8	54/ 3.9	156/11.2	122/8.7	

5. Services for "at-risk" or "high-risk" children who are NOT identified as handicapped are offered by the following agencies and individuals.

# %	
172/14.1	Day care
81/ 6.6	Extended family
173/14.2	Foster care
165/13.5	Homemaker services
54/ 4.4	Private agencies (Specify) ______
196/16.1	Public health nurses
184/15.1	Social workers
196/16.1	Women Infants Children (WIC)
______	OTHER ______
______	OTHER ______

ASSESSMENT OF SERVICES

F. PERSONNEL PREPARATION

Using the rating scales at the left and right of each area below, indicate first, how much you know about that area. Second, indicate how much you want to learn about that area to improve your expertise about comprehensive services to young children with special needs and their families.

How much do you know?
1 = not much 5 = expert

Want to learn more?
1 = no 5 = definitely

1	2	3	4	5		1	2	3	4	5
					Child Development					
	$\bar{x}$/SD	3.8/.6			Knowing how infants/young people grow and develop normally.		$\bar{x}$/SD	3.7/1.3		
		3.4/.9			Knowing how language develops and how I can help its development.			3.7/1.2		
		3.5/.8			Understanding methods for enhancing the social development of young children.			3.8/1.1		
		3.8/.8			Understanding the effects of stimulation on very young children.			3.7/1.2		
					Evaluation					
		3.6/1.1			Screening young children.			3.6/1.3		
		3.5/1.1			Assessing young children with special needs.			3.8/1.2		
		3.4/1.1			Understanding "intelligence tests" and evaluation procedures.			3.6/1.2		
					Funding					
		2.5/1.0			Funding and legislation for the handicapped.			3.6/1.2		
					Management					
		3.1/1.2			Being a case manager.			3.2/1.2		
		3.6/.9			Explaining handicaps to children, relatives and others.			3.7/1.2		
		3.4/1.1			Meeting with team members/families concerning infants.			3.5/1.2		
		3.2/1.0			Leading/managing groups.			3.4/1.3		
		3.3/.9			Working with aides/volunteers to develop their skills.			3.4/1.3		
		3.0/1.0			Conducting overall program evaluation.			3.4/1.3		
		3.7/.8			Working cooperatively with other agencies.			3.7/1.2		
					Medical					
		3.0/1.0			Understanding genetic influences specific to handicapping conditions.			3.9/1.1		
		2.7/1.0			Identifying dental and nutritional needs of young children with special needs.			3.4/1.2		
		2.7/1.2			Feeding and positioning of young children with special needs.			3.4/1.3		
		2.7/1.1			Adapting equipment to meet child's needs.			3.5/1.3		
		3.2/1.1			Using first aid and CPR techniques.			3.6/1.3		

ASSESSMENT OF SERVICES

How much do you know?
1 = not much 5 = expert

Want to learn more?
1 = no 5 = definitely

1	2	3	4	5	**Parents/Families**	1	2	3	4	5
	x̄/SD	3.2/.9			Understanding single parent and step parent issues.		x̄/SD	3.8/1.0		
		3.1/.8			Planning family involvement activities.			3.6/1.1		
		3.4/.9			Communicating with family members about their own needs.			3.4/1.1		
		3.7/.8			Teaching parents to work with their child.			3.9/1.1		
		3.2/1.0			Working with parent groups.			3.7/1.1		
					Professional Growth					
		3.0/1.0			Knowing about research in the area of early childhood.			3.8/1.1		
		3.5/.8			Getting the most out of professional conferences.			3.7/1.2		
					Services					
		3.5/.9			Knowing which services are available in the community.			4.0/1.2		
		3.0/1.0			Locating resources for medically fragile children.			3.9/1.2		
		3.2/.9			Finding/coordinating services of professionals/agencies for individual families/children.			3.8/1.1		
					Teaching					
		3.6/1.1			Providing the least restrictive environment for young children with special needs.			3.6/1.2		
		2.4/1.0			Working with the visually impaired.			3.6/1.2		
		2.7/1.0			Working with the hearing impaired.			3.6/1.2		
		3.1/1.0			Managing behaviorally disordered children.			4.0/1.1		
		3.3/1.0			Managing/organizing the learning environment.			3.6/1.2		
		3.6/.9			Setting limits, discipline and behavior management.			3.9/1.1		
		3.4/1.0			Developing or adapting a curriculum to meet individual needs.			3.6/1.3		
		3.7/.9			Identifying functional, age appropriate activities.			3.7/1.2		
		3.5/1.0			Implementing learning activities with individual children.			3.5/1.2		
		3.2/1.0			Collecting and analyzing progress data.			3.5/1.2		

ASSESSMENT OF SERVICES

AEA = Area Education Agency
CHSC = Child Health Specialty Clinic
DHS = Department of Human Services
HS = Head Start
LEA = Local Education Agency
MCH = Maternal and Child Health
UIH = University of Iowa Hospitals

2a. Inservice and continuing education opportunities are adequate.
CHECK ONE ONLY.

8.3%	Strongly agree	25.2%	Disagree
42.1%	Agree	6.6%	Strongly disagree
17.9%	Neutral/indifferent		

b. Inservice and continuing education opportunities are available.
CHECK ONE ONLY.

11.5%	Strongly agree	16.8%	Disagree
52.3%	Agree	3.6%	Strongly disagree
15.8%	Neutral/indifferent		

3. Identify the best FIVE inservice and continuing education sources.
NUMBER THE SOURCE IN DESCENDING ORDER. LEAVE ALL OTHERS UNMARKED.
FILL IN ONLY 5 BOXES AS THE EXAMPLE ILLUSTRATES.

5 = Best

AC = Area Colleges
DPI = Department of Public Instruction
O = Other
PO = Professional Organizations
Univ. = Universities and colleges (not UIH)

		3				5			
				4					
		2					1		

Agency

Sources	AEA	AC	DHS	DPI	HS	LEA	MCH	PO	Univ.	UIH	O (Specify)
Consultants											
Coursework											
Local workshops											
State meetings or conferences											
Telenet with visuals											
Television or video											
Topical conferences											

G. PUBLIC AWARENESS

1. Your agency provides public information about:

# / %	
183/17.3	Benefits of early intervention
161/15.2	Early indicators of handicapping conditions
198/18.7	General criteria for eligibility
241/22.8	Referral procedures
274/25.9	Services available

ASSESSMENT OF SERVICES

2. Your agency provides information to:

\# %
157/ 9.9 Community-based health centers
189/11.4 Day care providers
172/10.4 Hospitals
83/ 5.0 Neonatal intensive care units
116/ 7.0 Nursery care providers
257/15.5 Parents of preschool children
166/10.0 Pediatricians
153/ 9.2 Private agencies
202/12.2 Public agencies
165/ 9.9 Public health/maternity nurses
______ OTHER ______________________________

3. Your agency uses the following public awareness techniques:

\# %
13/ 1.9 Brochures
259/37.2 Information booths in public places
101/14.5 Media presentations to community groups
168/24.1 Newsletters
155/22.4 Public announcements (TV/radio/newspaper)
______ OTHER ______________________________
______ OTHER ______________________________

H. SUMMARY

1. Additional comments which you would like to share with the State Plan Advisory Council for Early Services group.

Prose Responses to Professional Needs Assessment

Item A2c **Offer suggestions for improving interagency processes**

Count	% of Responses	
32	19.5	Make a direct and general recommendation for more communication
44	26.8	Make a specific recommendation for enhancement of communication
9	5.5	Plan unilateral actions, with assigned roles, functions, etc, which are believed to be improvements
14	8.5	Plan mutual actions (which will be improvements)
20	12.2	Learn about each other
24	14.6	Improve procedures
2	1.2	Inform public about our individual services
6	3.7	Overcome problem of client confidentiality and refusal of client to authorize release of records which keeps agency from best serving needs of child
13	7.9	Other
164	100.0 Total	(More money, time, staff; more programs for parents of special needs children; more problem solving; more focus on child's family environment)

Item A3b **If an interagency council for young children with special needs exists in your community, indicate agencies or groups which are included in the council.**

Count	% of Responses	
3	6.0	Juvenile corrections
3	6.0	Daycare coordinator Exceptional Persons, Inc.
4	8.0	Physicians and dentists
1	2.0	Dietitian
1	2.0	WIC
3	6.0	Parents
8	16.0	Public health nurse
27	54.0	Other
50	100.0 Total	(DA, advocacy, local police, well-baby clinic, Headstart, Family Practice, Information and Referral Service, Specialized Child Health Clinic, Extension Service, ministers, mental health center, local hospitals, High-risk Infant Clinic, substance abuse, Job Service, preschools, Human Service Planning Council)

Item A4b **Which directories do you use most frequently to locate programs or services for young children with special needs and their families?**

Count	% of Responses	
6	2.5	Personal file list
42	17.4	Personal, professional contacts
31	12.9	Community directories (United Way, Crisis Line, Headstart)
13	5.4	County directories
53	22.0	Regional-AEA directories (Human Resources Directory-Greater Ft. Dodge Area [United Way])
38	15.8	State directories (Iowa Directory of Services for Persons with Developmental Disabilities, ISDH, Iowa City Hospital Schools and Clinics, Iowa State Extension Office)
12	5.0	Telephone directory
46	19.1	Other (DHS, Youth Services Dir., Families & Communities Working for . . . First Call for Help, Network, Information & Referral Service, all resources in office library, PHN Orientation Manual, VNA, What's Where in Parenting, Family and Children's Council, Family Resource Handbook by Office for Planning and Programming, foster group care lists, ICF/MR lists)
241	100.0 Total	

Item B1c **List specific duties of your agency's case managers.**

Count	% of Responses	
67	15.1	Is parent's initial contact, informs them of due process, and is their main, continuing source of support.
20	4.5	Arranges screening
29	6.5	Identifies child's needs
76	17.1	Arranges staffings, annual reviews, IEP
52	11.7	Makes referrals/receives referrals
60	13.5	Is the liason between parent/professionals/agencies
59	13.3	Monitors child's services - due process carried out (Coordinates services)

Count	% of Responses	
9	2.0	Instructs
73	16.4	Other
445	100.0 Total	

(Paper work, intervention, staff clinic, supervision of staff, evaluation of staff, take parents on schools visits to see programs, mental health, child abuse, assures that comprehensive evaluation takes place, court proceding, handles equipment for special needs)

Item B1e **If your agency has no specified case manager and you view this as a problem, elaborate.**

Count	% of Responses	
0	0.0	Gets job done
10	24.4	Efficiency
4	9.8	Task completion . . . opposite of task avoidance and buck-passing
9	22.0	Accountability/responsibility
1	2.4	Manages intake system to gather adequate information
3	7.3	Frees others to do their jobs: (i.e. case manager frees other professionals to do what they consider to be their primary job)
2	4.9	Creates an organizational structure
4	9.8	Helps parent coordinate services from different agencies
3	7.3	Provides support and information to parents
3	7.3	Other
41	100.0 Total	

Item C1 **Other activities which are a part of parental involvement in your program.**

Count	% of Responses	
2	4.3	Parent/child groups
2	4.3	Parent/child groups for 0-2.99
0	0.0	Parent/child groups for 3+
2	4.3	Social groups
1	2.2	Brochures
3	6.5	Notebook that travels back and forth from home & school
2	4.3	Parents attend therapy sessions and carry out home programs
3	6.5	Parents observe classroom
31	67.4	Other
46	100.0 Total	

(State Parent Educator Project, Parent education program "Exploring Parenting", infant/toddler classes for families, Well child Clinics, court involvement, parent training through home study manual, diagnostic-educational testing, medical referrals, parent-lending book library, individual parent training at our facility, securing financial & medical benefits & placement, field trips to fire station, library, etc.; homemaker assistance with home maintenance, give STEP, offer speakers & materials on various topics, videotapes of speech therapy sessions, IEP for their child, Policy Council Meetings)

Item C4 **Describe the problems of your agency's parent program.**

Count	% of Responses	
3	0.8	Problems with motivation of professionals
2	0.5	Disincentives (e.g. paper documentation) for working with parents
18	4.8	Inadequate time/energy
3	0.8	Parents viewed as difficult to work with so avoid them
2	0.5	Need to learn to work in an integrated fashion with other agencies
4	1.1	Need to improve notification to parents of meetings, services, etc.
1	0.3	Parents have precedence over professionals
1	0.3	Lack of showing enthusiasm & giving support to fellow workers
0	0.0	Problems with training of professionals
2	0.5	Teachers not prepared to work with parents of handicapped
1	0.3	Lack of training
2	0.5	Need to learn to consider the parents' feelings, thoughts, attitudes
1	0.3	Case manager & family therapists at low skill levels
9	2.4	Problems with caseload/paperwork of professionals
2	0.5	Individualize each case
1	0.3	Work closely with therapist, doctor and other parties in setting up plan of home care with child
3	0.8	Agency problems
22	5.9	It's clearly not a goal or priority for the agency.
3	0.8	While it may be an agency goal, no one has been designated as responsible for making it happen.
0	0.0	While it may be an agency goal and we have a responsible party, no time has been in anyone's work schedule to get the job done.

Count	% of Responses	
1	0.3	Program not geared toward parents of handicapped children
4	1.1	Information given to parents from various agencies is not always consistent
2	0.5	Inconsistency in dealing with families and their needs because some parents don't assert themselves
10	2.7	Agency is being reorganized/is just starting a parent program
2	0.5	Discontinuity of service - one team screens, a different team serves needs of child
2	0.5	Improve intra-agency communication so as to improve procedures
50	13.4	Problems with motivation of parents
40	10.7	Lack of parent support groups (Lack of interest, no transportation)
3	0.8	Lack of respite care facilities for infant/toddler handicapped children
2	0.5	Lack of toy-lending library
9	2.4	Lack of sufficient contact with professionals
2	0.5	Low income families - lack of financial resources
2	0.5	Persuading separated/divorced parents to work cooperatively with agency to benefit child
10	2.7	Lack of parental concern for child - don't want to get involved
3	0.8	Parents don't continue to attend meetings after child is placed
3	0.8	Parents not included in decision-making process
6	1.6	Problems with training of parents
3	0.8	Training is aimed too far over heads of most parents of handicapped children.
4	1.1	Training needs to be more frequent.
4	1.1	Training should cover a greater breadth of topics and emphasize a more realistic breadth of learning styles (less informational delivery, more hands-on stuff)
5	1.3	Training should meet needs of parents who have extremely varied educational and economic backgrounds
1	0.3	Agencies have too long a waiting list
3	0.8	Need parent activism training sessions
3	0.8	Need to have home visits so as to show parents how to work with children
1	0.3	Parental training is offered but many parents have conflict of other programs to attend
3	0.8	Lack of groups, advocates, training, etc.
10	2.7	Problems with the understanding (i.e. the information base) of parents
0	0.0	Don't understand the law

Count	% of Responses	
2	0.5	Don't understand schools or instructional process
2	0.5	Don't understand the needs of their children
2	0.5	Don't understand how much work there is to do with child
3	0.8	Have a fear of asking questions or of stating their opinions and
0	0.0	Parents are very involved in their individual situation but not in overall planning of programs
5	1.3	Parents are frustrated & overwhelmed at staffings/meetings due to number of people present
9	2.4	Other
16	4.3	Inadequate staffing
16	4.3	Inadequate funding
1	0.3	Inadequate facilities
4	1.1	Inadequate need of services
7	1.9	Lack of dedication and commitment on part of parents and/or professionals
20	5.3	Conflicting work schedules of professionals and parents
8	2.1	In rural area, don't have enough parents with similar needs living close enough to make travel realistic
5	1.3	Parents & staff need to learn more about other
6	1.6	Need more variety in program offerings
374	100.0	Total

Item C5a-5c **List strengths of your agency's present parent participation activities.**

Count	% of Responses	
4	0.9	Staff qualities
8	1.9	Staff committment
11	2.6	Staff skills
18	4.3	Staff openness/availability
9	2.1	Well-connected with other community agencies
2	0.5	Explains programs to parents
4	0.9	Innovative & creative
2	0.5	Excellent communication between team members who serve the various school districts
17	4.0	Staff other (sensitive to parents' needs, concerns, problems; full-time parent program coordinator, coordination of activities)

Count	% of Responses	
4	0.9	Quality of instructional system
7	1.7	Diagnosis and/or screening
2	0.5	Prestaffing procedures
5	1.2	Staffing itself
17	4.0	Instructional activities which involve parents
8	1.9	Instructional activities which involve parents and which take place in the home
4	0.9	Evaluation
4	0.9	Quality of referral
58	13.7	Other: (Home intervention component of classroom services, yearly needs assessment, no fee, daily "log" notebook, parents involved in case plan, parent volunteers in classroom, video tape of children in classroom for P/T Conferences, parent volunteers given recognition)
12	2.8	Quality of instruction/training for parents
19	4.5	Information adapted to parental needs
4	0.9	Delivery system suited to diversity of parental needs (i.e. it is individualized)
7	1.7	Parental involvement in planning of parent training
15	3.6	Location in the home
3	0.7	Availability of materials for use by parent and child at home
3	0.7	Variety of parent groups available
3	0.7	Regularly attend groups & meetings
1	0.2	Availability of information parents can access at any time
14	3.3	Other aspects of parent training program (Good speakers, actively involves parents)
0	0.0	Quality of counseling or other support for parents/families
3	0.7	Counseling
10	2.4	Advocacy/informing of legal rights
21	5.0	Parent support group
32	7.6	Availability of service
11	2.6	Quality of service (use this if quality rather than availability is stressed)
2	0.5	Child care is provided families
2	0.5	Other: (Explaining program goals of agency)

Count	% of Responses	
4	0.9	Administrative/legal/bureaucratic strengths
3	0.7	Rapidity/timeliness of communication
1	0.2	Can force parents to improve parenting and meet child's needs via court
1	0.2	Allocate money
13	3.1	Parents make decisions on Policy Council
1	0.2	Court orders that guarantee compliance
3	0.7	Positive qualities of parents
9	2.1	Are viewed as members of diagnostic-treatment team & consider themselves as important contributors
2	0.5	Fund raising
5	1.2	Other
25	5.9	Good communication between parents & staff
2	0.5	Agency provides or reimburses transportation
2	0.5	Staff sends newsletter
1	0.2	Resource guide produced for parents
1	0.2	Toy-lending library
1	0.2	Had been long established & well-accepted
422	100.0	Total

Item C6 **Describe ideas for improving parental participation in the program.**

Count	% of Responses	
28	13.2	Develop parent support groups.
1	0.5	For mothers less than 20 (who live near the agency)
4	1.9	Father's work day at school, Father/Kid Day out or a "Dad's" group
1	0.5	Parent interaction opportunities on days of evaluations
2	0.9	Improve quality of present parent program.
13	6.1	Make content of program pertinent to parent's needs.
4	1.9	Aim level of communication to parent's level of understanding.
1	0.5	Increase incentives/decrease deterrents of professionals working with parents.
8	3.8	Increase parent's awareness of what programs are available to them.
4	1.9	Have parents volunteer in child's classroom
2	0.9	Stress experiential tasks
6	2.8	Increase parents' desire to improve their parenting skills
4	1.9	Staff should be knowledgeable of parents' and children's needs

Count	% of Responses	
13	6.1	Other quality improvement (Continue to make parents responsible for specific IEP goals, View videos of child's classroom, Require parents to volunteer in classroom 1 day per month, Have parent advisory committee, Get both parents to attend counseling sessions)
4	1.9	Increase size of present parent group.
6	2.8	Increase rapport between parents and agency
4	1.9	Send frequent written reminders about parent support group meetings
1	0.5	Have a point system where points are earned by attendance
9	4.2	Increase contact with parents
3	1.4	Include parents in professional meetings
1	0.5	Require parent/teacher contact prior to referral
5	2.4	Provide/reimburse transportation
1	0.5	Improve image parents have of the agency
1	0.5	Have a specified advocate help parents through referral/staffing procedures
4	1.9	Provide child care
2	0.9	Plan more activities, e.g. potlucks
1	0.5	Have PTA's
3	1.4	Weekly newsletter, send home note when child achieves IEP goal, etc.; Rotate sites and times of meetings, Offer meetings on a more regular basis)
27	12.7	Offer more learning experiences for parents (i.e. workshops, parent's nights with speakers, parental training for parents of children with frail health, preventative education, LD in preschoolers)
4	1.9	Implement home visitation to do parent training
1	0.5	Staff teach adult ed courses
1	0.5	Develop program to work with parents of 3-21 year old population in their homes
6	2.8	Increase staff
2	0.9	Hire more parent advocates
1	0.5	Need OT/PT
2	0.9	Hire one person to be responsible for specific planning
1	0.5	Hire a parent educator to be liason between classroom and home skills
1	0.5	Plan staff according to needs of programs rather than traditional method of who has always been largest department
1	0.5	Need those who can put "network" process to work for the family
1	0.5	Need more qualified/specialized staff

Count	% of Responses	
8	3.8	Give staff more flex time to work an occasional evening/Saturday
		Collaborate between agencies
1	0.5	Need more referrals from other agencies & coordinated case management with these agencies
2	0.9	Need more unified coordination of services
1	0.5	Include interagency contacts & community development in job description of case manager
3	1.4	Other
2	0.9	Parents' Day in the classroom
6	2.8	Need more variety of parent groups
1	0.5	Assoc. of MR's needs to have more representation at local level
1	0.5	Hold staffing without parents & then notify them of the results by sending a representative to them
1	0.5	Stop depending so much on AEA for support, etc. to parents & start doing more on our own
1	0.5	Need a toy-lending library
1	0.5	Make parental involvement mandatory
212	100.0	Total

Item C7 — List services for which parents of handicapped children are currently paying at your agency.

Count	% of Responses	
2	3.3	All services
15	25.0	Foster care
7	11.7	Milk money and lunch
3	5.0	Outside services that were formally provided free by the agency (physical therapy)
2	3.3	Sliding fee for all services if not covered by third party payment
1	1.7	Clinic charges
3	5.0	Tertiary medical care
1	1.7	Immunization by donation
26	43.3	Other (Occasionally homemaking/childcare on sliding fee, Services after initial evaluations at Iowa City Hospitals, Private preschools, Medical exams if child not on title XIX or if parents don't fall below clinic cut-off level, PT, Evaluation & treatment by professionals, Outpatient variable based on capacity of parent to pay, Easter Seals [summer speech therapy, special materials like wheelchair, braces, etc.], Skilled nursing-home care program)
60	100.0	Total

Item D1 **Other screening programs are available for children birth through 35 months and 36 through 71 months.**

0-35 mos. Count	0-35 mos. % of Responses	36-71 mos. Count	36-71 mos. % of Responses	
7	5.6	2	5.6	Physicians
18	14.3	2	5.6	CHSC
20	15.9	4	11.1	UIH
8	6.3			High Risk (infant) follow-up
2	1.6			Community Health Care
		2	5.6	Project Catch
12	9.5			LEA
6	4.8			Child Diagnostic and Planning Services
8	6.3	7	19.4	WIC
1	0.8			School nurse
2	1.6	3	8.3	Specialized Child Health
4	3.2	2	5.6	MIC (Maternal Infant Care)
2	1.6	2	5.6	MECCA
2	1.6			VNA-CHC
1	0.8			Chapter 1
33	26.2	12	33.3	Other (School system, PHN, WCC, Woodward, Hospital other than UIH, Child Fair, ACES, Community Mental Health, Daycare, Kindergarten Roundup, Meyers Children Rehabilitation Institute, Children & Youth Services)
126	100.0	36	100.0	Totals

Item D2 **Other screening processes at your agency.**

Count	% of Responses	
		Motor
14	26.9	Fine motor
2	3.8	Gross motor
2	3.8	Behavioral
5	9.6	Psychological
2	3.8	Intellectual
1	1.9	Cognitive - verbal
1	1.9	Reasoning
1	1.9	Readiness for school
3	5.8	Physical
1	1.9	TB
7	13.5	Nutritional
1	1.9	Hematocrit

Count	% of Responses	
2	3.8	Dental
1	1.9	Family history
1	1.9	Immunization status
1	1.9	Adaptive behavior
2	3.8	Family/Social
3	5.8	Other (Parent questionnaire of basic concerns, nursing assessment)
315	100.0 Total	

Item D4 **Other means for providing screening results to parents.**

Count	% of Responses	
2	4.4	Doctors
2	4.4	Copies of test instruments
10	22.2	Personal conferences
4	8.9	Personal letters
1	2.2	Nurse
7	15.6	Staffings/staffing reports
1	2.2	Summary sheet
3	6.7	Checklists completed at screening
15	33.3	Other (Copy of referral, written report, send results back to agency who then notifies parents)
45	99.9 Total	

Item E1b **If agencies require various entrance criteria which create barriers, when and where does this occur?**

Count	% of Responses	
		Headstart
2	1.9	Location of parent's home
7	6.7	Income guidelines
4	3.8	AEA
2	1.9	1 year limit on extended evaluations
8	7.7	Meeting "special ed" criteria
1	1.0	Being labeled
1	1.0	Administrator's failure to recognize the need for preschool services
1	1.0	In rural counties, lack of 0-3 services for identified kids
1	1.0	Social worker services available for sp. ed. students only
1	1.0	Request for evaluation not accepted when parent not available

Count	% of Responses	
1	1.0	Testing & acceptance into program takes too long & is not available in summer
1	1.0	DHS
2	1.9	Parents are providing "minimal" care and doing damage
1	1.0	Inability to deal with emotional needs (which are nurturance, caring, consistency, etc.)
7	6.7	Income guidelines
1	1.0	When medical assitance is required but income precludes preventive assistance
1	1.0	Hard to get services to children if not MD or PH
2	1.9	Protection
		UIH
1	1.0	Length of time before child is seen
1	1.0	Distance to travel for services
		MCH
1	1.0	Decrease in funding caused services to children over 3 to be dropped
		CHSC
2	1.9	Inability to serve environmentally disabled
3	2.9	At-risk preschoolers who are not MD but are low average should qualify as developmentally delayed
8	7.7	Entrance criteria keeps children out who could benefit from services now. This would prevent some of the need for intense special ed services when children reach school age
3	2.9	No insurance and family is over financial guidelines
5	4.8	Class/Agency is overloaded - long waiting list
1	1.0	Child's label which is required for entrance to services frustrates and confuses parents
2	1.9	Duplication of agency services causes parents confusion over where to send child for help
2	1.9	When referring
12	11.5	Income guidelines
4	3.8	Other
1	1.0	Mental Health - long wait
1	1.0	Child Abuse - rude
2	1.9	Agency/School - lack of programs
2	1.9	Chapter I - location of parent's home
2	1.9	St. Luke's - keeps parents under economic stress
1	1.0	Some doctors - Recommend child should stay home until kindergarten

Count	% of Responses	
1	1.0	Regular programs - mainstreaming of handicapped
1	1.0	State - evaluations
2	1.9	All - cannot release information between agencies without agreements
104	100.0	Total

Item E2 **Indicate other social, health, or educational services which are available from your agency.**

Count	% of Responses	
1	9.1	Referral services
5	45.5	Home nursing on intermittant basis
2	18.2	Immunizations
2	18.2	Toy-lending library
1	9.1	Information network on assistive devices
		Other
11	100.0	Total

Item E3a **Other effective tracking systems used by agencies.**

Count	% of Responses	
2	33.3	Hospitals (other than UIH)
1	16.7	WIC
0	0.0	Public schools —
2	33.3	PHN
1	16.7	Easter Seal Society (Siouxland)
6	100.0	Total

Item E3b **Suggestions for improving tracking systems.**

Count	% of Responses	
6	7.0	Eliminate duplication and inconsistency
1	1.2	Master release form
2	2.3	Master IEP and goal forms
2	2.3	Uniform assessment forms and procedures
1	1.2	Unified, central service
3	[illegible].5	Do generally
		Other
4	4.7	Master agency in charge of records and evaluation

Count	% of Responses	
1	1.2	Clearing house agency
17	19.8	Enhanced interagency communication
3	3.5	Quicker interagency communication
1	1.2	Need closer communication between AEA & LEA for preparing schools for young children with sp. needs
2	2.3	Feedback forms sent at the time of the referral
6	7.0	Ongoing communication between sending and receiving teams
3	3.5	Reduce barriers to releasing data to agencies which have a legitimate need for information
1	1.2	Need for information changes from state to state
2	2.3	Use a case manager - transagency
1	1.2	Between UIH & AEA or LEA about exact recommendation for adaptive equipment
1	1.2	Better sharing of resources, ideas & information between Headstart & LEA
3	3.5	Enhanced interagency planning
1	1.2	Multi-agency staffing for service needs & follow-up
6	7.0	Master database
1	1.2	Master evaluation system Improve coordination between agencies
0	0.0	Specific actions
1	1.2	More time
1	1.2	More money
2	2.3	More frequent evaluation or monitoring
5	5.8	Systematic follow-up
2	2.3	Periodic reviews
1	1.2	Interdisciplinary teams
1	1.2	Keep files longer than 5 years after case is closed because client's tend to show up again years later
1	1.2	More use of PHN
1	1.2	More staff
0	0.0	Other
1	1.2	Thorough record keeping
1	1.2	Use phone instead of computer form letter when first contact is not effective
1	1.2	Include more educationally significant information
86	100.0 Total	

Item E4 **Other agencies that provide services for the following at-risk categories.**

	Environmental		Medical		Psycho-Social	
	Count	% of Responses	Count	% of Responses	Count	% of Responses
No responses	297	94.3	278	88.3	278	88.5
LEA	4	1.3	2	.6	2	.6
MCH			3	1.0	3	1.0
UIH	1	.3	12	3.8	12	3.8
Public Health Nurses	9	2.9	11	3.5	11	3.5
Other nursing						
MECCA	1	.3	2	.6	2	.6
CDPS			2	.6	2	.6
Child abuse agencies	1	.3	1	.3	1	.3
Other	2	.6	3	1.0	3	1.0
(Hillcrest Family Services, Blank Clinic, High Risk, WIC, VNA)						
			1	.3 missing	1	.3 missing
	315	100.0	315	100.0	315	100.0

Item E5

Agencies or individuals who offer services for "at-risk" or "high risk" children who are NOT identified as handicapped.

Count	% of Responses	AGENCY/INDIVIDUAL
1	0.7	Central Iowa Mental Health Center, Ames
1	0.7	Christian Home Association, Council Bluffs
1	0.7	Community Opportunities, Inc., Carroll
1	0.7	Des Moines Child Guidance Center, Des Moines
1	0.7	Dubuque/Jackson County Mental Health Cntr., Dubuque
1	0.7	Easter Seal Society of Iowa, Inc., Des Moines
13	9.1	Lutheran Social Services
3	2.1	Mental Health Center of Mid-Iowa, Marshalltown
1	0.7	Mental Health Insitute, Cherokee
2	1.4	Mercy Mental Health Center, Council Bluffs
1	0.7	Mid-Eastern Ia. Community Mental Health, Iowa City
1	0.7	Siouxland Easter Seal Center, Sioux City
1	0.7	Smouse Opportunity School, Des Moines
1	0.7	Southern Iowa Mental Health Center, Ottumwa
2	1.4	St. Luke's Methodist Hospital, Cedar Rapids
6	4.2	University of Iowa Hospitals & Clinics, Iowa City
1	0.7	University of Northern Iowa, Cedar Falls
1	0.7	Hospital Admissions, UIH
1	0.7	Physicians, pediatricians, UIH
1	0.7	P.O.S. with licensed psychologists
1	0.7	University of Iowa Dept. of Counseling Ed.
1	0.7	Counseling & Family Centered Social Agencies
1	0.7	Protective Service Specialists
1	0.7	Beloit of Iowa
1	0.7	Parent aides
2	1.4	Medical clinics
7	4.9	Area Education Agencies
3	2.1	Chapter 1
3	2.1	Catholic Social Services
15	10.5	Headstart
10	7.0	Iowa Children and Family Services
6	4.2	High Risk Follow-up Services
1	0.7	Community Nursing Service, Marshalltown
1	0.7	4 Oaks
1	0.7	Alternative Kindergarten, Marshalltown
1	0.7	Local preschools, Sioux City
2	1.4	Department of Human Services
2	1.4	Catholic Charities

Count	% of Responses	
1	0.7	Juvenile Court Services
1	0.7	SEARCH Clinic
1	0.7	Orchard Place
1	0.7	Private Service Providers
2	1.4	Private preschools
1	0.7	HS
1	0.7	Urban Ministry, Ft. Dodge
1	0.7	Well-Child
1	0.7	Schools
1	0.7	Parent Survival Program
1	0.7	In-Home Comprehensive Program
1	0.7	Early Developmental Intervention
1	0.7	Willowcreek Neighborhood Center
1	0.7	Project Aid
1	0.7	MECCA
1	0.7	Wabonsie Mental Health
1	0.7	Mental Health Center, Grant Wood
6	4.2	American Home Finding, Ottumwa
1	0.7	Florence Crittendon Home, Sioux City Area
1	0.7	Crisis Center, Ottumwa
4	2.8	Child Health Specialty Clinic
1	0.7	St. Francis Hospital Infant Apnea Program
1	0.7	Adult Child & Family Mental Health Assoc.
1	0.7	County Mental Health, Creston
1	0.7	Quakerdale Family Therapy
1	0.7	Exceptional Persons
1	0.7	Battered Women's Shelter
1	0.7	Mercy Child Guidance Clinic
1	0.7	Parents Anonymous
1	0.7	Tri-County Counseling Families, Inc.
1	0.7	Hearing & Speech Center, C.P.S.
1	0.7	Area Comprehensive Evaluation Services
1	0.7	Dubuque Mental Health Center
1	0.7	Mental Health, Peosta
143	100.0	Total

Item F3 — Identify the best five inservice and continuing education sources.

Count	% of Responses	
289	91.7	No Response
2	8.3	ARC
1	4.2	IAPTA
2	8.3	University Extension
1	4.2	IPBN
2	8.3	Hospitals
1	4.2	Workshops
3	12.5	ISDH
1	4.2	CHSC
9	37.5	Other: (Meyers, Iowa Lakes, NAEYC, Professional journals, Doctors, Local speakers)
2	8.3	Missing
315	100.0	

Item G2 — Your agency provides information to:

Count	% of Responses	
13	4.1	Any agency with permission for request for information (WIC, LEA, AEA)
1	.3	Private preschools
3	1.0	Anyone who can improve the child's needs
1	.3	Local groups
5	1.6	Local school districts
1	.3	Private physicians
1	.3	Pre-natal classes
2	.6	Other: (Private/Public groups & organizations)
27	8.5	

Item G3 Your agency uses the following public awareness techniques:

Count	% of Responses	
3	1.0	Use visuals (billboards, newspaper articles, posters)
6	1.9	Give presentations on various disciplines
1	.3	Visit preschools
3	1.0	Participate in health fairs/education fairs
4	1.3	Attend LEA or other professional organizations' meetings to increase visibility
3	1.0	One-on-one public relations
2	.6	Parent groups
1	.3	Annual open house
11	3.5	Other: (AEA, Phone calls, Letters, Have a recruitment day, Child-find Clinics, Home visitor counseling)
34	10.9	

Item H1 Additional comments you would like to share.

Count	% of Responses	
3	1.8	Comments on services: I don't work with handicapped children or preschool age children
15	8.9	Positive comment
1	0.6	Need more education & planning for "chronically ill/technology dependent" special needs children
1	0.6	Need more direct therapy intervention for infant/young child available through AEA
1	0.6	Professionals need more flex time so they can see working parents
0	0.0	Respite care services are needed by parents of handicapped children

Count	% of Responses	
1	0.6	Expand Headstart to serve a higher number of average income 4 year olds
1	0.6	Utilize extension services more
2	1.2	Problems with survey
3	1.8	Too long
0	0.0	Took too long to complete —
3	1.8	Jumps awkwardly from personal to agency point of vie
14	8.3	Feel unqualified to respond
4	2.4	Reliability/validity questioned
3	1.8	"My time is more valuable than this!"
1	0.6	Examples needed to clarify questions
1	0.6	Difficult to interpret
1	0.6	Not appropriate for physicians/pediatricians
0	0.0	Somebody blamed for problems
1	0.6	Medical community
0	0.0	Legislators
0	0.0	State officials
1	0.6	Federal Government, any branch
0	0.0	Universities, colleges, etc.
4	2.4	AEAs
1	0.6	School districts
0	0.0	Regular teachers
11	6.5	Other (Model of service, Parents, Administrators, Legal system & social services, Lack of a well-defined plan for working with special needs children)
1	0.6	Improve communication
1	0.6	Betweem UIH and communities a long distance away
3	1.8	Need ongoing communication between sending and receiving temas as child moves from one program to next (tracking)
5	3.0	Need improved communication between medical & educational agencies
2	1.2	Need a handbook of address, facilities, services (their fees & reductions) available in the state
6	3.6	Between all the parties that work with the child
1	0.6	AEA, UIH & PHN - increase referrals
1	0.6	Develop written standards for coordination of the care of special needs youngsters

Count	% of Responses	
3	1.8	Improve information dissemination, public relations
1	0.6	Need more parent involvement
2	1.2	Improve training of professionals
2	1.2	Administrators
0	0.0	Nurses
0	0.0	Doctors
0	0.0	Social workers
1	0.6	Teachers
1	0.6	Speech clinicians and/or audiologists
1	0.6	Occupational and/or Physical Therapists
2	1.2	Psychologists
3	1.8	Other Teacher & parents behavior modification in-service, In-service for professionals, Headstart home visitors)
0	0.0	Improve agency function
2	1.2	Intra-agency
3	1.8	Need systematic, comprehensive Child-find program for 0-6 year olds
3	1.8	Pair home intervention with the classroom program as early as possible
1	0.6	Need OT's & social workers
5	3.0	Interagency
2	1.2	At-risk preschoolers who are not MD but are low-average should qualify as developmentally delayed.
1	0.6	Improve intra-agency procedures with standardized forms, etc.
1	0.6	Need pediatric medical consultants available prior to evaluation & during staffings
2	1.2	Improve financial support
0	0.0	To families
0	0.0	To universities
0	0.0	To government
7	4.2	To AEAs
2	1.2	To school districts
4	2.4	To agencies
1	0.6	Target support to children with the most potential
0	0.0	To other
2	1.2	Other (service comments)

Count	% of Responses	
2	1.2	Early services seem adequate
12	7.1	Need more professionals providing services to young handicapped children (i.e. PT, OT, Teachers of Down Syndrome children, Residential psychiatric care for preschoolers, preschool psychologists)
2	1.2	Improve screening & follow-ups of high-risk infants in small towns & rural areas
2	1.2	Services are ineffective
1	0.6	Need better informed government representatives
1	0.6	Rely on AEA to do everything for our handicapped preschoolers
1	0.6	Need more daycare centers for 2 year old untrained children
1	0.6	The geographical area staff (AEA) has to cover is too large. Although the number of children is low, driving time and availability of service due to geographical location is a problem.
1	0.6	Program is going through structural changes (208)
168	100.0	Total

PROFESSIONAL COMMENTS CONCERNING SERVICES TO YOUNG CHILDREN WITH SPECIAL NEEDS

January 30, 1987

The following are summary comments made by professionals. (R. indicates respondent and the digit indicates code # of respondent). Missing digit — no comment made.

R.2 Early services seem adequate.

R.3 I feel we need more professionals providing these services. Those who are here are great, but they are overworked.

R.5 Too many resources go into various services, including "education" for seriously mentally handicapped. This may be a "good" political decision but is a bad service decision because it drains resources which could be applied to more intense remedial services toward rehabilitating children who have potential.

R.7 Early intervention is extremely important. Screening for high risk infants and follow up needs to be coordinated and much more uniform. The larger cities are generally at an advantage in this and the small town handicapped kids get "picked up" and medically diagnosed much later.

R.12 Public relations here is very poor as it is in many areas in state. I believe a brochure, explaining normal child development in layman's terms, should be made available to every mother at the time of her child's birth. The name of the AEA serving the area should be on it and any questions a parent may have could be directed to this agency. It is imperative that we get those referrals as soon as possible. All parents should be made aware of services available at the time of kindergarten round-up. Information should be available to anyone requesting it through school guidance offices. We are not getting kids soon enough because people do not know what is out there. More communication between DHS and AEAs particularly at the county level. We need their services, particularly in regard to financial concerns for those in need.

R.15 This is a terrible assessment. It reads laboriously. It does not apply to most issues. It is too long. My time is more valuable than this!

R.17 It is time for a full-scale evaluation of the model of delivery of services. Much professional time is spent not providing direct service to families. The consultative model has served its purpose. Also, would like to see less duplication of services between agencies.

Therapy services provided to children need to be clearly defined for parents as to what they should expect.

Administrative decisions are not always in the best interest of families and their needs. Again a more uniform understanding of the laws and stricter compliance would help eliminate any personal decisions made by an administrator who doesn't fully understand or believe in early intervention.

R.22 I think it needs to be noted that some preschoolers are not served because 1) the custodial parent isn't capable of understanding that their child needs help and 2) that some parents just can't be bothered to seek the help or to show up once someone else makes the first step for them.

I'm afraid I have no cure for these problems but if one can be found, a lot more children in need would be helped.

Inservices are fine and there are seminars and conferences often but I cannot attend unless the agency pays and they 1) don't have the money or 2) won't let us attend out-of-state conferences until we have worked here 2 years. I think if I am willing and able to pay my own way to conferences I should be allowed to go, as the agency/children will benefit.

R.23 I would appreciate a copy of the results of this survey.

R.27 The "case manager" structure for young children with special needs currently in Iowa is adequate but there is room for improvement. We need more staff to handle all the need. Also, I am satisfied with my agency's parent program but we could use more of these programs, particularly for working and single parents.

R.28 Any way which can coordinate services across agencies and not increase paper work requirements will be appreciated. I have had informal contact with people working in other agencies and it is amazing how little I know about their roles and goals as well as how little they know about the agency I work for. As a result of these conversations the level of cooperation has increased. I hope similar results can be obtained by addressing these issues at a state level.

R.29 At our local hospital we have a very progressive OB department. Babies (high risk and any that are developmentally handicapped, etc.) are referred immediately. AEA is very active and the local school system also has a great program. We also have a special school at Pleasant Hill. There is much support within the community.

R.32 A real concern at this level is that services continue to be expected with cuts in personnel — both support and instructional. Interesting enough, little administrative cutting is done.

From my perspective and from the perspective of many AEA and LEA colleagues the role of consultant needs to be more efficiently defined.

R.34 Do something about every other day kindergarten programs. I know they serve only the top end of the group you're interested in, but the lower half of that age group intellectually is suffering as well as the handicapped kids in the same group. Besides that, the school is being reimbursed for a full day's education and only giving a half day program equivalent.

R.39 The agency could really improve in the area of public awareness. I feel that there are a lot of children out there with special needs who should be served, but parents are unaware of services that our agency provides.

R.43 Always, always the need to improve referral rate from medical community to educational services.

Need to improve communication between Iowa City University Hospital to communities such as ours that are long distances apart.

Improve educational content of classes for preschool special education. Need more information in very young medical report reading, multi-handicapped, adaptive equipment and positioning.

Better informed government representatives.

R.44 I believe AEA services would be utilized more if the public was more informed.

R.46 Although Heartland provides a number of diverse services which appear to be of high quality, when one considers the needs of this particular population group, the goal of adequacy is often times unreachable. Increased emphasis on services for preschoolers will ultimately result in minimizing the effects of handicapping conditions on school age and adult populations. This is a primary example of an area where increased funding will result in increased services and ultimately enhance the quality of life of the target population.

R.48 Some of the terms in survey weren't clear. Wasn't clear on whether you wanted information from my own perspective or the perspective of the agency as a whole. Examples would have made questions clearer, i.e. EPSDT - is this a generic term or specific?

R.49 My work tends to be with older children. In the past 3 years I have probably only worked with 10 children ages 0 to 6.

R.56 I work specifically with the 3-6 year old population and happen to serve all preschool programs for children this age who reside within the Marshalltown School District. Having a consistent preschool team across programs facilitates movement along the continuum of services from least restrictive to most restrictive services. Private preschools, day cares, AEA 6 home intervention only students, Head Start, Chapter I preschool, Alternative kindergarten, and special education preschools all provide services to this age group. There are enough options to provide the best individualized programming, with little duplication (Head Start and Chapter I are very similar, although there are differing financial guidelines).

Efforts to invite representatives from receiving teams are consistently made to facilitate transitions (especially as children leave preschool programs to attend school-age programs). Records follow to assist in the transition, unless specifically requested otherwise by parents.

R.59 Our agency is a public school — most of this assessment is provided or taken care of by our AEA 12 in Sioux City.

R.62 I answered the questions in this survey to the best of my knowledge. I feel, however, I did not know enough to answer most of the questions regarding our agency's communication with others except for the hearing departments. I based a lot of my answers on this. Since this is the department I work in I know the most about it. Perhaps this also calls for more interdepartmental communication regarding the children's needs as well as between agency and parent communication. I do admit that I would know who to go to in our agency or others to get information for parents when necessary.

R.67 More money so we can deliver adequate service for these children. We are losing teachers and aids.

R.73 It takes dollars and people to implement services! The Department of Human Services has been severely cut in the lower population counties and provides very few services to this population.

R.75 In working with the environmentally deprived, abused and neglected young child, our greatest resource is the day care. It provides that child with at least some form of normal and healthy stimulation, socialization and safe environment Nutritional needs of that child are met as well as emotional needs.

Several things should happen. We need more centers available and of even better quality. This is also the most natural place for parent training to take place. The parents need to be required to spend some of their time at the center with the children — they can learn as they volunteer.

We need more centers that will take children not potty trained younger than two. The entire city of Des Moines currently has one center that will take a two year old not trained.

R.77 The AEA (Grant Wood) provides excellent support for the preschool handicapped classes in our area. The LEA depends on their support services.

R.78 As a school psychologist, I would like to become proficient in administering, scoring and interpreting neuropsychological tests on infants, toddlers and young preschool age children. I do feel that this kind of data, carefully collected and analyzed would permit professionals working with parents to better identify individual needs of a child, to program to meet these needs, and then to make some predictions as to the child's future functioning, his/her progress and subsequent needs on an annual basis.

We need better diagnostic/screening instruments with increased validity/reliability. Greater public education on hazards of smoking, drinking, detrimental life styles, etc. is suggested. Methods for reaching populations in underserved needs exploration. Certainly premarital counseling and genetic counseling is needed. Potential parents can be advised of risks in having children.

R.80 Medical and educational agencies are not working together in Ames. This causes a major rift in communication and continuity of information to parents which leads to confusion.

Parents are not finding our agencies' services (AEA and public education) by formal sources. It's a rather fly-by-night, hit or miss chance. It's a problem. Doctors do not refer children to us. They refuse to place our brochures in Peds or OB. Help!

R.84 More coordination is needed. I feel our relationship with DHS is very good and the need for more of the same is needed. Physicians are in need of inservice related to our training and services we provide as well as developmental milestones in young children to make cross referrals more appropriate.

R.87 As a classroom teacher I wasn't comfortable answering the questions that dealt with the "agency" as a whole. The directions said to leave the spaces empty if I didn't know. I did that for most questions. If I changed the question to pertain to my situation, I wrote it next to the question. I thought this was a thorough questionnaire. I hope this helps!

R.89 A handbook of addresses/facilities/services available in the state would be very beneficial! Also, which ones require payment and/or offer reductions, etc. would be invaluable.

R.91 I think our agency "team" is fragmented, even though individuals try to be effective. This is also true of the interagency network in this area.

I don't have time to spend on this before your deadline. I would like to say that I'd like to be part of the "solutions" and not just a problem identifier. Thanks for asking me for my opinion. I have many more.

R.92 Thank you for this opportunity.

R.95 Please shorten your questionnaire.

R.97 I think our agency does an outstanding job of trying to identify and meet the needs of young handicapped individuals.

R.101 Biggest problem right now is the geographical area staff have to cover. The numbers of children may be low but driving time and availability of service due to geographical location are big problems in some cases.

Extended evaluation classification has been a wonderful tool for us in making more accurate diagnoses which were impossible at an early age.

R.102 I believe that each child should be provided with full services according to his/her need. At this time we have no services by a physical therapist in our AEA! I feel strongly that we need one, at least on a consulting basis.

R.105 More inservices are needed throughout the state for early childhood educators. School administrators need to take more inservice training to become aware of the unique problems of early childhood education.

R.109 I am concerned that children 18 months of age are being placed in classrooms of 8-10 especially those diagnosed with Down Syndrome. I strongly feel they need to be in a classroom program but the numbers should be no more than 5 children to a teacher and an aide at that young age.

I feel home intervention is good but it should be paired with a classroom program as early as possible.

R.110 This survey takes longer than 40 minutes to complete. Early intervention programs for preschool handicapped children are extremely important as are support programs for parents and families at this level. We have kept longitudinal information on children for the last 9 years and we feel the positive results of the programs substantiate our efforts.

R.114 The greatest need in Heartland AEA is to provide better child find services at the 0-6 year level. We seem to have many children coming to our attention at kindergarten age who are mildly handicapped and would have benefitted from services prior to age 5. In addition, the agency needs to require inservice for many of the psychologists who are uncomfortable with evaluation of young children. They need direct practice and feedback on how to improve assessment of young children. For example, bring in Guidabaldi Ohio to do a workshop on the Battelle and use real children to demonstrate the use of this instrument. Or at least have a vareity of videotapes.

R.115 In central Iowa, we need a systematic comprehensive child find program. Too many students arrive at kindergarten round-up who would have been eligible for services during preschool years.

In addition, more personnel needs to be funded to improve the services to parents of handicapped children and to the children themselves. Parents of these children are not always good advocates for the child nor capable of following up with appropriate programming.

R.123 I am very concerned about the cutbacks and the effects they will have on our services.

I am concerned that some of the medical profession do not understand the importance of early intervention and therefore do not refer children to our program (it's getting better!) or still feel they will "outgrow" the problem or feel children should stay at home until kindergarten.

Also, I feel there are some "funding" and "territory" problems between agencies.

I strongly believe in the concept of early childhood education and services for preschool handicapped children. I wish we could also provide more help to borderline or behavior concerns or "grey area" children who need help but don't qualify for services under state guidelines.

I hate to see Headstart lose its transportation. We rely heavily on them and think they have proved their beneficial influence on low income/handicapped children.

R.127 We need more referrals from local physicians and "all" hospitals. (Only high risk for hearing program that requests follow-up for hearing assessments. With newborns it is Iowa Methodist in Des Moines and Iowa City University Hospital.)

Since funding was cut I can no longer attend national conventions and only one in-state per year. This is not adequate. There are no universities that are close.

R.133 I do not feel this survey was a very good measurement tool. It needed bi-annual as a choice for frequency as needed per case — intake, termination.

R.137 I know from talking with parents, other professionals and from my experience of being a Home Teacher that early education services are very important and need to continue.

This survey really made me think and I feel there was a lot of information covered that I didn't know a whole lot about.

Good luck!

R.138

1 I would like to see more and better parent involvement.
2 We need better support services, i.e. speech clinicians, physicial therapists, occupational therapists.
3 It would be helpful to have more SUPPORT from our consultant and coordinator.
4 More public awareness would be helpful. I have heard parents say "I didn't know about your program." We need to let the public know about the good things schools are doing.

5. Inservice in working with parents would be helpful; we are the direct communicator.
6. A resource directory of special services would be good.
7. Maintain the funding level per child in special education — more legislative support.
8. If teachers are to be evaluated and held accountable for our programs so should administrators. I believe in cross profession evaluations — administrators evaluate teachers, and teachers should evaluate administrators.

R.140 We need OTs and social workers on staff!
(From an itinerant preschool teacher)

R.141 I believe the AEAs provide excellent services to handicapped children and their parents.

R.142 ? Purpose of service of this survey with LEAs.

R.145 Many of my answers involve our local AEA for with preschool they are most involved. Also, our head teacher for our program does a good job in being a liaison between the two. Next year we will not have her and it will be interesting if the communication will still be as good for there are times we need an intermediate.

R.150 I found it impossible to complete this form. I work at U of I Hospital School. I do not know all the activities of the facility.

R.158 The school relies on the AEA for much of the program. It is very workable! All students come to the school system from AEA diagnosis and evaluation.

I would like to see a developmental delay (not MD) added to groups of students eligible for preschool/early intervention. I think there are children in the community who need the benefits of a special needs program, but are not eligible for the labels BD, PD, CM, LD or MH. This is not to be used as a "dumping ground" either. "High risk" kids deserve programming opportunities. I would like to see more money available for Child Find during summer months.

R.159 This survey has been one of the most frustrating things I have done all year. I feel I have wasted my time and yours. You have asked things I cannot possibly respond to accurately without considerable research, which I was not willing to do. This should've been sent to the Director of Special Ed.

I resent the time I have spent on this — however, I did answer as truthfully as I could.

R.160 I have been at my present job for 10 years, have specialized in preschool age psych evaluations and have seen a lot of growth in preschool from very limited services to much expanded services. I think it has helped to have stable leadership at state and our local level AEA so that planning is long term.

One program weakness I have seen over the long haul has been lack of behavior modification inservice to teachers and parents. What is done is more piecemeal patch-together as problems arise planning on specific kid basis vs preventative systems planning. See if teachers and others view it as a problem.

A second observation is the rapid change in parent centrality in planning and teaching as child moves from home to centerbased program, perhaps leaving behind some benefits of the home model.

However, all things considered, I have felt proud to have been associated with preschool via my role in preschool team evaluations. I feel that within the preschool department in our AEA that both leadership and teacher quality has been excellent. These are programs that sell themselves to parents by word-of-mouth.

I think it may periodically be beneficial to any agency serving young children to review some of the potential models and roles for parent involvement as well as rationale. I have always liked Chapter 9 "Parent Involvement" from EARLY CHILDHOOD EDUCATION FOR EXCEPTIONAL CHILDREN, ed. Jordan, Hayden, Karnes & Wood by CEC 1979, but there may be better concise summaries of role and model options. I think it helps any agency to look over a list of possible options and then ask "Why not?"

Perhaps especially in rural settings, which I like and see many advantages in, there is need for some cross-pollination of outside ideas.

R.163

1 Need more education and planning for the "chronically ill/technology dependent" special needs children.

2 Need more direct therapy intervention for the infant/young child available through the AEA.

R.165 I feel in picking/selecting persons to fill this survey out, social workers in general should not be included. Just because one is a social worker does not mean they have worked with or have any knowledge of special needs children to adequately fill out this survey.

I personally feel this was a big waste of my time with very little benefit to you. I do not work with a major portion of special needs children. This survey would have been more beneficial if it was filled out by our MR/DD social workers. One or two of them could have been randomly picked instead of using two social workers that have no case specifics or experience in MR/DD special needs children.

R.166 The AEAs do an excellent job.

R.167 This document was difficult to interpret.

R.168 This survey's questions covered a very broad range of areas that this agency is not directly involved with or is directly responsible for. Thus it was difficult to answer sections of this survey with either "yes" or "no".

This worker has not the experience to answer some of the statistical based questions. The need of the survey is something that needs done and the areas of the survey need to be addressed. However, I know I have had difficulty, as well as another person, with completing this survey as accurately as possible. The validity of the findings would be in question for me. If I can be of more assistance please contact.

Thanks,

R.171 We need funding for such services as Maternal Child Health Clinics so we can help those unable to afford the doctor.

R.173 A great many children are served by AEA 7's infant and preschool programs. I do not know how information is disseminated, but the community seems to be aware.

Getting emergency residential pyschiatric care, and getting local residential psychiatric care for a preschooler were impossible when we recently had a case in which this was necessary.

Sure would like to have funding for attendance at the excellent (but prohibitively expensive) conferences and workshops offered so often!

R.176 AEA evaluation and U of I Hospitals & Clinics should include detailed and specific check lists to assess the needs of these families for in-home nursing and homemaker/home health aide services, or each family should be referred to their local PHN Agency for evaluation. Many needs not apparent in a clinic, hospital or school setting may become major health problems later without early intervention and preventative health teaching in the home.

The Public Health Nursing Agencies have much to offer and I believe are under utilized in this area.

R.178 This survey may not reflect clearly information you are gathering. Family Therapy is a specialized branch of DHS. Moreover, my work covers rural areas.

R.179 If this assessment instrument is the sole or major vehicle for developing policy-making decisions, then considerable restructuring of this device is indicated:

1 Limit the content focus to include only service delivery or interagency articulation or service content/frequency/development.

2 Limit the target population of the respondents, e.g., direct care staff, administrators, consultants, etc.

3 Provide direction on how to rate interactions with other agencies, e.g., on the basis of overall experience, one or two contacts, hearsay?

4 Include an item covering the experience the respondent has working in the particular agency.

The survey covers too many diverse content areas in insufficient depth. No single individual could meaningfully respond to all items (i.e., questionable validity and reliability). No one denies the need to comprehensively evaluate services for this population. It is unclear how this instrument attempts to do so. Further, there are numerous potential biases and threats to validity which would make interpretation difficult.

R.186 It is difficult to coordinate the various service people (we) receive.

Perhaps a standardized form people could produce which listed the organizations and people involved in their care might be useful.

A booklet of available services with their areas of expertise would be useful.

R.189 Our agency does not have a preschool psychologist. I would like to see that happen. Most of us do preschool assessments so rarely that our skills are never fully honed and developed. It takes me much more time than I have available to adequately train for the completion of a preschool evaluation — I don't feel good about my skills in this area, and would like to develop them, but adequate resources are not available. Further, having a preschool psychologist to work with these students would create an 'expert' and more appropriate services would thus be provided to meet these children's needs.

R.191 Our services have improved tremendously in the past 10 years and your group as well as other state personnel are to be commended!

R.194 The greatest need for this department of the AEA would be to improve OT/PT services to infants and toddlers as well as preschoolers

Having recently moved to Iowa from another state I feel Iowa is miles ahead in providing quality services to preschool handicapped children. I would hope that that commitment to quality education remains.

R.195 I work mainly with children and young adults past the age of your survey.

R.200 I wasn't sure how to complete this survey. What I did was answer or respond to the items from my point of view as Project Manager and DC/RS Consultant. I cover six counties so each county is different. Since I'm not directly involved with direct client casework I don't feel I could respond to many of these items.

R.204 Our agency works in conjunction with other agencies, but does not provide the most important learning functions. We are able at times to assist with payment in various areas, work especially with state hospital schools and can assist in getting specialists to the community.

R.206 There has been a strong emphasis by AEA-7 to diagnose and plan for children in northeast Iowa through Child Find and follow-up services. It's getting better all the time and I hope they will continue to be funded. They also work very well with the Early Developmental Intervention Team at St. Francis Hospital, Waterloo which is another excellent program.

R.208 As a Home Visitor, I make referrals for family service to the Teacher-coordinator and Family Worker at my Headstart center-based preschool program. They in turn notify agencies and families.

HACAP Headstart staff are exceptional. They are creative, positive professionals.

Next year our program is going through some structural changes. The teacher will become a Family Development Coordinator teaching in classroom, making home visits and planning parent involvement and parent meetings for her center. The Home Visitor and Family Worker positions have been eliminated. The Family Worker's role at each center will be taken by 3 Family Service workers for total HACAP Headstart.

R.214 Provision of services to parents is dependent on our schedules working with theirs. To provide maximal services we should be allowed more flexibility so we can serve working parents (mothers and fathers) better.

The availability of pediatric medical consultants prior to evaluation and during staffings may also allow better coordination of services as the medical aspect is often not fully understood by other professionals dealing with young children with special needs.

I feel respite care services are needed by parents of handicapped infants and children. I am not aware of these services being available in this area.

R.215 I am sorry this is late. I was finishing end of year records and had to move to a new location. I saw the due date when I started filling this out today. Hopefully, you can still use it.

R.217 I hope you get some good out of this. I don't know how valuable my contribution to this can be as an audiologist.

R.226 This was very difficult to fill out! I felt unsure about many of the questions and answers.

R.228 This needs assessment survey appears disjointed. Some questions ask for agency perspective, some for personal viewpoints. There are questions such as G1 that could have requested a rating effectiveness, scattered throughout the survey. It would seem that the format of responding will be very time consuming in terms of data collection and that you may have little interpretable data as a result. Dealing with responses of yes/no or have/have not makes the question an absolute. The kinds and types and qualities of services vary—

"available and poor quality, limited availability, outstanding quality". You should have had a measurement person define the parameters in terms of interpretability for program needs and planning. It's a good start, though. Good luck.

R.230 In general, I feel interagency cooperation in our areas has been excellent. We still have areas to work on but continue to do so. I feel we make concerted efforts to collaborate on provision of services to children as effectively and efficiently as possible.

R.233 I feel our agency provides comprehensive services for young special needs children in cooperation with our local and state resource agencies. However, there is always room for improvement and fine-tuning, which is my personal goal for our program. Continued interagency cooperative arrangements will be further developed to insure no children with special needs get lost in the system or "fall through the cracks". This type of goal requires continued state and federal fiscal support to become a reality.

R.234 I believe a major problem exists with the OT/PT criteria. Children no longer meet criteria for hands on direct therapy they generally receive 1 time per month or 3 months and this only includes a consultative 30 minute visit with the parent/teacher/child. It clearly is not progressive in nature and I do believe strongly that at the preschool level this should be a priority. Teachers are not allowed to try equipment or materials that may look therapeutic in nature and therapists are not willing to spend the time to try them. This problem exists in every program that serves handicapped children with physical limitations in this area. Perhaps the State Department could review this problem that is looked on as a problem of an individual nature in this agency rather than a problem of a collective nature.

R.244 I would like to see the AEAs get more involved (serve) high risk or at risk children. Instead of just monitoring these children, perhaps offering some services may be possible, i.e., home intervention, or play groups once a week in which parents can share problems and concerns while a teacher works with the children.

R.250 I feel there is a strong need for regular or Headstart type (1/2 day) public preschools to serve 4 year olds because of the ever increasing amount of 2 parent working homes and single parent homes in lack of available extended family members in this transient society. Expanding Headstart to serve a higher number of average income might be a good way to start. These centers are also needed for more integration possibilities for centerbased handicapped students.

R.251 This was a difficult questionnaire to answer. I could not answer "for the entire" agency. I tried to answer as per my specific job or unit, but found I was sometimes answering for the agency anyway. Yet, not working specifically wth these children, I'm not sure what is really available.

You didn't really define "special needs" children for me. At times you called them "handicapped". If that is defined as having been neglected, abused or born into poverty, it means something different than an MR, visually or LD special needs child. I wasn't sure what you wanted out of this!

R.252 In my opinion early childhood services are extremely important in prevention of more serious life long educational disabilities and are therefore cost effective in personal, educational and economic terms. Our staff experience frustration in being allowed to serve only those children who are severely handicapped, while many whose delays/handicaps are marginal will never receive service until the weight of failure in school forces them to drop out. State guidelines appear too severe, especially in the area of LD where the "ounce of prevention" is in existence but unavoidable to a large percentage of young children. Our program is depleted every year, but the number of referrals remains constant, resulting in less time spent per child and less effective diagnosis and programming as staff case loads increase. In my opinion a major push/investment/commitment should be made statewide to serve children as early as possible rather than to decrease services.

R.255 Please don't send out questionnaires in the last month of school.

R.257 I think our agency provides good services to the 0-21 year old population. I think communication between agencies could improve. I also feel that we could more adequately track children so we're sure they're receiving the necessary services.

Sorry for the delay in sending this, but the last month of school is really hectic with numerous last minute referrals, IEPs, etc. Good luck with this project. If I can be of any further help, please don't hesitate to call or write.

R.260 An area of weakness in our early childhood programs locally is related to support services which because of limited professionals (with vacancies) and time, support services are becoming more and more consultative models with responsibilities falling on other professionals (teachers) and/or parents (adequate or inadequate) to make judgements and follow plans. Many parents in this area have chosen, at their expense, to seek outside agency services where professionals have a more "hands on" approach on a regular basis. Summer services or lack of is also a continual problem.

R.262 Our families are fragmented. They (if lucky) are assessed by a social worker, followed by a Visting Nurse, referred to mental health or family therapy for behavior training, referred to a clinic for medical screening, told what they need to do after problem identification. Most have no car or babysitter, and lack ability to comprehend system procedures. Is it any wonder we see little success?

R.264 With the decline of funds, staff is being stretched thinner and thinner still trying to provide the same amount of service but I question the same quality as in the past.

I am also concerned about the growing numbers of multiple disability children with fragile medical conditions (e.g. 100% oxygen). Our school districts are cutting nursing services and I feel a great concern for the liability we place on untrained staff (e.g. bus drivers, not to mention our medically untrained teachers and associates).

I also question the educational significance of programming for 2 year olds in full day 5 day a week settings. Are we just babysitting for large portions of the day?

R.266 Our local physicians (primarily pediatricians) need to become more aware of the services AEA provides. They appear confused about the scope of the services that are available.

More information needs to be provided about the benefits of early intervention and the need for early referrals to us.

I am concerned about the inadequacy of our follow up and tracking of our "high risk" children who do not qualify for services. We are in need of a better system to follow them as they can easily get lost until they surface again when they enter school.

R.269 After completing this survey, I realize we have no clearly defined, integrated way in caring for these children. If it does exist, the part we have helped with is small and communications are poor between agencies. We aren't aware of outcome of information we provide.

R.273 I feel there is a need for better coordination of services for young children with special needs in this part of Iowa. I was employed by Public Health in Linn County several years ago. At that time, Public Health Nurses were directly involved in a child evaluation clinic that was staffed by a pediatrician, social worker, speech therapist and several others. Possibly something like this could be set up through AEA.

R.275 In working with various agencies I have found over the years a lack of support for and usage of educators. The medical and social service areas have used our resources and information very little. They tend to eliminate educators from meetings that involve children and parents and make decisions without even bothering to consult. They spend time gathering information that has already been collected by AEA professionals. This is not only a waste of time but also taxpayers' dollars; for example, when Title 19 funds are used. Children have been placed out of homes and even though they are aware they are being served in programs, we are not advised and must go and look for children ourselves.

Also, the legal system does not look at the bearing its decisions has on the child's education. Judges continue to disregard educators' information and are more concerned with a "family image" than individual children. There have been decisions where children have thrived in foster care and have "died" again educationally when returned to a "poor" home environment. No one seems (DHS) to follow-up on these children. It's a teacher's nightmare to see this happen to young children.

R.277 I have just recently been employed in the preschool (Headstart) field. I have managed to do my job satisfactorily but have felt that I could offer more if I had been more informed. Through my employer I am offered training on a once a month basis leaving a lot of information unknown. Unless an individual seeks outside information through workshops, etc. s/he cannot fulfill the position to the capacity it entails.

Continuing coursework and workshops with actual study and hands on experience would be helpful.

R.273 Our agency is a Public Health Nursing service and this area is only one of the many services we offer. We refer children we would be concerned about to an agency for testing but we also do follow up after the child is evaluated. Emotional support is of great importance to these families. We do attend staffings in schools with social workers, AEA, parents, and the child where a workable plan is drawn up that everyone feels is attainable. I see us having monthly meetings in the near future. Our agency has referred 2 3-year olds for testing — one had many problems. In our areas we seem to have a good working relationship. We may talk to some many times a week and then not for six months depending on the referrals.

R.280 I would like to mention here:

1 We are a small agency.

2 I am a staff nurse for 4½ years with this group in a community where I do not live.

3 Perhaps as a "new" person on the block I am not aware of what is available or what is being done.

4 At our agency we do not actively educate or seek out the impaired youngster. We only screen and refer.

5 If, in fact, we are to counsel and support, I personally would like additional training. We do go into the home and give what emotional and constructive support we can. Area 6 does work with the special children, also. More communication and perhaps written standards for coordination of the care of these youngsters should be developed and published for us if it isn't already.

R.284 I'm sorry I couldn't complete all of these questions but many don't pertain to our services.

R.286 We have found University Hospital, visiting nurses and innumerable other private local agencies to be much more responsive, cooperative, and engaging than AEA. AEA is viewed as isolated and bogged by too many systems constraints.

The Area Community Colleges do a wonderful job of professional continuing education and should be commended for their efforts. More agencies/professionals should take advantage of this service. Only recently learned that AEA has professional education staff. I feel this is a duplication and this function could/should be yielded to the community colleges. Certainly wish DHS would utilize the community colleges instead of trying to do their own awful elementary core courses.

While the concept of AEA, particularly services to preschool, is excellent, all too often their administration and "tunnel vision" when it comes to engaging with other agencies/professions prohibits full services not only to children specifically but to community as a whole. They seem to have no understanding of how to actively engage with other agencies/professions. They seem only to be able to view things in "educational" terms and cannot relate to anything that cannot be included on an IEP.

I noted that extension services were not included in this survey. Feel this is also an untapped resource with wonderful possibilities re: information. The use of nutrition aides from extension service for children with special nutrition needs has been invaluable, especially in combination with visiting nurses. In-home health aides have also been of great service to physically handicapped children.

If extension services were utilized more, however, would certainly need more "real world" experience and need to learn to adapt information and vehicles for information to meet needs of much lower functioning consumers.

R.291 I found this a bit cumbersome to complete — hope it's done correctly.

R.294 As a result of our DPI evaluation, it was decided that occupational therapy should become more involved with the 0-35 mos. population. All of the staff definitely agree with this and have a summer staff person working on priorities for service. We are hoping to visit other agencies as well as plan on some further training regarding feeding problems. I hope this information is helpful to you.

R.298 I found this questionnaire not appropriate to physicians/pediatricians.

R.300 As I fill out this assessment, it amazes me how many services are available to special needs children and yet we miss so very many. Either they slip through the red tape or there isn't enough manpower or spots open in our existing programs. These are our children. If we can't do it for them who are we going to help?

R.305 This was very difficult to complete as our involvement with handicapped is limited.

R.306 My answers are based on the Pella Preschool Handicap Program, not the AEA.

Our area is in need of a Child Find to identify children with handicapping conditions. We also lack a parent support group and case managers where I feel there is a great need. The parents of children that are identified as handicapped do not have many resources for them as far as information, support or options. They turn to the schools often and as a classroom teacher, I do as much as I can to help the family.

R.309 All services to be effective need financial support and delineation of services provided.

Funding means extra people and time to implement programs and improve inter and intra-agency communication and networking.

Need strong support and court test of Handicapped Bill of Rights.

R.311 At DHS, the agency that in the past was "all things for all Iowans", now is more realistically: do as little for as short a time with as few staff and spend as little money as possible but give the public and the legislature the impression that DHS is meeting the legislative mandates and providing services to Iowans.

R.312 The recent budget cuts have had a drastic effect upon the availability of services and the ability to maintain the previous quality of services because new equipment cannot be purchased, old equipment cannot be replaced nor can testing equipment be purchased. The ability to attend workshops for professional growth has been limited because the money isn't there to send us.

R.313 I feel there is a great need for early services. However, our agency's use and interaction is difficult to assess due to our public nature. In addition, I do not handle these cases often as we have a specialist who has the large majority of cases with children of special needs. He would be more aware and more accurate in his answers than I can be.

R.315 We are not presently involved with a Maternal Child Health Clinic, but hope at some point in time we are able to be involved with consent of the Board of Health. (Page Co. Public Heath)

R.316 After going thru this assessment I realize how very little I know of what our community is doing for children with special needs. I felt that there needs to be more education not only to the general public but also to individual agencies. I have discovered that very few of the agencies in our area work together with one of the reasons being the problem of confidentiality. It is so strict it is even difficult for agencies to all work together on one case.

R.318 This is one of the most godawful assessment surveys I have ever seen.

Considering the fragileness of the data and the unwieldiness of this instrument, I sincerely hope that you disregard your findings and start over.

R.320 Sorry I could not comment or respond more knowledgeably, but I am new to this part of the state as well as new to my job. I am still learning what services/resources are available in the Council Bluffs area.

R.321 Services are disjointed in our community regarding your target group.

R.323 It is extremely difficult to address questions as we serve persons who are not only handicapped in traditional terms but any family seeking help due to family dysfunction for multiple reasons. As a broad range public agency providing both direct, purchased and referral services our interaction with agencies and individuals varies greatly within any given day.

Appendix C

Bold type indicates responses

ASSESSMENT OF SERVICES
FOR
YOUNG CHILDREN WITH SPECIAL NEEDS

1a. Who is answering this questionnaire?
CHECK ALL THAT APPLY.
216 Mother
61 Father
10 Single parent
2 Foster mother
____ Foster father
2 Grandmother
1 Grandfather
____ OTHER ______________________________
____ OTHER ______________________________

b. Mother's Age **30.2/5.8** Father's Age **33.2/6.8**

Child Age	# %	Child Age	# %
.5	**0**	**5.0**	**22/9.6**
1.0	**3/1.3**	**5.5**	**18/7.9**
1.5	**15/6.5**	**6.0**	**21/9.2**
2.0	**20/8.8**	**6.5**	**9/3.9**
2.5	**22/9.6**	**7.0**	**0**
3.0	**29/12.7**	**7.5**	**0**
3.5	**24/10.4**	**8.0**	**0**
4.0	**21/9.2**	**8.5**	**2/.9**
4.5	**22/9.6**		

2. What is your child's birthdate?
____ month ____ day ____ year

3. Was your child premature?
CHECK "YES" OR NO."
____ Yes
____ No

4. Briefly describe your child's disability or special needs.

BD incl Autism	Hrng Imp	LD	MD	Mult	Phys	S/L	Vis	Other/Bad
10/3.7%	13/4.8%	8/2.9%	74/27.4%	5/1.8%	94/34.6%	49/18%	12/4.4%	7/2.6%

5a. Did you suspect your child had special needs before it was actually confirmed?
CHECK "YES" OR "NO."
____ Yes
____ No

b. If "YES," what was your child's age when you suspected his or her special needs?
____ years ____ months

6. How did you learn of your child's need for special help?

ASSESSMENT OF SERVICES

7. How old was your child when s/he first began receiving services (i.e., early intervention, physical therapy, occupational therapy, speech therapy?
_____ years _____ months

The following question is included to help formulate possible associations between income levels and services available to families. Remember your response is anonymous.

8. What is your household's annual income before taxes are taken out?
CHECK ONE.

# %	
57/25.2	Under $10,000
33/14.6	$10,100 to $15,000
23/10.2	$15,100 to $20,000
33/14.6	$20,100 to $25,000
24/10.6	$25,100 to $30,000
23/10.2	$30,100 to $35,000
12/ 5.2	$35,100 to $40,000
15/ 6.6	$40,100 to $50,000
6/ 2.6	Over $50,000

A. ACCESS TO SERVICES

1. FIRST, indicate below the types of services (child and family) you looked for when you **first** learned that your child had special needs. SECOND, indicate whether this help was available.

Type of help looked for	**Was this help available?**		
(EX: physical therapist, nurse, parent support group, etc.)	Yes	No	Don't know
LIST	CIRCLE YOUR RESPONSE		
1.	Yes	No	Don't know
2.	Yes	No	Don't know
3.	Yes	No	Don't know
4.	Yes	No	Don't know

2. What are the **three** most serious problems you have faced in trying to get services for your child and family?
CHECK THREE.

# %	
56/17.1	Cost of services
46/14.1	Difficulty finding people who can help
21/ 6.4	Difficulty in scheduling services or getting appointments
77/23.5	Don't know what services are available
33/10.1	Family support services (example: child care for brothers and sisters, meals, lodging) not available
28/ 8.6	Not being eligible for services
14/ 4.3	Services you need are not available
18/ 5.5	Services are not available during non-working hours
34/10.4	Too far to travel for some services
_____	OTHER __________________
_____	OTHER __________________
_____	NO PROBLEMS WITH SERVICES

ASSESSMENT OF SERVICES

3. How did you find out about services available to your child and family?
CHECK ALL THAT APPLY.

# %	
58/25.3	Community agency (example: health department)
58/25.3	Families of other children with special needs
51/22.3	Family or friends
22/ 9.6	Pamphlets, brochures
138/60.3	Physicians, nurses, other medical personnel
69/30.1	School district (example: child find)
85/37.1	Service provider (example: teacher or therapist)
15/ 6.6	Television, radio, newspaper, magazine
______	OTHER ______
______	OTHER ______

4. What was available to help you learn more about your child's particular disability?
CHECK ALL THAT APPLY.

# %	
104/45.4	Books
58/25.3	Information provided by other parents
127/55.5	Information provided by your doctor or hospital
2/ .9	Movies
84/36.7	Pamphlets, brochures
2/ .9	Video-tapes
______	OTHER ______
______	OTHER ______

5. What services are available for brothers and sisters (siblings) of your child with special needs?
CHECK ALL THAT APPLY.

# %	
19/ 8.3	Books about sibling relationships
3/ 1.3	Camps for siblings
49/21.4	Involvement in their sister's/brother's special programs
3/ 1.3	Newsletters for siblings
5/ 2.2	Support groups for siblings
______	OTHER ______
______	OTHER ______

ASSESSMENT OF SERVICES

6. List the services for which you and your child have to travel over 50 miles **round** trip.

Medical

(EX: services in hospital or clinic)

1.
2.
3.
4.
5.

Educational

(EX: services in school or home)

1.
2.
3.
4.
5.

Support

(EX: occupational, speech, physical therapy)

1.
2.
3.
4.
5.

Social

(EX: social worker, counselor)

1.
2.
3.
4.
5.

7. If it were possible to have one person serve as a coordinator of services for each young child with special needs, it should be a:
CHECK ONE.

# %	
27/11.8	Doctor
30/13.1	Parent
8/ 3.5	Public health nurse
47/20.5	Social worker
49/21.4	Teacher
38/16.6	Therapist
______	OTHER ______________________
______	OTHER ______________________

B. COST OF SERVICES

1. List the sources which provide financial assistance for your child's care. This might include social security income (SSI), insurance, medicaid or others.

1.
2.
3.
4.

ASSESSMENT OF SERVICES

2. FIRST, list your total **annual** expenses for your child with special needs. SECOND, list those expenses which are part of the total expenses but are covered by insurance or other financial assistance.

	ANNUAL expenses***	**Expenses COVERED by*** financial assistance**
Hospitalization		
Lodging		
Loss of income		
Meals		
Medication		
Orthopedics		
Respite care**		
Special equipment		
Supportive services		
Occupational therapy		
Physical therapy		
Speech therapy		
Travel		
Vision		
OTHER ______________	______________	______________
OTHER ______________	______________	______________

**Respite care is child care provided so you and your spouse can have time away from your child with special needs.

***Very incomplete responses from parents. Almost surely not representative.

3. If what services would you participate if cost were not a factor:
CHECK ALL THAT APPLY.

# %	
91/39.7	Counseling
75/32.8	Evaluations
47/20.5	Occupational therapy
63/27.5	Physical therapy
70/30.6	Respite care (See definition in #2)
78/34.1	Speech therapy
______	OTHER ______________________________
______	OTHER ______________________________

ASSESSMENT OF SERVICES

C. PARENT INVOLVEMENT

1. What activities are available to you?
CHECK ALL THAT APPLY.

# %	
188/83.2	Conferences with service providers**
138/61.1	Contact with service providers when you take your child into the agency
71/31.4	Counseling
161/71.2	Home visits for your child
187/82.7	Individualized Educational Plan (IEP) meetings or staffings about your child
150/66.4	Informal discussions in your home with teachers or therapists
96/42.5	Legal rights information
131/58.0	Notes or newsletters about your child
129/57.1	Observations by teachers or therapists of you working with your child
23/10.2	Respite care
70/31.0	Support group meetings
89/39.4	Toy or book lending library
33/14.6	Training workshops
______	OTHER ______________________________
______	OTHER ______________________________

**Service providers are teachers, therapists, doctors, nurses, social workers, counselors and/or psychologists.

2. In what activities are you involved?
CHECK ALL THAT APPLY.

# %	
75/33.5	Borrowing toys or books from the lending library
172/76.8	Conferences with service providers
22/ 9.8	Counseling
130/58.0	Home instruction
163/72.8	Individualized Educational Plan (IEP) meetings or staffings
148/66.1	Informal discussions with service providers
50/22.3	Legal rights information
98/43.8	Observing your child at school
12/ 5.4	Respite care
109/48.7	Sending notes to the center or school
40/70.9	Support group meetings
21/ 9.4	Training workshops
42/18.8	Volunteering in the classroom
______	OTHER ______________________________
______	OTHER ______________________________

ASSESSMENT OF SERVICES

3. How do you feel about your participation in meetings or staffings?
CHECK ONE RESPONSE PER STATEMENT.

	Always	Most of the time	Sometimes	Seldom	Never
I feel comfortable asking questions.		1.6			
I feel confused and/or frustrated after the meeting				3.7	
I feel I have a role in making decisions about my child's program.		1.7			
I feel professionals listen to me.		1.9			
I feel professionals are understanding of my feelings.		2.0			
I feel that I have adequate time during meetings to talk and communicate my feelings and thoughts.		1.8			
I feel I can be open and honest about services I want for my child.		1.6			

4. What prevents you from "changing the system?"
CHECK ALL THAT APPLY.

# %	
26/17.0	Being labeled a "troublemaker"
82/53.6	Lack of information
47/30.7	Lack of self-confidence
56/36.6	Lack of time
89/58.2	Not understanding how the system works
35/22.9	Prior frustration when you've tried to change something
______	OTHER ______
______	OTHER ______

5. Indicate your satisfaction with the opportunities for you to be involved in your child's services within education, health and social services.
CHECK ONE PER AREA.

	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied
Education		1.6			
Health		1.9			
Social services		2.4			

6. What **two** things would make it easier for you to participate in school or Area Education Agency (AEA) activites for parents?
CHECK TWO.

# %	
100/47.4	Activities which might help your child or family
81/38.4	Child care provided
20/ 9.5	Daytime activities or meetings
63/29.9	Evening activities or meetings
50/23.7	Knowing you are needed or welcome
25/11.8	More information on parent rights
39/18.5	Support from other parents
18/ 8.5	Transportation provided
______	OTHER ______
______	OTHER ______

ASSESSMENT OF SERVICES

7. If you were planning a meeting that would really meet your needs as a parent, the purpose of the meeting would be:
CHECK TWO.

# %	
161/75.6	Current information about your child's disability
43/20.2	Educational legislation
54/25.4	Emotional support
77/36.2	Parenting issues (i.e., nutrition, discipline, etc.)
______	OTHER ______
______	OTHER ______

D. SERVICES

1. Rate the agency and individual services which you and your child have received or are receiving.
RATE ONLY THOSE WITH WHICH YOU HAVE HAD CONTACT.

	Very effective	Effective	Satisfactory	Unsatisfactory	Very unsatisfactory
Area Education Agency (AEA)	1.6				
Head Start	1.8				
Public school	1.7				
Your child's teacher	1.4				
Child Health Specialty Clinic (CHSC)		2.0			
Family doctor		2.1			
Local hospital		2.2			
Public health nurse		2.2			
University of Iowa Hospitals		2.1			
Counselor		2.3			
Department of Human Services (DHS)			2.8		
Homemaker services		2.3			
Social worker		2.5			
Women Infants Children (WIC)		2.0			
Occupational therapist		2.0			
Physical therapist	1.7				
[illegible]gist		2.4			
Spe[illegible] clinician	1.5				
Transportation	1.9				
OTHER ______					
OTHER ______					
University of Omaha	1				
Mecca II	1				
Linhaven Respite Care				1	
Play Therapy	1				
Opthalmologist				1	
Chiropractor	1				

E. COORDINATION OF SERVICES

1. Check whether your child has had or now has contact with the agency or individual daily, weekly, monthly or annually.
CHECK ALL THAT APPLY.

	Daily #	Weekly #	Monthly #	Annually #
Advocacy group	1	1	2	2
Area Education Agency (AEA)	44	114	16	13
Child Health Specialty Clinic (CHSC)	1	1	3	31
Day care facility	18	11	1	—
Head Start	14	3	1	3
Hospital				
Name: (See bottom of page)				
Name:				
Name:				
Physician	2	3	50	56
Private diagnostic/tutoring/therapy agency				
Name: Physical Therapy	0	9	3	1
Name: Other	7	27	50	50
Name:				
Public health nurse	4	11	11	12
Residential facility	4	1	2	2
Social services	—	4	25	13
OTHER Schools	16	2	0	0
OTHER Other	1	1	3	1

2a. FIRST, do you feel that medical staff, social workers and school personnel work well together and communicate with each other? SECOND, why?
CHECK "YES" or "NO."

133/65.5% Yes
34.5% No

b. Why?

Hospitals El	#	#	#	#
Iowa Methodist	0	1	3	7
Iowa City Hospital	0	0	0	5
Mayo Clinic	0	3	1	5
St. Luke's, Sioux City, IA	0	0	1	5
St. Luke's (Unknown city)	0	1	3	12
University of Iowa Hospital	4	1	18	49
University of Iowa Hospital School	0	0	1	14
Other	5	10	19	81

ASSESSMENT OF SERVICES

F. PARENT TRAINING

1. Using the rating scales, FIRST, indicate how much you know about the area. SECOND, indicate how much you want to learn about that area.

How much do you know? 1 = Little 5 = A lot						**Want to learn more?** 1 = No 5 = Definitely				
1	2	3	4	5		1	2	3	4	5
		1.6			Beginning a parent support group.			3.0		
		2.9			Knowing about social service systems (welfare, food stamps, WIC, etc.).			2.7		
		2.8			Locating comprehensive medical services.			3.4		
		2.5			Locating magazines/books about children with special needs.			4.0		
		2.3			Organizations available to help parents of children with special needs.			4.0		
		2.4			Parents' rights in special education (i.e. hearings or disputes).			3.8		
		3.0			Services available in your area for young children with special needs.			4.2		
		3.0			What an Individualized Educational Program (IEP) is and how you can help more with it.			3.8		
		2.6			What community services are available for your family and child.			4.0		
		3.3			Working with professionals.			3.7		
		3.8			Working with your child at home.			4.2		
		3.7			Your child's school program.			4.2		
					OTHER ______________________					
					OTHER ______________________					

ASSESSMENT OF SERVICES

G. CHANGES

1. Using the rating scales, FIRST, indicate the importance of each of the following suggested changes in services for young children with special needs. SECOND, indicate how practical each change would be to implement.

How important is it?
1 = Not at all 5 = Very

How practical is it?
1 = Not at all 5 = Very

1	2	3	4	5		1	2	3	4	5
		3.8			Assigning or person to help you with most interations h agencies.			3.5		
		3.1			Eliminating services which are provided by two or more individuals or agencies.			3.0		
		4.4			Improving day care services for children with special needs.			4.1		
		4.5			Improving parent training to it is more comprehensive and useful.			4.3		
		4.3			Increasing your contact with people with work with your child.			4.1		
		3.8			Increasing your involvement in policy making.			3.4		
		4.4			Increasing your involvement in your child's treatment.			4.2		
		3.7			Making entrance criteria for services less rigid.			3.4		
		4.2			Providing programs which are more suited to your individual needs.			3.8		
		4.4			Providing you with more information, resources and personal assistance.			4.3		
					OTHER ________________					
					OTHER ________________					

2. List important changes that you feel need to be made in the system.
   1.
   2.
   3.
   4.
   5.

H. SUMMARY

1. Additional comments which you would like to share.

Prose Responses to Parent Needs Assessment

Item A1b **Types of services sought when you first learned that your child had special needs. Were these services available?**

Yes	No	Don't Know	
17	3	0	Medical
24	6	0	Family Doctor (physician)/Clinic
1	1	0	Mobile Health Clinic
1	0	0	Special Care Center (residential)
2	0	0	University of Iowa Hospital School
5	0	0	High risk follow-up
8	1	0	Specialist
9	0	0	Opthalmologist
12	1	0	Pediatrician
3	0	0	Neontalogist
8	1	0	ENT
2	1	0	Allergist
			Medical Support Services
45	8	4	Home Nurse (PHN, county nurse)
5	0	0	Genetic Counseling
2	1	0	Evaluation facilities for ADD/hyperactivity
5	2	1	Help with care
2	0	0	Medical service to provide Apnea monitor
120	12	4	Educational/School/AEA
35	6	4	Teacher (Learning therapist, Educational developmental aid, Level tester)
35	4	0	Home Intervention
3	1	0	Headstart
31	2	0	Multicategorical Preschool (Speech, Special preschool for PH, Preschool for handicapped, Early learning program)
23	4	0	Special Education (PDC, early childhood, Smouse School)
12	0	0	Psychologist
4	0	0	Teacher of the deaf (sign)
3	0	0	Vision teacher
3	0	0	In-home tutoring
7	1	0	Support Services
165	11	8	PT
44	6	1	OT
77	7	1	SC
27	0	0	Audiologist (hearing aide specialist, hearing clinic)
6	0	0	Vision Consultant
15	1	0	Child Development Program (motor development, developmentalist)

Yes	No	Don't Know	
3	0	0	Infant Stimulation
3	0	0	Mental Health
9	1	0	Social Worker
8	0	0	Play Therapist/Play study group
2	1	0	Behavioral Consultant
1	0	0	Psychiatrist
9	3	0	Family counseling
1	2	0	Sibling support
0	3	0	Respite care
			Financial Aid
7	4	0	SSI
12	2	1	Title XIX
			Advocacy Groups
112	25	5	Parent support groups
1	0	2	Translator services
3	0	0	Mother group
2	1	0	Toddler group (play)
5	0	0	Other parents
2	0	0	"Pilot Parents"
3	0	0	Private/Public Agencies
3	0	0	WIC
3	0	0	Specialized Child Health Care
14	1	0	Specialized day care for handicapped/day care center/babysitter
4	1	0	CHSC
2	1	0	Shriners
2	0	1	State of Iowa Department of Social Services
2	0	0	Variety Club NICU Follow-up Program
3	0	0	Spina Bifida Assoc.
			Special Equipment
2	1	0	Wheel chair
1	0	0	Braces
9	3	0	Information
1	1	0	Libraries
3	0	0	Parenting classes
10	5	0	Other

-Didn't have to "look" for help. Hospital at time of birth took charge of special needs.
-Project Catch, Davenport, Ia.
-P.A.T.H.
-Didn't look for help because we didn't admit child needed help.
-Coordinator of services to help us obtain assistance.
-Model Waiver Program

Item A2 **Other serious problems faced in trying to get services for your child and family.**

Count	% of Responses	
		Lack of information about child's disability
3	7.7	Not knowing what services are needed/not knowing my child's needs.
2	5.1	Ambiguity caused by professionals not being able to come to an agreement as to what is wrong with the child.
1	2.6	Need earlier detection of handicap so needs can be served earlier.
		Quality of services
1	2.6	Hospital not following through on making referral when they said they would.
1	2.6	Have trouble finding GOOD services.
1	2.6	Need a babysitter who can handle child with special needs.
1	2.6	Difficulty with pediatrician in dealing with handicapped child - not supportive, blames parents for problem.
		Amount of services
4	10.3	Not being able to get the amount of therapy we feel child needs.
1	2.6	Professionals not willing to give adequate time at appointments - feel unimportant & rushed.
1	2.6	Funding cuts eliminating needed programs/personnel.
5	12.8	Not available in summer (PT, OT, SC)
1	2.6	Too many delays in being placed because of classes being full.
		Lack of financial support
1	2.6	Trying to get insurance to o.k. some services.
1	2.6	Cost of braces, wheelchair, etc. cause financial burden.
1	2.6	Lack of funding in our county.
		Communication
3	7.7	Convincing professionals that our child has a problem.
1	2.6	Convincing my husband/wife that our child has a problem.
1	2.6	Impersonalization by employees.
2	5.1	Disorganization of services
4	10.3	Red tape/long waits for appointments/their cancelling our appointments at the last moment.
1	2.6	Feel like I have to fight system to get anything done.
3	7.7	Transportation

Item A3 — Other ways you found out about services available to your child and family.

Count	% of Responses	
6	31.6	From my professional training (e.g. SW, N)
3	15.8	From previous experience working with handicapped
1	5.3	From having other handicapped children
4	21.1	From determination - just kept looking for help
2	10.5	From professional organization (e.g. MDA, Spina Bifida Assoc.)
1	5.3	From parents' counselor
1	5.3	Sought legal assistance - asked a congressman to help us seek out services & help us to obtain an "exception to policy" for services we needed but were not normally provided or available.
1	5.3	Parent support group

Item A4 — Other ways to help you learn more about your child's particular disability.

Count	% of Responses	
34	61.8	Information from our service provider (e.g. caseworker, SC, AEA staff, teacher, County Nurses' Office, Mental Health, therapist)
2	3.6	Information from a magazine, newspaper, radio, t.v.
1	1.8	Wrote Department of Health
1	1.8	A college report (University of Iowa)
7	12.7	From professional organization or national support group (Lower Syndrome Assoc., CEU, Down's Syndrome, National CP Organization, Spina Bifida, Williams Syndrome)
2	3.6	Nothing CURRENT available
7	12.7	Nothing available
1	1.8	Other -Hard to understand medical terminology in information.

Item A5 — Services available for siblings of your child with special needs.

Count	% of Responses	
4	5.1	Advice given by adults who care (e.g. parents, teacher, therapist)
1	1.3	Day care
1	1.3	Support group of families with a child who has same handicap (e.g. Down's)
1	1.3	Genetic clinic
19	24.1	Do not know

Count	% of Responses	
21	26.6	Do not know because we have no other chidlren.
2	2.5	Do not know because we haven't looked.
28	35.4	None
2	2.5	Other -Coloring book while brother was in hospital. -Baby not old enough yet for sibling involvement.

Item A6a

Medical services for which you have to travel 50+ miles round trip.

Count	% of Responses	
25	18.2	University Specialists (Surgery/Checkups, Iowa City University Hospital & Clinic, University of Minnesota)
1	0.7	ENT
6	4.4	Neurologist
3	2.2	Orthopedic
1	0.7	Opthalmalogist
1	0.7	Pediatric Psychiatry
1	0.7	Pediatric Cardiology
1	0.7	Urologist
2	1.5	Cardiologist
2	1.5	Special Schools
1	0.7	Boys Town
1	0.7	Vinton School
39	28.5	Clinics (Tests/checkups)
8	5.8	Eye (Wolfe Eye Clinic, Vinton Eye Clinic)
3	2.2	Genetics
2	1.5	U of I Developmental Clinic
1	0.7	Physical Therapy
1	0.7	Neuro clinic
1	0.7	Muscle clinic
1	0.7	Peds clinic
1	0.7	Specialized Child Health Care
2	1.5	Myelodysplasia Clinic
1	0.7	Drug monitoring
5	3.6	Specialists
11	8.0	Neurologist, neurosurgeon
9	6.6	Opthalmologist (eyes), DM Optometric Ass.
3	2.2	Otolaryngologist (ears)
10	7.3	Pediatrician
7	5.1	Orthopedist
2	1.5	Surgeon
1	0.7	Physiotherapist
2	1.5	ENT
1	0.7	Corneal specialist

Count	% of Responses	
25	18.2	Hospital services (Exams, surgery)
7	5.1	Iowa City Hospitals
1	0.7	High risk visits
1	0.7	Mercy, Des Moines
2	1.5	Shriners Hospital, Minneapolis, Mn.
1	0.7	Iowa Methodist Medical Center, Des Moines
1	0.7	Mercy, Clinton, Ia.
11	8.0	Doctor
1	0.7	Hearing aid specialist
2	1.5	Brace shop
1	0.7	Doctor who works with Rett girls (Huston, Tx.)
1	0.7	Dentist
11	8.0	Hospital school
18	13.1	Other -Some, Iowa City -Iowa City check-ups -Diagnosis & evaluation -Screenings at CDPS in Creston -Inhibitive casting -Division of Developmental Services -Behavior management -Follow up program

Item A6b Education services for which you have to travel 50+ miles round trip.

Count	% of Responses	
2	10.5	School
1	5.3	Monroe School, Cedar Rapids, Ia.
1	5.3	Garfield Community School, Cedar Rapids, Ia.
1	5.3	River Hills
1	5.3	Vinton - IBSSS
2	10.5	AEA
3	15.8	Preschool
1	5.3	PDC (Predevelopmental classes)
		University
4	21.1	Hospital School, University of Iowa
1	5.3	University Child Psychiatry Clinic
		Parental training
1	5.3	Inservice
1	5.3	Storm Lake Seminar for Down Syndrome parents
		Educational testing
1	5.3	Psychologist
1	5.3	Development

Item A6c

Support services for which you have to travel 50+ miles round trip.

Count	% of Responses	
3	11.1	Hospital school in Iowa City, Ia.
1	3.7	Therapy
12	44.4	PT
7	25.9	OT
2	7.4	S
3	11.1	Audiology
1	3.7	Preschool
1	3.7	PDC
2	7.4	AEA
		Evaluations
2	7.4	PT
2	7.4	OT
1	3.7	SC
1	3.7	Audiology
		Other
1	3.7	Pilot Parents
1	3.7	PCND

Item A6d

Social services for which you have to travel 50+ miles round trip.

Count	% of Responses	
4	20.0	Social worker
1	5.0	In LaCrosse, Wis. seen annually
1	5.0	In Iowa City, Ia.
1	5.0	Court
3	15.0	SS
3	15.0	Support group meetings
4	20.0	Parent
1	5.0	Univeristy Hospital School
1	5.0	University Hospitals & Clinics, Iowa City, Ia.
		Counseling
2	10.0	Genetic
1	5.0	Other -Not needed

Item A7

Others suggested to coordinate services for each young child with special needs.

Count	% of Responses	
1	5.0	None of the above.
2	10.0	Not a one person job. Should be a team effort.

Count	% of Responses	
4	20.0	AEA
3	15.0	A specific coordinator who does only this.
2	10.0	Person who sees the child most frequently, i.e. Sp. Ed. teacher
1	5.0	The one who would have the time & ability to do a good job.
5	25.0	Parent of a child with special needs who has college training.
1	5.0	Do not know.
1	5.0	Other -Person with medical background with handicapped children who knows that services are available.

Item B1

Sources of financial assistance for your child's care.

Count	% of Responses	
1	0.5	City/LEA/School
5	2.6	Public school system
1	0.5	Special preschool
		County/AEA
10	5.2	AEA
5	2.6	State
1	0.5	University of Iowa has given us a discount of services.
1	0.5	Iowa City found a fund to pick up our balance.
1	0.5	Clinic from Iowa City
		Federal
46	24.1	SSI
18	9.4	Title XIX
33	17.3	Medicaid
9	4.7	ADC
2	1.0	Hot lunch program at school
2	1.0	Food stamps
3	1.6	WIC
55	28.8	Insurance
18	9.4	Blue Cross/Blue Shield
3	1.6	Bankers Life
1	0.5	Federated
3	1.6	Metropolitan
1	0.5	Total Health Network
1	0.5	Quad City HMO
1	0.5	Aetna
1	0.5	Equitable of Iowa
1	0.5	Alcoa
		Non-Governmental Organization
1	0.5	Boys Town National Institute for Communication Disorders in Children

Count	% of Responses	
1	0.5	Muscular Dystrophy Assoc.
1	0.5	County Physical Therapy Assoc.
1	0.5	Operation New View Fuel Assistance
2	1.0	Shriners
2	1.0	Lions Club
1	0.5	American Cancer Society
1	0.5	Spina Bifida Assoc.
1	0.5	Variety club of Iowa (Equipment lending)
6	3.1	Private/Personal Funds
1	0.5	Our savings
15	7.9	None
1	0.5	Unable to find assistance
		Other
2	1.0	Title V, Title XIX
2	1.0	Work/Our jobs
1	0.5	None other than myself
1	0.5	Use to be Title XIX, now my own
1	0.5	Our income is such that some of it has been waived
1	0.5	Central States Health & Welfare

Item B2 Other total annual expenses for your child's special needs.

Count	% of Responses	
		Medical supplies
1	3.7	Eye patches
1	3.7	Tape & gauze for stoma care
1	3.7	Special feeding formula
2	7.4	Medical specialists
1	3.7	Eye checkups
2	7.4	Neurosurgeon
1	3.7	University of Iowa Peds Clinic
1	3.7	Pediatrician
6	22.2	Doctor appointments (checkups)
2	7.4	Outpatient evaluation
2	7.4	Hospital School evaluation
1	3.7	Dental appointments
1	3.7	Home adaptions
		Child care
1	3.7	Day care for handicapped
1	3.7	Institutionalization
4	14.8	None
1	3.7	Don't know
1	3.7	Sandler/Brown Consultants

Item B3 — Other services you would participate in if cost were not a factor.

Count	% of Responses	
		Unusual types of counseling/therapy
1	3.7	Music therapy
1	3.7	Genetic counseling
		Additional therapy
1	3.7	SC in summer months
1	3.7	OT in summer months
1	3.7	PT
		Educational for child
1	3.7	Preschool
1	3.7	Hearing impaired
		Educational for parents
1	3.7	Parenting class for ADD/hyperactivity
1	3.7	National conferences on Down's Syndrome
1	3.7	Workshops
		Emotional support
2	7.4	Parent support groups
1	3.7	Sibling support groups
		Medical
1	3.7	Special eye, ear exams annually
1	3.7	Annual physical exams
1	3.7	CP clinic in another state
1	3.7	Vision
1	3.7	Special equipment
1	3.7	Help with childcare/house chores
		Other
1	3.7	We get all these free of charge.
3	11.1	No matter what the cost, if it would help we would participate.
1	3.7	Anything else available.
4	14.8	None of them.
1	3.7	We get all of these except respite care by AEA 6 with no cost.

Item C4 — What prevents you from changing the system?

Count	% of Responses	
		Financial
1	2.7	Don't have the funds.
1	2.7	Lack of funds to school system

Count	% of Responses	
		Community & peer pressures
2	5.4	Could cause trouble for my child.
1	2.7	Afraid of being seen as a mother who cannot accept that her child has a problem.
1	2.7	Not understanding what, if any, other alternatives are available.
2	5.4	Lack of other parents being involved as a unit to insure the benefits of our children.
		Other
6	16.2	Nothing
19	51.4	Don't feel it needs to be changed now.
3	8.1	Have had no interest in changing system
1	2.7	We're satisfied but know of others who are not.

Item C6 — Two things that would make it easier for you to participate in school or AEA activities.

Count	% of Responses	
1	8.3	Have the therapist come to child's home.
1	8.3	More flexible times - my working hours make arrangements difficult.
3	25.0	Distance to AEA activities
1	8.3	Child care (trache knowledge) for special needs child
2	16.7	Reason to participate/"sincere" encouragement from professionals to get involved.
1	8.3	More time
1	8.3	If my husband/wife would participate
1	8.3	NA - We already take advantage of all services.
1	8.3	Other -Making known what activities are available (1)

Item D1 — Other agencies/services which you and your child receive.

1 = very effective, 5 = very unsatisfactory

University of Omaha
MECCA II
Linnhaven Respite Care
St. Francis Waterloo Early Intervention
Play therapy
Local opthalmologist

1 = very effective, 5 = very unsatisfactory

Chiropractic care

Hearing clinician

Other
- -Shriners (1)
- -Child's doctor (2)
- -Parent support group (1)

Item E1 **Other agencies/individuals with which your child has contact.**

Hospitals:
- Iowa Methodist (also called Iowa Mothodist Medical Center IMMC)
- Iowa City Hospital (not to be confused with University of Iowa Hospital)
- Mayo Clinic
- St. Luke's Medical Center, Sioux City, Ia.
- St. Luke's (city not given)
- University of Iowa Hospital
- University of Iowa Hospital School (not to be confused with University of Iowa Hospitals & Clinics)

Private diagnostic/tutoring/therapy agency:
- Physical therapy

Miscellaneous:
- School (Sp. Ed. teacher, Smouse, Helen Keller School)
- Preschool
- Multicategorical preschool (Vail)
- WIC
- Tri Med Home Medical Supply Co.
- Professional Nursing Service
- Dental
- Project Catch
    - -Lekotek
    - -Homemaker Services

Item E2		**Do you feel medical staff, social workers and school personnel work well together and communicate with each other?** **NO: Why?**
Count	% of Responses	
		Problems with numbers
6	3.8	Interaction is hampered by the number of children serviced & large geographical distance between our agencies & individuals.
1	0.6	Inadequate staff - more to do than they can handle.
		Problems with training
8	5.0	Overspecialization - each gets very involved in his own role & has little contact with others who work with child.
1	0.6	Our local hospital had no information about my child's disability, nor could they make referrals as to who might be able to help us.
1	0.6	Doctors and social workers in our small rural area are not well-informed about services available for premature babies.
1	0.6	At residential setting, often no communication between shifts, nurses & living unit, etc.
2	1.3	Medical & educational therapists have different philosophical backgrounds: medical = clinical, educational = home & family.
1	0.6	Big gap between medical & school in my community. I have educated my child's doctor.
		Problems with attitude
1	1.3	They seem to be in competition with one another.
1	0.6	The doctors seem to resent it when everyone gets together & more or less puts them "on the spot".
3	1.9	The physician has no interest in our child's education or disability.
1	0.6	Each professional is very strong minded & feels s/he is always right & wants to be in full control.
1	0.6	They don't seem to see a need to work together.
1	0.6	They don't like each other.
		Problems with effort
1	0.6	Medical facility did not make a referral to AEA when requested.

Count	% of Responses	
2	1.3	Medical staff & school personnel work to help each other but SW of DHS is not the best at helping anyone.
2	1.3	SW not concerned with our child - hinders rather than helps situation.
1	0.6	Do not receive summaries of our son's clinic visits - we leave not knowing where we stand in child's total health care.
4	2.5	SW & school teachers work well with each other & day care staff but doctor's office doesn't contribute much.
9	5.6	Problems with communication
2	1.3	They have difficulty making contact with one another. (Can't catch each other in.)
9	5.6	Discrepancies & contradictions between them - one tells you one thing & the other tells you another.
3	1.9	The doctor gets written reports, but never responds to the information.
1	0.6	Agencies are reluctant to send my child's records to other agencies.
3	1.9	We need to have more team meetings so everyone is on top of what is happening.
17	10.6	Don't share information well - no one assumes role of coordinator.
2	1.3	Written reports of evaluations from U of I to doctors & AEA take too long - 5-6 weeks.
6	3.8	No communication between medical staff & school except through parent.
1	0.6	Schools receive information from medical staff, but parent has to carry information from school to medical staff.

YES: Why?

Count	% of Responses	
		No problems with numbers
1	0.6	They are all in the same geographical area.
2	1.3	U of I contacts all.
1	0.6	As best as their caseload allows.
1	0.6	Good training
2	1.3	Good attitude
17	10.6	They put my child's best interest first.
4	2.5	They get involved with each child's needs.
7	4.4	They work efficiently & in a well-organized manner.
3	1.9	They are very responsive & open.

Count	% of Responses	
1	0.6	Extend extra effort
1	0.6	They have meetings as often as we request.
1	0.6	They make referrals.
3	1.9	They do the follow up as they promised they would.
24	15.0	Good communication
22	13.8	They send reports back and forth to each other.
1	0.6	They communicate their findings in language we can understand.
6	3.8	They are accessible to one another.
1	0.6	Educational agency always sends reports back to our family doctor.
3	1.9	Doctors contact AEA after visits to keep them up to date.
2	1.3	There are staffings, IEP meetings.
8	5.0	Other -It took us a long time to find the professionals that work well together & benefit our child. -Haven't worked with them long enough to know whether or not they communicate well. -Never had any problems. -I don't know.

Item G2 **Important changes you'd like to see in the system.**

Count	% of Responses	
4	3.2	More financial support
7	5.6	For families who don't qualify for aid under present system.
1	0.8	More clinics available for low income families to give children shots, etc.
3	2.4	For middle income families who must buy their children special equipment like braces, wheelchair, etc.
1	0.8	Out of state aid should be accepted.
1	0.8	Entrance criteria should be less rigid.
1	0.8	Be able to keep AEA services even though your child is also getting additional private therapy.

Count	% of Responses	
1	0.8	Want free health care without going through an agency's red tape.
1	0.8	Mandate total health care for children after they leave NICU.
2	1.6	Education for parents
9	7.3	Parents need to know all of their options so that they can make responsible decisions.
9	7.3	More information needed on my child's disability.
5	4.0	More parental awareness as to how they specifically can help their own child
5	4.0	Someone to explain the forms and paperwork.
1	0.8	Provide more after-work hours training.
2	1.6	More classes in sign language so can help my hearing impaired child.
1	0.8	Educating parents to teach others.
4	3.2	Improve parent training program - need more parent assessments.
1	0.8	Have fewer "classes" for parents & more "hands on" help.
		Education of special needs children
3	2.4	Child should be able to have the same teacher each year rather than having to adjust to a new one.
5	4.0	Should be less labeling - want recognition of ability rather than disability.
2	1.6	More mainstreaming - hire teacher aides so handicapped can better survive.
4	3.2	Parents should be more involved in their child's education, esp. early training.
1	0.8	More services available in small town schools.
3	2.4	Need more special programs in schools. All schools, esp. elementary, should have a disabled class. Need special programs for autistic in schools. Need more special preschools.
1	0.8	Have speech therapy in private school.
1	0.8	Need more home intervention.
		Education of the community
6	4.8	Increase their understanding of special needs children so that they can participate better in the child's experience.
1	0.8	More understanding from employers of parents' need to miss work to take child for checkups, tests, etc.
1	0.8	More ramps, extra wide doorways, etc. to help facilitate handicapped in wheelchairs, etc.

Count	% of Responses	
		Medical
1	0.8	More research done on how to detect special needs children when they are young.
2	1.6	More studies done on special children & their needs.
1	0.8	Family doctors getting more involved & aware of needs of handicapped children.
1	0.8	Less delay in setting up evaluations at university setting - take approximately 6 wks.
1	0.8	Provide better pediatric therapy sevices for our child.
1	0.8	Provide comprehensive evaluation centers in Iowa.
1	0.8	Provide comprehensive CP clinic in state.
		Legal issues
1	0.8	Better laws on child abuse.
1	0.8	Faster termination of parental rights in case of child abuse by a parent.
1	0.8	State laws that specify what each AEA & school system must provide & to what extent.
3	2.4	Make certain the people who are assigned to work with handicapped child are doing their job.
1	0.8	Children with special needs must have more protection - leave them in their homes.
1	0.8	Don't let state or federal government "mainstream" all special needs children.
1	0.8	Guidelines for some services are too rigid.
1	0.8	Need transportation guidelines.
3	2.4	Provide advocates to avoid the frustrations of working with the "system".
		Professionals
4	3.2	Earlier notification to parents of their child's disability. Refer when problem first spotted.
2	1.6	More professionals needed at schools so child can receive more intense help.
1	0.8	More AEA OPT's to make home visits every week.
2	1.6	More qualified personnel in home care.
2	1.6	Don't overload AEA workers and SWs.
5	4.0	They shoudn't make parents feel stupid when they are trying to explain their child's problems. Use simpler terminology in their reports.
14	11.3	Need better communication between professionals who work with child and parents. Need more 1 to 1 communication, more genuine caring, more openness.

Count	% of Responses	
1	0.8	All public school teachers should be trained to work with handicapped.
1	0.8	More AEA workers who can work with kids rather than be afraid of them.
		Services
23	18.5	Make the public aware of their services. A list of services available (all related to handicap) should be at 1 place, e.g., the doctor's office.
4	3.2	Transportation subsidized or provided for non-driving families/bussing.
4	3.2	Diversify more according to needs.
1	0.8	Have more summer programs (e.g. SC, PT, etc.).
2	1.6	More services for the varied levels of special needs.
2	1.6	Use more high-tech equipment, e.g. audio testing.
4	3.2	Need services closer to home/centralization of services.
2	1.6	Quicker transfer of information from one agency, clinic, etc. to another.
		Central computer so government agencies are more organized.
5	4.0	Need more daycare services for children with special needs.
		Emotional support
12	9.7	More support groups. More support groups w/others outside our immediate community.
2	1.6	More family counseling.
1	0.8	Need respite care to also include in-home care when parents are away.
1	0.8	Need genetic counseling.
1	0.8	Need more activity groups for parents & children.
3	2.4	Need respite care.
1	0.8	Need more parent "rap sessions" instead of always having a speaker at meetings.
		Other
1	0.8	Have more places for families to stay like Ronald MacDonald House.
1	0.8	Parents need to have more say about their child's future.
5	4.0	Want everyone to work together for good of the child.
1	0.8	Need for a better way to identify private individuals who can care for a child with special needs.
3	2.4	Need less red tape & shorter application process.

Count	% of Responses	
1	0.8	Need help in dealing with placement of child in residential setting - how to choose one, sibling bonds, etc.
1	0.8	Services of various agencies need to be coordinated rather than each one trying unsuccessfully to do everything.
1	0.8	Have had very few problems but this is probably due to my knowing the "system".
12	9.7	No changes needed at this time. Child too young so don't know system yet.

Item H1 **Additional comments you'd like to share.**

Count	% of Responses	
		Professionals
3	2.3	Had to work very hard to convince them that something was wrong w/my child.
3	2.3	Use labeling less.
6	4.5	Increase number of OPTs and SCs in the schools.
1	0.8	Let same teacher/therapist work w/child year after year.
1	0.8	Don't want them to make me feel like they are better than I.
1	0.8	Amount of paperwork gets in way of their helping.
1	0.8	Give me conflicting information (at Smouse).
1	0.8	Should be people who want to work together with all & who will communicate honestly.
		Community
1	0.8	Treats my children & me without respect because we are on ADC & SSI.
4	3.0	Increase community awareness of special needs children.
1	0.8	More understanding from employers of parents' need to miss work to take child for tests, checkups, etc.
1	0.8	Local home economics teachers could identify students with interest & patience to babsit a special needs child. They in return could receive class credit for working with a recommended therapy.
		Medical care
1	0.8	Need a neurosurgeon in Northwest Iowa
4	3.0	Doctors, esp. pediatricians, need to be up on information & services for children w/special needs.
1	0.8	Doctors need to follow a child w/special needs closer than he does a normal child.

Count	% of Responses	
1	0.8	Doctors need to show genuine caring & treat child as an individual.
1	0.8	Wish going to U of I Hospital wasn't such a time-consuming, frustrating experience.
		Education for parents
10	7.6	Increase awareness of available services. (Could have 1 phone number parent could call to get started in right direction.)
7	5.3	Provide information about the disability (e.g. Twinese, autism, Soto's Syndrome).
1	0.8	Need books & materials on the child's disability for his siblings.
1	0.8	Need more training, education in general.
1	0.8	Want to talk to someone who is specialist in Turner's Syndrome.
2	1.5	Need to know how I can help my own child.
1	0.8	Parents need an advocate or someone to teach them how to cut through the red tape of system.
		Parental involvement in child's services
3	2.3	Encourage parent involvement.
2	1.5	Parents should help more with it & not expect teachers to do it all.
1	0.8	Would like to attend more of their functions but cannot because parents have other school age children.
4	3.0	Should be advocate for their child. Must be persistent until they get the services the child needs.
2	1.5	I'd like to be more involved in political scene so I know how laws, budget cuts, etc. will effect my child.
1	0.8	Want more contact with child's professionals.
4	3.0	Emotional support
2	1.5	Need information on how to start a support group.
5	3.8	Need a specific kind of support group (e.g. parents of autistic children, parents of children who are hydrocephalic w/limited motor skills & very short attention span).
1	0.8	County SWs need to be more in tune with special needs of parents of handicapped children.
2	1.5	Need information on how to qualify for respite care.
1	0.8	Family counseling would be great benefit.
		Financial support
4	3.0	A family's income should not be a factor in providing for services.

Count	% of Responses	
1	0.8	This is the biggest problem in raising a handicapped child. Without help we couldn't raise our child.
1	0.8	People of high income don't qualify for much so we have to turn to more drastic measures like residential placement rather than help in the home.
2	1.5	Need financial support for people who do work & try to do for themselves.
1	0.8	State should offer family funds to care for their severely disabled children in own home rather than putting them into a state-funded facility.
1	0.8	Title XIX keeps us from getting better jobs.
		Services for child
8	6.1	Increase local programs whenever possible - reduce the service area geographically.
1	0.8	Offer after working hours.
2	1.5	Make a combination of home visits & at-site training.
2	1.5	Want to be assured that as he gets older & improves he will qualify for services.
5	3.8	Need summer therapy services.
2	1.5	Programs seem to be geared for the more severe disability - need some for more mild problems.
2	1.5	Reduce duplication of services & duplication of testing (AEA & medical)
5	3.8	Quit taking good services away.
1	0.8	They are available in our community but are very hard to get at because of the amount of paper work & long waiting lists.
		Communication
2	1.5	University of Iowa needs to improve its communication.
1	0.8	Need to improve between all who work with child.
1	0.8	Need telephone lists of AEA supervisors for complaints on services.
1	0.8	Need better communication between all professionals working with child so there aren't conflicting opinions, goals & therapies.
		Other
2	1.5	Don't want child to be pushed into school until he's 5.
4	3.0	Want to raise child as close to normal as possible — Want to keep child in as "normal" a setting as possible.
2	1.5	System needs no changes at this time.

Count	% of Responses	
6	4.5	Don't feel qualified to respond/don't know system cause child only mildly handicapped/only been working in system short time cause child is very young.
1	0.8	State is desparately lacking in care facilities.
1	0.8	Increase mainstreaming.
10	7.6	Unfavorable response (e.g., survey takes too long; some questions like B2 are vague; problem with home intervention when siblings are involved, toys should be shared; AEA not working with U of I well; CHSC in Burlington; reevaluate WIC program).
29	22.0	Favorable response about services received from AEA.
45	34.1	Other faborable response -Assessment is good overview of services usually thought of as being fragmented. -Prefer local medical help received (e.g., IMMC) to U of I Hospital. The local facility treats us more personally & simplifies scheduling.

Parent Comments Concerning Services to Young Children With Special Needs

May 12, 1987

This file contains quotes (partially edited for spelling and grammatical errors) from parent returns. Each parent's comments will be prefaced by her/his ID number.

The first two responses will be attempts at absolutely accurate transcription. The rest will involve the editing mentioned. Also ellipses ". . . ." will be used to eliminate what appear to be irrelevant passages.

1 There are alot of comments I could make, due to my experiences with my youngest son. My frustrations with some professionals. At times I knew there was something wrong. I not only had to convince ________ father and his family, but the specialists in the ENT. I had to convince them and ended up having to educate myself so as to push them into finding out what the problem was and what course to take to help ________. Because ________ was premature and had the problems he has and did have I had to quit my job as a manager of a Pizza Hut to take care of him since there was no insurance I was forced to apply for ADC and medicaid to make ends meet. Now I can't get away from ADC cause I can't find a job that will support my kids and myself, pay for babysitting, and cover medical costs. The pressure the community places on my children and myself for being on ADC & SSI. That only lazy, free loaders are on ADC & SSI. Which is not true in this or all other cases. We can't afford to make ends meet we can't make extra money to survive on without being penalized by ADC or SSI and I can't afford to break away and get a job that will cover our costs in this area. Which puts a great deal of stress on me as a single parent and my children.

So I feel there should most definitely be changes in the Social Services program. I realize not all people on ADC & SSI are on the up and up but there are people such as my children and I who are being punished for it.

I Love children whether they have special needs or not and there are probably alot of things that need to be done and I have comments and ideas on all of them, All to numerous to write down But I hope this information I have provided the questions I have answered helps you in some way.

17 So far we have been very pleased with the people from AEA. What helps the most is that I have known the physical therapist assigned to our little girl all my life. That really improves the amount of "faith in the system". I know her family, background, training etc. & am more than willing to do as she tells us to as I know that she knows what she's doing. I don't have that faith or trust when we have a different therapist like up at Mayo Clinic. Knowing her therapist makes it more personal & I feel she is more concerned about our child than a stranger to the situation would be. If we moved, I'd want to take her along with us to continue working with ________, or I'd take ________ to her home if she asked. The therapists name is ________. What an angel.

Signed,

____

2 Need a neurosurgeon in Northwest Iowa.

3 A family's income should not have to be a factor in providing for services. We don't make a profit — when you take out for everyday expenses and daily living, we got a lot of bills before we had a usual impaired child. How are we to know this when we bought a house, applied for credit cards, etc? Standards are too low for some people to receive help when need it. That is why some families get frustrated like us.

4 It is difficult to have a special needs child in a small community as there is no source for support, limited programs and limited funding for programs with so few children involved. It is a constant battle. We need to be able to have programs locally whenever possible and to integrate our children into the community so they will be accepted for what they are. Churches and civic groups need to become involved also. It can be a struggle to even get a Sunday school class for handicapped children. We have been fortunate to have friends and relatives who are supportive and help out when we need them. There is now a preschool handicap program in the school which is super but I feel a little let down that the school didn't make any attempt to educate older children about handicaps. It might help siblings to have their peers more understanding of handicaps. Also, future programs for our child are in question certainly locally. I hate to think of sending my child a distance away for classes everyday in the winter. It is not a pleasant alternative.

6 It took almost 1 year before our son was diagnosed and many doctors. The only way I became aware of services for him was to ask teachers when I was enrolling our daughter in preschool. A speech therapist helped get things rolling when our son was 3 years old.

I wished the public was more aware of C.P. People gasp when I say our son has it. Since he was diagnosed I have met several children and adults who have C.P., where before I rarely saw it. And I'm used to working for mentally retarded-handicapped plus as a nurses' aid in nursing homes.

7 I would really like information on starting a support group and on books for siblings.

8 It is very hard for me to answer these questions as I am not the mother. Another thing is that our foster baby is not that handicapped. If you didn't know, you would never know anything was wrong with him. AEA comes in every week and are doing a good job. As for any other services, we have never heard of them, probably because we really don't need them. Maybe if our child were worse, or if we ever get another one that is worse, we would look for more of these groups or organizations for their help.

9 I would like to see more services or programs offered after working hours with more parent involvement. I've had home visits and thought they were very helpful because my child felt more relaxed and comfortable at home, although I feel he also needs some group involvement to help him become more assertive and possibly help him to express himself. Right now I'm having a problem trying to make arrangements to get him to a speech specialist due to their hours being 9 to 3 and both of us working and we don't know anyone to take our child.

10 At this point we are happy with ________ services other than the U of I Hospitals needing to be a little better on communication. We see little need for change. This may change as ________ gets older.

Whereas I don't feel a need, right now, for parent groups and masses of information, ________ father does feel more of a need in these areas. They are available and his father will participate in them.

Right now what I find the most difficult is that others don't allow us to treat ________ normally. I don't want Down's Symdrome to become the focus of our whole lives but it seems we're always being invited to special meetings, getting questionnaires, etc. What we want most for ________, ourselves and our other son is as normal a life as possible.

11 As a parent having 3 children go through the Home Intervention Program, it has helped me grow as a parent. They have understood me and helped me with my children. I just wish that more parents would help with their child's education. Teachers can't do it ALL.

13 I wish I could just get my little boy back and live our lives. This is a good book. I checked everything possible.

Thanks a lot for your help,

____

14 I amy very thankful for all the help and support my child has received here in Cedar Rapids.

We moved from Texas a year and a half ago and I was concerned what I was going to do to help my child to become normal.

It also is a concern of mine if my child adapts so well and is doing so good will the services be taken away because he is not as underdeveloped as he was when he started. As stated, his is a genetic disorder and no one knows what is normal for my son. He has to develop what is normal for himself rather than what others say is normal.

15 I think these programs are great, it is just some of the people who work at them when they make you feel like you don't know what you're talking about. It makes it hard to explain to someone like that. Sure maybe some of us parents haven't gone to college or onto other schools but we are around the child and know what she/he can do and how she/he does it. We may not know the medical term for what the child does — all we can do is tell them what's going on.

Some of these people make me feel like they think they are better than I am, but I have news for them. I'm just as good as they are. Maybe not any better, but just as good!

18 For every step we tried to make, we were faced with negatives. We received no assistance and could find none. All the doctors we saw were very negative about a child they couldn't figure out or give a reason for his/her problems.

We were lucky to have family support for we couldn't find any other. The AEA was pretty good but they seemed to have problems helping because of all the paperwork.

What we really need at this time is information.

19 My daughter is kept in a special school in Charles City, Iowa. I wish there was a facility closer so we could visit her more often.

20 The hardest part for us is the lack of information about Soto's Syndrome.

21 I don't like how the state pushes children into preschool saying how important early education is. I feel children should learn at home with the parents until they are at least 5 years old.

The government is trying to tell parents how to raise their children more and more everyday and they're pushing HUMANISM. Very wrong!

Secular schools are getting worse all the time. They're teaching children wrong morals and values.

22 I have had no problems with any services, etc. Everyone involved with my type of child was there and ready with information and help.

23 So far all services that we have received have been excellent. All people have been helpful, understanding and listen to any problem.

Right now I see a need for more OT & PT's in the school where my son is. There is only 1 of each and there are 3 rooms of preschool kids and they can have up to 10 children in each and then there are autistic rooms and the older kids. I don't see how they can see everyone. And as they get more children it's going to be impossible.

24 We're very satisfied with the preschool and the progress made by our child.

25 As parents we are able to take whatever time is needed to attend/schedule additional school conferences, hospital visits or whatever is needed.

I do wish that there were a support group locally that did not specifically deal with mental retardation, cerebral palsy or profound handicaps. We are dealing with a very bright child that talks and understands extremely well and can walk and do most things, but who does have problems in motor and attention development.

27 The more parents are educated to do things for their own children, the less intervention is needed by government agencies.

30 Our speech and occupational therapists seemed too busy to schedule regular appointments. Our son is now in preschool and it's up to the teacher and/or system to be sure he's seen often enough. It's harder for me to monitor because I don't take him personally to see them.

I really enjoyed the seminar held at NITI .... sponsored by AEA allowing parents to choose short seminars of interest to them. We started our own parent support group. AEA's hands were tied in giving names; they could only recommend us to parents and leave it up to them to contact us. We try to meet monthly except during summers. It gave us a chance to get to know each other before our children started school together. The older ones gave us an idea of what to expect.

I would like to see services through the summer. I felt our son was needy of it this year, especially speech, but we "winged" it.

32 I have filled this out to the best of my knowledge. Some things I didn't understand . ... More children today are either behind or need special help. I have twins who both have special needs. Thanks for letting me be a part.

34 There is some duplication of services which is not necessary.

36 I feel like my son's entrance into the multicategorical preschool at Vail is the best thing to happen to him. The AEA 12's interactions with my son and our family have been helpful for us and my son's progress is unbelievable. I am remiss that we didn't know of our son's learning disability sooner and that we didn't become invovled with AEA sooner.

Thank you for this opportunity to help.

37 Everything is going real good at home and she's doing better.

38 I have had one bad experience with AEA. The rest have shown a genuine concern for my child.

39 Please inform me as to where I can get more information on Autism. No one seems to know.

I'm sorry I can't answer all of the questions as ________ does not require special services more than attending school for behavior disability.

Thanks,

____

40 Our AEA has been really terrific in the teaching and physical therapy of our child.

Financial aid is always the biggest problem of raising a handicapped child. Most people don't realize it takes more to raise them than it does to raise a normal child.

With continued help we will be able to raise our handicapped child at home where with the continued education she may someday function as any other normal child.

41 Overall I would say that people we've worked with have been excellent except that labeling a child is something they do too freely! Upon meeting our child for the first time this year (age 4) as we discussed possible programming and her future year, our teacher stated "You know she's probably only trainable." A statement like that should be used only after that person has evaluated her. It certainly makes us wonder if she'll be objective with our child.

Parent involvement is extremely important and should be encouraged.

42 We have had very good luck in our resource finding and help getting. We receive SSI and Medicaid which is greatly needed and appreciated. The school system has been very cooperative and willing to listen to and adjust as we see the need. I feel that people who have problems really don't apply themselves in a cooperative manner.

45 I would like to see more information about twins and their special problems provided to the public. This information .... should be contained in pamphlets and given to the parents of twins and other multiples. There also needs to be more information presented on twinese, the language that develops between brothers or sisters.

49 Services we have had so far have been excellent.

50 We have been very happy with the services we have received from AEA. I feel like the AEA has been a life-saver. I've learned how to motivate my child to work hard in learning; it's been a good feeling achieving our goals with help.

I do feel the doctors need to be able to provide more information and be more supportive. Ours gave us no information at all except the diagnosis of Down's Syndrome. We found out about a parent support group from a family and they told us about the AEA. I feel doctors, especially pediatricians, need to be up on information and services.

51 I'd like to give praise to pediatricians, Child Health Specialty Clinics and AEAs. They all work together well and have referred my child to these agencies. They have helped a lot . . . . A lot of people still do not know about these agencies though.

I feel family doctors, county hospitals and county social workers need to be better informed about services for the handicapped children. A lot of people I know take their special children to a family doctor (maybe because they can't afford to travel far to a specialist or because they just don't know where else to go.) I know I have to travel far to go to my child's pediatrician, but I've learned from experience that family doctors just can't help much and they don't follow the child as closely as a pediatrician does. And it's been worth it because I've gotten more help from other agencies my child's pediatrician has referred us to! Special children need to be followed up more closely by a doctor and need the closeness and love a pediatrician can offer. I have both a family doctor and a pediatrician . . . . Our pediatrician spends more time with me as a parent, informing, suggesting and supporting me in raising my children, especially since I'm a young mother. I feel he is very understanding of the problems I face everyday.

52 My son was receiving excellent speech therapy at his school until the AEA decided to move her to a different district. My son uses a mixture of sign language and language board right now and is a good candidate for a computerized voice box. Switching speech teachers has slowed his progress a lot because the new person comes in with her own ideas and has to learn the kids all over again.

Also the amount of physical therapy and occupational therapy my son receives is very little. They have gone to the teachers positioning the children and teaching them. We have to take our son to a hospital to at least get some physical therapy and to help me learn more exercises. We need to give these kids more therapy and quit taking good services away from them. Our goal is to make them as self-sufficient as possible.

54 AEA V has been super for ________.

55 I feel at this time that my son is receiving excellent help through Grant Wood. However, there are times when I wonder if more could be done than I'm unaware of. Also, I sometimes feel that programs are geared for more severe problems. My son's problem is mild so it is hard to make him fit the programs. Being we have two older children, it is also hard to attend certain functions.

60 We have had very good service from Grant Wood AEA since I contacted them in 1981. They have . . . . directed us in the care we have received for our daughter.

I know there are a lot of people who don't know how or don't try to seek help for their children's needs . . . . but this has not been our situation.

Any services we have not utilized have been out of a concern for us to keep our daughter in as "normal" a setting as possible, i.e. we have never joined the organization for retarded persons. After 5 years I believe we have made the right decisions in these areas.

62 I feel, at this point, very satisfied with the services provided by AEA IV. My ignorance of programs, materials, etc. available is due to not being aware of the AEA and its services until I had a child with special needs. As I stated earlier, our son is one year old, therefore, he is not at an age where he is in the school system.

63 The services are available in our community but they are very hard to get at. There is a lot of paper work to do and there is always a waiting list.

People of high income don't qualify for much so we have to look for more drastic measures like residential placement rather than help in the home.

I am a college grad in the area of special education and I find it extremely difficult to find services sometimes and then to get all the paperwork done. How do less fortunate or less educated parents survive in this system the way it is?

64 WIC program has time and time again tried to over rule our doctor's orders with the . . . . to the point that they turn people in for child abuse for not complying to what they want you to do even if a doctor said not to do it. After this had happened to us, we felt that type of service was not for us, and we removed ourselves from the program. I feel if they are going to do this type of thing they need doctors and not nurses working as doctors.

65 At this point we are extremely satisfied with the services provided by our family doctor, the staff and doctors of the U of I Hospitals and Clincics and the AEA. As a result, we see no real changes that are necessary. We have been provided with an abundance of information and training through the above sources. The home intervention program of the AEA is excellent.

67 ________ will be 3 in December. Some questions that we have are: If he begins in a preschool handicapped program in December, is this the appropriate setting? What about social interaction? As he gets older, should he be involved in a regular preschool program as well? An aide would definitely be needed due to his physical handicaps, would AEA provide this in a regular preschool? Will a regular preschool teacher accept ________ into her program? Can he be in both a preschool handicapped classroom and regular preschool and receive adequate therapy? Would a computer be a good purchase for ________ even though his speech is excellent? His hands are involved but he is learning to do some things. What type of a computer? What adaptations can be made for his hands to manipulate? What software?

This is typically what is available for physically handicapped children under 3 years of age:

If a child is severely mentally handicapped, she/he can begin in a self-contained center-based program as young as 2 years, or even younger in some cases. However, if you have a child such as ________ who is moderately to severely physically handicapped but no problems with speech or cognitive skills, there is only OT available 45 min. per week which is not nearly enough for a child that involved. (When he is 3, he is eligible for a preschool handicapped center-based program.) In the past, we have asked for an additional COTA to be hired so children at home could receive OT twice a week but was told that there was "no money". Services must begin early!

In addition to OT, my sitter did bring ________ in once or twice a week for PT to our center-based program. For this school year, I asked that ________ be bussed in for therapy daily and our Special Ed Director said that was okay. Most parents just accept that the above is all there is and don't ask for more where in some cases something could be worked out.

Also, it's very hard to test ________ due to his motor involvement, most tests use many motor skills. Therefore, are we getting a true picture of his intellectual abilities? I wish we had a person in our AEA to evaluate children and set up a computer program for them and make switches or adaptations if needed.

68 Due to drastic cuts in funding, both for AEA and school districts, we are experiencing elimination of certain programs and also personnel. For example, there are 2 less therapists at the school my child attends than a year and a half ago. He does not receive as much one-on-one therapy. Also, a special physical education class for handicapped students was almost eliminated except enough parents spoke out in defense of it at an AEA Board meeting. We need to express how important it is both to Federal and State Governments not to cut funding for special education.

70 ________ has been in in-home programming since she was 3 months of age. I have been very satisfied and gratified for the Grant Wood AEA.

She is now starting a 2 morning a week special education class in Atkins, Iowa in cooperation with the AEA. I'm hopeful and optimistic this will be as rewarding and helpful to both her and me.

73 Need OT and PT during summer months.

75 Our daughter's needs are very much less as compared to other special children's needs and I may not represent very well the majority of people using services.

.... We have been very happy with our local AEA and with the genetics clinic in Iowa City, Iowa ....

78 Our daughter was born with Spinabifida and is very "normal" except for the use of her legs. We go to the Hospital Schools in Iowa City, Iowa for routine care for urology, neurology, any orthopedic services and physical therapy.

We use AEA services provided here in town and enjoy all the help they can provide.

I wish people who do work and try to do for themselves could get help financially with their handicapped children for the extra expenses they bring.

80 When our twins were born and needed special help we didn't know where to turn. The hospital set up some appointments and it all just sort of fell together. They were both seen by whoever needed to see them whenever they needed to be seen. We weren't aware of all the programs available to our sons and I honestly feel, had it not been for these programs our sons may very well have been seriously physically handicapped. Because of the therapy and genuine concern of the AEA workers and staff our sons can live a very normal and healthy life. We are indebted to everyone for all of their help and love for our boys.

81 This has been difficult to answer as I don't know that much about the services available. We have only worked in the speech department.

84 We have been very fortunate to be in Iowa City and close by the hospital where ________ gets all his medical care. We also have a very good daycare center available for the special needs child. AEA has been very good and has always kept us well informed and up to date. Their services have really helped ________ development progress faster than we believed it would

85 Why did you send this booklet to me? How did you get my name and address? A lot of these questions don't pertain to the information provided to me and second of all some information I don't feel is any of your business or concern.

88 Don't send any more of these things to me, please.

89 Our daughter is only two and has Down's Syndrome. She has been very healthy so far so we really haven't had many problems other than her 4-5 month delay in mental development. A "Keystone" teacher is coming to our home one hour a week. We do feel she would be able to learn much more if she were in school at least part time every day as one hour a week just isn't enough. This isn't possible as she would have to go to school 20 miles from our home. She's an energetic and willing learner but we feel we don't have the knowledge a special education teacher could give her. The "Keystone" agency has been very cooperative and very helpful.

91 Services were provided in the home when our child was 9 months old. Now she is in a preschool program. I hate to think what our life as well as hers, would be like had not early PT and OT services been provided. She will now be able to develop her full potential.

92 ________ has a very bad behavior problem and it needs a lot of work. His behavior at home, in stores and when he goes places to visit is awful. But at school he has good behavior. His behavior in public gets on my nerves and embarrasses me. My other son has bad behavior in public, also. I want and need help with my children's behavior. They need to learn what "no" means and know I mean no when I say it. I shouldn't have to tell them to mind 3 or 4 or 5 times — twice should do it.

My kids need Big Brothers — their father takes no interest in them.

Mother

93 We appreciate all the help we have gotten from the Keystone people and overall are very satisfied with things being done to help our son . . . .

95 I'm concerned about the bussing situation. My son is a little over 2 years, and rides the bus for 1½ hours before school and 1½ hours after school for a total of 3 hours a day.

My son is in a class for the deaf — 5 children and 3 teachers — excellent! He is doing very well. But I'm concerned whether this wonderful schooling will continue with less than 5 children because a couple will be moving to first grade next year.

96 I have been pleased with University Hospital School. The personnel do listen to the parents and are willing to work with you. However, I am much more impressed with Grant Wood. They really are organized — treat each child and parent as individuals, listen to needs, share ideas and give support when needed.

Being a nurse I was aware of some of the needs ________ and our family needed and asked for help. I do feel a person needs to be somewhat aggressive and needs to become involved with the services as much as possible.

This assessment did take a long time to complete. I hope I was as complete as need be.

97 We have 2 autistic boys. They attend the same preschool which causes serious problems from being together. We always think that they could be getting more help. There are 13 students in this preschool — too many. They need lots of special help, individual and in small groups. We want the best for our boys — a good life.

We think we should be getting SSI because we are suffering with 2 autistic boys. But because we're farmers owning machinery and livestock we can't get it. We think this is unfair. We don't get any respite care either.

We need a summer program . . . . Our 3 year old autistic boy will be residing at the Child Psych Unit the entire month of October. We'll really miss him, but must remember it's for his benefit.

I know this is supposed to be confidential but if you have any questions you may call me at ________ .

all I think it is an excellent program.

99 We enjoyed participating in this assessment of needs although some of the questions were a little vague. For instance, under the Cost of Services section, annual expenses can vary a great deal from one year to another. At least in our case it has.

100 I have no negative comments as all results from my child's program have been very satisfactory. I am very pleased with the change in my child since the beginning of his program (3 years) to present (6 years). His teacher of two years (Disabled-Handicapped Class) was excellent and his speech therapist was also. There was even a summer speech session available for my child after his first year at preschool so he could continue a regular routine all year. He is enrolled in a regular kindergarten class, doing excellent, and is not currently thought to be in need of speech therapy. His speech, when last tested, fell into normal 5-6 year old range. He will be retested in December. I am most grateful to Title XIX, as it paid for all his tests and programs. And I would not have been able to do so myself.

109 With our son's special needs we have discovered how desparately lacking the state is in regard to care facilities. There is only 1 skilled facility in Iowa for children. Funding for other levels is also a problem. Many parents from Story County must travel 1½-4 hours to visit their children.

Respite care is a wonderful resource available today. We were not aware of any 3 years ago.

It would be great if county social workers were more in tune with the special needs of parents with handicapped children. The amount of apathy was amazing. In our experiences the best information and support comes from other parents.

113 We have always had good results with the people at University Hospitals. We have taken several children there in almost every department over 16 years.

Two things that would help parents who are there on a regular basis, as well as patients and families who use these facilities:

1. There needs to be a place to eat at the hospital 24 hours a day. The big dining room is only open at certain hours; so are some that just serve lunch. We often take food with us in nice weather and eat outside. There are many nice areas for this.
2. There needs to be another parking ramp or large lot within walking distance.

Our AEA is very good, understaffed at the present time, but they give good service.

114 My son will soon be 4 years old. He has been going to preschool since he was 2½. I enjoy it because school has relieved me of a lot of stress. When he was little I took on the job of his therapy and training. It was well worth it! When he was a year old the label was severe mental retardation. Now he is testing out close to his normal age group. Except for not being able to walk or sit well ________ is just like the regular kids. He talks well and has a personality that doesn't quit. I'm grateful services are available and attitudes are changing towards physical and mental handicaps. I hope in the future services keep improving and that State and Federal funds keep coming in. It seems more and more children are being born with special needs. I think the public needs to be more aware of birth defects and causes so we can produce the healthy children of tomorrow. Thank you for letting me participate in this survey.

116 ________ is now attending an all day kindergarten where she is in a learning disability classroom and also receives speech therapy . . . .

117 At the University of Iowa Hospitals in Iowa City, Iowa the doctors are very poor plus you have so many doctors telling you different things. When we took my daughter to Iowa City at the age of 1 month old the doctors told me not to take my daughter home because by the time we got home (Burlington, Iowa) she would be dead. And when we go back for check-ups they still tell me she is going to die. She is 3 years old and she is still alive. I don't think a doctor can tell the exact time your child is going to die. The nurses in Iowa City are great and the people at Hospital School are great, too. I really don't care for the doctors at all.

Thank you for sending me this and if you need me again, I am more than welcome to help.

120 From January 1986 to May 1986 ________ made a lot of progress in preschool and with the speech clinician. During the summer he potty trained himself which made me very happy . . . . He is starting Headstart Home Base this year. I will have to see what happens with that.

122 ________ is currently in the infant program in our home. He is visited by . . . . an AEA infant teacher. We are satisfied with the work she does. The main problem is our 2 other children and her. She comes in the door with a big bag of toys and doesn't want the other 2 kids to touch them. If the other kids drag them out she gets disgusted.

My husband works days, so he can't take the kids out of the house and I like to help her with ________ and she likes me to be right there so I can't take the other kids outside. I'm certainly not going to put them in their rooms for an hour and a half. We feel in a situation where siblings are involved the toys should be shared.

123 We received our speech therapy from the Grant Wood AEA and were very pleased and satisfied with the services they provided. We receive medical care at SUI for our son and are more satisfied now that we have adjusted to their system. But we have not had a contact with any other parents dealing with Chronic Hepatitis B, even through HOLT and I guess this is where we feel most alone. There is not a large number involved that a support group would be feasible but it would be nice to have contact with other parents facing the same uncertainties.

I am not really qualified to answer these assessment questions because I am not that knowledgeable about all services and how they are provided. I know some because of my involvement as a nurse at our county well-child clinic.

124 I am very happy with all the hope I have gotten for my children because I would have had a lot of problems if I would not have had this hope.

Thank you

125 We need to have education people have information for parents on groups like ARC and parent support groups in the area.

How do people qualify for respite care? Our child's handling is not as serious as many we've seen but with the need for both parents to work full time and with 4 other children our time seems stretched to the breaking point. Our marriage is strong, but I can see that this could really be a strain on a less solid relationship . . .

Why does this survey have to be in such a heavy (cover, etc.) booklet and such heavy paper? We could just as easily answer on fewer, lighter weight sheets. The money ultimately comes from us taxpayers. Why waste it? Use it on the kids.

128 I would like to be able to volunteer at preschool.

129 I believe and also know ________ is receiving excellent services provided by AEA. She loves her school and that is very important in our lives.

130 Respite care is needed so badly along with rural support groups.

131 I cannot praise our AEA enough. I would have done a lot with ________ no matter what. But ________ progress would not be as far or this quick without the AEA educating me to work with him. Without the AEA, I'm sure ________ would still be in a state of depression . . . .

If there is something I've missed or if there is more information you would like to have on ________ you may contact me.

132 I thought the programs were pretty well rounded until the government started fund cutting.

134 Small children shouldn't have to go to school 5 days/week. A 3 year old needs rest/naps. It's too much for them.

135 We had unusual circumstances as ________ was born by emergency C Section, then a couple months later when we were in Iowa City with him I became ill and had emergency surgery for removal of appendix, ovary and tube due to staph infection from C Section. I was off work till the end of June. So we basically had little income for several months and mounting bills. Because of our usual income, however, we don't qualify for any assistance. The stress of accepting a child's defect, coupled with illness and financial problems have made going from a family of three to a family of four extremely difficult. I feel family counseling would be of great benefit to all "new" families of infants with birth defects, just as part of the overall services offered by AEA. So far we've been extremely pleased with all AEA personnel and feel ________ is being encouraged to reach his full potential.

I am very interested in keeping abreast of proposed legislation re: educational funding for the handicapped. They've come a long way in the past 10 years but much more needs to be done. I am also doing my best to learn all I can about Down's Syndrome and never pass up an opportunity to discuss it and encourage organizations to get involved in supporting the various agencies available to help the handicapped. We are very fortunate to live in Iowa as it is one of the very few states that recognizes the importance of early home intervention.

I think AEA personnel should be active the entire calendar year. The trend indicates the earlier home intervention is commenced, the better. What do people with newborn babies do between May and September?

Any time you need information for your studies, please feel free to contact us. We are more than happy to cooperate in any way we can. Four short months ago upon learning ________ had Down's I thought my world had come to an end. Now I look at it as a new beginning. I'll always feel saddened that ________ had to be afflicted but it won't hamper me from taking pride in his achievements. He's quite a guy.

136 I am very satisifed with the help I received for my son. I think things were handled excellently at AEA and they were very happy to help and explain things to us.

138 I feel that my child was very lucky to be able to attend the preschool classes. I hate to think what kind of situation we would be in now, if not for the AEA. I do wish that I could have more contact with teachers.

My son has made steady progress in his speech and behavior in this last year, but I need to learn more to help him because sometimes I feel I am holding him back.

139 We are basically happy with the services we have gotten. We did have an AEA Occupational Therapist who didn't do much, but have a new one now.

141 I feel Heartland should be acknowledged for the help they give to a lot of children. They should be given an A+ in finding out some children with problems. Thank you.

143 I wish we could get into some play groups of special needs and regular needs children. I feel it's important for special needs children to be around non-special needs children, especially in preschool.

144 We've been delighted with ________ experiences with AEA VII since his first environmental contacts as a home instruction student receiving physical and speech therapy. He's now enrolled in ________ preschool in Cedar Falls (UNI) and he's doing exceptionally well. We can't say enough good things about ________ and the whole concept of the preschool.

145 All in all I feel my child has had good care although sometimes I feel that I am in the dark regarding some important decisions for her.

147 Our child's medical needs are very complex. We haven't fit into many of the programs. We live in Iowa but had to go to Minnesota for the transplant so we don't qualify for Iowa aid or Minnesota programs. Being he's a child with an adult problem we haven't received any help in the form of books or parent support groups. Living on the Northern edge of Iowa it's too far to go to Des Moines or Iowa City for kidney programs. Our AEA has been great but they don't have any other child with this extent of medical physical problems. Many of our medical situations are experimental. When we get through them the medical facility asks us for help in setting up their program. We have been caught in the middle between our insurance company and the Social Security-Medicare and in paying these medical bills before we have received insurance money, but yet there is no one who can help us. How do we find out about programs other than AEA's?

148 My son ________ is almost 2 years old. If it wasn't for Occupational and Physical Therapy through AEA 16 he would still probably be needing these services but he is all done. He still needs hearing tests and teachers, though.

149 I feel children with special needs should have funds provided for their care, regardless of income. The current program only discourages a parent from being his/her best in his/her field (i.e. wage increases) or even from getting a job. I believe these kids need more examinations, especially the first 2 years. An Iowa City doctor told me ________ heart should be checked regularly, especially the first year. I don't have the income to spend $20 for every office call, but yet I know it's important.

I would like to commend .... of the Genetic Counseling Services in Des Moines .... Also, thanks to the County Nurse for her support immediately upon coming home from the hospital and her regular visits. She, too, shows her concern ....

150 I've been involved with Smouse Home Intervention and the Daycare for Exceptional Children. I was very pleased with the Daycare. I have mixed feelings towards Smouse. I get conflicting information from them and I feel some of the teachers and other staff are quick to label a child without knowing what the child is capable of actually doing. The teacher we have now sits and watches for 20-30 minutes and wonders w. he won't perform for her.

154 I feel that as a parent we are basically on our own until our kids are school age (other than AEA) and this to me is a sad and frustrating life. It might be nice to have a list of children in the area and have the kids and parents talk to each other from time to time.

Our thanks to all of you who are working so hard to improve the lives of our special kids!

155 Overall, I'm very thankful for all of the services that were given to us. The doctors, speech therapists, teachers and social workers have been very helpful and compassionate in dealing with our son.

The only main problem I see is that if you don't have a premature baby you'd never know about all of the programs that are available. I know I have talked with several parents who wished they had known about the programs my son is in.

157 Just one more gripe about AEA. In May of '86 I terminated physical therapy services through the AEA under the advice of our pediatrician and the physical therapy department at Iowa City. And since then I have tried to get a physio-ball so her private physical therapist could come to the home because of health problems. I was told NO! And his reason was because I didn't have their therapist in my home, even though she wasn't doing her job to start with. No exceptions they say! It's a Crock! I can honestly say that I have never gotten any real help from AEA. One more thing, I requested a feeder seat; they brought me out one, my daughter is 2½, the chair fits my 5 year old, then they found another one, that one fit my 8 month old. I was told that was all they could find. End of story. I have heard nothing since. I have also requested information on numerous things and I have been told they don't know. If they don't know, who should?

Another subject that is just ridiculous in the Social Security Administration — We applied for it at the time of our daughter's birth, it took the 9 months for them to decide she was disabled, she qualified for 2 months and she hasn't qualified since. So we rely on our private insurance which just doesn't cover enough.

158 The "normal" child has the preschool classes open to them. But the children with special needs don't have this. Smouse School has to go all over town to locate these preschool classrooms. And I feel that it is unfair. I have twins who have special needs.

160 This system amazes me when I think 2 years ago I had no idea it existed. I have found all services and people extremely helpful. I am grateful to all the help given our son. The one disappointment was the wasted day at the clinic in Burlington on September 11. Somehow I got the wrong impression of what it was.

162 I feel, as a parent, that as soon as a child is born and has been diagnosed with disabilities, services should be offered, along with information about these services as soon as possible. Contact should be made sooner.

163 Most of our medical contacts have been great. We deal with the frustrations of one child on Title 19 and the run around every time he needs something. We have waited over 2 months for approval of a walker for him before the supply vendor will bring it. They keep requesting more information on already given facts: "Where does he live? Can he walk? Does he have braces?" We feel "taken" but there seems to be no way to fight it when they don't say "yes" or "no". If there is a way to mobilize these people I would like information on that!

169 I think I could write a book, but I won't as I see I only have one page. First and foremost I feel as a parent of a severly handicapped child many conflicting feelings that I must face each and every day. My daughter is 4½ and I am agonized by her future and our family's. I am torn by the most wrenching feeling of the possibility that someday I may no longer be able to care for her in our home. The thought of having to place her in a residential care center is more disturbing to me than her death. I want to care for her in our home. But, as she becomes bigger and heavier I am not sure if it is possible. I am also concerned about the effect it would have on my husband/myself and our 2 other children, to place a child who is so loved by all of us. We know everything about her and the thought of someone else who does not have an interest in her, taking care of her is very much a concern. I believe most parents would prefer to care for their severely disabled children in their own home. But more services need to be provided for care in the home on a regular basis. I know in the State of Michigan parents of severely handicapped children are given a monthly subsidy to care for

their children in their own home instead of opting for placement in state funded facilities that are very costly to the state. With those funds parents could pay for extra care that was needed, make improvements to the home to provide adequate space, purchase necessary items such as attends, special equipment, etc. I think the State of Iowa should check into that program and offer it to parents of children who are classified as severe/profound — no matter what income bracket the family is in. A family that has a severely disabled child should NOT be evaluated on the income that it has but rather the support that family needs — emotionally more than financially — and make that family's life as normal as humanly possible.

Thank you for your efforts and giving me the opportunity to express my views on a subject that is very important to me.

170 AEA has done wonders for my two sons and in just a short time. Things I couldn't get doctors to listen to, they have found were problems. Doctors told me they were fine, of course now they know otherwise through Project Catch and AEA. I do feel that all parents who feel that there are problems with their children should be allowed testing regardless of what the doctors think.

I cannot thank Project Catch and AEA enough for all the help and progress they have given me and my sons. At least now we can communicate, and they are doing better all the time . . . .

Something else I would like to comment on is about my son ________, age 4. September 21 ________ got his thumb caught between the sprocket and chain of his sister's bike. He lost his thumb at the knuckle. Other than Tylenol with codeine and the doctor's next appointment, I was told nothing except he lost it. I told ________ he lost it at home, but yet when he had the bandages changed and saw it, it really upset him. (Me, too!) The doctor did hug him and showed compassion, but I have asked around and met men who have lost fingers and thumbs who were more than glad to show ________ their hands and show him they still work. They even told me what the doctor will be doing or want until it's healed (which he didn't). One of the men is a neighbor. He said he has met a lot of men who have lost fingers and arms and so forth. He said even after 5 years it helps to talk to someone like him. He meets them where he works selling car parts. Until this happened to ________ I didn't even know. The other 2 men were at stores. I know for women who have breasts removed and other medical problems they do have support groups, pamphlets, and people to see. I have had all kinds of people including a teacher who told be they used to spin their bike tires like he was doing (which I didn't know he was doing). They said they didn't know that was dangerous. (________ dad almost lost the same thumb doing the same thing.)

What I'm trying to say is: I think the medical profession could have helped us more, by informing us what the care is for an amputation, how long not just telling you a week at a time. And ideas or pamphelts for him to see like they did for his tonsillectomy and adenoids and tubes. It is so frustrating because I love him very much and I don't know how else to help him cope. I hope other parents with children who have lost a lot more don't have to go through this . . . . If it were a hand or leg, I couldn't go it without support.

172 Don't know system well enough. We haven't been in it long.

173 I would be willing to be involved in any way that I can help my child and other children. Since I am not very familiar with the system (my child is young) I am not aware of a lot of groups and services, but would welcome contact with them.

176 Overall, I have been very pleased with the services my daughter has received. Most of my daughter's services have been through the AEA. I feel they have done an excellent job of assessing my child's needs and informing me of them. The handicap preschoool is an excellent program. It gives my daughter an opportunity to be in the public school before she starts kindergarten. It also gives the therapists and teachers an opportunity to observe her developmental learning skills before she starts her formal education. This has given us a "headstart" on assessing her learning needs and answered

many of the questions I have about her starting kindergarten. It has made me much more relaxed and assured that her special needs will be taken care of when she starts her formal education.

178 I have not been involved in the system very long. So I have not seen as much as some other parents. What I have had access to at this point has been quite satisfactory and am relatively happy with the services I have received.

I'm sure as time goes by I will start running into obstacles with the "system" (mostly educational, as my child is healthy) and would like to learn how to hurdle them now instead of having to later.

179 I feel the AEA program has been very helpful and has given me hope for my child and some emotional support. I would like to see more programs started in this area for the disabled child, i.e. respite care/home help, support groups.

181 On the whole we are very pleased with the services with AEA 6. It has helped our child a lot. The testing seems to be a little rigid though, for example, ________ doesn't know the difference in monies, the reason being we haven't discussed it with him yet, but they marked him down for it instead of explaining that it's never been brought to his attention. Other than that, we are satisfied.

183 It would be nice to see information about children like ours, and what to expect. Our daughter is always going through stages that normal children do not go through. Examples:

1. Screaming when people walk in the house.
2. Screaming (fussing) because of running water from a kitchen faucet.
3. Being touched, makes her pull away or scream/or be very fussy.
4. Scared of strings attached to clothing.
5. Eating habits (our daughter at age 3½ years is finally on some table foods that have not been ground first).

Normal children outgrow stages a lot faster, while with handicapped children it's frustrating because it seems to take forever for handicapped children to overcome their fears.

187 We receive most of our major help through the Shrine Hospital for Crippled Children Twin Cities Unit. If available a van can drive you up. They pay for the hotel and give a food allowance. They pay for all prosthetic devices, hospitalization, doctors, operations. For my child or any with an orthopedic or physical handicap I believe they are the best. Whereas at Iowa City they may have seen 20 one-legged babies, at Shriners they've seen thousands. They don't pay part — they pay all.

192 We have been with the AEA now for about 5 months. So far they have treated us with great respect and seem to understand our needs with our child.

194 More information should be provided to the public about what services are free or of a nominal fee within the community. Especially see that physicians know what is available. We knew nothing about all the free help/services available through the Public Instruction System, i.e. speech testing, therapy, handicap preschool programs, if we hadn't done a lot of digging ourselves. It appears that if these free services were more available for public information a lot more children would get the help they need!

196 I think that perhaps it would be helpful to know what our feelings as parents were when we realized we were faced with the care of 2 disabled children (twins) with very special needs. We were determined to give them the best care we could, but at the time we took them

home from the hospital, we were totally unprepared for the problems we were about to encounter. We were unaware of resources or what services could be provided and by whom. We understood very little about the ineffective services we did manage to obtain. We felt there was no one to help us and everything was so disorganized —actually, our first 9 months of at-home care was absolutely an unforgettable "nightmare". The trauma and burdens associated with our attempts to handle this situation nearly broke up our home. Finally, we were impelled to acquire the assistance of a state legislator who persevered to penetrate the bureaucratic-minded system of conglomerate services on behalf of our disabled children. We are still learning!

p. 10, F. Parent Training

.... If we had not been aggressive parents in search of most of these services, we probably would still not have known many of these services exist, or their functions. It seemed to be a secret —what government funded, etc., programs were available and not easily accessible. Especially the IDHHS; they do not want the parent too knowledgeable. Parent awareness of availability of services is definitely a disturbing on-going problem!

p. 8, D. Services

WIC is definitely not geared to serve the child with special needs which I intend to point out. I feel strongly that the handicapped or disabled child should be a priority in receiving their services. However, it has become apparent to me that the WIC program is so determined to be "effective", that they have failed to allow themselves the flexibility to deal with the child who desperately requires their assistance more than any other within the state. I understand completely how rules and regulations for the WIC program must be enforced uniformly in order for their system to work in accommodating the number of clients they serve. I have 2 older (healthy) children also who were both on the WIC program as infants, so I am familiar with their set-up after my 8 years of association with them. When my twins came home from the hospital with many special needs, they both required a sterile pre-bottled "preemie" high-calorie formula which is not available in retail stores anywhere. After much commotion (and large out-of-pocket expense for us, I might add) they finally approved a pharmacy to order the product. The pharmacy never trusted that WIC would always reimburse them monthly so consequently they did not want any quantity on hand. We would continually run out and ended up making many more trips than was necessary just to pick up the formula a few cases at a time.

Moreover, we became aware that the pharmacy was charging WIC an outrageously inflated price for each case of formula. We suggested an alternative method whereby our regular supplies vendor could deliver (no additional cost for delivery) the formula at a wholesale price thus benefiting everyone involved. WIC, however, would not even consider this idea because the vendor was out-of-state. Therefore, they continued to pay far more than necessary for the same product with less service.

Persons engaged with the WIC program treated us as a "bothersome" case, often times exhibiting rudeness and a totally uncaring attitude. Because of the twins' severe health problems we were unable (per doctor's orders) to take them into the WIC clinics where they would have been exposed to other children with possible childhood infections. (This created another battle.) To certify, recertify, and pick up the WIC checks during their specifically scheduled time slots was becoming (and still is) nearly impossible for us. (To prevent abuse, they insist we pick up our tickets or checks in person —as if someone else could use this formula!) On the particular time of the particular day assigned for our pick up appointment we must appear regardless of whether:

1. Our twins may be in the hospital 90 miles away.
2. We are making either a scheduled transport to or from the hospital or doctor.
3. We may not have a nurse on duty to care for our disabled and high-technology dependent children at home in order for me to leave.
4. We have unexpected conflicts with another various service at that particular time.
5. My husband is working.
6. We are out of town for other reasons.
7. The weather is inclement for our 30-mile venture.

8 Even though we have a nurse caring for the twins, they are too sick for me to leave alone with her in case an emergency should arise at any time.

9 We could send another person, who could easily pick up the checks for us if we hadn't already used up our 2 allotted proxies.

There are no exceptions; if we are unable to get those checks for the month (worth approximately $480) then we are forced to forfeit that service, resulting in another financial burden of somehow bearing that cost ourselves. I would very much like to see the entire WIC program re-evaluated for the purpose of finding a better way to serve the child with special needs (and his family). The local administrators of this program claim to speak for those at the state level .... in this case, I hope they are wrong!

197 We would like physical therapy once a week, instead of once a month. The same with speech therapy through public education. We may have to seek outside services. It's hard to rate services as I have not seen them much through the years. The U of I Hospital genetics counseling is excellent. However, some of the other services at Iowa City could be provided in Des Moines.

198 This assessment gave me a good overview of the services for my child. With services so fragmented it's important to look at them in one picture and evaluate them.

200 Before having ________ we had worked with handicapped children and have two relatives with Down's Syndrome, so we already knew the system to a certain degree. I do feel though that parents without this background could feel very lost. It would be so helpful if there was one phone number that you could call and they could give you the first steps you need to take to get services for your child and family.

The hospital social worker (Mary Greeley Medical Center) came to me and said, "You do this first, this second, this third, etc." It gave me direction and I was taking action then immediately to get help. It is needed.

201 AEA has been a very valuable source to our family for emotional support as well as financial.

Title XIX is a life saver when it comes to cost. But it also keeps us in a bind when it comes to getting better jobs .... This is one subject that needs to be approached by the government.

204 I hope I helped but ________ is doing well. I haven't talked to his teacher yet, but his AEA 6 provided me with information about how ________ has caught up in his mental, now he just needs help with his behavior problem. I hope we can see some improvement. AEA 6 really helped him a lot. The only thing that upset me was in his evaluations they make him sound mentally retarded and he isn't. I hope it doesn't hurt him in his life when he gets older. They explained without putting a name to his problem he would (not) be entitled to the program.

207 We feel we have an excellent AEA staff (AEA VI). There were some duplication of testings of our son, but I was assertive in not allowing "extra testing."

We are more at ease now that all of our services are being taken care of in the Des Moines area. They have excellent specialists, without the horrendous scheduling ineptness that U of I Hospitals/Clinics have. IMMC is much more personalized and efficient, without loss of good, quality care. Our local specialists/family physicians are also excellent.

208 When we found ________ to be disabled we did not know where to go for evaluation and rehabilitation care nor did the area social services. We still lack information on available services and it took us better than a year to find a support group.

212 We are very happy with the services we've received so far. Our child's handicap is relatively mild so I know nothing of the needs of others with more severe problems.

We are very concerned, however, for our child to fit in with a normal classroom as much as possible. Can an aide who has extra (but not exclusive) time for him offer the assistance he needs to gain confidence in a bustling kindergarten environment?

Also, if local home economics teachers would identify students with the interest and patience to babysit a special child .... perhaps offering class credit for working with a recommended therapy.

214 For the most part, I'm very happy about the care and help we've gotten for our daughter. The most confusing thing for us has been the differences in the expectations and checklists used by the different people who see our daughter. For instance, our in-home teacher has been working with her on holding a crayon and making marks on paper. Then the occupational therapist (she comes around about once every 3-4 months) comes to see our daughter and leaves a list of things to work on — one of which is snipping with scissors — our daughter isn't quite 2½ years old! Do "normal" children snip with scissors at age 2½?

215 Perhaps because our daughter is so young and the services we have received were beyond our expectations already, we have no suggestions for improvement. We have had very satisfactory results and been more than pleased with her teachers and therapist. Perhaps there is more we all should be doing, but I don't know what. One of the things ________ has taught us is patience and that some things cannot be rushed.

From what I have read, we may come upon a time when teachers are not so great and services are lacking, but it certainly hasn't happened yet.

However, we do feel very strongly that the special services ________ has received have been vital to her development and our survival and would strongly oppose any cuts in funding for this most important work.

(From an attached note)

.... I am not able to be very active in meetings, but I am a freelance writer and frequently have articles published in the REGISTER in Des Moines and in many varied publications. Part of the reason this is late is because my first book just came out. If I can ever help by writing articles relating to our children and the value and importance of the help they are receiving, please let me know.

Sincerely,

____

217 Finding the help I needed for ________ was easy for us because this is our second time through it. We have two children with special needs. I wish people who do not have children with special needs could understand what those children and their families go through. Most people do not know what special needs are. I do not know where there are any support groups — just to have someone to talk to at times when things get rough for me. But I know we are a close family and things work out okay. I hope my answers will help out. I was not real sure about some of them. If you have any questions please call me.

Thank you for caring,

____

218 My daughter just turned 5 years old and I've learned a lot in those 5 years and have lots more to learn in years to come. I'm grateful for all the services that are now available for my daughter .... for I want the best for her .... as I do for all of my children. I have found, since my efforts with her overall growth are much more demanding of me than with my other children, I'm very possessive about her growth and abilities she does finally achieve.

Consequently, if I feel an injustice is occurring in the system I find myself standing up a lot firmer for my daughter's rights. I know I'm not the only parent that feels this way . . . . you learn a new kind of assertiveness. I've just experienced my first real frustration with my daughter's school and AEA and I voiced my opinion to the appropriate individuals. If nothing else occurs from it, at least I voiced my opinion and was listened to.

I feel AEA came through with the situation which was at hand. I also feel they were open listeners and allowed me to state my opinion adequately. The situation has been handled and settled and hopefully all concerned have learned from it. I feel the most important aspect of having a child with special needs is dealing with people who are willing to honestly communicate and work together with you.

221 I would like to see handicapped children mainstreamed into the schools in their area. Busing them so far and being on a bus for 1½ hours each way seems very unfair.

222 I can't say enough good about our AEA 4. If it wasn't available or taken away it would be devastating to our family and our special needs child. I would like to have more involvement in my child's school and would like to observe him more in school. Also, have the foster grandparent program which is a tremendous benefit to everyone involved. Also, I've seen a great benefit from the Parent Education Program.

225 At this point in my life I do not feel support groups are as important to me as they would have been 3 or 4 years ago. Back then I would sit down and work with him, but without any results. My husband was and still drives truck so I had to do everything which seemed bad enough much less work with a son that had allergies which caused his hearing to be all messed up. At age 2 years he still couldn't say his name and what he did say was Greek. I would always have a good cry it seemed every night. What information I wanted or needed I got from family, friends and what I dug up. Once I got some information all I had to do was ask for more information or possible leads from who I had already contacted.

227 Most of the services I have had have been excellent. I find most of the people very caring. They try hard. Sometimes I wish we could have the services of a bigger hospital evaluation like at Iowa City without the time and trouble of driving so far and staying so long. Usually you have to wait for a long time to see each agency that evaluates your child and that gets frustrating.

230 It's been my experience that lines of communication are always open and welcome, but "follow through" and contact in general often tediously difficult. Some questions I've asked answered with "I don't know" instead of "I'll find out". Two things mentioned on previous pages I feel very strongly about — my opinions and reports are not taken as seriously as I'd like. I'm trying to help my child. I would not say he could do something he can't, or vice-versa. I feel pushed into areas repeatedly after I've said "no". The other is the summer program or rather, lack of it. I don't think learning stops in the summer, or should be neglected. My child was just beginning to show progress when dropped for summer. We felt helpless during the summer, and very frustrated.

I feel a lot of the people I've been involved with are not wholeheartedly committed. I have a serious concern that the principal or superintendent of school district is aware of involvement of these services — especially with pre-schoolers. I know about files and such, I also know they do talk to teachers, etc. I can see it may work for the child, but believe in more cases would work against. I'm considering discontinuing because of this. I think cancellation is all too common — I mean of appointments, and on very short notice. I plan my week, or try to, around these appointments, which are sometimes cancelled only minutes before scheduled. I don't understand why transportation costs allowed for some programs, not for others — for instance, developmental preschool, but not speech therapy. I do see there could be more needing speech help, but could be determined by income level and need rather than blanket coverage.

Also, I would like to see more teaching of the parents to help the child rather than the "service providers" working more or less alone and on one-to-one with the child. I'd enjoy more ideas and expertise sharing, and home access to books and manuals. I don't get much feedback about why, how or what to change, or what their opinions are. I also sometimes feel offended by inferences about my child I feel are wrong.

Thanks for the opportunity, sorry I am too late, just now read the deadline! I have been too busy!

231 I feel that the Department of Human Services has done nothing for the development of my son. The social worker I have from DHS doesn't know who I am or has not even told me of services available for my son. My son is developing well but according to DHS is not eligible for SSI because he is doing so well. I have applied 3 times and was denied each time. I am a single mother going through college plus taking care of my son. SSI would help benefit us.

232 I am very pleased with the help we've gotten through the AEA. Everyone seems to be very caring and willing to do all they can for our child. My oldest daughter has a speech problem and they helped her, also. I'm sure I couldn't afford the therapy that our youngest gets throug AEA. She seems to enjoy the work and gets along real well with everyone.

Appendix D

SUGGESTIONS FOR STATE PLAN

I. PROBLEM AREA (Check appropriate area)

_____ Coordination between agencies
_____ Location of services
_____ Specialized information or training
_____ Getting into the service system
_____ Parent and family support services
_____ Indicated changes in the service system (OT, PT, respite care, day care, incentives for parents to care for their severely handicapped children at home)
_____ Other ______________________________

II. SPECIFIC PROBLEM

III. IDEA FOR SOLVING PROBLEM (Be as specific as possible)

IV. COST & EFFORT (Resources & time required to implement solution)

V. EXPECTED RESULTS

IF ADDITIONAL SPACE IS NEEDED, PLEASE WRITE ON THE BACK. ALSO, PLEASE ATTACH ANY MATERIAL YOU FEEL WILL BE HELPFUL.)

SUMMARY
of
STATE PLAN SUGGESTIONS
from
SPACES MEETING

APRIL 8 & 9, 1987

PROBLEM AREA: COORDINATION BETWEEN AGENCIES

1. **PROBLEM:** Not able to get continuity of care from the many services (my child) receives. (Team approach)

   SOLUTION: Allowing direct service providers the time to visit other agencies and provide time and space for providers to meet to discuss common interests (child).

   COST & EFFORT: Staff time. Cost would include days provided to meet without having to "make-up" the time. Allowing direct written communication.

   EXPECTED RESULTS: More uniformed delivery of service. Dissolve overlap of services. Continuity of philosophy of service needed.

2. **PROBLEM:** State agency commission from DH, DE, and DHS needs to actively support interagency coordination in providing services for children with special needs.

   SOLUTION: Governor sign an executive order mandating commissioners from DH, DHS, and DE to support interagency coordination among departments. Commissioners assign staff, free up time for meetings and learning about each department's programs. Cross training of staff of the three departments.

   COST & EFFORT: Development of written materials by each department of the agencies' responsibilities (i.e., what Medicare will cover, etc.).

3. **PROBLEM:** Community (or regional) agencies often have no structured, predictable interagency forum to assess community needs, available resources, and problem solve.

   SOLUTION: Within the AEA regional structure, community-based interagency planning groups should be formed with representatives from the AEA, county social service, CHSC, MCH and private providers (including a pediatrician or family practitioner).

   COST & EFFORT: Staff time for a monthly meeting. Organizational/meeting planning time from a lead agency staff person (1 FTE (from 99-457 state grant) for each regional planning group).

   EXPECTED RESULTS: Improved information sharing, professional trust-building and shared planning.

PROBLEM AREA: COORDINATION

4. **PROBLEM:** Lack of several good models of interagency coordination that could be replicated or adapted to fit local needs. Concentrate on health, education and DHS.

   SOLUTION: Identify three different but effective local models that are working in the state. The first year offer incentive monies to focus on development of interagency collaboration, case management and family focus planning at the 3 sites. The 2nd and 3rd year provide support monies to the sites to provide training/replication for others in the state.

   COST & EFFORT: Commitment by agency and staff — time and energy. Coordinator/liaison part-time: $10,000. Materials: $3,000. Following year: $15,000.

   EXPECTED RESULTS: Models for replication would be established. Better service to families provided. Interagency collaboration.

5. **PROBLEM:** Often referrals to or involvement with other agencies are blocked by present special education rules (usually confidentiality or payment responsibility). Many families are involved with several different agencies with no communication.

   SOLUTION: Take a look at the rules and see if there could be "changes" made that would allow agencies to cross lines when reasonable. Example: Counseling is an identified need but cannot be provided by AEA. "Refer" to DHS counselor.

   COST & EFFORT: Staff time. Perhaps legislative effort.

   EXPECTED RESULTS: Improved services to children and families. Improved cooperation among agencies.

6. **PROBLEM:** Knowledge of case management skills. Identified by teachers as a need area: OTs, PTs & MDs.

   SOLUTION: Examine case management models. Task force train select group in case management.

7. **PROBLEM:** Need for information regarding family support.

   SOLUTION: Workshop regarding community resources, case management, networking, communication, transition, advocacy. Present regionally during summer to target audience.

   EXPECTED RESULTS: Increased service to families in need. Increased coordination.

180

PROBLEM AREA: COORDINATION

8. **PROBLEM:** Staff awareness of functions and services of other agencies appears to be inadequate.

   SOLUTION: Ongoing inservice for staff (including secretaries, receptionists, etc.) to acquaint them with functions and personnel from other agencies.

   COST & EFFORT: The activity could be incorporated into current preservice and inservice activities.

   EXPECTED RESULTS: Improved coordination and less frustration in the provision of services and distribution of information.

9. **PROBLEM:** Lack of awareness of services and activities of other agencies.

   SOLUTION: Scheduled meetings among agencies that should occur at several levels in the organizational structure.

   COST & EFFORT: These activities should be incorporated into regular work schedule.

   EXPECTED RESULTS: Heightened awareness of greater cooperation and efficiency in the delivery of services.

10. **PROBLEM:** Need for parent counseling — shortage of services in this area.

    SOLUTION: Develop continuum of services idea for areas to put into place (i.e., mental health for serious problems to Pilot Parent referral if contact with other parents is all that is needed.

    COST & EFFORT: One day inservice/planning for interagency group of providers to determine 1) what is generally available and 2) how to determine with families what service is available. $700.

    EXPECTED RESULTS: Areas having an awareness of what counseling services are available and appropriate for different cases.

*11. **PROBLEM:** Hard to serve children: medically fragile, low incidence, chronically ill, etc.

SOLUTION: Use this target population as an opportunity for agencies to learn and work together in a) staff development, b) case management, and c) family plan.

* Not based on needs assessment data.

18

PROBLEM AREA: LOCATION OF SERVICES

1. **PROBLEM:** No complete comprehensive developmental testing facility within central or western parts of Iowa (money going out-of-state for these services).

   SOLUTION: Provide week-long or day-long clinics where the evaluation team travels around the state a couple of times a year. These clinics could be specific to age group and disability.

   COST & EFFORT: Use staff already in place. Travel: $50,000. Clinic space: $5,000.

   EXPECTED RESULTS: More children being served because of availability of service. Money spent out-of-state will come back. Child and family seen in familiar environment.

2. **PROBLEM:** Lack of awareness of what's available.

   SOLUTION: Central referral agency which possesses all available resources within the given community and across the state with eligibility guidelines spelled out clearly by the agency receiving referrals.

   COST & EFFORT: Resource determination would be analyzed through what is currently available and population needed to be served. Potentially, at least 1 or 2 staff full-time. Initial training for this type of work. Computer hotline.

   EXPECTED RESULTS: Parents have one entry place to seek informational services (including support and system).

3. **PROBLEM:** Certain types of services — particularly health services — are less available in rural areas. Families must have available time and transportation to get the services they need.

   SOLUTION: Outreach programs, decentralization and/or networking with other agencies can make these services available. In some cases the problem can be solved with multi-agency cooperation (e.g., specialized Child Health Clinics in additional locations.

PROBLEM AREA: LOCATION

4. **PROBLEM:** Lack of accurate, current information on public, private and voluntary agencies serving preschool children with special needs.

   SOLUTION: Cooperate with State DD Council which is putting the Iowa Directory of Services for Persons with DD into a computer in cooperation with the Hospital School.

   COST & EFFORT: Limited consultant time to review data base and assure inclusion of resources for preschool populations.

   EXPECTED RESULTS: Improved access to statewide information.

PROBLEM AREA: SPECIALIZED INFORMATION OR TRAINING

1. **PROBLEM:** More in-depth professional education for parents — parents and professionals together.

   SOLUTION: Design state special education conference to include parent education. AEA to sponsor several parents to attend.

   COST & EFFORT: Registration and lodging for persons. Scholarship stipends.

2. **PROBLEM:** Increased numbers of professionals trained.

   SOLUTION:
   1) Focus on recruiting in high schools by AEA consultants.
   2) Some states pay for needed training out-of-state by students if they return and work for specified time in state. This could be done for pediatric PT since there is no in-state program. Is this done already?
   3) Summer Institutes for specific support staff on pediatric issues. Paid participation, again, could be personnel prep grant.

3. **PROBLEM:** Need for training. The need is very different among agencies and among professionals within agencies.

   SOLUTION: A summary of the self-assessed need for training should assist those responsible for inservice training of the above groups.

   COST & EFFORT: The summary would have to be pulled out and sent to the different agencies.

   EXPECTED RESULTS: Some of the agencies would use the information for inservice planning.

4. **PROBLEM:** Need for increased knowledge of medical issues for AEA, LEA.

   SOLUTION:
   1) Development of print and video modules on specific procedures related to technology (tube feeding, ventilator, etc.) which teach staff, parents about the specific procedures. Use grad students at universities.
   2) Allow staff to travel to hospital/medical center for direct training for specific children.

   COST & EFFORT:
   1) Personnel if hired.
   2) Development, reproduction of services.

PROBLEM AREA: TRAINING

5. **PROBLEM:** Need for training for AEA, LEA personnel in case management.

   SOLUTION:

   1) Develop training module/sessions which can be used at preservice or inservice level.

   2) Develop case manager philosophy, procedures which could generally apply to state.

   COST & EFFORT:

   1) Money for material development — person, print/audio materials.

   2) Dissemination of materials to preservice institutions to LEAs or identify someone to go out and do training.

6. **PROBLEM:** (In the document there is no specific statement which says this issue is a problem but the sense of much of the data supports the problem.) The B-3 home-based teacher needs a tremendous number of skills. I still believe this is difficult to accomplish in a 4-year program even with the changes in new certification guidelines.

   SOLUTION: Task Force to address how appropriate training for B-3 should occur and at what level.

   COST & EFFORT: Time from several people to meet and discuss the issue.

7. **PROBLEM:** Not enough pediatric PTs and OTs to serve population.

   SOLUTION:

   1) Encourage salaries that are commensurate with OT/PTs in other settings.

   2) Support OT/PT associations lobbying for tuition relief or state schools.

   3) Opt for more efficient service delivery in training models (i.e., consultation or train others).

   COST & EFFORT:

   1) $100,000. (I imagine you'd have to deal with each AEA.)

   2) $0-$1,000.

   3) Training model: $60,000 derived from grant.

   EXPECTED RESULTS:

   1) More OT/PTs going into school systems (and remaining there).

   2) Passage of legislation that will allow for out-of-state tuition loans or new in-state schools.

   3) More children "served;" however, less direct intervention.

PROBLEM AREA: TRAINING

8. **PROBLEM:** Train individuals to determine and serve need not establish categories!

   SOLUTION: Establishment of classroom criteria for placement and providing service according to child need.*

   * This may take a change in way funding stream has been established.

   COST & EFFORT: Training.

   EXPECTED RESULTS: Looking at child first and child with a disability second.

9. **PROBLEM:** Primary care physicians (pediatricians and family physicians) are frequently unaware of community resources or how to refer to them.

   SOLUTION: Contract with CHSC (from 99-457 state grant) to train its regional pediatric consultants to be resource persons to colleagues within the region (through hospital staff and medical society meetings, CHSC newsletters, and referrals to CHSC PNPs).

   COST & EFFORT: Fund a training workshop for physician consultants.

   EXPECTED RESULTS: Improved physician awareness and networking.

10. **PROBLEM:** Professionals have identified need for more knowledge in special areas in SPACES assessment.

    SOLUTION: Share results of SPACES assessment with respective agencies. Offer to collaborate with training efforts. These could be written materials, site visits, workshops, inservice, etc. Sharing info on inservice. Develop a state plan for professionals serving families with young children with special needs — could be done regionally.

    COST & EFFORT: TA Network personnel and "other agency" personnel. Money for regional inservice, workshops: $20,000.

    EXPECTED RESULTS: Professionals would receive necessary training. Opportunity to meet and work with other professionals from other agencies.

PROBLEM AREA: TRAINING

11. **PROBLEM:** Headstart teachers identified "teaching" as an area for training.

    SOLUTION: Invite participation of Headstart teachers to ongoing AEA inservices, regional conferences, etc. Utilize TA-Network to train Headstart teachers in principles of instruction and behavior management.

    EXPECTED RESULTS: Better experiences for youngsters. Interagency cooperation.

12. **PROBLEM:** Get additional info to parents regarding specific disability.

    SOLUTION: Find and/or create simple means of sharing specific information (i.e., pamphlets, videos, bibliographies).

    COST & EFFORT: Bibliographies (some are available). TA-Network and AEAs to develop and distribute to 1) educators, 2) physicians, etc., 3) parent connector persons.

13. **PROBLEM:** LEA teachers, AEA, Headstart and DHS identified the need for additional medical information. Do we assume this is for more info on medically fragile?

    SOLUTION: People need info at specific times.

    - Video on asthma seizures, eating disorders, etc.
    - Research and explore existing networks.
    - Local experts
    - School nurses
    - PNPs

14. **PROBLEM:** Parents want (need) specific information about child's problem area.

    SOLUTION: Booklets produced about specific disabilities.

    COST & EFFORT: Staff time: Summer project 2 full-time. Printing: $2,000. Dissemination to AEAs: $1,000.

    EXPECTED RESULTS: Specific and consistent education information for parents that can be given when the parent wants it.

PROBLEM AREA: TRAINING

15. **PROBLEM:** The need for parent education specific to their perceived needs. Needs would probably fall in the areas of 1) disability specific information, 2) available services, 3) financial information, 4) long range planning, 5) transition.

SOLUTION:

1) Develop needs assessment (information wanted) to use in specific localities and inservice packets to correspond. The packets would probably list resources (i.e., films, etc. that give good info regarding disabilities, maybe a computer disk for local personnel to "fill in" specific services from a general outline, resource persons to present on financial assistance and planning and transition.)

2) Inform each service provider in agency about survey results — what is it that parents want.

3) For staff needs, provide district/AEA inservice director of survey results.

4) Develop computer program that can give info at appropriate level for audience.

5) Develop file or notebook which parents can add to over time.

COST & EFFORT:

Time required: 1 week.

Persons: Interagency committee.

Cost: Expenses and stipend for committee: $2,500.

Materials: $1,500.

EXPECTED RESULTS: A basic packet of information parents appear to want most and a means to individualize inservices would be available to agencies/persons serving the B-5 population of children with disabilities.

PROBLEM AREA: GETTING INTO THE SERVICE SYSTEM

1. **PROBLEM:** NICU infants and children with chronic illness, disabilities not receiving services.

   SOLUTION: Mandate by regulation that any child admitted to a level II or III nursery be followed by that facility for developmental screening and referral until child is 8.

   COST & EFFORT: 2-4 full-time staff — nurse practitioner, OT, speech, developmental specialist.

   EXPECTED RESULTS: All "at risk" (NICU) children would get services if needed.

2. **PROBLEM:** Respondents did not know about tracking systems.

   SOLUTION:

   — Development of criteria for tracking at risk infants and children.

   — Maintaining a master data base of all children with special needs.

   — One agency responsible for tracking who would be in charge of records and evaluation of service.

   — Training of agency personnel in understanding the system and accurately submitting data.

3. **PROBLEM:** Professionals viewed genetic services to be inadequate for children from birth to 71 months.

   SOLUTION:

   — Survey professionals to discover why genetic services which are statewide are considered to be inadequate.

   — Provide education about genetic services to administrators, teachers, and psychologists (largest number completing forms).

   — Assess whether more than two clinics per year is needed in some geographic areas (review data).

   — Clinical staff, if they were available in the community between clinics, would enhance visibility and continuity of services. Probably only possible with a regionalized health care facility.

PROBLEM AREA: GETTING INTO SYSTEM

4. **PROBLEM:** Parents of young children often do not know "how to start" to use the system.

   SOLUTION: Prepare a "Guide to Services" for Iowa parents (print resource) which is updated at least every two years. The Guide should be simple so that it could be distributed in quantity.

   COST & EFFORT: Writer (consultant part-time for 3-4 months). Printing in bulk.

   EXPECTED RESULTS: Increased parent knowledge of system.

5. **PROBLEM:** There are currently adequate screening services to identify children potentially at risk for handicapping conditions, but referral agencies have constraints in resources and manpower delaying timely evaluation.

   SOLUTION:

   — Review screening instruments used to determine if children at greatest risk are being identified as early as possible and referral for follow-up.

   — Train screeners to ensure accuracy in administering the screening instruments. Annual review.

   — Explore what role parents and/or paraprofessionals with proper training can provide. If treatment starts early many of these children should need short-term follow-up.

PROBLEM AREA: PARENT AND FAMILY SUPPORT SERVICES

1. **PROBLEM:** Families want counseling.

   SOLUTION: Department of Health gives services within the structure of Department of Education with after school hours.

   COST & EFFORT: MSW position at each AEA. Cost to be divided among DE, DH, DHS.

   EXPECTED RESULTS: Better adjusted families. Intact families.

2. **PROBLEM:** Parents wish to have more "information" about their child's specific disability.

   SOLUTION: Enlist TA-Network personnel to develop concise yet informative "packets" on common disability areas (e.g., CP, MR, spina bifida, etc.).

   COST & EFFORT:
   TA time: 30 days @ ?

   Printing: $300.

   Dissemination: $100.

   EXPECTED RESULTS: Materials available to educators to share with parents. Make available to PHNs.

3. **PROBLEM:** Professionals cited the need for offering more parent support groups. Problem may be lack of knowledge of how to facilitate (lack of skills in facilitating).

4. **PROBLEM:** Lack of available counseling services.

   SOLUTION:
   1) Determine what is already available (perhaps it is not being used?).
   2) Initiate (or expand) parent-to-parent counseling model.
   3) Determine what kind of additional counseling is needed (e.g., financial, family, related to disability, etc.).
   4) Use PL 99-457 means for those services if guidelines permit.

PROBLEM AREA: PARENT AND FAMILY SUPPORT

5. **PROBLEM:** Parents want to meet with parents whose children have similar (specific) needs one-to-one.

   SOLUTION: Ask parents who are already in the program if they'd like to support another family (permission). As part of the intake ask new parents if they would like to meet another parent. Have "parent coordinator" make match and have experienced parent call new parent.

   COST & EFFORT:
   - Parent coordinator staff time: $2,000.
   - Computerized info.
   - Coordinate children's disabilities/parent interests.
   - Coordinate parent training to help parents become good parent support people.

   EXPECTED RESULTS:
   - One-to-one support for new parents.
   - Coordinating parents to help themselves which creates self-esteem.
   - Allows parents to share personal resources info.

PROBLEM AREA: INDICATED CHANGES IN THE SERVICE SYSTEM

1. **PROBLEM:** Inflexibility of working day and contract year of persons providing direct services to children and families regarding summer vacations, lack of flex time so that persons can be compensated for Saturday or evening hours.

   SOLUTION: Maybe the State Department of Education could strongly encourage AEAs to extend contracts of some staff, especially those serving the B-3 populations and newly identified children, as much as it has provided incentive for summer center-based programs through incentive monies and application for those funds. Also, flex time should be emphasized for this population.

   COST & EFFORT: Summer services: $135,000. Flex time: No cost.

   EXPECTED RESULTS:
   1) Continuity of services for those who need it most.
   2) More effective services being provided by staff who are more willing to give Saturdays and evenings as they have some compensation.

2. **PROBLEM:** Concern regarding correct identification of disabilities in children with BD and LD in 3-5 population and in B-3 population, in relation to the time required by staff to evaluate for those disabilities when their time could be better spent with support/intervention activities.

   SOLUTION: Adapting the DD (developmentally delayed) label for 3-5 population with some very specific guidelines and specifications.

   COST & EFFORT: Expenses for a committee to meet one day to set guidelines.

   EXPECTED RESULTS:
   1) More staff time for writing and implementing interventions for children or providing family support activities.
   2) Less "mislabeling" of mildly handicapped children.

PROBLEM AREA: CHANGES

3. **PROBLEM:** How to improve day care for young children with special needs.

   SOLUTION:
   1) Personnel prep grants to selected agency for training family day care providers.
   2) Extra stipends for family day care providers.
   3) Utilize community colleges for training delivery or extension system.

   COST & EFFORT: Federal money for training program.

4. **PROBLEM:** Respite care

   SOLUTION: Inservice for respite providers chosen by parents (i.e., grandparents, friends, etc.). A packet of information could be put together as a general outline with specifics to be filled in by local providers.

   COST & EFFORT: 1 day or 2 days for interagency service providers to develop packet: $2,500.

   EXPECTED RESULTS:
   1) Parents would be comfortable with persons providing respite.
   2) Persons providing respite would be more comfortable with the child they are caring for.

5. **PROBLEM:** Daycare — not being able to afford adequate care while parents works and keeping siblings together.

   SOLUTION: Allowing parents to pick and train their own child care provider in the home but still get subsidized to help alleviate the cost factor of work vs. child care.

   COST & EFFORT:
   - 1 million - statewide (to be on sliding scale to all parents to pay what they can afford. Paid staff person within state regions to monitor and determine eligibility.
   - Have employers give child care provisions to parents so they have flexibility to be at home when needed, so parents do not have to make work vs. home full-time.
   - Tax break for those employers who give provisions for parent of handicapped children.

PROBLEM AREA: CHANGES

6. **PROBLEM:** Lack of services over summer.

   SOLUTION:
   1) Skeleton personnel available over summer, or
   2) Year round services for at least B-3. (This would be my preference.)
   3) Look at all agencies who would be able to provide services and have at least one cover the child.

   COST & EFFORT: Increased cost for personnel.

   EXPECTED RESULTS:
   1) Increased parent satisfaction.
   2) Increased quality of services to children.
   3) Decreased amount of time between identification and initiation of service delivery for children identified in late spring/summer.

7. **PROBLEM:** Lack of financial incentives for parents to care for handicapped children at home.

   SOLUTION: Political action — have tax deduction for moderate or severely handicapped children (similar to current deduction for blindness on tax forms).

   COST & EFFORT: This is a political process that would not solve the problem but would assist. No additional grant monies would be necessary.

   EXPECTED RESULTS: Would allow small incentive to parent in contrast to high cost of institutionalization.

* 8. **PROBLEM:** Financial coverage must be determined before equipment is purchased for families. If it (ins. Title XX) is not traditionally covered, payment by someone else needs to be determined so the family does not receive an outrageous bill it cannot cover.

* 9. **PROBLEM:** Day care for children with special needs.

   SOLUTION: Devise plan for "training" of day care staff. Look at certified teacher rule.

   COST & EFFORT: Consultants.

   EXPECTED RESULTS:
   1) Integration of handicapped with nonhandicapped peers.
   2) Respite care.

* Not based on needs assessment data.

PROBLEM AREA: OTHER

1. **PROBLEM:** Parents are not compensated for time or child care to participate in interagency projects while professionals use work time and materials. Volunteer reimbursement.

   SOLUTION: Allowing grant money or agency scholarships (tax deductible) to parents who use their services and use their ideas for improving services.

   COST & EFFORT: Budget ahead for 10% of input at conferences and meetings of future development by parent input.

   EXPECTED RESULTS:
   - More direct needs become known and met.
   - Parents become more competent policymakers.
   - Parent/professional relationships improve.

2. **PROBLEM:** Lack of communication about ongoing follow-up by a variety of agencies.

   SOLUTION: The need for one ongoing monitoring system that guarantees follow-up in all aspects of parent/child needs and provides communication of that assessment* and determination of who is responsible to provide services.

   * Assessment of how the services are working and if they are providing appropriate type and level needed.

   COST & EFFORT: You could incorporate this into your central referral agency within a given community (must be close to where the child and family live). Must have "agency" but in (time to meet and to implement). Training for workers who will provide services and ongoing staff to support said service.

   EXPECTED RESULTS: Better coordination/prevention of children and families falling through the cracks.

3. **PROBLEM:** Lack of criteria improvement of the identification process of children 36-71 months with behavior disorders and learning disabilities and mental disabilities.

   SOLUTION:
   - C.E.U. workshops for professionals.
   - Development of educational materials describing the characteristics, screening/assessment process, and successful approaches that enhance learning and quality of life.
   - Explore why these children are not being identified and develop strategies to increase appropriate services for these children.

PROBLEM AREA: OTHER

* 4. **PROBLEM:** Inability to identify (refer to the right sources) young children with serious handicapping conditions to be served. (This is somewhat of an eligibility problem but also a communication problem.)

SOLUTION: Need to have health professionals trained to assess infants more acutely in need (high risk) and ability to provide ancillary services to prevent more complications.

COST & EFFORT:
1) Training costs.
2) Health, education coordination time (I think much of this is availability but not coordinated). Research in availability and appropriate measures. Communication linkages.

EXPECTED RESULTS: Serving the younger child more appropriately.

* 5. **PROBLEM:** Each of these problem areas and solutions may lead us into defining how each of us can, by ourselves, change within the "I" system. However, an across-the-board solution may promote partnership and better cooperation such as in the awareness area. A "training" or "inservice" for parents and professionals to learn about all new services would be wonderful.

COST & EFFORT: Staff and parents commitment. Training materials development in how to use the various systems.

EXPECTED RESULTS: Partnership.

* Note based on needs assessment data.

Appendix E

PARENT FORUMS

Four parent forums were held within the State to validate information which had been collected in the printed survey. The topics included within screening, case management, services & parent training were used to stimulate discussion among the parents. Neutral facilitators and locations were used for these forums.

Each of these forums was video taped and reviewed by a Drake University research team.

QUESTIONS FOR STATE PLAN GRANT PARENT FORUMS

Screening

When did you first suspect your child was not developing normally?

2. How did you learn of the services available through various agencies?

Case Management

1. Who is helping you find services for your child?
2. What exactly is this "case manager" doing for you?
3. What do you like?
4. What would you change?
5. Who would be the logical person to provide case management for you given the agencies you deal with?
6. If a social worker is providing services to your family who is his/her employer?

EXAMPLES: (Use only to stimulate discussion)

AEA
DHS
Private
Head Start

Services

1. Is respite care, day care, and babysitting available for your child with special needs?

If YES, what has been your experience and where is this available?

If NO, do you have suggestions on what could be done so these services are available?

2. Do you feel counseling for parents of children with special needs should be included in a service plan for families?

   Why?

3. What could be done so that you would attend school activities or become more involved?

   EXAMPLES: (Use only to stimulate discussion.)

   - Activities which might help your child or family
   - Child care provided
   - Daytime activities or meetings
   - Evening activities or meetings
   - Knowing you are needed or welcome
   - More information on parents rights
   - Support from other parents
   - Transportation provided

Parent Training

1. How could parent training be provided to you in order to be more useful and comprehensive?

2. What training would you like (if any)?

Appendix F

Parent Forum
Conclusion

Parents of pre-school children with special needs have a positive view of the services that are available to their child. They also have defined concerns and needs. It appears from the strong positive comments under education that the services for the children provided by the Area Education Agencies are good. However, the needs of the parents appear not to be met, as evidenced by the negative comments addressing non-educational issues. These needed services are, for the most part, available, but a communication and coordination mechanism is needed to insure that the family's needs as well as the child's needs are met. (The needs of the entire family during these early years of the handicapped child are as strong as those met by direct service to the child.)

The affective information is not totally reflected by the quantitative data. The intensity (tears, gestures, facial expressions, and raised voices) with which the parents expressed these needs were more evident when discussing their own needs than when discussing services for their child.

Iowa's existing Early Childhood Special Education programs are perceived as being very strong. However, to more fully service these families, additional information is needed to determine the specific needs of urban vs rural families as well as the differentiation of needs for families of mildly disabled children versus those with children having severe mental and/or physical disabilities.

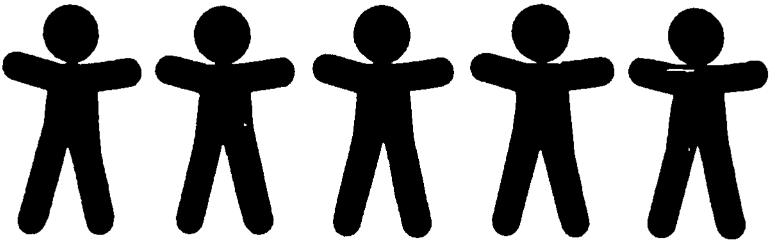
The largest problems seem to stem from inadequate communication and coordination between service agencies. The parents agree that they ultimately must be responsible for decisions about their child. However, they feel inadequate to know everything that is available. Advocates for these parents are needed to help them deal not only with the educational, financial, and legal issues of having a disabled child, but also with the responsibilities, fears, frustrations, and family emotions that confront them at the same time.

This information reflects the results of a categorization and compilation of research data done by the following research team in the Summer of 1987 on the Drake University
Campus as part of the Early Childhood Planning Grant.

Deb Burke
Lisa Hennon
Kathy Patton
Kay Swan

Advisor: Dr. S. Pike Hall

Young Children with Special Needs in Iowa



A Brief Report of Professional and Parent Views

December, 1988

Iowa Department of Education

PROJECT STAFF

Joan Turner Clary, Consultant
Early Childhood Special Education
Department of Education
Bureau of Special Education

Peggy A. Cvach, Ed.D.
Program Consultant
Mountain Plains Regional Resource Center
Drake University

S. Pike Hall, Ph.D.
Associate Professor, Special Education
Graduate School of Education
Drake University

I. Introduction

This summary focuses on Iowa's young children with special needs and their families. The purpose of the summary is to provide concise information about the current status of services for young children with special needs and their families based on a 3-phase. statewide needs assessment process.

In October. 1985. the Department of Education was awarded a State Planning Grant for Young Handicapped Children. The State Planning Grant was designed to gather useful information. In particular. the information was to support: (a) developing a more coordinated and cost effective continuum of services. (b) ensuring that all young children with special needs receive the services they need. and (c) maximizing the creative use of existing state and local resources. The State Planning Grant Needs Assessment was the first step in this process.

The objectives for developing and using the Needs Assessments were to identify (a) what services are available. (b) which of these services are working. and (c) what can be changed to make the service system better.

This brief summary and its recommendations center around five areas: (a) accessing and receiving services. (b) case management. (c) communication and coordination. (d) parent participation. and (e) training. Most of the recommendations were made by State Plan Advisory Council for Early Services (SPACES) members. The SPACES recommendations are a response to the data and distinct from it. Each of the SPACES members brings diverse and profound experience to bear upon the data while making conclusions that are not strictly supported by it. SPACES input was obtained in a systematic manner through the use of a form which specified the problem as defined in the Needs Assessments. the solution proposed by the Council member. the cost and effort projected. and the expected results from the proposed action. In most cases. it can be assumed that these recommendations will have a statewide focus. Specific agencies and role groups may wish to look further at the data contained in this document in order to make more specific recommendations for their disciplines or agencies. Some issues indicate a need for further study of the exact problem before any corrective action can be taken.

This report does not attempt to provide all the answers or ideas to improve comprehensive services for young children with special needs. Its intent is to offer ideas from which to build and creatively use the numerous financial and human resources within Iowa.

A comprehensive review of the Needs Assessment data is provided in *Young Children with Special Needs in Iowa: A Summary Report of Studies of Professional and Parent Views.*

For your copy. contact: Joan Turner Clary. Consultant
Early Childhood Special Education
Department of Education
Grimes State Office Building
Des Moines. IA 50319
(515) 281-3176

II. Action Steps

This document focuses on an interagency approach to comprehensive services for young children with special needs. Five action steps have been identified: (a) improving access to and receipt of services. (b) exploring case management. (c) increasing communication and coordination among service providers and agencies. (d) increasing the quality of parent participation. and (e) offering an array of training options to parents and service providers. A brief summary and specific suggestions are provided for each action step.

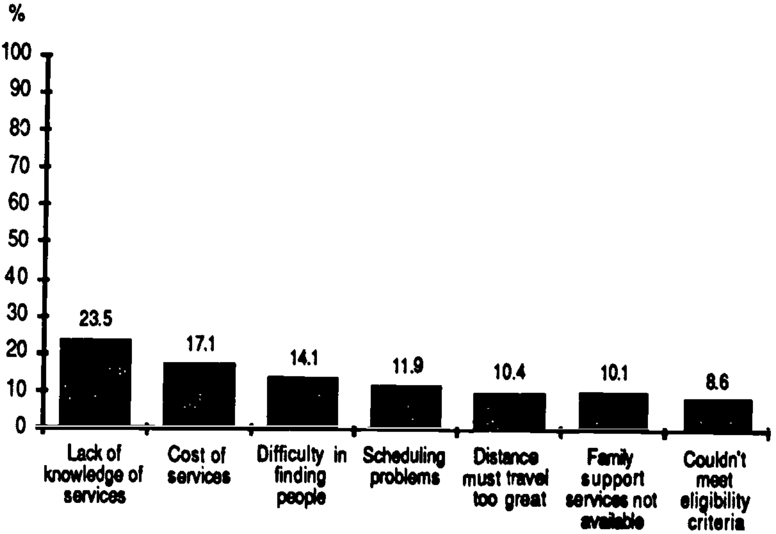
ACTION STEP 1

Improve the access to and receipt of services

Accessing and receiving services within a reasonable time frame appear to be a concern to professionals and parents. The data show that. on an average. the time between the onset of suspicion that a problem may exist and the receipt of service is seven months While parents may suspect that their child has a problem. they often have serious problems finding someone who can help them confirm or deny their troubling concerns.

Figure 1 gives a picture of the specific problems parents face in getting services for their child.

Figure 1
Percentage of Parents Who Have Problems Securing Services



Parents most frequently turn to the medical community for information and guidance when first entering the service system. The majority of parents are successful in obtaining assistance when they talk to either physicians or physical or occupational therapists. A few parents first seek assistance from parent support groups; however, parents do not always find a parent support group when they want one. This is even more true when it comes to respite care, child care, financial support [except Supplemental Security Income (SSI)] and direct training on child behavior.

Suggestions for making the transition into services smoother and the receipt of services less cumbersome include:

- Establish a central referral agency.
- Maintain information on available resources and eligibility criteria for receiving services in conjunction with the central referral service.
- Promote the elimination of duplicate services.
- Make home instruction and related services available to families throughout the calendar year as opposed to "a school year."
- Match "seasoned" parents with "new" parents.
- Expand the tracking of young at-risk children
- Explore the confidentiality issues of one tracking system which necessitates the sharing of information across agencies.
- Provide inservice to agency staff about tracking efforts which are currently underway in the State and how to input and access those systems.
- Develop a multi-agency plan for counseling services based upon the resources available within the region and the intensity of the family's needs.
- Review the availability of medical follow-up services for Iowans residing in rural and Western portions of the State.

ACTION STEP 2

Explore Case Management Issues

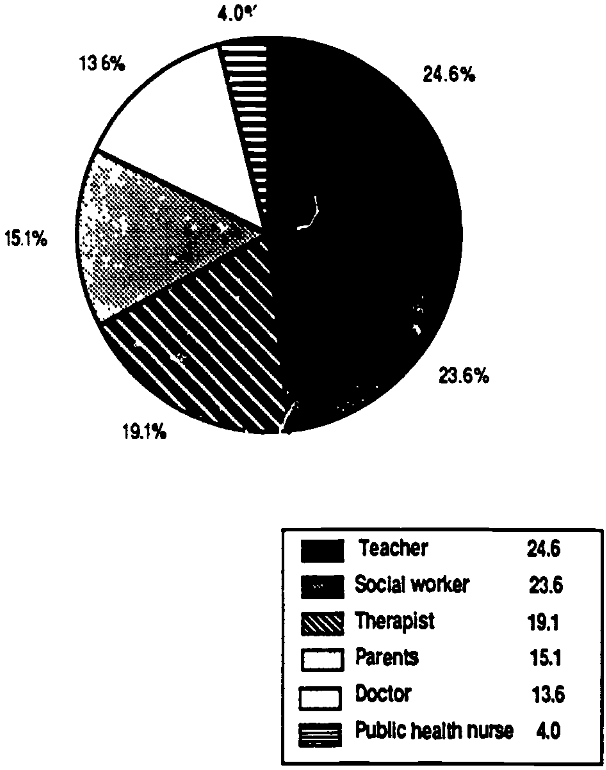
With the implementation of Public Law 99-457, case management has become an important national topic for young children with special needs and their families. Within the parent and professional Needs Assessments, a *case manager* is defined as a person in charge of assisting families of young children with special needs in most interactions with agencies. The data show service providers and parents have various perspectives about case management.

Professionals feel that their agencies have case managers. It appears. however. that each agency defines the role of its case managers differently. This lack of a consistent role description for case managers and/or case management systems affects the quality of services for young children with special needs and their families. particularly when parents have to deal with several agencies at the same time (or one after the other). Even with the lack of a formal case management system. parents frequently report that professionals work well together and communicate to the degree that hectic schedules permit.

Parents offer differing opinions about who they would like to see coordinate service for their young child with special needs. Figure 2 lists the parents' responses.

Figure 2

Percentage of Professionals Who Parents Choose as Case Managers (N=199)



A recommendation for case management is to:

- Establish a task force to explore case management issues, develop a philosophy, and recommend procedures which could be implemented in Iowa.

ACTION STEP 3

Increase Communication and Coordination Among Service Providers and Agencies

All of the data gathered in the Needs Assessments points to a critical need for increased communication and coordination among service providers and parents. Communication among agencies, within agencies, and between agencies and the public is a concern.

Professionals note that interagency communication exists. The most common interagency activities include providing referrals and transferring records. Service providers rarely meet to solve problems or plan services for families that they have in common. The parents' view that service providers could communicate more often and do more than exchange reports reinforces the professional responses.

Intra-agency communication appears deficient. Information gleamed from a number of data sources, none of which is individually conclusive, leads to the impression that people within the same agency communicate infrequently and often do not know what the other is doing. This lack of communication negatively affects both the amount and quality of information provided to families about their specific child.

Parents request that agencies develop improved public communication procedures so that they and professionals have a better awareness of available services.

Strong leadership and commitment are needed as individuals and groups work together to improve services. The following recommendations will lead to stronger interagency collaboration.

- Recognize the importance of interagency coordination and the increased levels of communication required to effectively serve young special needs children and their families.

- Acknowledge the extra time required for proper coordination of services.

- Use flexibility in assigning case loads to staff who serve this population.

- Formulate a regional structure which reflects the community needs and resources.

- Form community-based interagency planning groups with representation from Area Education Agencies (AEAs). Department of Human Services (DHS). Child Health Specialty Clinics (CHSC). Maternal and Child Health (MCH). and private providers (to include pediatricians or family practitioners).

- Identify and examine exemplary interagency models for replication throughout the State.

- Establish pilot sites for developing and adapting models which are new to Iowa.

- Promote staff awareness by offering ongoing inservice training to staff (including secretaries. receptionists. etc.) to acquaint them with functions and personnel from other agencies that provide services to young special needs children and their families.

ACTION STEP 4

Increase the Quality of Parent Participation

Overall. service providers and parents feel that adequate opportunities are given to parents for input into services the families receive. Professionals are satisfied with their agency's parent program. Many providers view parents as being highly involved in the decision making process. Parents confirm this by sharing that they feel they have a role in making decisions most of the time. Both groups. however. feel that the collaboration between parent and agency staff should be improved.

Professionals want to do more with parents but note that overworked staffs. inadequate funding. and the resulting lack of energy prevent the development and delivery of quality parent participation programs. They also observe that they do not know what parents want and thus feel that they are unable to assess families' needs accurately

The most prevalent level of parent participation is seen in activities which meet the requirements of P. L. 94-142 for Individual Educational Plan (IEP) staffings or conferences. Parents do feel that they have ample time to share at these meetings and that they are comfortable attending them. Data show that in addition to staffing attendance. parents frequently communicate with service providers via notes and telephone calls. A few parents participate in training and support groups that are available to them: more would participate if the training and support activities were better suited to their individual needs. Figures 3a and 3b show the percentage of services that is available to parents and used by parents.

Figure 3a

Individual Percentage of Services (Available)

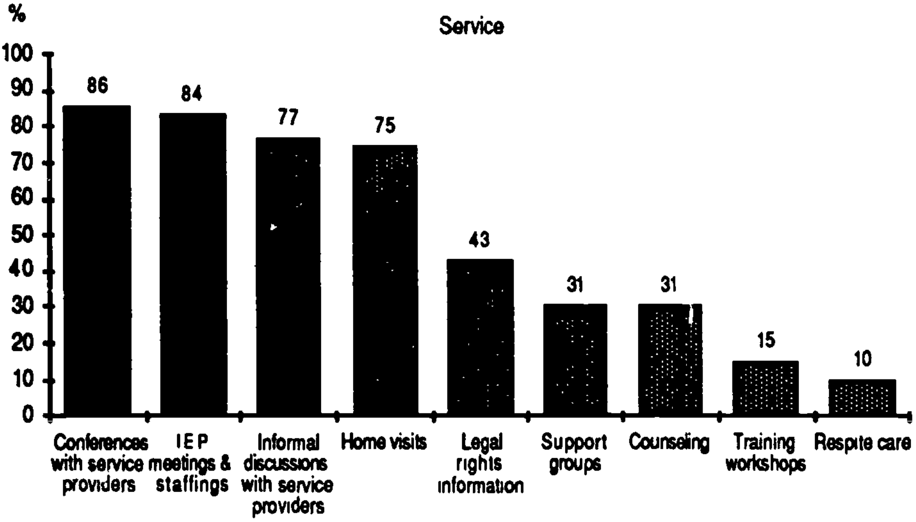
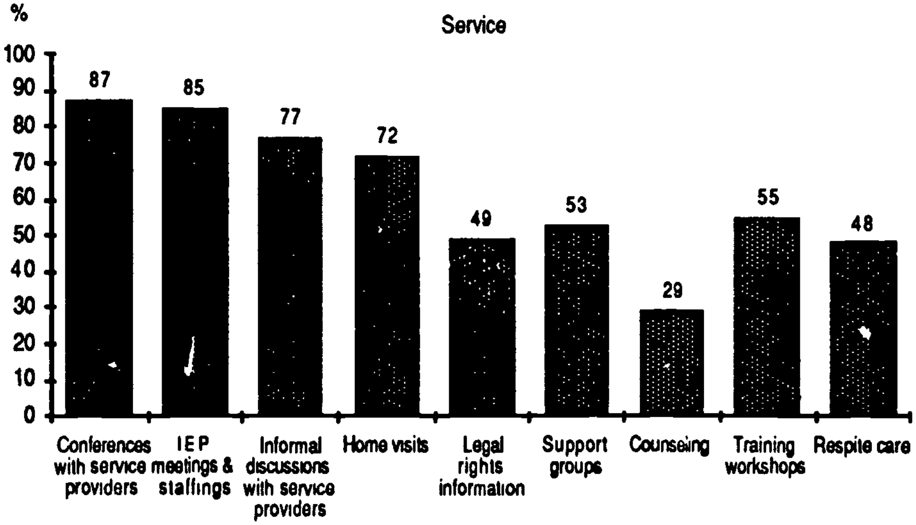


Figure 3b

Individual Percentage of Services (Used, Given, Availability)



New options for individual parent participation must be provided. The following recommendations are a beginning.

- Develop and routinely update a "Guide to Services" for Iowa parents and professionals.
- Offer vouchers or other incentives to parents who participate in projects and/or training which are beneficial to other parents or professionals.
- Make greater efforts to include parent participants and presenters at the State Special Education Conference.
- Provide the opportunity for parents to participate in inservice training for respite care providers who are chosen by the parents.

ACTION STEP 5

Offer an Array of Training Options to Parents and Service Providers

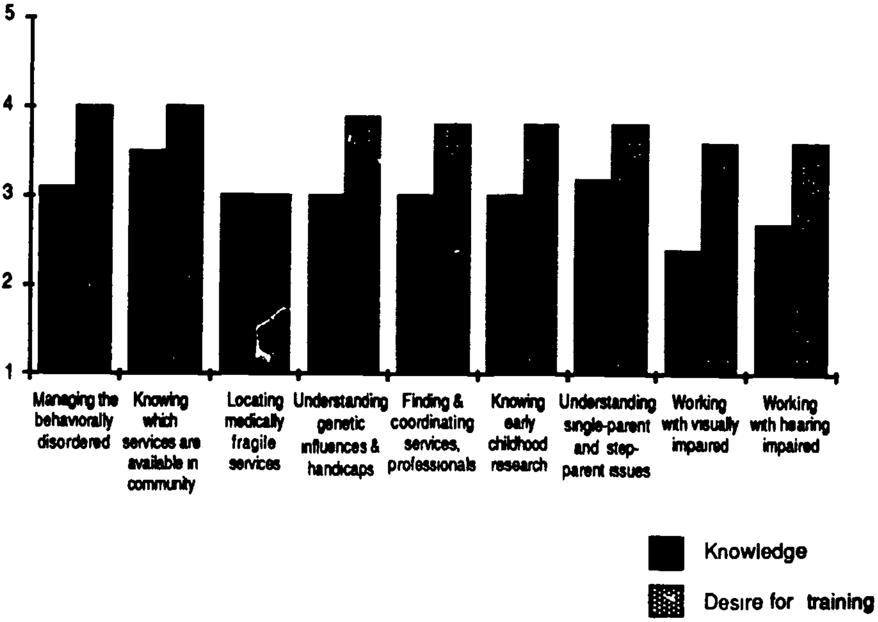
Professional training which seems most needed includes the following topics:

- managing children with behavior disorders.
- understanding genetic influences.
- locating services for children with special health care needs.
- knowing about early childhood special education research.
- finding and coordinating services.
- knowing about various services. and
- understanding single- and step-parent issues.

Working with low incidence populations such as children with visual or hearing impairments is also important. Figure 4 shows professionals' average scores for knowledge in and desire for training in these areas

Figure 4

Professional Knowledge in and Desire for Training*



Agency training issues are

- Area Education Agency (AEA) personnel want training in medical and support areas:
- Department of Human Services (DHS) staff want training in medical and development areas:
- nursing agency staff prefer training in teaching and development: and
- other health agencies request support, teaching, and development training.

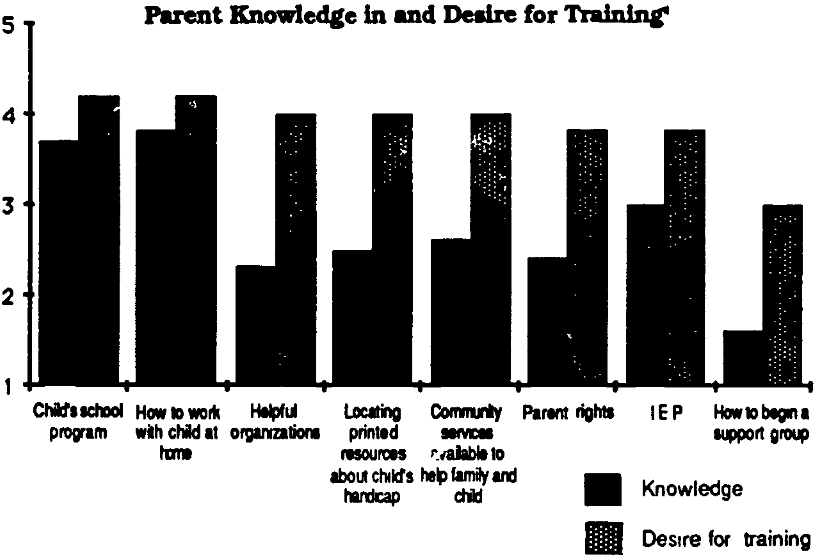
Parents want more knowledge of

- helpful organizations.
- community services.
- their rights.
- how to get material that will help them understand their child and his her disability.
- how to start a parent support group.
- the IEP and their child's school program, and
- how to work with their child at home.

Figure 5 shows parents' average scores for knowledge in and desire for training in these areas

Figure 5

Parent Knowledge in and Desire for Training



Suggestions for making training more suited to individual needs and desires include.

- Offer regional workshops for parents and service providers about community resources. case management issues. networking. communication. and transition.

- Develop concise. informative "packets" (e g . pamphlets. videos. and bibliographies) about specific disabilities.

- Use community colleges as training sites for family day care providers.

- Make genetics training more easily accessible to service providers and parents.

- Promote joint training efforts between agencies and groups whenever possible and feasible.

- Train resource personnel (e.g.. CHSC regional pediatric consultants) to provide information on community resources to primary care physicians.

- Form a task force to address personnel preparation procedures for the training of staff who are to serve children birth to three and their families.

- Clarify the content. level of training (graduate or undergraduate). and competencies required to serve children birth to three and their families.

- Explore the payment of partial costs for out-of-state training in return r a commitment of "X" number of years of service in Iowa.