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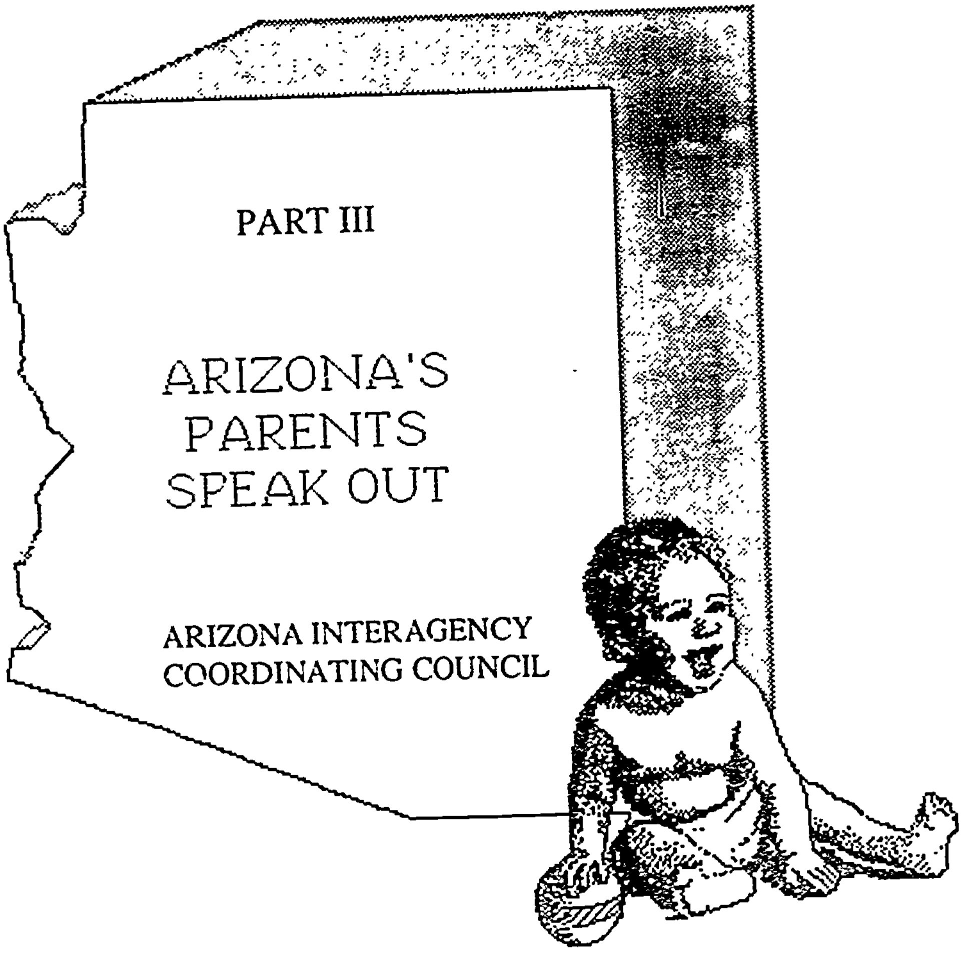
ABSTRACT

This report is the final in a series designed to assist in the planning and development of a comprehensive, coordinated service delivery system for Arizona infants and toddlers who are developmentally delayed or at risk of developing handicapping conditions, and their families, as outlined in Public Law 99-457. It documents the needs of Arizona's families as identified by a statewide, representative sample of 536 parents and caregivers who were interviewed concerning their involvement in meeting their child's needs, the nature and type of services they were receiving, their satisfaction with the services, their need for other services, financial needs, information needs, and emotional support needs. Services evaluated include medical, rehabilitative, educational, family programs, and low-income family services. The report offers a profile of the sample, summarizes interview responses, and identifies unique needs of different ethnic groups and of rural versus urban residents. An executive summary discusses four conclusions specific to financially stable families, families with low incomes who are not Arizona Health Care Cost Containment System (AHCCS) recipients, minority families, and AHCCS recipient families, and offers one conclusion concerning all families. An appendix describes the project design, sample, methodology, and analysis. (JDD)

BIRTH TO 3

PLANNING FOR ARIZONA'S FUTURE

Assessing the needs of infants and toddlers who are developmentally delayed or at risk of developing handicapping conditions and their families



PART III

ARIZONA'S PARENTS SPEAK OUT

ARIZONA INTERAGENCY
COORDINATING COUNCIL

DEPARTMENT OF ECONOMIC SECURITY
PHOENIX, AZ 85061

Early Childhood Planning Project

Assessing the needs of infants and toddlers
who are developmentally delayed or
at risk of developing handicapping conditions
and their families

Part III

ARIZONA'S PARENTS SPEAK OUT

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PREFACE

This report is Part III of a series of three publications prepared for the Arizona Interagency Coordinating Council. The purpose of this series is to assist in the planning and development of a comprehensive, coordinated service delivery system for infants and toddlers who are developmentally delayed or at risk of developing handicapping conditions and their families.

The publication series consists of the following three reports. (1) Understanding Arizona's Agencies; (2) Discovering Who Will Be Served; and (3) Arizona's Parents Speak Out.

Understanding Arizona's Agencies, Part I, is a report identifying the key agencies in the State of Arizona who have been designated by the Arizona legislature and U.S. Congress to respond in a variety of ways to the special needs of young children and their families. The purpose of the report is to provide policy-makers, service providers, and parents with a summary description of the legislated programs in the State of Arizona that have been mandated by federal and state laws, and interpreted at the policy and implementation level within the respective agencies. A description of each agencies' mission, eligibility requirements, and services is provided.

Discovering Who Will Be Served, Part II, is a report on the number of children in the State of Arizona in need of special services, based on the prevalence and incidence of certain characteristics in the population and an interpretation of the broad definition of who needs early intervention provided in P.L. 99-457. Three distinct groups are considered. (1) children who are experiencing developmental delays, (2) children who have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay, and (3) children who are at risk of having substantial developmental delays if early intervention services are not provided. The report provides numerical projections of the size of the target population through the year 2,000, and graphic displays of the geographic and ethnic distribution of the target population across Arizona.

Arizona's Parents Speak Out, Part III, reports on the needs of Arizona's families as identified by the parents and caregivers of young infants and toddlers who are developmentally delayed or at risk of developing handicapping conditions. A Statewide, representative sample of 600 parents served by Arizona's key agencies were surveyed in face-to-face interviews with trained interviewers. Respondents were asked questions related to the nature and type of services they were receiving, their satisfaction with the services, their need for other services, financial needs, information needs, and emotional support needs. The report summarizes their responses, as well as identifies unique needs as represented by different ethnic groups and rural vs. urban residency.

ACKNOWLEDGEMENTS

The authors wish to express appreciation to the following persons and agencies for their assistance in completing this study:

To the 601 families throughout the state of Arizona who agreed to endure an hour long (or more) face-to-face interview in order to share with the interviewers information about their child's problems and needs and intimate knowledge about their family lives. May their time and effort not be in vain

To the interviewers who endured Flagstaff winter weather to receive training and conducted the interviews tirelessly and with strong professional commitment to the findings that would result

To the individuals from the following Arizona agencies who agreed to assist in identifying and soliciting the participation of the families. Office of Maternal and Child Health, Newborn Intensive Care Program, Children's Rehabilitative Services, Division of Developmental Disabilities; Arizona School for the Deaf and Blind, and Northern, Central, and Southern Child Evaluation Centers.

To Marlene Morgan, who as the Executive Director of the Arizona Interagency Coordinating Council and our Contract Manager, provided unwavering support, enthusiasm, and commitment to this project and its potential for influencing positive change for young children and their families.

To the many individuals behind the scene who provided patient and exceptional support to the project staff, in particular, Maureen Snopek, Patricia Mahalish, Cindy Trojaniak, Susan Immel, Martha Probst, and Ken Walters, to Bob Horn and Marci Gerlach for the creation and development of our cover page.

ARIZONA'S PARENTS SPEAK OUT

Executive Summary

The successful implementation of Public Law 99-457, Part H, will depend in large part on the State's ability to establish an early intervention system that is responsive to parental perception of the needs of infants and toddlers who are developmentally delayed or at risk of becoming handicapped.

This report represents the results and conclusions of interviews that were conducted with 536 families throughout the state of Arizona. All of the families have children less than four years of age who have special needs. The families reside in every county of the state. They are members of every major ethnic group in the state, come from diverse economic situations, and live in both rural and urban communities.

Most of the families consist of households with married couples. Ten percent (10%) of the families are single adult households. Mothers remain the primary caretaker in most cases, even though at least 52% of them work.

Most of the children have had extensive medical services, including newborn intensive care, medical specialists, developmental screenings/evaluations, special medical tests, lab fees, special medications, and special equipment and supplies. They are experiencing developmental problems, but have received few rehabilitative, educational or family support services.

Five key subjects were explored with the parents in order to better understand the needs of their young children and their families:

- Are parents receiving the information they need to make important decisions about their child? What kinds of information do parents of children with special needs want and where do they get their information?
- What kinds of services are children and families receiving, who pays for it, and are parents satisfied with it?
- What is the nature of parental involvement in meeting their child's needs?
- What are the emotional support needs of parents who have children with special needs and who is giving it to them?
- What are the main financial issues for families with children who have special needs?

The answers to these questions yielded a large amount of information about Arizona's families. The body of the report contains detailed descriptions of the parent responses, with a summary of the major points at the end of each section as it relates to the above questions.

For the purposes of this executive summary, 5 critical points will be discussed. They represent conclusions from a synthesis of all the information provided by the parents and suggest areas for immediate action.

These critical points are delineated with respect to four distinct groups of families who are at risk for being unable to meet their children's special needs. Some of the characteristics of each of these groups make them unique and contribute to the need for different strategies in order to effectively address their needs. The last critical point discussed is relevant to all the parents and their families.

The four groups of families that were identified for purposes of discussion are[a] : (1) financially stable families, (2) families with low incomes but non-AHCCCS recipients, (3) minority families, and (4) AHCCCS recipient families.

Financially Stable Families

Critical Point #1: Parents of financially stable families who have children with special needs may be at risk for unemployment, leading to reduced incomes, jeopardizing medical insurance coverage, and resulting in a reduced capacity to secure the services necessary for their child's needs.

Families in this group can be generally characterized as having annual incomes greater than $20,000. They represent the largest group of families out of the four identified (approximately 40-50% of all families needing services). Most of them have at least one parent who is employed, have private, medical insurance, and are ineligible for state-supported services for low income families.

There was a clear relationship between the annual income of the family and the amount of money the family spent because of their child's special needs. That is, the higher the annual family income, the more money was spent out-of-pocket to meet their child's service needs. The average annual expenses for children with special needs was $7,970.

This group of parents also reported that two major sources of payment for the services their child is currently receiving are family income and private, medical insurance, two sources tied directly to employment.

Even though children from families who have private insurance and higher incomes are more likely to be receiving a range of early intervention services, no rehabilitative, educational, or family support service is received by a majority of all parents. Unfortunately, less than half of the families reported having insurance policies that support the cost of physical therapy, case management, or home-based educational instruction, among other early intervention services.

In spite of the importance of continued employment for parents who have children with special needs, they may be at risk of unemployment. The unemployment rate for the overall group of parents in this study is much higher than for adults in general. Fourteen percent (14%) of the families reported that no parent in the family was employed.

The income of many families was reduced because parents have quit their jobs or cut back on the amount of work they were doing in order to care for their child. Many parents reported that child care was either too expensive, or that specialized care was not available. Others indicated that it was too difficult to rearrange their work schedule in order to meet their child's needs. Only 1% of the parents indicated they did not want to work.

SOLUTION #1A: **The most important action that can be taken by the state to meet these families' needs is to insure the parents' continued financial stability by providing services to employed parents which will enable them to continue their employment. In addition, barriers to employment should be removed for parents who are currently unemployed.**

Child care must be affordable and accessible, with specialized care available when necessary. Incentives could be designed for employers

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[a] Detailed descriptions of the families can be found in the body of the report. Generalizations are used here to simplify the discussion of the main implications of the study.

who allow flexible work schedules. Respite care should be made more available, especially for parents seeking increased educational opportunities that will result in job-related advancement.

SOLUTION #1B: Closely related to the employment issue is the availability of medical insurance coverage that supports the cost of some of the early intervention services for young children. A detailed analysis of state insurance laws as it relates to the minimum insurance coverage required of all policies delivered in the state of Arizona for newborns and young children should be conducted. Changes in the minimum requirements for payment of targeted early intervention services, such as physical therapy, should be identified and implemented.

Families with Low Incomes, Non-AHCCCS[b] Recipients

Critical Point #2: Families with low incomes, but who are not AHCCCS recipients, are unable to support the financial needs of their children in all areas, including medical, rehabilitative, educational and family support services. Their children have the lowest participation rates in the existing service delivery system and are at great risk for school failure.

Families in this group (approximately 15-20% of all families needing services) have been referred to in the past within the human service delivery system as "notch group" families. They are typically families with incomes less than $20,000 per year. Most, however, have incomes over $10,000, making them ineligible for many state-supported programs, such as AHCCCS. There is likely to be one parent working, but at substandard wages and without the benefit of private medical insurance.

Children from these families are the most at-risk for developmental problems that are likely to continue upon entrance into the school system. They have the lowest participation rates in the early intervention services identified in this study when compared to the other children.

This may explain why families representing this income group were not easily identified for inclusion in this study, which depended upon the client caseloads of several state agencies for soliciting parental involvement. This group was underrepresented in the sample by 11%.

These families are less likely to have medical insurance, and, therefore, their children are less likely to be initially identified through the medical community, the major source of early identification for all other children.

SOLUTION #2A: Many of these families are likely to be recipients of the WIC program (Women, Infants, and Children food supplements). Twenty-five percent (25%) of the families in the sample were recipients of WIC. Therefore, a model identification program should be developed in which all children in the WIC program receive a standard, state-of-the-art developmental assessment to increase the number of children in this income category who are identified as in need of early intervention.

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[b] Arizona Health Care Cost Containment System

SOLUTION #2B: Cooperative efforts with the state Job Training Partnership Administration (JTPA) should be developed in order to improve the employability of disadvantaged parents from this group so that family income can be increased.

SOLUTION #2C: Legislation, regulations, and policies that would increase the provision of private medical insurance to employees in low-wage positions should be pursued. This would help reduce state-supported expenditures and improve the child's access to early intervention services.

SOLUTION #2D: The need for state support of some of the services needed by children within this group will continue to be greater than for children in higher-income families. The provision of and payment for early intervention services could be determined through a sliding-fee-scale service system, where appropriate and consistent with state statutes.

SOLUTION #2E: The Interagency Coordinating Council should join advocacy efforts initiated by the Arizona Council for Mothers and Children and the SOBRA Coalition in order to encourage legislative changes that would increase the number of uninsured women in this group who would be eligible for state-supported prenatal health care.

Minority Families

Critical Point #3: Minority families are much more likely to have low incomes and experience higher rates of unemployment, with increased inability to pay for the kinds of services their child may need. Native American children have the lowest participation rates compared to children from all other major ethnic groups in the range of early intervention services identified.

Twenty-five percent (25%) of the states' population of children are minority children. Hispanic and Native American families are much more likely to be recipients of state services for low income families than White families. This suggests that minority families are overrepresented in the lower income categories.

Native American children are particularly underrepresented in the service delivery system in the area of medically-related services. In spite of the fact that the Indian Health Service is a health care system established to meet the medical and health care needs of Indian people, very young Native American children are not receiving the same level of medical care as other children.

The survey shows that Native American children received significantly fewer surgeries, were seen by fewer medical specialists, received genetic counseling less frequently, and had used special equipment and supplies for their child less often. They were much less likely to receive physical therapy, and they were hospitalized much more frequently than other children for reasons other than surgery.

SOLUTION #3A: Since over half of the Native American families in the survey are recipients of AHCCCS, a group of families the survey found had the highest participation rates in the early intervention services, a study should be conducted to identify discrepancies between the level of AHCCCS services contracted through the Indian Health Service and those provided by other contracting organizations.

Indian Health Service personnel may need training in the identification of children with special needs and the kinds of early intervention services they need to reduce long-term developmental problems and school failure.

SOLUTION #3B: The Interagency Coordinating Council should establish goals related to improving Native American children's access to medical services, and assist in identifying strategies for eliminating the discrepancy between services received by Native American children and their families and other ethnic groups in the state. A cooperative effort between the state and the federal program for Native American children should be articulated.

The strategy should address the lack of availability of trained professionals on reservations, a condition that may be contributing to the children's poor access to rehabilitative services. This strategy might include special monetary incentives supported by the federal government for individuals willing to work in rural, reservation environments.

AHCCCS Recipient Children

Critical Point #4: Children who were AHCCCS recipients had the highest participation rates in medically-related services. They were also receiving 6 other early intervention services significantly more often than other children. This includes physical/occupational therapy, assistance with coordinating services, nutritional advise, speech and language therapy, respite care, and transportation.

Families who are recipients of AHCCCS have the highest unemployment rate of all families in the sample (32%). The AHCCCS program, in conjunction with the Arizona Long-term Care System for children with developmental disabilities, appears to be greatly enhancing many children's access to early intervention services. Thirty-three percent (33%) of the families interviewed in the study were AHCCCS recipients.

However, 2/3 of the children in the sample who are enrolled in AHCCCS are children from rural communities. While this results in a very positive program for children who are typically isolated from services, children in Maricopa county are much less likely to be AHCCCS recipients.

SOLUTION #4A: Continued effort should be given to enrolling all eligible children into the Arizona Long-term Care System to insure that they have the opportunity to participate in early intervention services.

SOLUTION #4B: Strategies for improving the equity of services that are provided to children in this program and policies that support the full range of early intervention services should be sought. This may require state statutory changes in areas where federal law allows broader service options under this program than currently available from the state.

SOLUTION #4C: A special campaign should be instituted to find and enroll children and families in Maricopa county in the AHCCCS and ALTCS programs.

Critical Point #5: The majority of parents agree that what they want most is more information about the services that are available for their child.

A majority of parents are not getting access to information relevant to the child's rehabilitative, educational, and family support needs. There appears to be no coordinated system from which parents can access information about services of this type.

The exception to this is medically-related information. Most parents appear to be receiving medical advice and information from the medical doctors. They report that this information is useful and that the doctors are supportive.

Without access to important information, however, that would help them function more effectively as parents of children with special needs, parents feel confused, deceived, dissatisfied, and spend an excessive amount of time seeking information for their child. This may contribute to the need to quit their jobs in order to care for their child.

The degree to which a family may need assistance coordinating services for their child will depend on a number of factors, including the complexity of problems the child has, family income, family access to a social support system, and the level of knowledge the parents have regarding what services are available. The more the parents can be empowered with information about the service system, the less their need for assistance with coordinating services.

SOLUTION #5A: **If doctors are the major source of information for parents, then professionals in the state-supported service providing system need to identify a strategy for disseminating information about the rehabilitative, educational and family support system through the medical community.**

A user-friendly, computerized information system could be designed and placed in doctors' offices throughout the state. Most parents of these very young children are seeking medical services for their child. While acquiring these services, they could learn about additional early intervention services available for their child by interacting with a computer system located in the doctors' offices. This effort could be supported through a partnership with the private sector.

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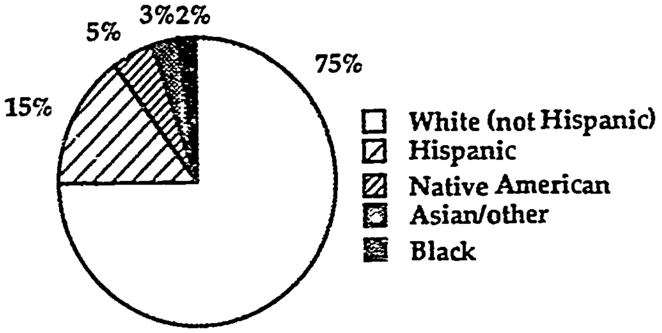
The following report is a detailed summary of the findings generated by the face-to-face interviews conducted with families throughout the state. A description of the study design, sample, and methodology can be found in the appendix.

PROFILE OF THE SAMPLE

Parents from 536 families were interviewed. They provided their perceptions of the needs of their children who are developmentally delayed or who have special needs. Data on 584 children from these 536 families was collected and analyzed. The children were an average of 2 years old.

The families live in every county of the State, with rural and urban families represented in equal proportion to their residency patterns in the State.[a]

Children from every major ethnic group in the State are included: (1) White [not Hispanic] (75%), (2) Hispanic (15%), (3) American Indian (5%), (4) Black (2%), and (5) Asian/other (3%). Major ethnic groups other than White are each underrepresented in the sample by 2% or less.[b]



Child's Ethnic Background

Profile of the Families

The following variables characterize the families participating in the survey

Family Income

- The median annual income for families in the sample was $20,000-$29,999.
- Income levels from less than $5,000 to over $75,000 were represented; incomes between $5,000-$20,000 were underrepresented by 16%, and incomes of more than $50,000 were substantially overrepresented.
- 33% of the families were receiving AHCCCS.
- Hispanic and Native American families were much more likely to be receiving AHCCCS than White families.

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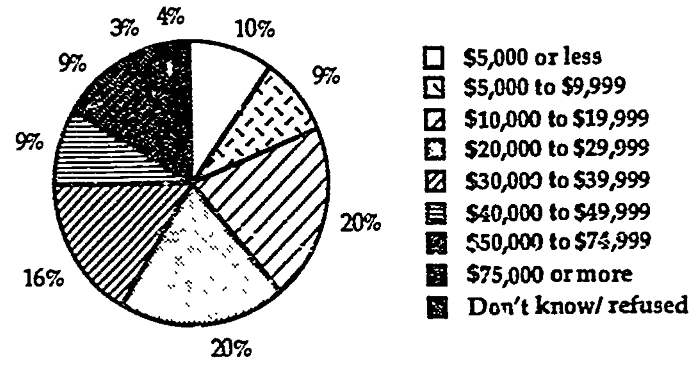
[a] Geographic differences are discussed throughout the report. A description of the 3 major geographic categories used in the comparative analyses can be found in the appendix. Only items where statistically significant differences were found are discussed.

[b] In the sections that follow, unless otherwise indicated, comparisons between ethnic groups will be based on the 3 major groups (White, Hispanic, American Indian), because sample sizes for the others are too small.



Total Household Income

Caregiver Educational Level

- The mean educational level of the primary caregivers was 13 years of school.
- The range of educational level was from one year of school to 19 years or more; individuals with educational levels less than 12 years were underrepresented by 6%.

Family Structure

- 78% were households with married couples.
- 10% were single adult families.
- 13% had three or more adults who were 18 years or older living in the home.
- One household reported 18 adults in the home.

Family Size

- The average family size was 2.4 children.
- The median family size was 2 children.
- 84% of the families had 3 or fewer children (17 years of age or younger).
- 11% of the families had more than one child who had special needs or was developmentally delayed, and was 3 years of age or less.

Primary Caregiver [c]

- The mothers were most frequently mentioned as the childrens' primary caregivers.
- The mother was primary caregiver in 88% of cases.
- The father was primary caregiver in 4% of cases.
- The grandmother was primary caregiver in 3% of cases.
- The baby-sitter was primary caregiver in 3% of cases.
- Other relatives and adults were mentioned in 3% of cases.

Maternal Age

- The mean age of mothers at the time of their child's birth was 28 years.
- Maternal age at the time of the child's birth ranged from 12 years of age to 47 years.

Employment Status

- 86% of the families had at least one wage-earner.
- At least 52% of the mothers were employed.

Special Expenses for the Child's Special Needs

- The average annual expenses for the child's special needs was $7,870.
- The median expenses for one year were $500.
- The range of expenses for one year was $0-$600,000.
- 8 urban families spent more than $150,000 each.

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[c] Primary caregiver cares for child at least 14 hours per day.

Profile of the children

The children whose needs are identified in this report can be characterized by the following information.

Profile of the Children

[N=584][d]

	Characteristic		Number	Percent
Age	<1 year		132	23%
	1 year		173	30%
	2 years		119	20%
	3 years		132	23%
	4 years		28	5%
Sex	Female		236	41%
	Male		340	59%
Birthweight	Very low	(<1500 gms)	105	18%
	Low	(1500-2500 gms)	134	23%
	Normal	(2500-4000 gms)	295	52%
	High	(>4000 gms)	38	7%
Gestation[e]	Preterm	(<37 weeks)	337	58%
	Term	(37-42 weeks)	172	30%
	Postterm	(>42 weeks)	70	12%
Babies who spent time in Newborn Intensive Care Unit			376	64%
Babies Receiving Services through Newborn Intensive Care Follow-up Program			190	47%

[d] Not all categories add up to 584 total children because of refusals, unknown, and missing data.

[e] Parents indicated whether or not their child was born early, on time, or late, and by how many weeks. Their responses have been regrouped such that responses of more than 3 weeks early are called preterm, 3 weeks early to 2 weeks late are called term, and more than 2 weeks late are called postterm.

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Functional and Developmental Problems of Children

- 16% of the parents reported that their child has not had any problem.
- 66% of the parents reported that their child had 2 or more problems.
- 9 parents reported their child had 11 or more developmental problems.
- Problems with walking or talking were the most frequently cited problems.

Problems Children Have Had

[Parents could select all that apply]

Problem	Number	Percent
Can't move around or walk as well as he/she should	245	42%
Doesn't babble or talk as well as he/she should	238	41%
Had a physical health problem that was corrected	220	38%
Has a continuing serious physical health problem	196	34%
Is slow to learn	185	32%
Has trouble seeing	121	21%
Can't think as well as he/she should	111	19%
Is too fussy	103	18%
Has trouble hearing	96	17%
No problems	93	16%
Has seizures	92	16%
Other	77	13%
Is too quiet	72	12%
Has a behavior problem	63	11%
Doesn't smile, laugh, or look at me	35	6%

As the above table shows, the children of the families represented in this study have had a variety of problems, with every likely functional problem represented. Only 16% of the parents reported that their child has never had any of these problems. These may be children who for medical reasons were placed into the Newborn Intensive Care Unit at birth, but who have exhibited no subsequent problems since delivery. It may also represent children who received one time only medical services through Children's Rehabilitative Services.

Ethnic Differences

Ethnic differences were reviewed by identifying the number and percentage of children from each ethnic category who were identified by their parents as experiencing problems selected from the above list. Children from the different ethnic groups did differ on the nature of their problems as identified by the parents.

First, White, Hispanic and Black children were the most similar in terms of the kinds of problems they were experiencing as identified by their parents. As a group, they most closely represent the rank order of conditions as indicated in the above table.

Secondly, Native American children were the most dissimilar as a group. Although problems with babbling and talking were selected most frequently by all parents as a problem, only 29% of the Native American children were identified as having this problem. Black parents also selected this item the most frequently, but it was selected by 67% of the group.

There was no single item identified by the Native American parents as representing the kinds of problems their children were having or have had above the 29% response rate for the item 'doesn't babble or talk as well as he/she should'. The remaining responses were distributed throughout the entire list, with the exception of 'doesn't smile, laugh, or look at me'. No Native American parent identified this as a problem.

On the other hand, Black parents were the most homogeneous as a group. On 4 of the problem items, 50% or more of the parents selected them as a problem. In addition to the response related to talking, the following items were selected by a majority of the Black parents: (1) can't move around or walk as well as he/she should (50%), (2) had a physical health problem that was corrected (50%), and (3) has a continuing serious physical health problem (50%).

Black parents reported proportionately fewer problems with vision than other parents (8%), while reporting the greatest number of problems with hearing (25%). They also reported the highest number of problems with behavior (25%). No Black parent selected 'no problems' when responding to this question

Asian parents were the most likely to select 'no problems' in describing their child (35%). They selected the item 'is slow to learn' equally as frequently (35%).

Summary

The results of the study summarized in this report represent the perceptions of parents from throughout the state of Arizona. Every county and every major ethnic group were represented in the findings.

The families represent every economic group and all educational levels of people in the state of Arizona. On every major demographic characteristic, the sample of parents included in this study resembles very closely individuals from the State.

The children appear to represent children with very early identifiable developmental and medical problems. The majority of the children have experienced more than one problem. Most parents in this sample have had annual expenses above that normally experienced by other parents of young children.

The authors of this study feel that a significant effort was made to secure a representative sample of families with children who have special needs and that to a great extent, this has been achieved. These findings, therefore, can be used by policy-makers as guidelines to improving services to all families who have young children with special needs.

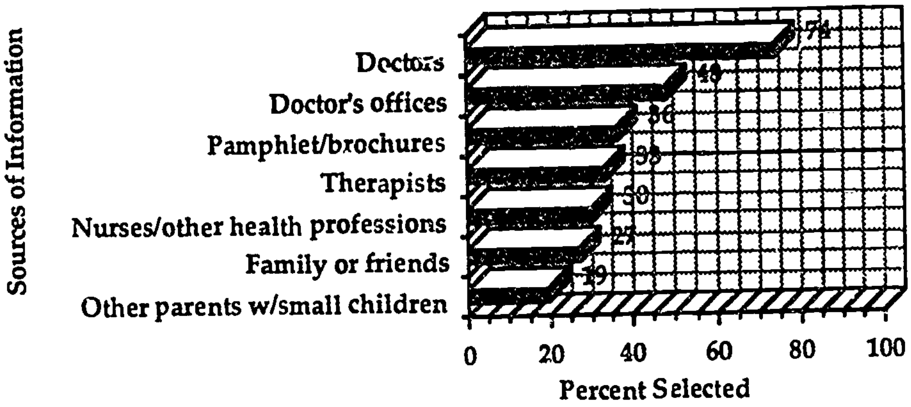
PARENTAL PERCEPTIONS OF INFORMATION NEEDS

Parents were asked about the kinds of information they need as a parent of a child with special needs. Questions about their sources of information were asked in order to identify the best strategies for disseminating information to parents. Parents also reported on the kinds of problems they have had in getting information about their child.

Where do parents of young children with special needs get information?

Sources of Information for Parents [a]

[Parents could select more than one item.]



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[a] The information for this table is combined from 3 separate questions in the survey.

Doctors, including pediatricians, were the only source identified by a clear majority of the respondents as providing them with useful information about their child. Therapists and nurses were the second and third most frequently cited people to provide useful information.

Family or friends and other parents were more likely to be cited as sources of information than individuals representing state and private agencies such as a Developmental Disabilities agency caseworker, public health nurse, Pilot Parents, social worker, teacher, counselors, and lawyers. Individuals from these and other groups were identified as useful sources of information by less than 19% of the parents in the sample.

Other sources of information that were infrequently identified as useful (less than 20% of the sample) were mass media sources, hotlines, lectures, agencies, libraries, hospitals, and healing ceremonies.

Geographic Differences

Differences between the 3 geographic groups were identified regarding the parents' source of information. Pilot Parents ranked higher (7th) as a source of information for Maricopa County parents than for parents in Pima County (14th) and rural counties (13th). Developmental Disabilities (DD) caseworkers ranked higher as a source of information for Pima County parents when compared to parents in the other two groups. Teachers were more frequently identified as a source of information for rural parents than for parents in Maricopa and Pima Counties.

Parents from Maricopa County reported getting information from pamphlets and brochures more frequently than expected, while Pima County parents selected Evaluation Programs as a source of information more frequently than expected when compared to the other groups.

Rural residents were more likely to get information from hospitals, selecting doctors' offices less frequently than expected in the comparison.

Ethnic Differences

A larger percentage of Native Americans ([illegible]8%) identified doctors as the individuals from whom they get the most information than was identified by White parents (75%) and Hispanic parents (70%). Native American parents ranked therapists as a source of information much lower than White and Hispanic parents, while public health nurses ranked second as a source of information for Native American parents.

Native American parents were also much more likely than expected to select hospitals as a source of information than White and Hispanic parents. White parents indicated agencies as a source of information more frequently than expected when compared to Hispanic or Native American parents.

What kinds of information do parents want?

Parents were asked to select one item from each of four categories that represented the kind of information they needed as a parent: (1) about their child, (2) about being a better parent, (3) about services, and (4) other concerns. The only information item that was selected by at least 50% of all the parents was information about what services are available. The four information items from the 4 categories selected by 20% or more of the sample were the following items.

Information Parents Want Most

[Parents could select one item from each category]

Item	Number	Percent
What services are available	268	50%
How to be a better parent	177	33%
What services are required by law to be available	157	29%
What are the educational needs of my child	109	20%

About Their Children. Only 11% of the sample indicated that they did not need any more information related to their child, didn't know or refused to answer this question.

When asked to indicate the single most important information about their child that they felt they needed, the parents varied greatly in their selection. No single item received more than 20% of the parental responses. This suggests that parents have very idiosyncratic needs such that interventions with the family and child must be sensitive to the individual needs of each family.

The following table illustrates the types of information related to their child that parents selected as important to them.

Information Needs About Child

[Parents could select one item]

Item	Number	Percent
Educational needs of my child	109	20%
What things children do at different ages	100	19%
My child's disability	94	18%
What my child will be like as he/she gets older	78	15%
What happens when my child becomes school age	77	14%
I don't need any more information about my child	49	9%
Other	19	3%

Geographic Differences

Rural parents indicated they wanted information about their child's educational needs much more frequently than expected when compared to parents from Maricopa and Pima counties.

About Being A Parent. Thirty-three percent (33%) of the sample agreed that the single most important information they wanted about being a parent was how to be a better parent in general.

Once again there was no strong consensus regarding the importance of any one of the various information items listed. The frequency and percentage with which parents indicated their need for information on items related to being a better parent are listed below.

Information Needs About Being A Parent

[Parents could select one item]

Item	Number	Percent
How to be a better parent in general	177	33%
How to care for my child's physical needs	89	17%
How to keep going from day to day	75	14%
I don't need any more information about parenting	65	12%
Helping siblings understand my child's needs	35	7%
Family recreation ideas	27	5%
Dealing with reactions of others	24	5%
Dealing with my child's brothers and sisters	20	4%
Other	11	2%

About Services. Of all the items regarding information needs that parents were asked to respond to, information about the availability of services was the most frequently selected item by the parents. Fifty percent (50%) of the parents indicated that they wanted more information about what services are available. Responses to items related to service information were the following.

Information Needs About Services

[Parents could select one item]

Item	Number	Percent
What services are available	268	50%
I don't need any more information about services	80	15%
How to get services	69	13%
What services my child needs	63	12%
Where to get toys and materials for my child	27	5%
Where to get equipment	15	2%
Other	6	1%

Geographic Differences

Rural parents were much less likely than expected to indicate they did not need any information about services for their child than parents from the urban counties.

Ethnic Differences

Native American and Hispanic parents selected the information item "how to get services" more frequently than expected. This would be consistent with the earlier finding that these two ethnic groups were getting information from agencies less frequently than White parents. It appears that agency personnel are interacting less frequently with Native American and Hispanic parents than with White parents, or that when interactions occur, information is not conveyed effectively from the perspective of minority parents.

Other Concerns. When asked about any other concerns, information about services that are required by law to be available was the most frequently selected item (29%). Sixteen percent (16%) of the parents said they don't need any additional information, which was the second most frequently selected item in this list. Another 5% indicated other information than listed or don't know/refused. The responses to items in this category were the following.

Information Needs About Other Concerns

[Parents could select one item]

Item	Number	Percent
Services that are required by law	157	29%
I don't need any additional information	84	16%
Finances	59	11%
Will, trusts, providing for the future	53	10%
Parents' rights in relation to special child	40	8%
Single parents' concerns	36	7%
Time management	24	5%
Where to get counseling	24	5%
How to find and join advocacy groups	17	3%
Other	11	2%
How to get legal help	9	2%
Stepparents' concerns	6	1%

Ethnic Differences

Native American parents indicated that they wanted information on parents' rights in relation to their handicapped child more frequently than expected when compared to parents from the other two ethnic groups.

What kinds of problems do parents have in getting information?

When asked about problems they as parents have had in getting information, many of the parents felt that the following conditions were true.

Problems Parents Had

[Parents responded to each item]

Item	Number	Percent
I had to find out lots of things on my own or by chance	365	68%
I have gotten confusing information from different sources, or incomplete or wrong information	316	59%
People telling me about my child's problem did not give me information about the services available	293	55%
People didn't tell me why they couldn't provide the service	227	42%
I feel I have gotten the run-around	225	42%
People said they would find things out for me and then did not do it	194	36%
I have had other problems	188	35%
People ignored my requests for information	160	30%
I have felt someone didn't want to provide a service for me, so they didn't tell me about it	109	20%

On the other hand, seventy-five percent (75%) of the parents felt that they were told about their child's problems when they began services. Sixty-eight percent (68%) of the parents felt that they were told what could be done for their child.

Geographic Differences

Maricopa County parents were more likely than expected to report that they were not given information about the services available. Although the majority of all parents felt that they had to find lots of things out on their own, parents in Maricopa County and rural counties selected this item more frequently than expected when compared to parents in Pima County.

Ethnic Differences

When compared to Hispanics and Native Americans, White parents were much more likely than expected to indicate that they had had "other problems" in addition to those listed. Native American parents reported more frequently than expected that they were not told why a service could not be provided.

Hispanic parents were much less likely than expected to feel that they had been told what could be done for their child.

Summary

Parents reported that the medical doctors are their major source of information about their child's needs, with no geographic differences found, and Native American parents selecting doctors even more frequently than Whites and Hispanics.

In general, the parents felt that they had received information about their child's problem and about what could be done for their child. However, Hispanic parents were less likely than White and Native American parents to feel that they had been told what could be done for their children.

The kind of information parents are receiving about their children appears to be information that may only be relevant to the child's medical condition, the logical type of information to be provided by the child's medical doctor.

Information relevant to the child's rehabilitative, educational, and family support needs and the range of services available to the child with special needs who could benefit from early intervention have apparently not been made readily available to parents. This is in spite of the fact that 41% of the parents indicated that their child has a case manager. Rural parents as a group were more likely than urban parents to indicate a need for information related to their child's educational needs. Native American and Hispanic parents reported a greater than expected need for information on how to get services.

When information of this nature is not provided by the medical doctor, there appears to be no other single source of information for parents to access, therefore, it results in confusion, excessive time on the part of the parents finding an adequate source, some feelings of deception, and dissatisfaction.

Medical doctors are in a position to play a key role in linking parents to non-medical sources of information and services. State agencies need to identify a mechanism for improving parental access to service information and educating the medical community on an effective procedure for creating this linkage.

Professionals in the pivotal role of serving families who have children with special needs, such as case managers, should be more effectively trained regarding the range of services available in the State, both public and private, and how to successfully link families to these systems. Strategies for communicating more effectively with minority parents need to be explored.

State agency personnel and other professionals can serve an important role in advocating for families and empowering them with accurate information about the services the State offers for families with special needs.

Educational opportunities for parents should be more readily available and emphasize the provision of knowledge related to what early intervention services are available in the State for their child and family, parenting skills in general, and the educational needs of their child.

SERVICE USAGE AND SATISFACTION

Subsection I: Medically related services

Parents were asked a series of questions related to the types of services their children received, who had paid for the services, and their satisfaction with the services. There are 3 major subsections to this section of the report. The first subsection deals with services the children have ever received since birth, primarily concerned with medically related services. The second subsection addresses issues related to services the children are currently receiving, focusing more on rehabilitative and educational services. The third subsection covers services for low income families only.

Has your child ever had the following medically-related services?

Parents were asked to indicate whether or not their children had ever had any of 14 medically-related services that were identified. Below are pie charts showing those services that a majority (51% or more) of the parents indicated that their children had received in the past.

In addition, parents were asked to indicate who had paid for the service. The following is a list of payment sources from which they selected.

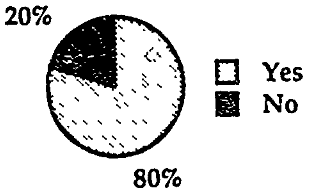
Payment Sources
[Parents could select all that apply]

- Self
- Private Insurance
- AHCCCS (Medicaid)
- Department of Economic Security/Div. of Developmental Disabilities (DES/DDD)
- Children's Rehabilitative Services (CRS)
- Public Health Services (PHS)
- Newborn Intensive Care Program (NICP)
- Arizona School for the Deaf and Blind (ASDB)
- Child Evaluation Center (CEC)
- Relatives or friends
- Community fundraisers
- Public School
- Hospital
- Church
- Private non-profit organization
- County
- University
- Other

The bar graphs accompanying each pie chart illustrate all the payment sources for each service in which at least 1% of the parents indicated that payment was provided by the identified source. Parents could indicate more than one source of payment.

Was your child in a Newborn Intensive Care Unit at the hospital?

Has your child ever gone to a medical specialist?



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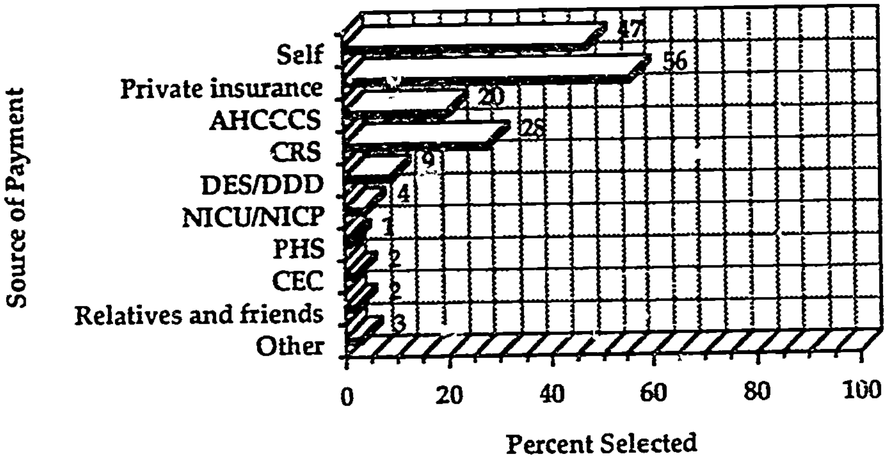
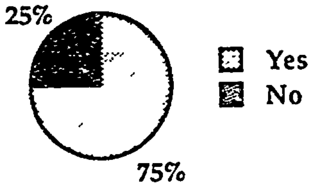


Has your child ever had developmental screening or evaluations?



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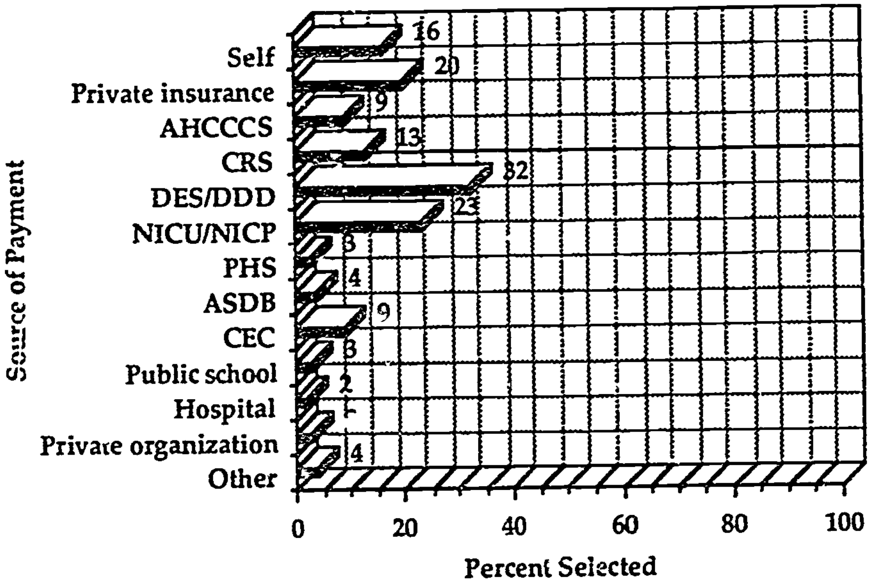
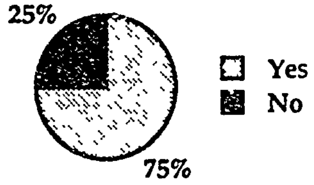


Has your child ever had special medical tests, lab fees, etc.?



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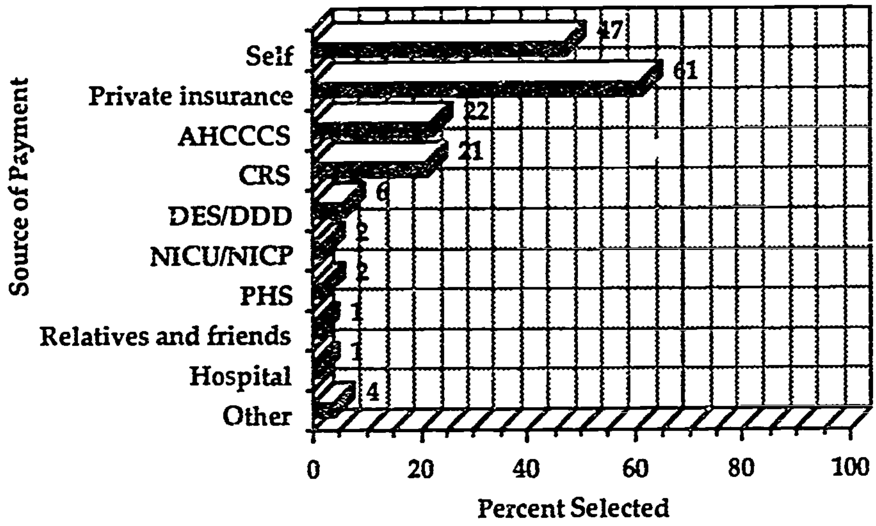
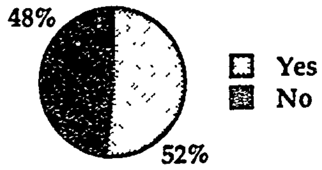


Has your child ever had special medications?



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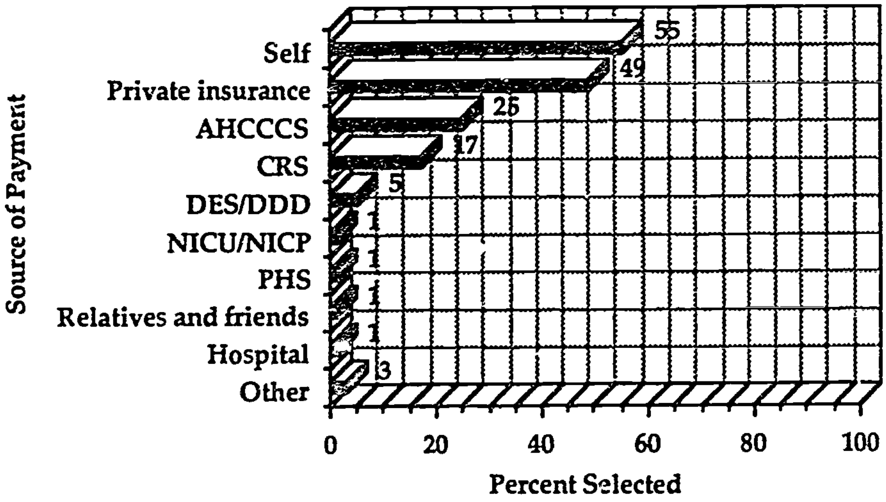
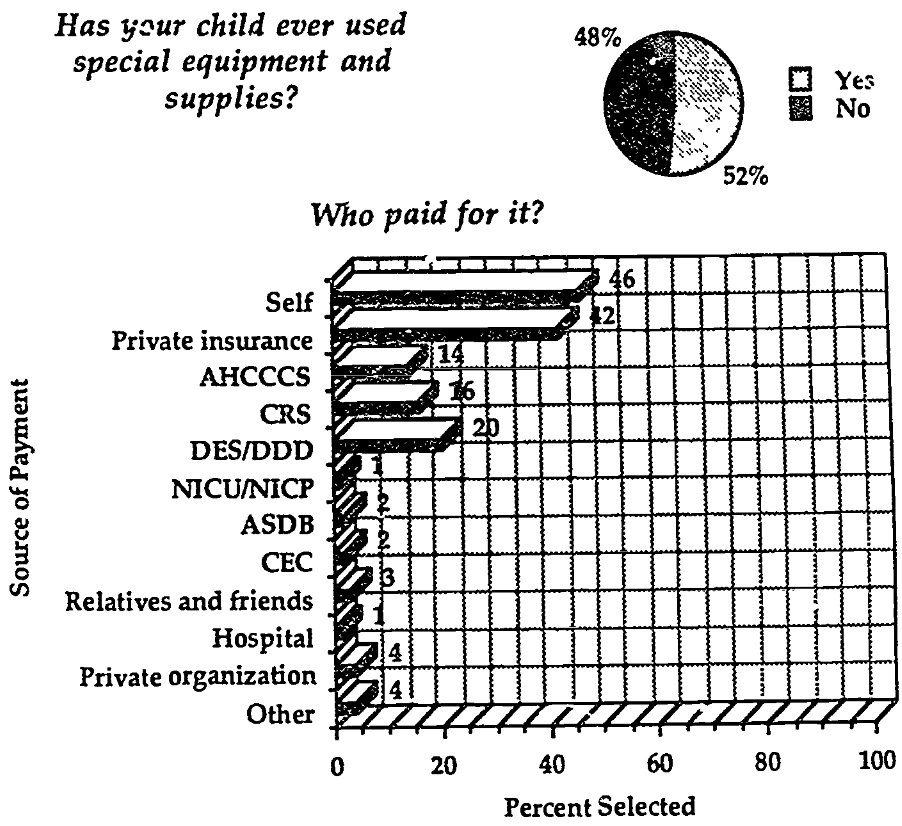




There were 5 additional services that 25%-50% of the parents indicated that their child had received. They were. (a) surgery (48%), other hospitalizations (43%), lodging and meals away from home (35%), special food or dietary supplements (32%), and genetic counseling (25%).

The pattern of payment was similar to the above, in that the individuals themselves and/or private insurance were a source of payment for the greatest number of families. CRS supported some of the costs of surgery for 30% of the children and genetic counseling in 17% of the cases. AHCCCS helped pay for surgery for 22% of the children and other hospitalizations in 24% of the cases.

While 35% of the families indicated that they had used lodging and meals away from home, 89% reported that they had supported the cost of this themselves The costs of special foods or dietary supplements were also supported primarily by the parents (66%).

Three final items were reported to have been received by less than 20% of the children: (a) private/2nd opinion testing for learning problems (17%), (b) special healing ceremonies (13%), and (c) legal services (9%).

Private/2nd opinion evaluations were most likely to be paid for by the individual and private insurance. Special healing ceremonies were paid for by a source other than those listed (30%), by the church (23%), or by the parents (15%). Legal services were used infrequently, but when they were, they were paid for primarily by the parents (44%) or other source (21%).

Geographic Differences

Several geographic differences were found when comparing parents from Maricopa, Pima, and rural counties and the kinds of services they had received for their children. There were significantly more babies from the 2 urban counties in newborn intensive care than expected when compared to rural residents. There were significantly more children than expected from rural counties who had other hospitalizations (not including surgery or at the time of birth) than children from Maricopa and Pima counties.

Children from Maricopa County were more likely than expected to have used special equipment and supplies when compared to the other two groups.

Finally, a significantly higher number of rural families than statistically expected reported that they had used lodging and meals away from home when compared to families from the 2 urban counties.

Ethnic Differences

There were statistically significant ethnic group differences in the frequency with which services had been received on 5 of the 13 items related to medical services. There is a clear pattern of service delivery to Native American children that differs from that of White and Hispanic children. Native American children appear to be the least likely to have received any of these services than children from White and Hispanic families.

The following table summarizes the percentage of children from each ethnic group who had received the identified service.

Percentage of Ethnic Group Children Receiving Services

Item	White	Hispanic	Native American
Had surgery[a]	48%	54%	21%
Had other hospitalizations[a]	42%	45%	74%
Gone to medical specialists[a]	83%	78%	56%
Had spec. medications[b]	52%	57%	32%
Had spec. medical tests, lab fees	76%	74%	63%
Received genetic counseling[a]	28%	17%	11%
Had special food or dietary supplements[b]	34%	29%	14%
Had developmental screenings/evaluations[b]	79%	71%	63%
Had private/2nd opinion testing	17%	19%	4%
Used special equipment & supplies[a]	56%	46%	25%
Used lodging & meals away from home[b]	36%	28%	50%
Used legal services	9%	8%	11%
Had special healing ceremonies	15%	11%	18%

[a] Statistically significant differences at the $p<.05$ level.

[b] Approached statistical significance ($p<.09$).

Native American children had significantly fewer incidences of surgery than expected when compared to the other two groups. On the other hand, the Native American children were hospitalized for reasons other than surgery or at the time of birth much more frequently than expected in the comparison.

Additionally, Native American parents reported that their children received care from medical specialists much less frequently than expected when compared to the other two groups.

Families from the White ethnic group (28%) were much more likely to have received genetic counseling than Hispanic (17%) or Native American (11%) families They are also much more likely to have used special equipment and supplies than children from either Hispanic or Native American families.

A higher percentage of Native American families had to travel and use lodging and meals away from home for their child than the other two ethnic groups (although this was not statistically significant at the p<.05 level).

Interestingly, there was very little difference in the frequency with which the different ethnic groups reported seeking and securing special healing ceremonies for their child.

Family Income Differences

AHCCCS recipients were significantly more likely to receive surgery than children from any of the other income categories. More than half (58%) of the children who were AHCCCS recipients had had surgery. The percentage of children from the other income categories receiving surgery were the following. (a) less than $10,000 (36%), (b) between $10,000-19,999 (41%), (c) $20,000 or more (44%).

Similarly, most children receiving AHCCCS (52%) had had other hospitalizations (not including surgery or at the time of birth). Fewer than 40% of the children from each of the other income categories had had other hospitalizations.

Families with incomes of $20,000 or more were much more likely to have received genetic counseling, 63% of all families receiving this service were from this income category. AHCCCS paid for 29% of the families receiving genetic counseling. Parents in low income categories and non-AHCCCS recipients are unlikely to receive this service.

Families in the income category of $10,000 to $19,999 were significantly less likely to have received developmental screenings or evaluations than children from families in the other income categories.

Finally, AHCCCS recipients were significantly more likely to have used legal services than families from the other income categories.

Summary

The responses of the parents suggest that most of the children in the sample had had some kind of medical complication that required the attention of a medical specialist and special medical tests to evaluate the child's condition. Over half of the children had used special equipment and supplies and had had special medications, while almost half had had surgery and other hospitalizations.

The cost of these medical services is being primarily paid for through private insurance and by the families themselves. AHCCCS and CRS are supporting some of the medical expenses for families who are income eligible, which is consistent with their agency missions. Thirty-three percent (33%) of the families in the sample reported that they were enrolled in AHCCCS.

There is one service that the parents reported was financially supported more often by the agency then through private insurance and themselves. Seventy-five (75%) of the children had received developmental screenings or evaluations that were paid for most frequently by the Department of Economic Security/Division of Developmental Disabilities (DES/DDD) and the Department of Health/Newborn Intensive Care Program. Parents reporting DES/DDD as the source of payment include families who are recipients of AHCCCS.

It is very positive that such a large number of children are receiving developmental screenings at a very early age. This process should facilitate the identification and enrollment of children with developmental problems into early intervention services.

It may be necessary for the state agencies who are providing developmental screenings to interface with the private medical community in this activity in order to insure that all children are appropriately screened and increase the likelihood that early identification of all developmental problems is successful.

Unfortunately, there are some serious inequities in the state in regard to access to these medical services. Geographic differences suggested that children in the large, metropolitan area of Maricopa County had access to and had received special equipment and supplies for their needs more frequently.

As one would expect, rural parents are having to travel more than urban parents to access services, and hence, spend more money on lodging and meals seeking these services. Lodging and meals are expenses that are rarely supported by private insurance and state agencies, so families typically bear the cost of such expenses.

This may create a barrier to service for many rural children whose families can not afford to pay for expenditures required to access services in the urban areas.

Even greater discrepancies occur between different ethnic groups and their access to services. By far, the most serious problem for the state in regard to ethnic disparity is the poor access to services that Native American children have. A consistently lower number of Native American children are receiving the identified medical services when compared to Hispanics and Whites. Hispanics are also more likely to receive fewer services than Whites, but not to the degree of discrepancy experienced by Native American children.

This is due in part, no doubt, to the fact that most Native American children in Arizona live in rural, isolated areas of the state and receive their medical services predominantly from the Indian Health Service. The Indian Health Service has experienced a decreasing purchasing power over the last 10 years and this may have created constraints on the types and level of medical services offered to children. Medical specialists and medical tests, delivered less frequently to Native American children, would most likely be delivered in the urban areas.

The expense of lodging and meals, experienced by most rural families, would also create a barrier to Native American families needing to seek services in the urban communities.

The State's role and responsibilities in meeting the needs of young Native American children should be assessed and agency policies and practices need to be implemented that are consistent with the State's responsibilities to Indian children. The State should establish goals related to improving the equity of medical services to voung Native American children commensurate with that of other children in the State.

There also appears to be significant inequities in the services the families have received based on family income for several of the service types.

Children who are AHCCCS recipients were more likely to have had surgery and other hospitalizations than the other children in the sample. It is difficult to assess the reason for this discrepancy.

Family access to genetic counseling appears to be very limited, and is most likely to be received by parents with incomes of $20,000 or more. Genetic counseling is infrequently paid for by the state agencies. **Since many developmental disabilities represent preventable conditions, it would benefit families and the State to make genetic counseling more readily available.**

Finally, it appears that there are many families who fall within the category of $10,000 to $19,999 annual income and who are not getting access to developmental screenings or evaluations for their children. These are families who are not AHCCCS recipients, yet have incomes that may prevent them from securing this kind of service The children from these families also appear less likely to be hospitalized or have surgery, so are not readily identifiable through the medical community.

This service represents another early intervention service that can lead to preventive strategies for children and families. **Agencies should attempt to identify ways to reach children and families falling into this income range where barriers to service may exist and children may remain unidentified.**

SERVICE USAGE AND SATISFACTION

Subsection II: Rehabilitative, educational, & family support services

What services do you currently get/use?

Parents were asked about 13 services that their children or family currently receive. Most of the services on this list were related to rehabilitative, educational, or family support services. The services that parents were asked to respond to were the following.

List of Services Parents Were Asked About

- Transportation provided by someone else
- Parent or family education classes
- Home visitor
- Respite care (help with child care)
- Physical or occupational therapy
- Speech and language therapy
- Vision or hearing training or screening
- Behavior therapy
- Nursing care in the home
- Assistance with coordinating services
- Center-based classroom or group instruction
- Nutritional advice
- Counseling (including spiritual/religious

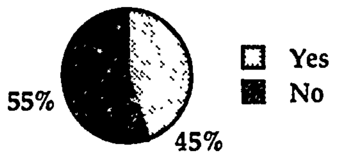
Secondly, a series of questions were asked of the respondents depending on whether or not they indicated that they (a) were or (b) were not receiving the service. The first information presented pertains to parents who indicated that they were currently receiving the identified service.

There was no service that a majority (50%) of the parents were currently receiving. The children in the sample and their families were receiving an average of 3.2 services at the time of the interviews. The range of the number of services received by the children/families was 0 to 11 services, with a median number of 3 services. Eighty-three (83) families reported receiving no services. There was not a significant difference across the ethnic categories in the number of services currently received.

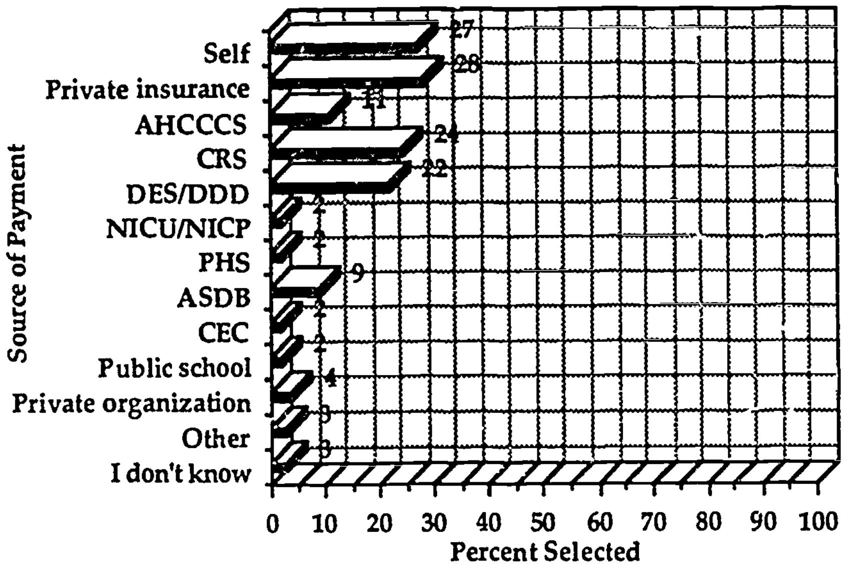
There were seven services that 25% or more of the children/families were receiving. Pie charts are used to display the responses of the parents about these 7 services in terms of whether or not they were currently receiving the service.

The subsequent bar graphs depict the primary sources of payment for each service. The sources of payment are the same as those used in the previous question. Parents could select all that apply. Only payment sources in which at least 1% of the parents selected that item are included in the following bar graphs. An average of 1.25 payment sources were selected by the parents for each service. That is, most parents selected only 1 or 2 sources of payment for each item.

Do you currently get/use vision or hearing training or screening?

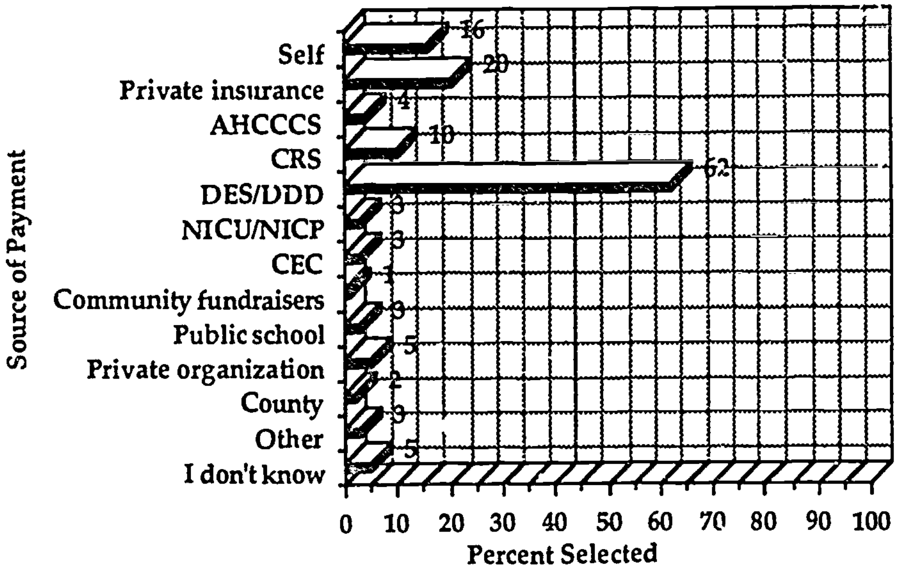


Who pays for it?

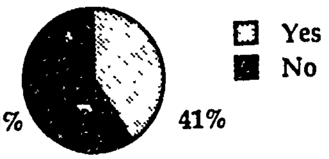


Do you currently get/use physical or occupational therapy?

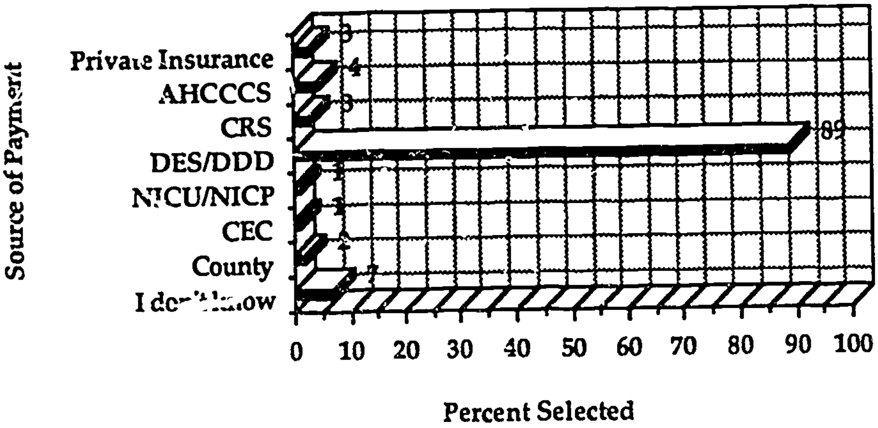
Who pays for it?



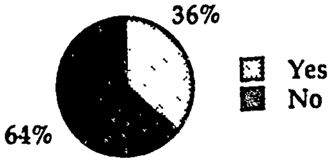
Do you currently get/use assistance with coordinating services (Case Manager)?



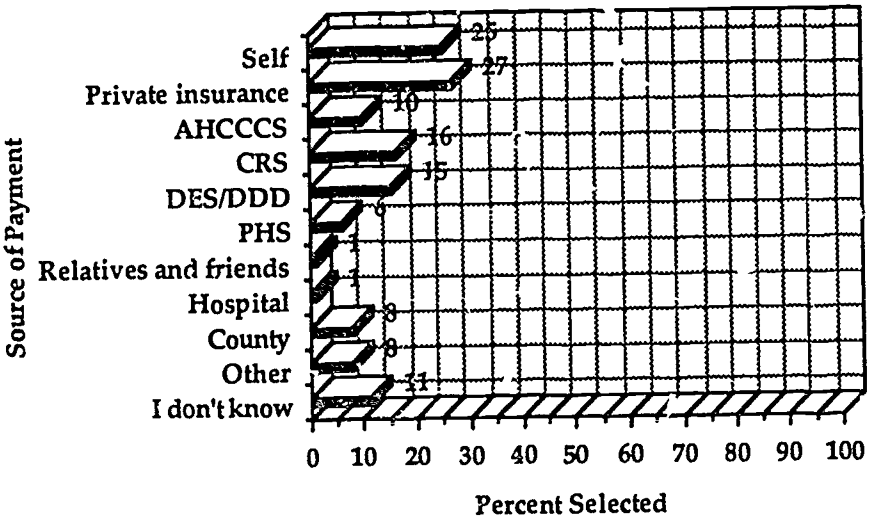
Who pays for it?



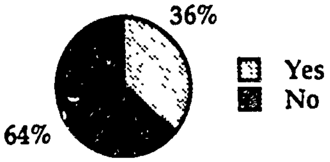
Do you currently get/use nutritional advice?



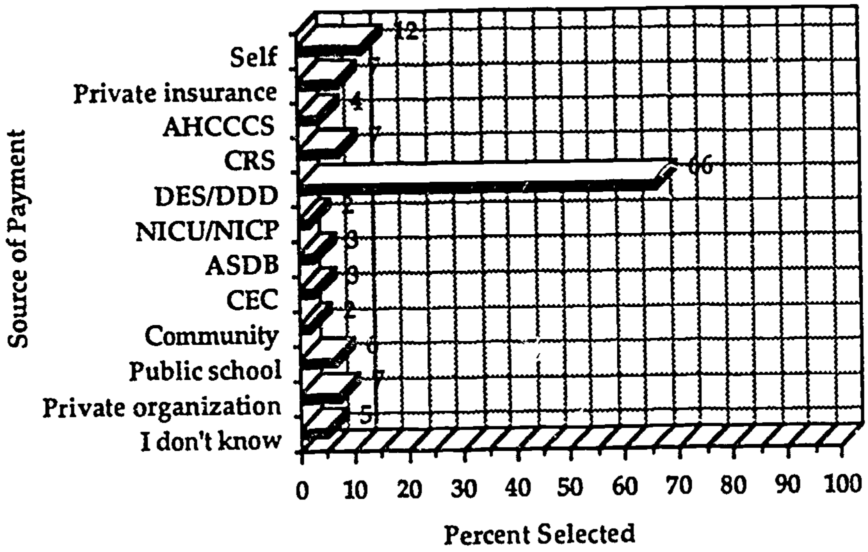
Who pays for it?



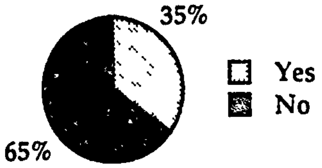
Do you currently get/use speech and language therapy?



Who pays for it?



Do you currently get/use a home visitor?



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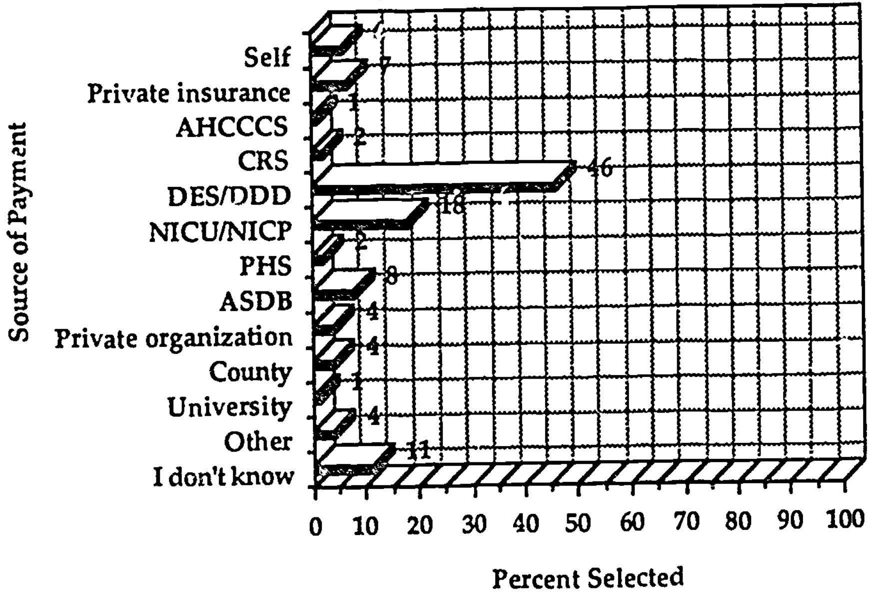
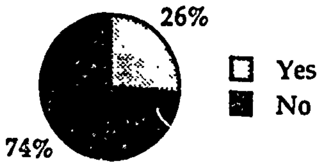


Do you currently get/use center-based classroom or group instruction?



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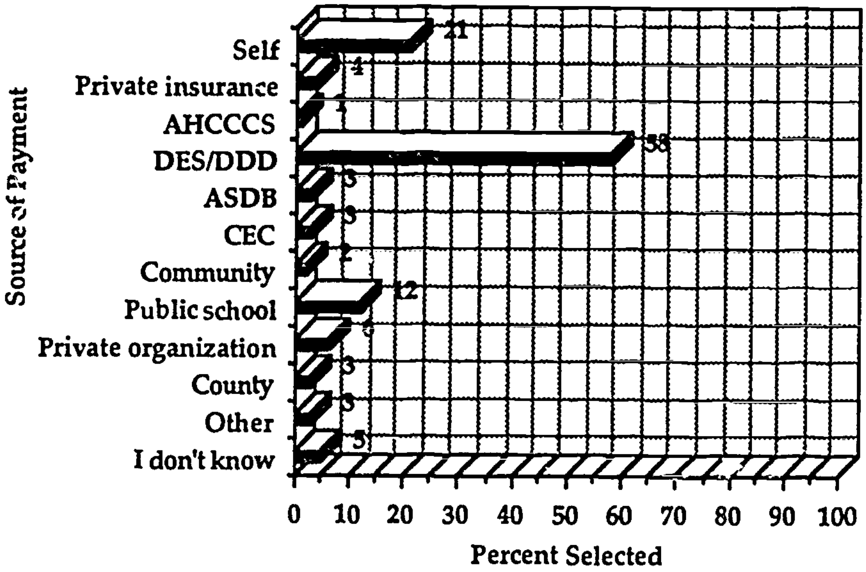


Less than 25% of the families were receiving the other services on the list. A summary of the number and percentage of families receiving these services is provided below.

Services received by less than 25% of families

Service type	Number receiving	Percentage
Respite care (help with childcare)	96	17%
Transportation provided by someone else	85	15%
Counseling (including spiritual/religious)	69	12%
Parent or family education classes	66	11%
Behavior therapy	28	5%
Nursing care in the home	25	4%

Perhaps the most significant finding regarding the type of rehabilitative, educational and family support services families reported on is the fact that there is no service that a majority of the parents were receiving for their child. Of the rehabilitative therapies, physical or occupational therapy was the most commonly received service with 42% of the children receiving it.

It is also one of the services most likely to be paid for by the Division of Developmental Disabilities. However, included in this response are parents who are AHCCCS recipients and DDD eligible (see section on Family Income Differences). Most families who receive this service get it at least once a week.

Only 41% of the parents reported that they were receiving assistance with coordinating services for their child. Parents reported that the Division of Developmental Disabilities was the agency most likely to pay for this service. AHCCCS recipients who are also DDD eligible are included in this response, also

A very limited number of parents are receiving case service coordination from other state agencies. This may account for .e response by the parents regarding the need for more information on what services are available.

There is some variance in the frequency with which families are receiving case coordination. Forty percent (40%) receive it at least once a month or more frequently, while 30% only receive it several times a year.

Approximately 1/3 of the parents reported that they were receiving nutritional advice, speech/language therapy, and a home visitor. In spite of the fact that 47% of the children are enrolled in the Newborn Intensive Care Follow-up Program offered by the Office of Maternal and Child Health, only one parent indicated they were getting nutritional advice from the NICP. Only 12 parents reported receiving nutritional advice from the Public Health Service.

For children who are receiving speech therapy, the majority get it at least once a week. It is also most likely to be paid for by the Division of Developmental Disabilities and AHCCCS. Only 1/4 of the families were receiving center-based classroom or group instruction.

Only 17% of the families were receiving respite care. Very few families were receiving counseling or parent/family education classes. In light of P.L. 99-457 and the emphasis in Part H of the Act requiring greater attention to the needs of families, these services, which appear to be minimally provided to date, may need to be significantly increased in terms of availability and family access.

Geographic Differences

The delivery of services within the 3 different geographic groups were more similar than different. The percentage of parents within each geographic group was calculated and compared descriptively.

There were only three services that suggested some difference: (1) vision/hearing training or screening, (2) respite care, and (3) home visitor services.

A larger percentage of rural parents (54%) reported that their child had received vision/hearing training or screening than parents in Pima (47%) or Maricopa (40%) counties.

More parents in Pima county received home visitors (47%) and respite care (30%) than parents from Maricopa county (30% and 14% respectively) and rural counties (37% and 10%, respectively).

Parents from rural counties selected more frequently the item 'I don't know where to go to get this service' as the reason they do not currently get/use the services than parents from urban counties.

Rural parents also selected more frequently items related to the services being too far away and transportation problems when identifying reasons for not receiving the services.

Ethnic Differences

Ethnic differences were found regarding the provision of 3 services. (1) physical or occupational therapy, (2) home visitor and (3) transportation.

Native American children were much less likely to receive physical or occupational therapy when compared to Hispanics and Whites. This is consistent with the parents' reports that these therapists were less likely to be a source of information for Native American parents.

On the other hand 52% of the Native American families reported that they currently receive a home visitor. This is significantly more than expected when compared to the other two ethnic groups. Hispanic parents, however, reported receiving a home visitor much less frequently than expected.

Finally, White parents were much less likely to receive transportation assistance than Hispanic and Native American parents, who receive it at a rate higher than expected.

Family Income Differences

There were 6 services in which significant differences were found regarding the provision of services to families from different economic categories. These 6 services are. (1) physical or occupational therapy, (2) assistance with coordinating services, (3) nutritional advise, (4) speech and language therapy, (5) respite care, and (6) transportation.

In all cases, families who were AHCCCS recipients were significantly more likely to receive the above services than families from all other income categories.

Half (51%) of the families receiving AHCCCS reported that their children were receiving physical or occupational therapy. Children from families with incomes between $10,000 and $19,000 were least likely to be recipients of this therapy (26%).

Half (54%) of the families receiving AHCCCS reported receiving assistance coordinating services. This is significantly more than all the families in the other income categories. Families with incomes less than $20,000 and not receiving AHCCCS reported the least amount of assistance with coordinating services. Approximately one-fourth of the children from these families receive this service.

AHCCCS families were also significantly more likely to be receiving transportation services than all other families. Twenty-seven percent (27%) of AHCCCS families reported that they receive transportation services, while less than 10% of the families in each of the other income groups are receiving transportation.

Lastly, AHCCCS enrolled families and families with incomes less than $10,000 are much more likely to receive respite care than all other families. Almost 1/4 of the families enrolled in AHCCCS and very low income families reported receiving respite care, while less than 13% of families with incomes greater than $10,000 received respite care.

In most instances, the families with the lowest participation rates across all service types were families in the $10,000 to $19,999 income range.

Age Differences

A comparison of the types of services currently received by children of different ages was conducted in order to determine if service delivery was being differentially given.

Children less than 18 months of age were significantly less likely to be receiving the following services. (1) physical/occupational therapy, (2) vision/hearing training/screening, (3) assistance with coordinating services, (4) speech and language therapy, (5) center-based classroom or group instruction, (6) respite care, and (7) transportation.

Questions about service delivery. Three additional questions were asked of the families who indicated that they were currently receiving a service. The three questions were. (1) How often do you get the service? (2) How do you feel about the service? (3) Have you ever had any of these problems with the service? The responses to each of these questions will be discussed below.

How often do you get the service?

When a family indicated that they were receiving a particular service item, they were asked to identify how often they were receiving the service. The parents were asked to select a frequency rate from the following list.

Frequency of Service

- At least once a week
- At least once a month
- Other
- 2 times a month
- Several times a year
- Don't know

The following table presents a summary of the services, and the percentage of parents receiving the service at the identified frequency.

Summary of the Frequency of Service Provision[a]

Service	Frequency of Service					
	At least once a week	2 times a month	At least once a month	Several times a year	Other	Don't know
Center-based classroom or group instruction	75%	5%	2%	7%	11%	0%
Speech and language therapy	64%	14%	8%	7%	6%	1%
Physical or occupational therapy	63%	15%	9%	8%	4%	1%
Behavior therapy	50%	11%	21%	18%	4%	0%
Counseling	45%	9%	16%	19%	12%	0%
Nursing care in the home	36%	8%	12%	20%	20%	0%
Home visitor	38%	10%	10%	31%	9%	2%
Respite care	27%	12%	6%	29%	20%	3%
Parent or family education classes	26%	12%	11%	38%	14%	2%
Assistance with coordinating services	11%	11%	18%	30%	24%	6%
Vision/hearing training or screening	6%	3%	5%	43%	43%	1%
Nutritional advice	5%	4%	34%	43%	13%	1%

[a] The percentages are based upon the subgroup of parents receiving each respective service.

The service that was delivered at a high frequency to the largest percentage of participants was center-based classroom or group instruction. Although only 26% of all parents were receiving this service, 75% of those getting the service received it at least once a week.

Therapies were the next most frequently delivered service (physical/occupational, speech/language, and behavior therapies). Physical therapy was the second most frequently delivered service (42% of all families). The majority of families receiving physical therapy (63%) were receiving it at least once a week.

Speech and language therapy was being delivered to only 36% of the families. However, of those receiving this therapy, 64% were getting it at least once a week.

Assistance with coordinating services was the third most frequently cited service received, and was identified as a current service by 41% of the families. Forty percent (40%) of the families indicated that they receive this assistance at least once a week, two times a month, or at least once a month. Fifty-four percent (54%) indicated they receive it only several times a year or at other times.

It is interesting to note that although only 15% of the families indicated that they were receiving transportation as a service, 47% of those receiving it indicated they receive it at least once a week.

Two services received by over one-third of the families (vision or hearing training or screening and nutritional advice) were most likely to be delivered several times a year, although a larger number of parents (43%) indicated that the vision/hearing service was delivered at a frequency other than those specifically listed for selection.

Only 38% of those receiving a home visitor were getting the service at least once a week, while another 31% got a home visitor several times a year.

Very few families were receiving respite care (17%), but of those receiving this service over one-fourth received it at least once a week. Another 30% of those receiving respite care get it several times a year.

How do you feel about the service?

In order to obtain the level of satisfaction parents have with the services they are receiving, parents were asked to identify how they felt about each service by selecting from the following list.

Feelings About Service

I wish things were very different
It's okay for now, I think they are pretty good
Don't know
I would like some changes
I'm really pleased

The following table summarizes the parental responses to the question related to their satisfaction with the services they are receiving.

Summary of Parental Feelings About Services Received

Service	Nature of Feelings				
	I wish things were very different	I would like some changes	It's okay for now, things are pretty good	I'm really pleased	Don't know
Vision/hearing training or screening	5%	11%	28%	51%	5%
Physical or occupational therapy	5%	17%	19%	58%	0%
Assistance with coordinating services	13%	24%	26%	32%	5%
Nutritional advice	5%	12%	35%	46%	2%
Speech and language therapy	7%	17%	24%	50%	2%
Home visitor	3%	10%	24%	61%	1%
Center-based classroom or group instruction	3%	9%	23%	64%	1%
Respite care	7%	20%	21%	38%	12%
Transportation	20%	18%	22%	35%	5%
Counseling	6%	10%	22%	61%	0%
Parent or family education classes	6%	17%	29%	47%	3%
Behavior therapy	4%	14%	39%	36%	11%
Nursing care in the home	4%	8%	32%	48%	4%

Of all the response options given to parents to indicate how they felt about the services they were receiving, the response choice 'really pleased' was selected most frequently by the parents, with the exception of behavior therapy (whose most frequent response was 'it's okay for now, I think they are pretty good').

The second most frequently selected response option was 'it's okay for now, I think they are pretty good'. Generally speaking, parents who are receiving the services are satisfied with the service they are receiving.

However, there were 6 services in which more than 20% of the parents indicated they 'would like some changes' or 'that they wished things were very different'.

As the table above indicates, these 6 services and the total percentage of parents indicating a need for improvements are the following: (1) transportation (38%), (2) assistance with coordinating services (37%), (3) respite care (27%), (4) speech and language therapy (23%), (5) parent or family education classes (23%), and (6) physical and occupational therapy (21%).

Have you ever had any of these problems with the service?

Parents were asked to identify the kinds of problems they have had with the services they receive. They were given a list of problems to pick from and could select all that applied to their situation. The list of problems they could select from were the following.

List of Problems with Services

Problems with services
There is too much time on waiting list
I have to wait too long for services to start after I am eligible
The times for appointments are inconvenient
It is too expensive
The transportation is too costly, not available, etc.
The application forms or process is too complicated
The application asks too many personal questions
It doesn't suit my individual needs very well
There is not enough respect for personal dignity
There are too many staff changes
The service is not available often or consistently enough
The service is not effective for child
There are too few staff, caseloads too large
It is not well coordinated with other services
There are not enough services/sessions too short
The facilities are inadequate
It is inconvenient/inappropriate location
I have had no problems
Other
Don't know

For all services, parents selected most often the response choice 'no problems with the service'. For 10 of the 13 services a majority (greater than 50%) of the parents selected this item. The range of the percentage of parents selecting this item across the 13 services was from 39% to 71%. No other single problem item was selected by the parents at this level of frequency.

The following table illustrates the number and percentage of parents selecting the response item 'no problems with the service' for the 13 services.

Summary of Parental Response to Service Satisfaction
'I have had no problems'

Service Item	Number Selecting (total # receiving)[a]	Percentage (total % receiving)[a]
Counseling	49 (69)	71% (12%)
Vision or hearing training or screening	174 (259)	67% (45%)
Nutritional advice	141 (210)	67% (36%)
Home visitor	135 (202)	67% (35%)
Behavior therapy	16 (28)	57% (5%)
Center-based classroom or group instruction	81 (149)	54% (26%)
Physical or occupational therapy	129 (243)	53% (42%)
Speech & language therapy	109 (206)	53% (36%)
Transportation	45 (85)	53% (15%)
Parent or family education classes	35 (66)	53% (11%)
Nursing care in the home	12 (25)	48% (4%)
Respite care	38 (96)	40% (17%)
Assistance with service coordination	94 (239)	39% (41%)

[a] The number in parentheses represents the total number of parents in the sample receiving the service; the percentage in parentheses represents the percentage of parents in the entire sample receiving the service.

Counseling (including spiritual and religious) was the service for which the greatest number of parents indicated they had no problems (71% of parents receiving service). The counseling service, however, is being received by only 12% (N=69) of the total group of parents in the sample.

The service that was selected by the parents as having the most different kinds of problems was 'assistance with coordinating services'. Parents selected an average of 2.4 items from the list of problems when responding to this service type. The overall average number of responses selected by the parents for each service type was 1.6 (the range was 1.2 to 2.4).

The following table illustrates the kinds of problems parents have had for the 6 services that were identified by more than 20% of the parents as in need of improvement.

Types of Problems for Services in Most Need of Change

[Parents could select all that apply]

Problems with Services	Service Type					
	Transportation (N=85)	Assistance with coordinating services (N=239)	Respite care (N=96)	Speech and language therapy (N=206)	Parent/ family education classes (N=66)	Physical or occupational therapy (N=243)
There is too much time on a waiting list	4%	17%	0%	6%	3%	7%
I have to wait for too long for services to start, after I am finally eligible	6%	23%	3%	6%	2%	6%
The times for appointments are inconvenient	9%	5%	4%	7%	5%	8%
It is too expensive	1%	1%	7%	7%	6%	8%
The transportation is too costly, not available, etc.	12%	3%	4%	4%	3%	5%
The application forms or process is too complicated	2%	3%	2%	0%	0%	0%
The application asks too many personal questions	1%	2%	2%	0%	3%	0%
It doesn't suit my individual needs very well	7%	10%	20%	5%	17%	3%
There is not enough respect for personal dignity	1%	3%	4%	1%	3%	0%
There are too many staff changes	4%	24%	4%	4%	5%	3%
The service is not available often or consistently enough	14%	20%	16%	19%	20%	19%
The service is not effective for child	4%	7%	7%	10%	3%	4%
There are too few staff - caseloads too large	7%	31%	15%	13%	2%	10%
It is not well coordinated with other services	7%	18%	4%	5%	6%	4%
There are not enough services/ sessions too short	4%	14%	10%	19%	12%	17%
The facilities are inadequate	6%	5%	2%	2%	0%	3%
It is inconvenient/ inappropriate location	5%	4%	7%	7%	7%	9%
I have no problems	53%	39%	40%	53%	53%	53%
Other	9%	7%	14%	2%	11%	3%
Don't know	4%	1%	6%	2%	2%	1%

One problem item stands out as frequently cited across the services, 'the service is not available often or consistently enough'. Issues related to parental need for information about service availability were also identified under the section on parental information needs.

Although most parents whose children were receiving physical or occupational therapy and speech/language therapy are getting the service at least once a week, there remains a group of parents who feel that the services are not enough or that the sessions are too short. This was also identified as a problem for the small group of parents receiving respite care.

Assistance with coordinating services was problematic for parents in terms of long waiting lists, delays in the service, too many staff changes, frequency of service, too few staff with large caseloads, and ineffective coordination with other services.

There was no service in which more than 10% of the parents felt that the service was not effective for their child.

Why don't you get the service?

Parents who indicated that they were not currently receiving the identified services were asked why they did not get the service. Parents could select all items that apply from the following list.

List of Reasons Why Parents Were Not Getting Service

Not eligible
Don't want/my child does not need
I don't have information about this service
I don't know where to go to get this service
It's not as important as some other things
Takes too long to get there; too far away
Treatments take too long
Too much waiting to get the application approved
Too much waiting to get an appointment
Too much waiting when I go for an appointment
Don't know

My child is on the waiting list
I'm tired of fighting for it
Cost
Hours of service don't fit my schedule
Transportation problems
I don't care for the person who works with my child
I have no child care for my other children
Paperwork is too long or difficult
The procedure is painful for my child
Other

For all services, the most frequently selected response from parents who are not currently receiving the service was 'I don't want/my child does not need' the service. The range of percentages of parents selecting this response option across the services was 43% to 78%.

The second most frequently selected response option for all services listed but one was 'I don't have information about this service'. The range of percentages of parents selecting this response option across the services was 9% to 39%. The exception was the service of nursing care in the home. The second most frequently selected reason for not receiving this service was 'not eligible' (12%).

The average number of response options selected by the parents as reasons for not currently receiving the services was 1.2, that is, parents selected only one reason most of the time.

The three response items 'not eligible', 'don't want/my child does not need', and 'I don't have information about this service', account for 88% of all responses to this question. The remaining 12% of the response choices made from the list are dispersed throughout the list and show no clear trend.

These responses would appear to confirm the interpretation that . parents seek eligibility for services, are determined eligible for services, and receive the service, then there are few problems with the services being delivered for the majority of families.

It also confirms the suggestion that many parents do not have sufficient information about the educational and rehabilitative services available for families and children in the state and their desire to receive more information about these services.

Summary

Access to the range of educational, rehabilitative and family support services identified in this study appear to be limited for the majority of parents. There is little consistency among the families regarding the type of services their children were receiving. There was no service a majority of the families reported receiving. A majority of the families (59%) reported that their child was receiving 3 or fewer services.

The service received most frequently and by the greatest number of children was physical or occupational therapy. Forty-two percent (42%) of the children were reported to be receiving this therapy, and most of them (63%) were receiving it at least once a week.

The finding that less than half (41%) of the families are receiving assistance with coordinating services may help explain why so many parents indicated that they needed more information on the services available and how to access those services. Children who are recipients of AHCCCS were the most likely to receive this assistance.

Indeed, children who are recipients of AHCCCS were the most likely to receive each of the services in question than any other categorical group. The finding that the Division of Developmental Disabilities was indicated as a major source of payment for many of the services may have to do with the fact that AHCCCS eligible children who are developmentally delayed are administratively assigned to the Division of Developmental Disabilities for their services.

Families with incomes between $10,000 to $19,999, and not recipients of AHCCCS, showed the lowest participation rates across all service types.

Rural parents were more likely to indicate that they were not receiving the service because they didn't know where to go to get it. They also identified the services as being too far away more frequently.

Native American children were the least likely to be receiving physical or occupational therapy, although it is the rehabilitative service received by the greatest number of children. Children below 18 months of age were less likely to be receiving most rehabilitative, educational and family support services.

Parents are generally satisfied with the services they receive, with the majority of parents indicating that they are 'really pleased' or 'that things are pretty good' with the services.

Transportation and assistance with service coordination were the two services identified by more than one-third of the parents as in greatest need of change. The most frequently cited problem with transportation was that the service is not available often enough.

Problems with assistance with service coordination were identified by the parents as related to too long a waiting period to be determined eligible, too many staff changes, and infrequency of service.

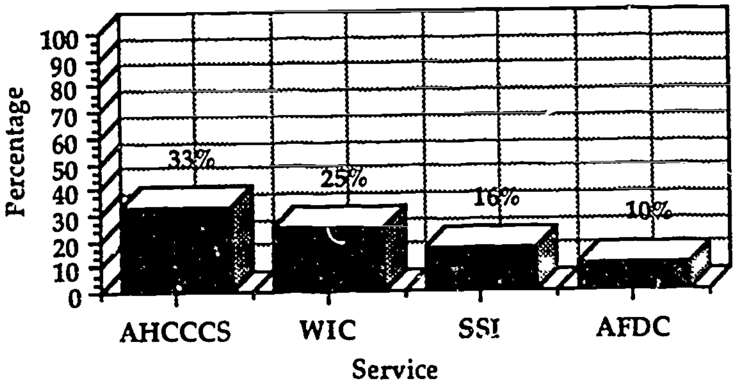
Generally speaking, almost half or more of the parents not receiving a given service reported that they did not want or that their child does not need the service. However, many parents reported that they did not have information about the service.

Subsection III: Low Income Family Services

Subsection III of the Service Usage and Satisfaction Section of this report is related specifically to four services in the state for children and families who must meet a low income eligibility requirement, in addition to other programmatic requirements.

The four services included in this section are: (1) Women, Infant, and Children (WIC) food supplements, (2) Aid to Families with Dependent Children (AFDC), (3) Arizona Health Care Cost Containment System (AHCCCS), and (4) Supplemental Security Income (SSI). Parents were asked whether or not they currently receive any of these services.

Percentage of Children Receiving Income-Related Services



The parents who indicated that they were currently receiving the above services were also asked to identify any problems they have had with the service. Consistent with the responses by parents in the previous service section, the item selected most often by the parents from the list of problems provided to them was 'I have no problems'. The percentage of parents selecting this item for each service was the following: (1) WIC (63%), (2) SSI (50%), (3) AHCCCS (43%), and AFDC (42%).

The average number of problems selected by the parents for each service was 1.9 items. SSI had the fewest problem items selected for an average of 1.2 selections per parent.

Parents reported the greatest number of problems with the AFDC program. The average number of problems selected by the respondents to this question was 2.9 items

While 42% of the parents receiving AFDC indicated that they have had no problems, over 20% indicated problems in the following areas: (1) the times for appointments are inconvenient (20%), (2) there are too few staff, caseloads too large (25%), (3) there are too many staff changes (27%), (4) the application asks too many personal questions (28%), and (5) there is not enough respect for personal dignity (28%).

Other problem items were selected by the parents receiving AFDC and were distributed across the list with less than 20% of the parents selecting any one item

Similarly, other than an indication that the greatest number of parents have had no problems with the 3 other services, items selected by less than 16% of the parents were distributed across the problems on the list, with no clear consensus by the parents of what the problems in service delivery may be.

Parents not currently receiving these 4 services were asked to identify the reason why they were not getting the service. Over 50% of the parents in the sample indicated that they were not eligible to receive these services.

The following table displays the percentage of parents selecting the four most frequently selected response items across the 4 service types.

Four Most Frequently Selected Reasons For Not Receiving Services[a]

Service	Not eligible	I don't have information about service	I don't want/ my child does not need service	I don't know where to go to get service
AHCCCS	65%	12%	18%	3%
AFDC	60%	26%	15%	8%
SSI	54%	27%	11%	8%
WIC	51%	24%	20%	10%

[a] Parents selected the response item 'other' as the fourth item most frequently selected for AHCCCS, selected by 6% of the parents; because it is difficult to interpret and for purposes of providing succinct table summaries, it has been eliminated in this table.

All other items were selected infrequently, and less than 5% of the time.

Geographic Differences

There were highly significant differences between geographic groups for 2 of the above service programs when comparing children's participation in these services.

Significantly more rural children than expected are participating in the WIC and AHCCCS programs, while fewer Maricopa children than expected are enrolled in these 2 programs. At least 1/3 of the children from rural areas were getting WIC, compared to less than 1/5 of the children from Maricopa county.

Similarly, 42% of the children from rural areas are receiving AHCCCS, while only 28% of the children in Maricopa county are enrolled.

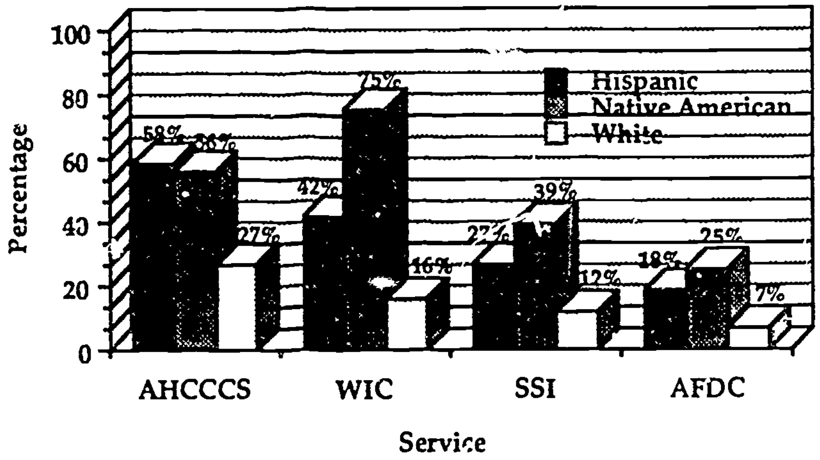
Parents from Pima County reported a higher rate of problems with AFDC than parents from Maricopa and rural counties.

Ethnic Differences

There were very significant, clear ethnic differences in who was receiving the four services requiring income eligibility. For each service (WIC, AFDC, AHCCCS, and SSI) Hispanic and Native American children were much more likely to be receiving the service than expected. Whites were less likely to be receiving the services when compared to the other two groups.

The following graph illustrates the percentage of children from each of the three major ethnic categories receiving the 4 services.

Children From Each Major Ethnic Group Receiving Services



Summary

Since AHCCCS was designed to serve only the very poorest of families, it is somewhat surprising that 33% of the sample were receiving AHCCCS at the time of the survey. This represents a higher percentage than anticipated. It is consistent, however, with other data from the survey that suggests that AHCCCS children are receiving medical, rehabilitative, and educational services at a level at least equal to higher income groups. Therefore, AHCCCS families were readily identified for inclusion in the sample because of their participation in other State services.

Children from rural areas were more likely to be receiving WIC and AHCCCS than children in Maricopa county. Hispanic and Native American children are represented at a significantly higher level than expected as recipients of all 4 income-related services than White children. Over half of the Hispanic and Native American children in the sample were receiving AHCCCS.

Although 25% of the entire sample was receiving WIC, 75% of the Native American children and 42% of the Hispanic children were receiving it. WIC recipients reported the highest level of satisfaction with the service they received.

A very small percentage of the sample was receiving AFDC (10%). Parents reported more problems with this service than with the others. Although the different programs have different income eligibility requirements, the discrepancy between those receiving AFDC and those receiving AHCCCS would suggest that AFDC is underserving a large group of families.

The kinds of problems reported by the parents in relationship to the AFDC program suggest ways in which the agency could make the delivery of services more satisfactory to the parents.

Approximately 25% of the parents in the sample reported that they did not have information about AFDC, SSI, and WIC. This would suggest a need to improve the strategy for informing the public about these programs and encouraging full participation in the programs by all families and children who are eligible.

These strategies must be sensitive to the sources of information utilized by different ethnic groups and for children and families in different geographic areas of the state. Special efforts should be targeted at Maricopa county and the large metropolitan area where isolation from the service system appears to be occurring. Low income White families may be underserved.

PARENTAL INVOLVEMENT

Parents were asked about the nature of their involvement in meeting their child's needs and their satisfaction with the professionals they have interacted with. Parents reported a high level of involvement in activities as it relates to securing and participating in the delivery of their childrens' services. The following table summarizes their responses.

What Is the Nature of Parental Involvement in Your Child's Services?

[Parents responded to each item]

Item	Number	Percent
I help make decisions about my child's program	505	89%
I transport my child to treatment	471	83%
I do some of the therapy for my child	433	76%
I advocate for my and my child's rights	420	75%
I help give information and support to other parents	403	71%
I coordinate my child's services	397	71%
I observe my child during therapy	366	65%

As the table shows, a large number of the parents are participating in meaningful ways in the delivery of their children's services.

For parents reporting that they did not currently do any of the above listed activities, they were asked if that were something they would want to do. Between 83%-95% of the entire sample either are participating in the above activities or want to do the above activities as it relates to their child's needs. The parents selected the item 'I help make decisions about my child's program' the most frequently when asked if they do or want to do this activity (N=538). Only 19 parents (3%) indicated that they did not want to do this activity. Only 7 (1%) were uncertain and indicated they did not know whether they would like to make the decisions about their child's services.

There were four additional activities in which less than half of the parents were currently participating. They represent the following items and responses.

Parental Involvement in Services

[Parents responded to each item]

Item	Number	Percent
I attend program planning meetings about my child	211	38%
I am a volunteer, aide or assistant in my child's program	175	32%
I help with fundraising for agencies	149	26%
I am on an advisory or policy-making board for an agency	37	7%

For parents who are not currently doing these activities, 30%-40% would want to do them. Less than half the parents are currently participating in program planning meetings about their child.

Geographic Differences

A greater number of parents from Maricopa county coordinate their child's services than expected when compared to parents from Pima county and rural counties. Seventy-four percent (74%) of the parents from Maricopa county reported coordinating their child's services, while only 63% of rural parents reported doing that activity.

Although only 38% of the entire sample reported attending program planning meetings about their child, fewer Maricopa county parents attend such meetings about their child when compared to parents from Pima county and rural counties.

Pima county parents are slightly less likely (p<.06) to transport their child to treatment than other parents. While 25% of Pima county parents are not transporting their children for treatment, only 15% of Maricopa county parents and 18% of rural county parents are not transporting their children to treatment. Parents from Maricopa county indicated that they would like to transport their child more often, while rural county parents indicated they would like to do this less often than expected when compared to the urban county parents.

Of the parents who are not currently observing their child in therapy, Pima county parents were more likely to indicate that they would like to observe their child, while rural parents indicated their desire to observe their child's therapy less often than expected when compared to other parents.

Although most parents are doing some of the therapy for their child, rural parents not currently involved in this activity were much less likely to indicate that they wanted to help with some of the therapy for their child when compared to urban parents.

Ethnic Differences

Although a majority of all parents reported that they help make decisions about their child's program, fewer parents of minority children, Hispanic and Native American, are engaged in this activity than expected when compared to White parents.

Parents of minority children are also less likely to coordinate their child's services than White parents. Less than half of Native American parents reported that they are engaged in this activity.

Native American and Hispanic parents are also significantly less likely to help give information and support to other parents when compared to White parents. Fifty percent (50%) of Native American parents and 59% of Hispanic parents reported that they did this type of activity, while 73% of White parents reported being engaged in helping other parents. Native American parents are also less likely to serve as a volunteer or aide in their child's program when compared to Hispanic and White parents, who reported begin engaged in this activity at very similar rates (36% and 33%, respectively).

Would Any of the Following Help You to be More Involved in Meeting Your Child's Special Needs?

[Parents could select all that apply]

Item	Number	Percent
Getting all the information about services that are available	406	76%
Having more knowledge on how the system works	75	51%
Having more time	261	49%
Getting all the information about my child that the caseworker has	234	44%
Easy access to my child's records	226	42%
Having people respect my observations and point of view	177	33%
Having child care for my other children	126	24%
Having enough time to talk with service providers	21	23%
Having professionals use language that is easy to understand	118	22%
Having fewer frustrations when I try to change something	116	22%
Having people help my family assess its own needs	97	18%
Individual conferences or meetings with program staff	99	19%
Having written follow-up after a planning meeting	83	16%
Having more self confidence	77	14%
Having people listen to my family better	74	14%
Other; Don't know/refused	58	11%

Families provided an average of 4.7 responses each to the above question. The responses to this question were consistent with the kinds of information parents indicated they wanted in a previous section. That is, the majority of parents want more information about what services are available and more knowledge on how the system works. The parents feel that they could be more effective in meeting their children's needs if they had this information.

Few parents indicated that they wanted assistance assessing their family needs or having people listen to other family members better. Issues related to the family as a whole did not emerge as a parental need.

Less than 20% indicated that having individual conferences or meetings with program staff would be helpful, although only 38% are currently attending program planning meetings.

Ethnic Differences

Native American parents ranked the item 'having professionals use language that is easy to understand' much higher than Hispanic and White parents. Native American parents also ranked the item 'having fewer frustrations when I try to change something' much lower than other parents.

Parents were asked about their satisfaction with the professionals they have dealt with. The following responses were given.

What Have You Liked the Most About the Professionals You Have Dealt With?

[Parents could select up to 3]

Item	Number	Percent
They are caring and compassionate	352	66%
They are knowledgeable and skilled	184	34%
They listen to parents, want their input	172	32%
They are honest about my child's abilities and disabilities	167	31%
They take time with me and my child	164	31%
They focus on what my child can do, give me hope	127	24%
They treat my child carefully and are sensitive to his/her needs	131	24%
They play with my child	78	15%
They treat me like a team member, use my contribution	62	13%
They treat/respect me as a person first	37	7%
They include all family members	24	5%
Nothing; Other; Don't know/refused	21	4%

What Have You Found Difficult or Frustrating in Dealing With Professionals?

[Parents could select up to 3]

Item	Number	Percent
They are too busy	192	36%
Don't know/refused	102	19%
Other	105	20%
They don't listen	92	17%
They lack knowledge/skill	64	12%
They don't treat me as a person first, respect me, they act superior	62	12%
They don't pay attention to all the things my child can do	59	11%
They focus too much on my child's limitations, don't allow me to have hope	55	10%
They are not caring and compassionate, don't acknowledge emotions	51	10%
They don't tell me the "bad" news	50	9%
They don't accept my contribution	36	7%
They don't include all my family members	26	5%
They don't understand my child or treat him/her carefully	25	5%
They are not realistic, don't acknowledge my child's limitations	21	4%

The majority of the parents agree that the professionals they have interacted with are caring and compassionate. There was less consensus, however, on the rest of the items.

Only 1/3 of the parents felt that the professionals were knowledgeable and skilled. About 1/3 of the parents felt that the professionals listened to them or wanted their input. Less than 1/3 felt that the professionals were honest with them about their child's abilities and disabilities, or took time with them. Less than 1/4 reported that the professionals focused on the positive things their child could do or treated the child carefully.

While parents were given the opportunity to select up to 3 items for their response to the above questions, they selected less than an average of 2 items from the question asking them what they have found difficult or frustrating in dealing with professionals.

There was no majority response by the parents agreeing on the items related to their frustrations in dealing with professionals. The item receiving the most consensus (36%) among the parents was related to the professionals being too busy. If professionals are conveying the message that they are too busy, that message may result in the feeling by parents that professionals don't listen to them.

The parent responses also suggest that although few professionals include all members of the family in the interactions, this has not caused much frustration for the parents.

A large number of parents (almost 40%) indicated that they don't know what has been frustrating in dealing with professionals, refused to answer, or indicated that some other reasons than those listed had caused them frustration and difficulties.

Geographic Differences

Parents from Pima county ranked the item 'they treat my child carefully and are sensitive to his/her needs' much higher than parents from Maricopa and rural counties.

Pima county parents also selected the item 'they focus too much on my child's limitations, don't allow me to have hope' more often then Maricopa and rural county parents.

Parents from rural counties selected the item 'they don't treat me as a person first, respect me, they act superior' less often than urban county parents.

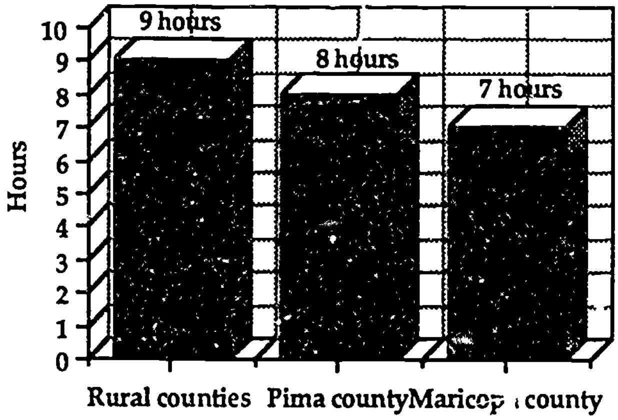
Ethnic Differences

Native American parents selected the item 'they focus on what my child can do, give me hope' more often than White or Hispanic parents. Native American parents selected less often 'they listen to parents, want their input' as an item they liked most about professionals when compared to White and Hispanic parents. No Native American parent selected the item 'they include all family members' as a characteristic they liked most about professionals.

On the other hand, Native American parents selected the item 'they don't include all my family members' more often than parents from the other two groups.

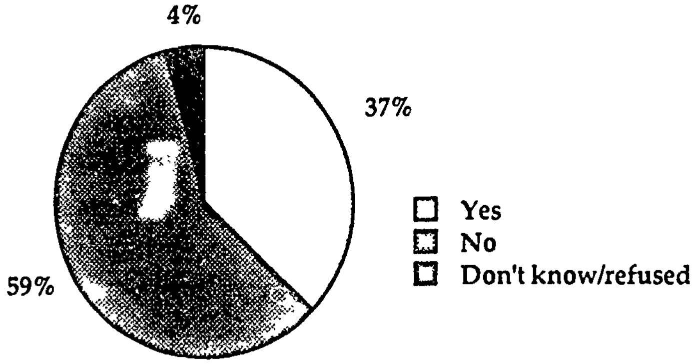
White parents selected the item 'they don't listen' more often than Hispanic or Native American parents when identifying what they have found difficult or frustrating about dealing with professionals.

How Many Hours Do You Spend Traveling Each Month to Get Your Child's Needs Met?



The average amount of time spent by the parents traveling to secure services for their children was 7.6 hours per week. One-fourth of the parents travel less than 1 hour each month. As the bar graph illustrates, rural parents travel slightly more than parents from the urban counties, but not significantly so.

Have You Had a Meeting, With an Agency, and Signed Some Papers Which List Your Child's Goals and the Services He/She Is Supposed to Receive (Like an IEP, IPP, or an IFSP)?



Most of the parents have not participated in a program planning meeting that resulted in a document explaining their child's goals and services.

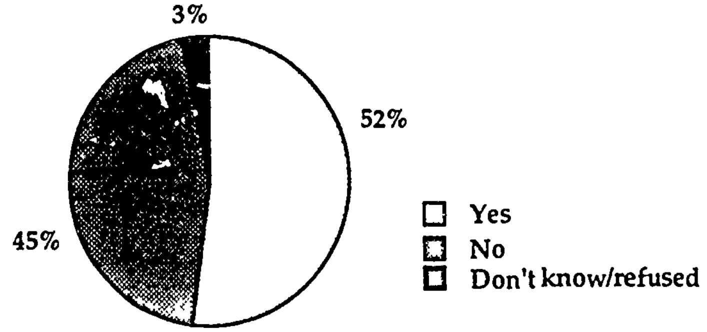
Geographic Differences

Parents from Maricopa county were much more likely to report that they had not participated in a meeting about their child's goals and services, while parents from Pima county were much more likely to have attended such a meeting.

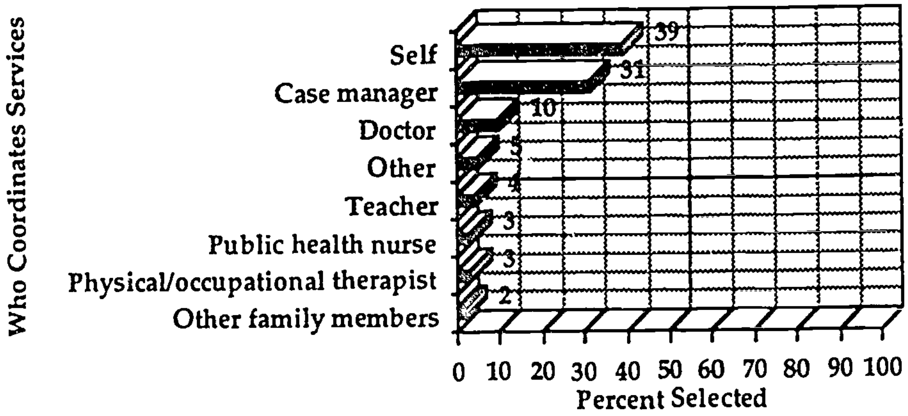
Ethnic Differences

Native American parents were much less likely than White or Hispanic parents to have participated in a meeting about their child's goals and services.

Does Your Child Have One Person Who Coordinates the Services He/She Gets?



Who is it? [a]
(Parents could select one)



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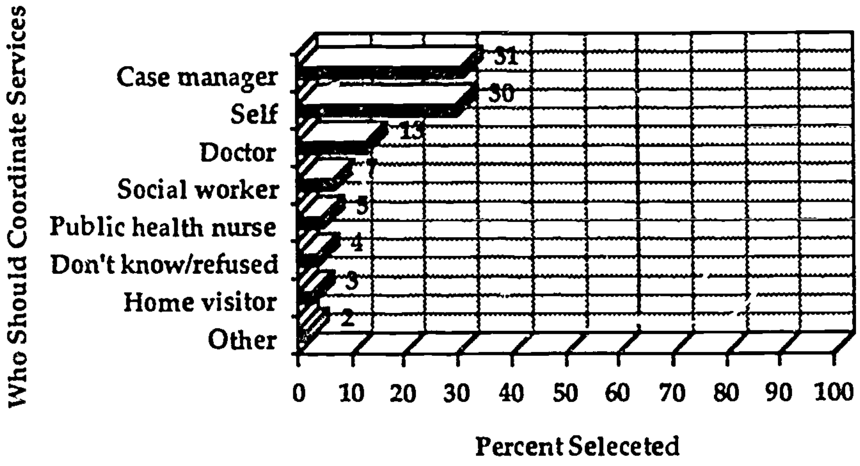
[a] Responses representing less than 2% of the sample are not included.

Who Do You Think Should Coordinate Services Or Be Responsible For Making Sure Your Child Has All the Services He/She Needs? [a]
[Parents could select one]



[a] Responses representing less than 2% of the sample are not included.

When coordination of services occurs, it is usually done by the parents themselves or a case manager (who is most likely to be paid by the Division of Developmental Disabilities or AHCCCS).

Most parents agree that either they or the case manager should be responsible for coordinating services.

Other individuals that were selected less than 5% of the time as the person who should coordinate services included. other family member, friend, another parent, traditional/spiritual healer, home visitor, teacher, speech therapist, physical/occupational therapist, and other.

Geographic Differences

Rural parents were more likely to report that the case manager should be someone other than themselves or a case manager, when their responses were compared to those of urban county parents. The responses, however, were distributed across the other categories such that no single person was identified.

Pima county parents selected the case manager as the person who should be responsible for coordinating services more often than expected when compared to the other two regions.

Ethnic Differences

Native American parents reported more often than White and Hispanic parents that their child does not have one person who coordinates the services he/she gets. Over half of White (52%) and Hispanic (57%) parents reported a case service coordinator for their child compared to 40% of Native American parents. No Native American parent reported themselves as their child's service coordinator.

More than twice as many parents (13%) in the Native American sample selected public health nurses as the individuals who should coordinate the child's services when compared to White or Hispanic parents.

White parents selected the case manager as the person who should do the service coordination more often than expected when compared to the minority parents. Minority parents were more likely to select someone other than the case manager.

Summary

The parents reported a high degree of involvement in their children's services Perhaps most important is the fact that 89% of the parents indicated that they participate in the decision-making activities related to their children's services, while an additional 6% would like to.

The majority of parents are involved in a variety of activities as it relates to their child's special needs. They transport their children to services, do some of the therapy for their child, advocate for their child, help other parents, coordinate their child's services, and observe their child during therapy.

Although most parents are transporting their child to services, the majority (63%) also indicated they did not want or need transportation services. Parents reported that they are spending approximately 7-9 hours per month transporting their child to services.

Only 30% of the sample of parents are getting assistance from agency professionals with coordinating their child's services. Most parents indicated they do not need this service.

Interestingly, the items parents selected most often as something that would help them be more involved with meeting their child's special needs was 'getting all the information about services that are available' and 'having more knowledge on how the system works.'

The selection of these two items by the majority of parents as the activity that would help them the most to meet their child's needs is consistent with the findings related to the parents' information needs in an earlier section.

That is, parents are reporting very consistently that they feel they do not have all the information they need to help their child. Meeting parents' basic information needs is in contrast to the kinds of activities the parents selected much less frequently as activities that would help them, such as having help with child care, having people help the family assess its own needs, and individual conferences or meetings with program staff.

Only 14% of the parents selected the item 'having more self confidence' as an activity that would help them as parents. It appears that the parents already have a high degree of self confidence in their abilities as parents. They view themselves as decision-makers and as the responsible parties in terms of meeting their child's special needs.

Supporting evidence for this characterization of the majority of parents comes from an earlier section in this report asking parents about their informational needs. When asked what kinds of information they would like about being a parent, they reported simply that they would like 'being a better parent in general.'

Although only 38% of the parents reported that they have attended a meeting with an agency and signed some papers that describe their child's goals and services, only 19% of the parents selected individual conferences or meetings with program staff as a useful activity in helping them be more involved in meeting their child's special needs.

Certainly, Individualized Family Service Plans and the conduct of meetings to develop the child's plan is identified in Public Law 99-457 as mandatory for a child to receive services. However, professionals involved in planning meetings with parents may need to focus more on providing parents with information about the types of services available across the interagency service network, and inform the parents on how to access these services.

This appears to be the most valuable information for parents and it is information that they are not currently receiving from the service providing community.

It is also important to recognize that there is a small percentage of families for whom family needs assessment and family involvement may be important. It may be the case that most parents appear not to want or need their family members to be involved in the early intervention process at the point where the parents interface with the professionals and service providing community.

The majority of parents felt that the professionals serving their children were caring and compassionate. Only a third of the parents felt that the professionals were knowledgeable and skilled, listened to parents and wanted their input, were honest about their childrens' abilities and disabilities, and took time with them.

The professional characteristic parents found most frustrating was that the people are too busy

This characterization of the professionals who have worked with the parents suggests that parents do not have a lot of confidence in the professionals' abilities as it relates to determining what their child's special needs are.

Rather, the parents appear to be fairly independent and self-sufficient when it comes to helping their child. They are confident in their parenting abilities and in their ability to insure that their children receive the services that have been identified for them.

In other words, parents who have young children with special needs view themselves as parents first and foremost. They appear to assume the responsibility for parenting their child as they would any of their children. They seem to convey the fact that if they are armed with the right information, they will assume the responsibility to seek and secure the services they feel their child needs.

It may be that when parents are empowered with relevant information about their child and the kinds of services available, that they will perform as competent parents and make decisions for their child as the needs arise.

This generalized picture, however, should not blur the fact that there exists a small group of parents, perhaps 20-25%, who could benefit from a greater level of professional involvement, in decision-making as well as with other family members. Approximately 20% of the parents indicated that they would like help assessing their family needs, and 14% felt that they could benefit from more self confidence and having people listen to their family better. Four percent (4%) of the parents indicated that they did not want to make the decisions about their child's program.

Although parents from different geographic areas of the state and from different ethnic groups were more alike than different, there were several issues characterizing differences that are worth summarizing.

Pima county parents appear to have a slightly higher level of involvement in activities related to their child's special needs. They reported having attended planning meetings with an agency to develop their child's goals and the service plan at a rate higher than other parents.

Of parents currently not observing their child during therapy, more Pima county parents indicated that is something they would like to do. They were more likely to identify professionals as being careful with their child and sensitive to his/her needs.

The Pima county parents were also more likely to report receiving a home visitor service. That perhaps explains why Pima county parents are less likely to report that they are transporting their child to services.

Slightly fewer Maricopa county parents, however, seem to have formal contact with professionals. More parents from Maricopa county reported that they are coordinating their child's services. They also are attending program planning meetings at a rate lower than parents from Pima or rural counties. More Maricopa county parents indicated that they would like to transport the child more, perhaps in order to secure more services.

Fewer rural parents wanted to increase their level of involvement than urban parents when it came to certain kinds of activities.

Rural parents were less likely to indicate that they wanted to transport their child more, they currently have the highest amount of travel time each month (9 hours). Fewer rural parents indicated that they wanted to observe their child in therapy or help with therapy. They were more likely to select a case manager other than themselves as the person who should coordinate services.

In terms of ethnic differences, Native American and Hispanic parents showed lower participation rates related to certain activities when compared to White parents.

Fewer Native American and Hispanic parents reported themselves as engaged in decision-making, service coordination, helping other parents, and volunteering.

No Native American parent indicated themselves as coordinating services for their child. The Native American children were also less likely to have one person coordinating services for them. Fewer Native American parents have attended an agency meeting related to their child's goals and services.

Native American parents were much more likely to indicate that having professionals use language that is easy to understand would be helpful to them.

White parents were more likely to feel that professionals don't listen to them.

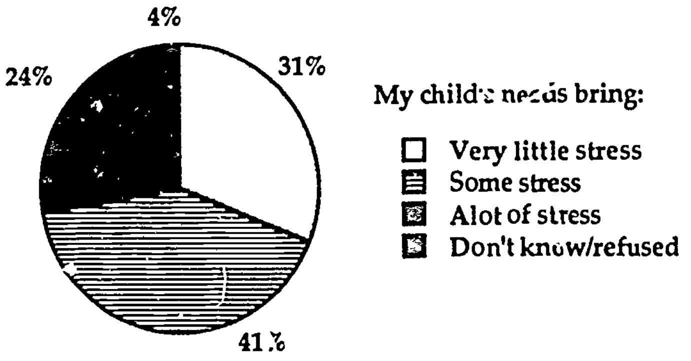
It appears that professionals need to identify strategies for engaging minority parents in the process of serving their children and assess the needs of minority parents as it relates to parent involvement. It would also be important to identify child outcomes as they are affected by the level of parent participation in the delivery of the child's services.

Professionals serving young children should attempt to develop interactions with parents that emphasize parents' identification of their child's needs, with the professionals' role shifting to the assumption of more responsibility for informing parents on how and where they can get their child's needs met.

EMOTIONAL SUPPORT NEEDS

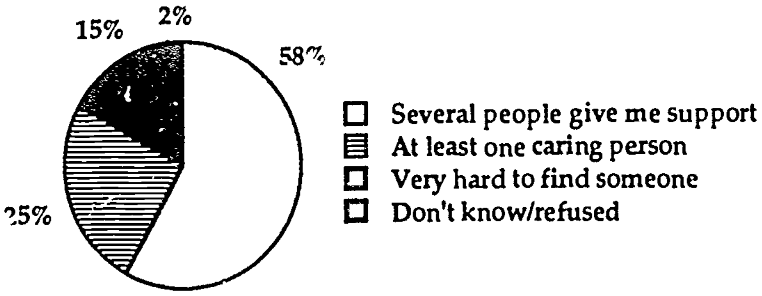
Parents were asked a number of questions about the emotional support that they as a parent are receiving and need, such as helping them feel better, giving them courage, having someone who cares about them. The following responses were made

Which of These Describes Your Feelings the Best?
[Parents could select one]

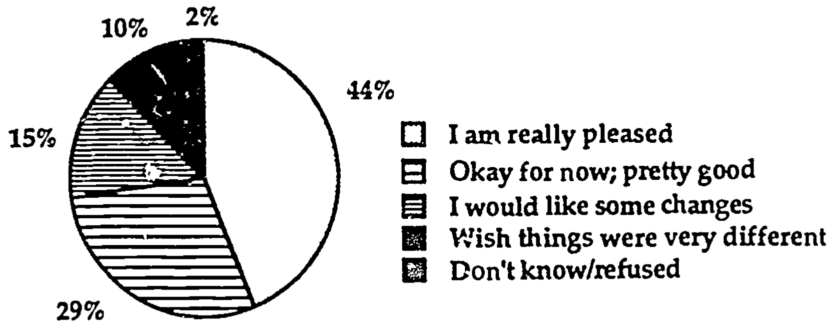


Less than 1/3 of the parents indicated that their child's needs bring very little stress. Almost 1/4 of the parents reported that their child's needs bring a lot of stress. Almost half of the parents felt that their child's needs bring some stress.

If You Were Feeling Low or Wanted to Talk Over a Problem, How Easy Would It Be to Find Someone to Talk With?



How Satisfied Are You With the Emotional Support You Receive?

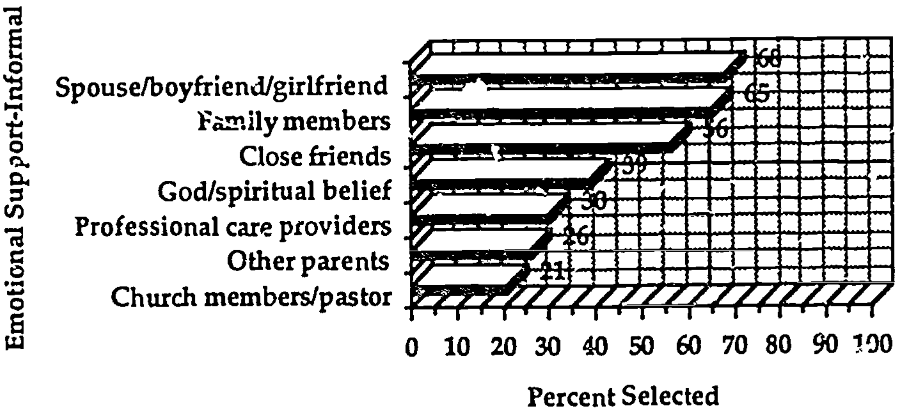


Most parents have at least one caring person they can go to for emotional support. However, there is still 15% of the parents who reported that it is very difficult to find someone to talk with.

Most parents are satisfied with the emotional support they are receiving, but 1/4 of the parents indicated that they would like some change or wish things were very different.

Who Gives You the Most Emotional Support? [a]

[Parents could select all that apply]



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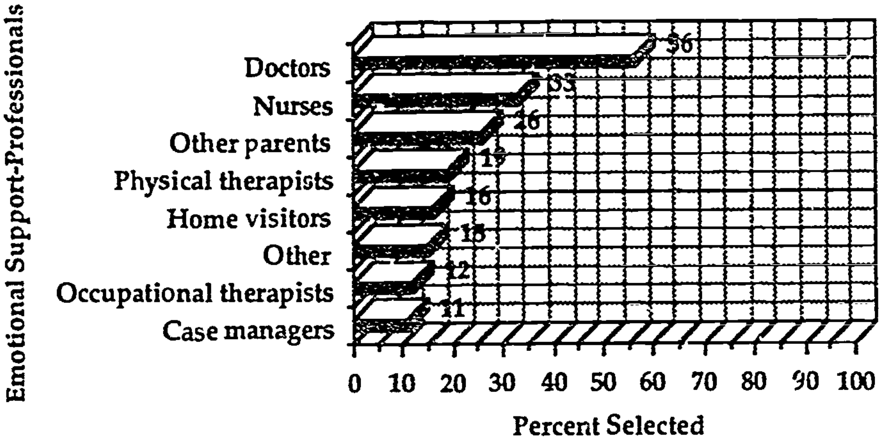
[a] Only items representing 20% or more of the parental responses are shown.

Which Professional People Have Given You the Most Emotional Support?

[Parents could select all that appiy]



Most parents reported that their spouses, family and relatives give them the most emotional support. Over a third of the parents indicated that their spiritual beliefs provide them with emotional support. Parent support groups were selected by 10% or less of the sample. Only 2% of the sampie indicated that they had no one to give them emotional support.

The majority of parents also selected doctors as the professional group providing them with emotional support. No other professional group was selected by a majority of the parents. Nurses and other parents were selected by at least 1/4 of the group of parents. Most professionals were not viewed as providing emotional support, although parents characterized professionals in general as caring and compassionate.

Other professionals, such as speech therapist, center teacher, counselors, psychologists, teacher aides, and bus drivers, were infrequently selected (less than 10%) as people who provide emotional support. With tne exception of the speech therapist (36% of the families are receiving speech therapy) this is due in part to the fact that the young children in this sample are not encountering many of these professionals at a high frequency yet.

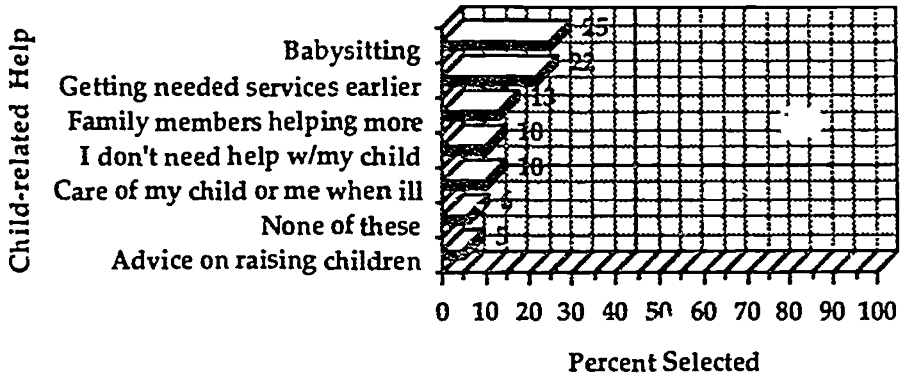
It is interesting to note that 5% of the sample have obtained emotional support from traditional/spiritual healers. In addition, despite the long list of individuals from which the parents could choose, 15% of the sample indicated that there were professionals other than those listed who provided emotional support to them.

What would make your life better for you?

Since improving services to their child is not the only way to make life better for parents, they were asked to identify other changes that would help relieve stress and help them cope with their responsibilities. Four categories were identified. (a) help with your child, (b) help with household chores, (c) help with finances, and (d) more personal support. The following responses were given.

Help With Your Child

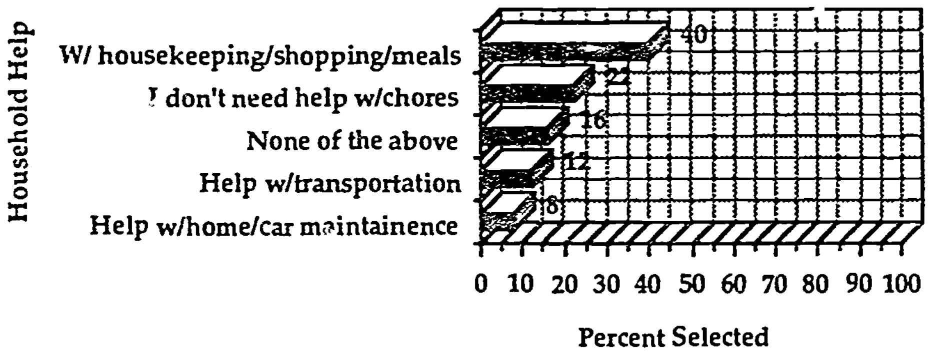
[Parents could select one item]



Other items that were selected by less than 5% of the parents were 'help with feeding or bathing my child', 'don't know/refused', 'toys', 'other', and 'legal advice'.

Help With Household Chores

[Parents could select one item]



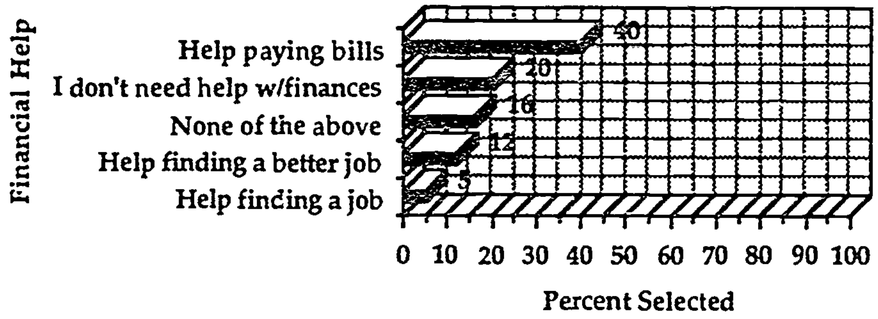
Three additional items were selected by less than 1% of the groups. 'help with moving', 'other' don't know/refused'.

It is important to note that 22% of the sample indicated that they did not need help with household chores. Another 16% indicated none of the above items. Anecdotal comments by some of the parents suggested that this is an area of responsibility that all parents have, regardless of the special needs of their child, and there was not an expectation that other people would play a role in relieving stress related to these responsibilities.

Other items selected by less than 10% of the sample included help with home or car maintenance or repair, help with moving, and help with transportation. Although transportation is currently provided to less than 15% of the families, there was not a strong indication that transportation assistance would help relieve stress and help them cope with their responsibilities better.

Help With Finances

[Parents could select one item]



Less than 5% of the parents selected the items 'other' and 'don't know/refused'.

Almost half of the parents indicated that their life would be better if they had help paying the bills. However, it is again significant to notice that 20% said they did not need help and another 16% indicated none of the items.

More Personal Support. There was only one item that more than 25% of the sample chose as an indicator of a way to help make their life better and relieve stress. Thirty-four percent (34%) of the parents indicated that *"more time for myself or ourselves"* would help make life better.

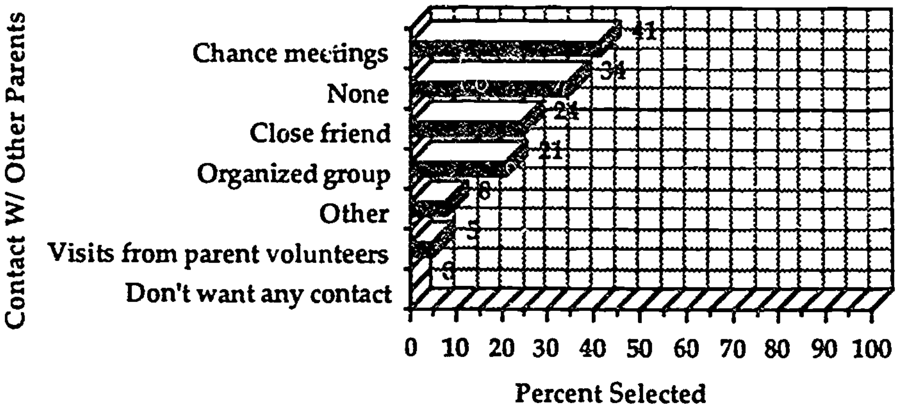
The remaining items on the list were selected infrequently. The other items consisted of the following. help with personal problems, help with marital problems, friendship/more time with friends, counseling, more recreation and fitness, more time for spiritual/church activities, help dealing with feelings about the handicap, and better family relationships.

Fifteen percent (15%) of the parents indicated that either they didn't need more personal support or none of the above items applied to them.

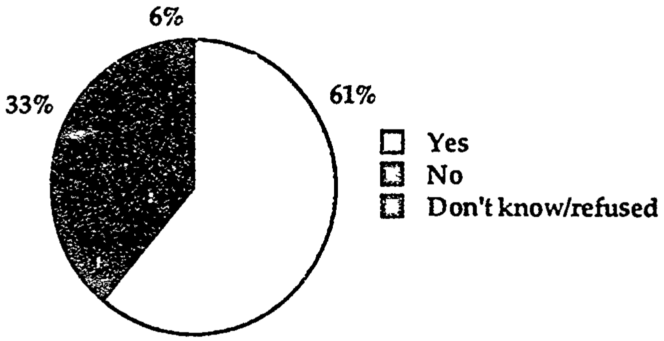
It appears that most parents are satisfied with their family lives and their ability to deal with everyday stress and responsibilities, and that they do not have an expectation that anyone else would assume responsibilities for these tasks.

What Kind of Contact, If Any, Do You Have With Other Parents of Children with Special Needs?

[Parents could select all that apply]



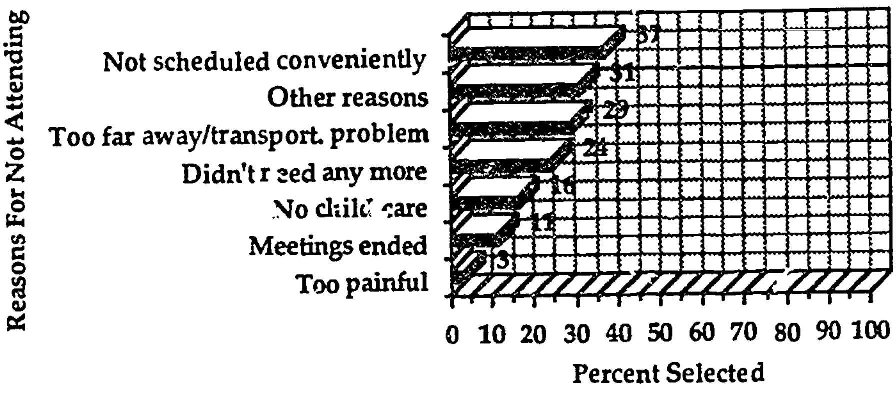
Would You Be Interested in Attending a Parent Support Group?



Although almost 300 parents indicated that they would like to attend a parent support group, only 24% (N=126) reported that they had ever attended such a meeting. Of those who have attended parent support meetings, most (62%) do not attend at least once a month.

Only half of those attending (55%) indicated that they liked the meetings a lot, while most of the rest of the parents (40%) said the meetings were "okay". Only 4% of those who have attended parent support meetings said they did not enjoy them.

Half of the parents who have attended parent support groups indicated that they had stopped going for the following reasons.



Why Parents Stop Attending Parent Support Groups
[Parents could select all that apply]

There was no clear consensus on the part of parents regarding the reasons why they had stopped attending parent support groups. This is apparently a highly individual matter, and as one might anticipate, there are many diverse reasons why parents do or do not attend parent support meetings.

Ethnic Differences

Although the largest percentage of parents from each of the 3 major ethnic groups reported that they had several caring people they could go to for emotional support, some group differences were found.

Native American parents were significantly less likely to indicate that they had several caring people to go to when compared to Hispanic or White parents.

Hispanic parents were much less likely to indicate that they were 'really pleased' with the emotional support they receive. White parents, on the other hand, selected this item much more frequently than expected when compared to the other two ethnic groups.

Native American parents were much more likely to report that their child's needs bring very little stress than Hispanic or White parents.

Summary

Most parents reported that they experience some stress because of their child with special needs. Most parents, however, reported that they are receiving emotional support from their informal networks and are satisfied with the level of support they receive. They are most likely to receive support from their spouses and other family members. Doctors were identified as the professionals who have provided most parents with emotional support.

About 1/4 of the parents, however, indicated that they experience a lot of stress because of their child's special needs. Approximately 20% to 25% of the parents reported needing some changes in their lives as it relates to the emotional support they are receiving.

In order to try to characterize the types of families in which parents were reporting a lot of stress because of their child's special needs, analyses were run on several variables to determine the relationship between parental stress and other key variables.

The variables that were analyzed in relationship to the parents' degree of stress were. (1) the number of problems the parents reported the children as having, (2) the number of adults in the home, (3) the level of family income, (4) the amount of extra money the family had spent because of the child's special needs, (5) the ease with which the parent could find emotional support, and (6) ethnicity.

Three variables emerged as clearly related to the degree of stress reported by the parents. First, the more developmental and medically-related problems the parents reported the child as having, the more likely the parent reported that their child's special needs bring a lot of stress.

That is, parents with a lot of stress have children who have almost 3 times as many problems as children in families where parents report some or very little stress.

Secondly, families who reported spending no money out-of-pocket for their child's special needs were much more likely to report that their child's special needs bring very little stress.

Thirdly, parents who reported that it is very hard to find someone to talk with for emotional support were significantly more likely to report that their child's special needs bring a lot of stress.

The other 3 variables were not significantly related to the degree of stress experienced by the families. This information is important because it may assist professionals in determining the critical issues to consider when assessing family needs and providing family support services for them.

The first two variables suggest that the more severe and complicated the child's problems are, the more parents will experience increased stress. The third variable reinforces the importance of intact informal support networks for families with children who have special needs, and the increased stress parents may experience without satisfactory emotional support.

There was a great deal of diversity in the parent responses when asked what kinds of changes in their lives would make life better for them. Parents gave the impression that regardless of their child's special needs, they did not have the expectation that other people should assume responsibility for areas of their lives that are not unique to them as a parent of a child with special needs, such as home or car maintenance, help with care of their child or themselves when they are ill, help finding a job, counseling, or more recreation and fitness time.

The items that received the most consensus, although by less than half of the group were 'help paying bills' and 'help with housekeeping/shopping/food preparation'.

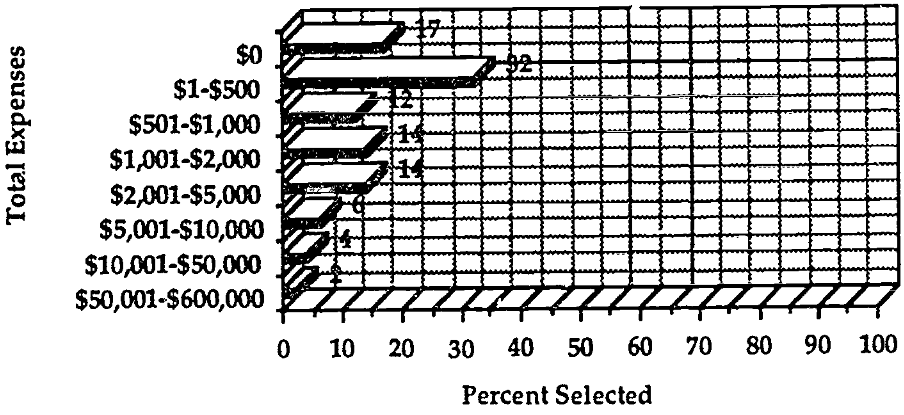
Most parents have very little contact with other parents of children with special needs. Often times the contact is through chance meetings, like at the place where services are provided.

The majority of parents, however, indicated that they would be interested in attending a parent support group. Less than 1/4 of the parents have ever attended such a meeting.

FINANCIAL ISSUES

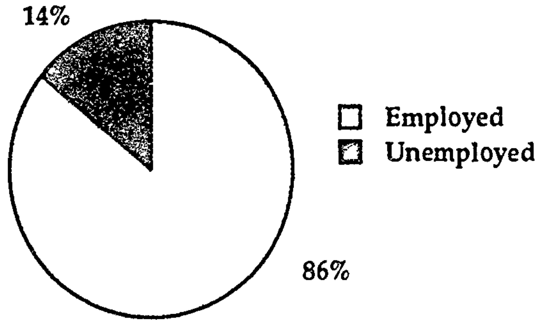
Parents were asked a series of questions related to their employment, financial situation and the expenses they incur related to the special needs of their children The following responses were obtained.

How Much Did Your Child's Special Needs Cost You In the Last Year (money out of your own pocket)?



Over 1/4 of the families reported spending $1,000 to $5,000 annually for their child's special needs. Forty-two (42) families spent $10,000 or more in one year on their child's special needs. Eighteen families from Maricopa county reported spending $25,000 or more in the last year for the special needs of their child. The average annual expenses for a child's special needs was $7,870.

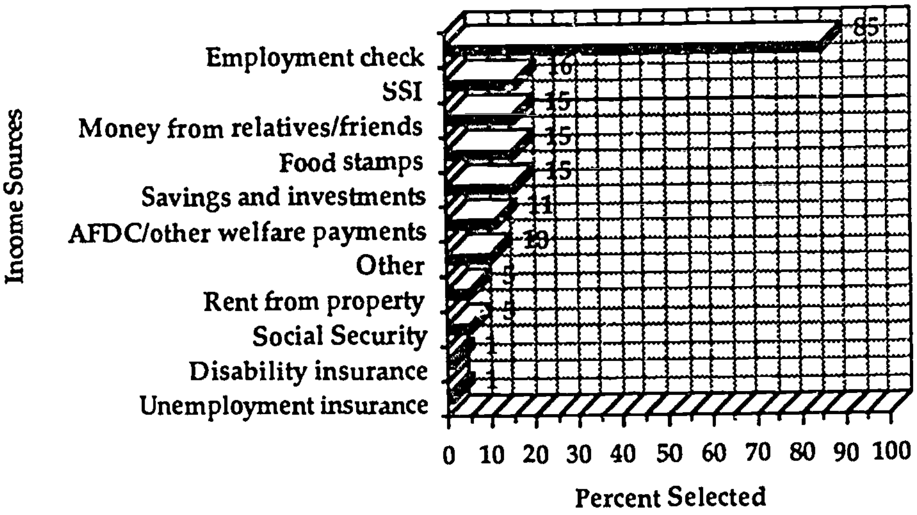
Are You Or Your Spouse (boyfriend/girlfriend) Currently Employed?



Of those families who reported that they have at least one parent employed, 60% have two wage earners. If one of these is the mother, this suggests that at least 52% of the mothers in the entire sample are employed.

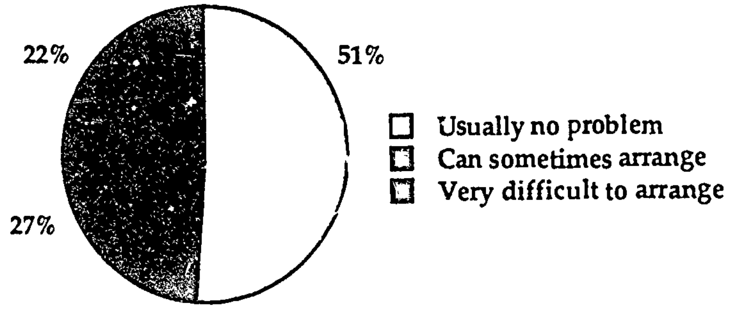
What Are Some Different Ways Your Family Gets Money or Things to Live on?

[Parents could select all that apply]

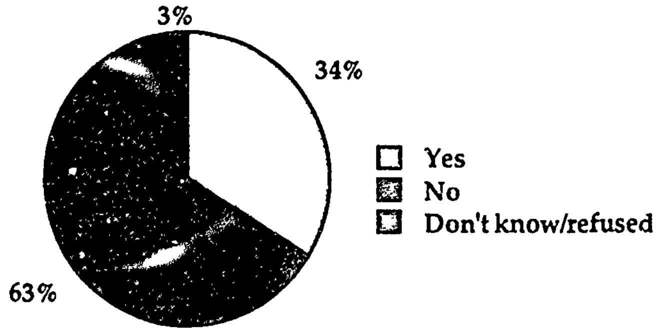


Clearly, the single most common source of income is from employment. Less than 20% of the families are receiving other kinds of financial support.

When You (or your spouse) Want to Get Time Off or Change Your Work Schedule to Do Something for Your Child, Is It Possible?



Do You Think You (and/or your spouse) Would Be Earning More Income If Your Child Did Not Have Special Needs?



About 1/3 of the parents felt that their earning power has been inhibited because of their child with special needs. When asked what prevented them from earning more, the following responses were given.

Reasons For Not Earning More Income

[Parents could select all that apply]
[N=183]

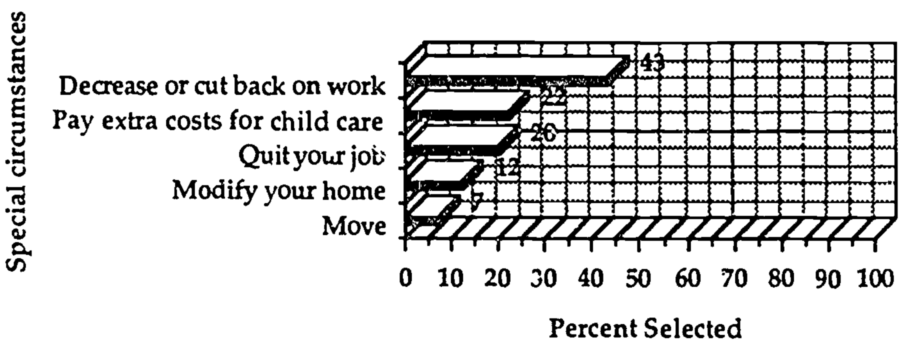
Item	Number	Percent
I quit my job to care for child	84	46%
Child care is available, but too expensive	67	37%
I don't have time to go to school or job training	56	31%
No one available is skilled enough to care for my child	46	25%
I am unemployed because I need to transport child to services	44	24%
I am too tired to work, or to work more	43	24%
I take time off to care for my child and it gives me less pay	39	21%
I quit or slowed down my job training to care for my child	38	21%
Insurance benefits would decrease	34	19%
I take time off work to care for my child, and it keeps me from getting promotions	31	17%
Other	27	15%
I do not want to work	18	1%
Don't know/refused	1	0%

Of the 183 parents who felt they were earning less income, almost half (46%) were earning less because at least one parent quit their job to care for the child full time. The need to quit their jobs may be due in part to the fact that half the sample reported that it is sometimes very difficult to arrange their work schedule for their child. This is coupled with the fact that child care may be available, but too expensive for the family. One-fourth (25%) of the families felt that their child's needs required special care, and that no one was available who could provide it for them.

Almost 1/3 of the parents felt that their child's special needs had prevented them from pursuing additional job training in order to earn a higher income. Approximately 25% of the parents indicated that their time was used to transport their child to services or that they were too tired to work.

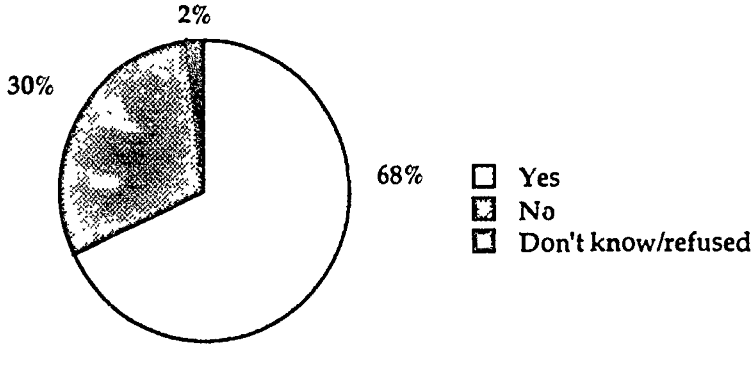
A smaller percentage of parents indicated that the care of their child interfered with their job in such a way that it resulted in reduced income. Only 1% of the parents indicated that they did not want to work.

Have You Or Your Spouse Ever Had To Do Any of the Following Because of Your Child's Special Needs?
[Parents responded to each item]

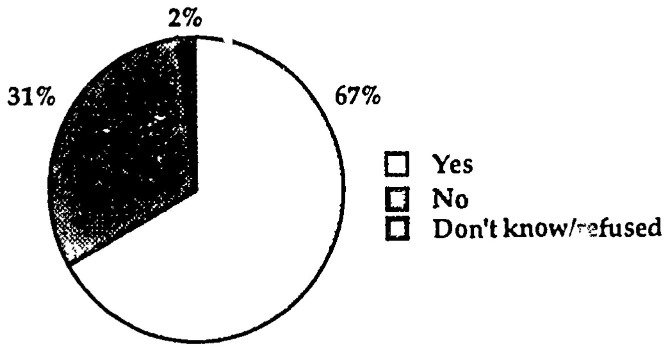


Parental responses to the question related to changes in the family circumstances as a result of their child's special needs confirm that almost half of the families have had to decrease or cut back on the amount of work they were doing. Almost 1/4 of the families indicated that they must pay extra costs for child care. Few families have modified their homes or moved because of their child's special needs.

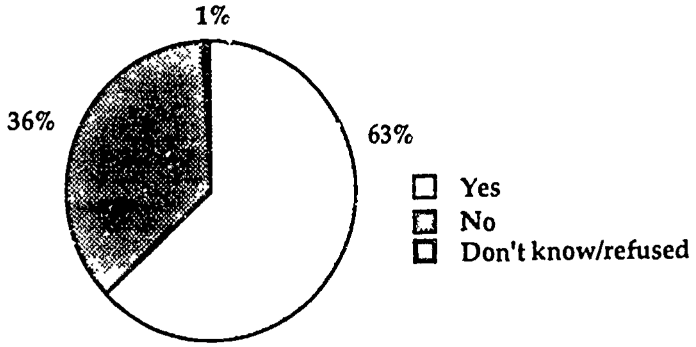
Have You Ever Found That Your Income Is Too High for You to Receive Free Services Or Benefits?



Do The Costs Still Cause Problems With Money for You?



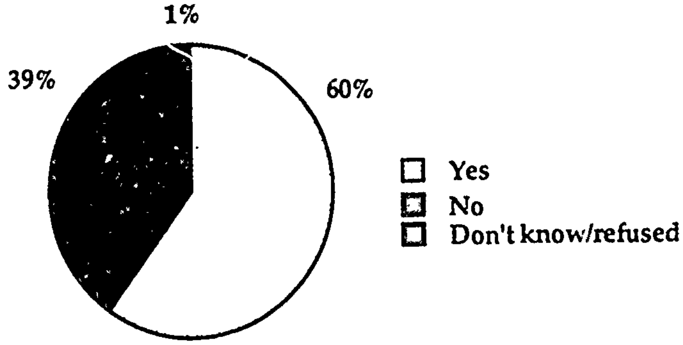
Have You Had Trouble Knowing Whether You Could Get Help Paying for Services and the Things Your Family Needs?



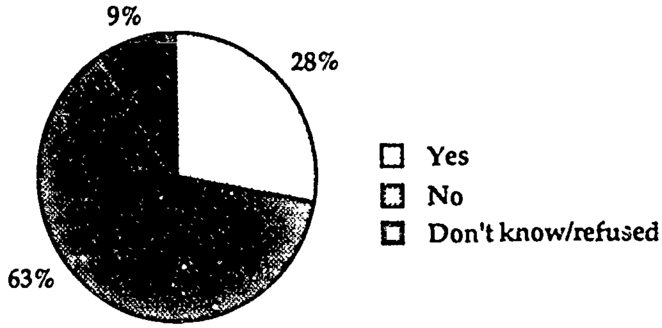
The parental responses are fairly consistent in indicating that almost one-third of the families in the sample qualify for some type of state-supported service or benefit, with medical assistance under AHCCCS representing the service available to most of this group.

However, of those families who have not qualified for state-supported services (N=364), more than 2/3 feel that they have experienced problems with their financial situation, and are uncertain whether or not they could receive help paying for their child's services and other things the family needs.

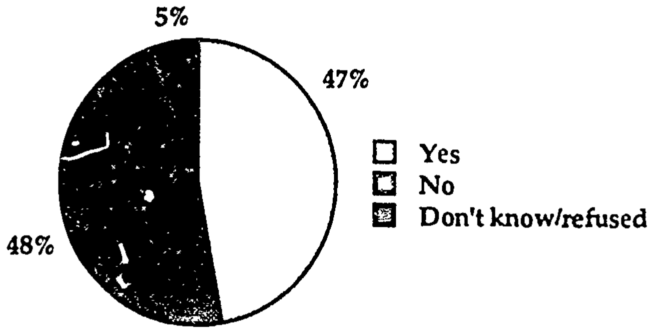
Do You Have Private Insurance Which Pays for Some of Your Child's Services/Costs?



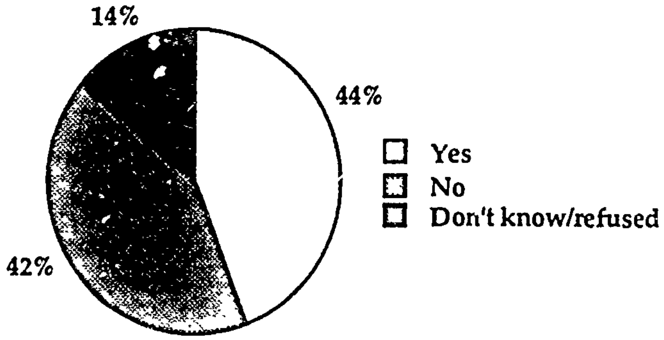
Does Private Insurance Currently Pay For Any Therapy Services?



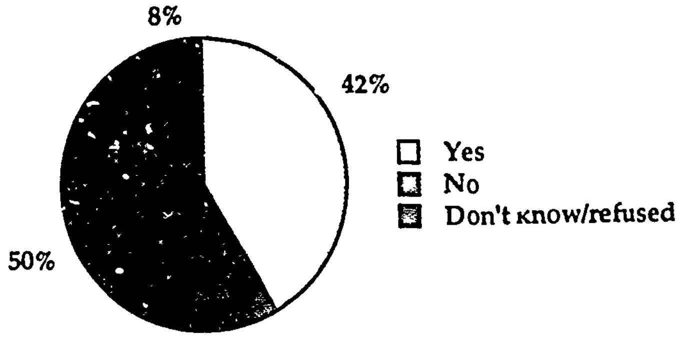
Does Private Insurance Pay for All Therapy Expenses After the Required Deductible?



Does the Insurance Company Put Limits on How Often You Can G Some Services, or for How Many Months You Can Get Them?



Are There Other Services That Are Not Paid for At All?



Which Services Are These?

[Parents could select all that apply]
N=135

Item	Number	Percent
Special food or dietary supplements	53	39%
Special equipment or supplies	52	39%
Speech or language therapy	45	33%
Home visitor	40	30%
Occupational therapy	37	27%
Parent or family education	37	27%
Specialized transportation	33	24%
Counseling	31	23%
Genetic Counseling	31	23%
Behavioral therapy	30	22%
Vision/hearing training or screenings	30	22%
Physical therapy	29	22%
Medical tests or lab fees	25	19%
Nursing care in the home	25	19%
Traditional/religious ceremonies	24	18%
Medical diagnosis, 2nd opinion	20	15%
Medication	20	15%
Other	19	14%
Medical specialists	13	10%
Don't know/refused	13	10%
Hospitalization	6	4%
Surgery	4	3%

Approximately 2/3 of the sample have some kind of insurance which pays for some of their child's services/costs. Almost 2/3 of those families with insurance indicated that the insurance does not pay for any of the therapy costs. Of those families whose private insurance coverage includes therapy, almost half do not receive full payment for the child's therapies after meeting a required deductible.

Almost half of the insurance policies have limits placed upon them in regard to the frequency or duration of the benefit.

Almost half (42%) of the insured parents indicated that the insurance company does not pay for certain services at all. These results parallel the findings reported earlier regarding who pays for services the child has/is receiving.

Insurance companies are most likely to pay for medical services such as medical tests, diagnoses, medication, medical specialists, hospitalizations, and surgery.

They are less likely to support the costs of specialized diets, equipment and supplies, rehabilitative therapies, education, counseling, and transportation.

Geographic Differences

There were 18 cases in which the families reported spending \$25,000 or more in the last year prior to the interview for the special needs of their child. All of these families resided in Maricopa county.

Maricopa families were also slightly ($p<.06$) more likely to decrease the amount of their work because of their child's special needs than families in the other two geographic areas.

Pima county families (18%) reported modifying their homes for their child more often than expected when compared to families in Maricopa county (10%) and rural areas (10%).

Family Income Differences

Parents of families who are AHCCCS recipients or with incomes less than \$10,000 were more likely to be unemployed than parents of higher income groups. Thirty-two percent (32%) of the parents from AHCCCS-recipient families were unemployed, while 27% of parents from families with incomes less than \$10,000 were unemployed. Ninety-nine percent (99%) of the families with incomes greater than \$20,000 had at least one parent employed.There were significant differences in the total annual 'out-of-pocket' costs for their children with special needs when comparing families of different income categories.

Based on the findings from previous sections, it is not surprising that families who are AHCCCS recipients were more likely to report that they had no out-of-pocket expenses related to their child's special needs when compared to the other income groups. The previous section on service usage reported that AHCCCS recipients were much more likely to have their child's services paid for (supported by the AHCCCS program).

In terms of out-of-pocket expenditures in the range of \$100-\$10,000, families with incomes greater than \$20,000 were much more likely to spend more than \$1,000 for their children than families from the lower income categories.

Conversely, families with incomes between $10,000-$19,999 were significantly more likely to spend less than $1,000 annually for their child's special needs when compared to the other income categories.

Half of the families with incomes less than $10,000 (who were non-AHCCCS recipients) reported spending $100 or less for their child's special needs.

Sixty percent (60%) of the families receiving AHCCCS reported that their income is too high to receive other free services or benefits.

Almost 3/4 of the families with incomes less than $20,000, including those in the category representing an income of less than $10,000, reported that their incomes were too high to receive free services or benefits. This may represent a lack of knowledge of the income requirements for various state-supported programs, a lack of success with the agencies in securing eligibility, or the desire not to be recipients of state-supported programs.

Not surprisingly, most families with incomes over $20,000 reported that they were ineligible to receive free services or benefits. Also, families in the higher income category were significantly more likely to have private insurance when compared to families in the other income categories.

Fewer families with incomes of less than $10,000 had private insurance than statistically expected when compared to families in the other income categories. However, this is not surprising, since 27% of the parents in this group are unemployed What is surprising, however, is that in spite of the fact that 3/4 of this income group are employed, only 1/4 of the families reported having private insurance which pays for some of their child's services/costs.

Summary

Employment and the ability to earn an income for their families play an important role for parents of children with special needs.

Employment is the primary source of income for the families, with 86% of the families reporting at least one parent as employed. The rate of unemployment for the parents in the sample (14%) is higher than the State average for all adults.

Families where both parents are unemployed are most likely to be families who are AHCCCS recipients or families with incomes less than $10,000.

A substantial percentage of parents (34%) felt that they would be earning more if their child did not have special needs. Parents reported several barriers to employment and higher incomes.

The income of many families was reduced because almost half of them quit their jobs, or cut back on the amount of work they were doing in order to care for their child.

Many parents reported that child care is too expensive or that there is no one available who has the special skills required to care for their child.

Many parents reported that they don't have time to go to school or secure job training and that that prevents them from earning more income. Some of the parents are unemployed so that they can transport their child to services.

Only 1% of the parents who reported that they would be earning more income if their child did not have special needs indicated that they did not want to work.

These findings have increased significance when considered in light of the fact that (1) most of the services currently being received by the children and families is being paid for either by the families themselves or by private insurance, and (2) there is a direct relationship between family income and the amount of money spent by the families on the child and his/her special needs.

Almost 40% of the families do not have private insurance. Regretfully, although 3/4 of the families with incomes less than $10,000 have at least one working parent, only 1/4 of these families have private insurance. These families, often referred to as the working poor, are working for very low wages and without the benefit of private insurance.

Parents from the families in this income category also report that they have often found their income to be too high to receive free services or benefits. Children from families in this income category are the most at risk for being unserved. Indeed, that may be why they could not be readily identified for inclusion in this sample and are underrepresented as an income group.

Even for families who have private insurance, most policies are not covering the cost of rehabilitative therapy, educational and family support services.

As reported in a previous section, most of the families are not receiving rehabilitative therapies, educational, or family support services for their child or family. Fortunately, 33% of the families are recipients of AHCCCS, a program that is providing significant support for the medical needs of this group of children.

Policy-makers and the agencies involved in attempting to establish a statewide system of early intervention services for families and children with special needs should recognize the barriers to employment and higher income experienced by many of the families and develop solutions to reduce the unemployment rate amongst these families and advocate to improve the wages and insurance options for the working poor.

It is the impression of the authors of this study that most families prefer to solve their own problems and be given the option to perform as a parent of a child-they do not perceive themselves as parents of a 'developmentally delayed' child.

Given the current status of the service delivery system for this group of children and families, it would be to the benefit of the State to (1) remove as many barriers to employment as possible in order to improve family income, and (2) improve the private insurance options for children with special needs. These two solutions will create greater independence on the part of the parents to solve their own problems and allow them to function more normally as a family.

APPENDIX

A Description of the Project Design, Sample, Methodology, and Analysis

Design

The study consisted of a needs assessment survey research project, which gathered descriptive data through face-to-face interviews. Comparative analyses were conducted on selected variables by predetermined groups.

Sample

A sampling strategy was designed to result in the inclusion of all families with children 3 years of age or younger who are developmentally delayed or at risk of becoming handicapped, and currently served by the Arizona service delivery system.

Seven key Arizona agencies/organizations were identified to solicit parent participation through a letter submitted to all parents on the agency caseloads with children born after January 1, 1985. The agencies participating were. Department of Health Services, Office of Maternal and Child Health and Children's Rehabilitative Services, Department of Economic Security, Division of Developmental Disabilities, Department of Education, Child Evaluation Centers, and Arizona State School for the Deaf and Blind.

Approximately 10,000 letters were mailed requesting parents participation in the study. The response rate was approximately 10%. Letters were submitted to all parents indicating a willingness to participate and interviews were scheduled. Every effort was made to extend the opportunity to participate to families that did not have telephones or whose primary language was other than English. A total of 601 interviews were conducted.

Analysis of the sample indicated that minority children were underrepresented by 2%, that the family income category of $5,000-$20,000 was underrepresented by 16%, and that parental educational levels less than 12 years of school were underrepresented by 6% when compared to the demographics of the state as a whole. Every county of the state was represented.

The term 'White' is substituted for the more accurate term 'White [not Hispanic]' throughout the document.

Survey Instrument

The instrument used in this study was a questionnaire administered during face-to-face interviews with parents in their homes. A closed-question format was used throughout.

Questionnaire content was determined by conducting a thorough analysis of the professional literature regarding the key issues facing families with children who have special needs and by parental input through a Parent Task Force. The Parent Task Force completed a brainstorming session to identify major issues.

Six general categories were identified and formed the basis for development of individual question items. The 6 categories were. (1) demographic information, (2) parental information needs and sources, (3) services received and service satisfaction, (4) parental involvement in service delivery, (5) emotional support issues, and (6) financial issues.

Drafts of the questionnaire were mailed to all Parent Task Force participants, as well as to a number of other professionals for their review and comments. The questionnaire was also pilot-tested with 10 families by four members of the research team. All comments and feedback were considered and contributed to the final version of the questionnaire.

Procedure

Interviewers from throughout the state of Arizona were recruited through local newspapers, regional agency administrative offices, school districts and universities. Twenty interviewers were hired and trained.

Interviewers were trained during one of two twelve-hour training sessions. The goal of the training was to achieve skilled, reliable and standard interviewing techniques.

Interviewers were observed after receiving information about interviewing techniques and observing several interviews being conducted. Each interviewer was subsequently observed at least once on site during the actual conduct of the interview with a family. All interviewers were closely supervised by two project staff.

Interviews were conducted in the respondent's home except in a few cases in which this was not feasible. Interviews took approximately one hour to complete. Families had the option of being interviewed in a language other than English. Languages in which interviews were requested to be conducted included Spanish, Navajo, Tag a-Log, and sign language. Approximately 3% of the interviews were conducted in Spanish.

All survey respondents were informed of their right to refuse to answer any question or to end the interview before completion. This information was presented by telephone when the interview appointment was made, and again on the day of the interview before the interview began.

Responses were recorded in a customized, standard, booklet consisting of computer-scannable bubble sheets. Interviewers checked the survey booklet after each interview to remove any stray marks and make sure that all answers were clearly marked.

Analysis

Of 601 interviews that were conducted, the responses of 536 families, who have a total of 584 children with special needs under the age of 4 years, were included in the final results.

Two units of analysis were used, depending upon the nature of the question. (1) child specific items, and (2) family specific items. The interviewer training booklet describes which questions were asked that were child specific, and hence, could result in parents answering the question more than once if they had more than one child under the age of 4 years with special needs.

Descriptive statistics were prepared on all survey items, resulting in sample frequencies, percentages, means, medians, and modes as appropriate to the item.

In addition, statistical analyses were computed on selected questions in order to conduct a comparison of major findings by: (1) ethnicity, and (2) geography.

Ethnic comparisons were conducted on the 3 major ethnic groups in Arizona (White, Hispanic, and Native American). Sample size did not permit comparison of findings from other ethnic groups.

Geographic comparisons were conducted by grouping the responses into 3 geographic regions. (1) Maricopa county, (2) Pima county, and (3) rural counties (all other counties in the state).

To a more limited degree, two additional group comparisons were conducted by. (1) age, and (2) family income. An age comparison was conducted on selected items in the Service Usage and Satisfaction section to determine whether or not the age of the child contributed to the likelihood that the child was receiving services.

The sample was grouped into 4 categories in order to determine whether or not family income contributed to the provision of services or helped explain differences in the family responses to selected items. The 4 income categories were. (1) AHCCCS recipients, (2) families with incomes less than $10,000, (3) families with incomes between $10,000-$19,999, and (4) families with incomes of $20,000 or more.

Statistical results are reported in the document for only those comparative analyses that yielded statistically significant findings at the p<.05 level, unless otherwise indicated.

All numbers displayed in the report have been rounded to the nearest whole number according to standard practice.

Appendix 16