

**Systematic Treatment of Autism and Related Disorders  
Weisskopf Child Evaluation Center  
Department of Pediatrics  
University of Louisville Health Sciences Center**

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# **Parental and Caregiver Satisfaction with Services, Utilization, and Costs in Kentucky**

## **A Preliminary Analysis for Autism Spectrum Disorders**

August, 2004

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# Parental and Caregiver Experiences with Services, Utilization, and Costs in Kentucky

## A Preliminary Analysis for Autism Spectrum Disorders

August, 2004

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In collaboration with members of the State of Services Committee of the **Autism Spectrum Disorders Advisory Consortium (ASDAC)**, the **Kentucky Department of Mental Health and Mental Retardation Services**, the **State Interagency Council for Services to Children with an Emotional Disability (SIAC)**, **Dr. Craig Anne Heflinger** of Vanderbilt University, and **Dr. John McGrew** of Indiana University-Purdue University.

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# State-of-the-Art Treatment of Children with Autism Spectrum Disorders

## Background on the ASDAC Consortium

The Autism Spectrum Disorder Advisory Consortium (ASDAC) was formed in March 2002 at the request of the State Interagency Council for Services to Children with an Emotional Disability (SIAC). The Consortium was charged with providing a unified voice to assist SIAC in understanding the needs of children and youth with Autism Spectrum Disorders.

The Consortium is a 31-member body consisting of parents representing various support groups from across the state as well as representatives of parents who may not be associated with support groups. The Consortium also includes providers of services to children with ASDs and their families as well as representatives from local and state level educational authorities.

## Background on Autism Spectrum Disorders

Autism Spectrum Disorders refer to a complex group of related disorders marked by impairments in communication and socialization, and by a limited range of interests. Although sometimes not diagnosed until school age, Autism Spectrum Disorders develop early in life and are generally life-long with implications for mental / behavioral health, education, and community and family adjustment.

Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD- NOS) are described in the Diagnostic and Statistical Manual of Mental Disorders<sup>1</sup> and are considered Autism Spectrum Disorders. The degree to which different characteristics affect a child depends on the level of severity of impairments in the following areas:

- Children with autism have problems in *three* core areas (socialization, communication, restricted patterns of behaviors and interests).

- Children with Asperger's have problems in *two* areas (socialization and restricted patterns of interests).
- Children with PDD-NOS have problems in *socialization* and *one* of the two other areas (communication or restricted patterns of behaviors and interests).

Autism Spectrum Disorders are diagnoses based on behaviors, not medical tests. In order to accurately diagnose Autism Spectrum Disorders, the child should have a comprehensive evaluation by professionals with expertise in differentiating behaviors from typical and atypical development. Autism Spectrum Disorders affect children differently and two children can meet different combinations of the diagnostic criteria. Working with one child with autism does not mean another child will need the same strategies. Autism, the typical Autism Spectrum Disorder, often occurs with other disorders such as cognitive impairment, fragile X syndrome, Down syndrome, and tuberous sclerosis. At least 10% of children with autism have a comorbid medical condition. The cause of Autism Spectrum Disorders is unknown and most likely results from many factors, such as a combination of genetic, environmental, and neuropathologic sources.

Autism is not rare and affects as many as 1 out of about 600 children. When considered with the related disorders (Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified), as many as 1 out of 160 children are affected. Autism is a lifelong disability with no known cure. Although a small number of individuals may make significant improvements, relative weaknesses in social and communication skills remain.

## Principles of Treatment for Autism Spectrum Disorders

Summary statements from various sources such as the National Research Council,<sup>2</sup> the National Early Childhood Technical Assistance Center sponsored Forum on Autism Spectrum Disorders,<sup>3</sup> research summaries on intervention outcomes,<sup>4,5</sup> and practice guidelines<sup>6,7</sup> together provide guiding principles of effective practice for young children with autism, which are summarized below:

- There are no known cures for autism
- Children do not benefit equally from the same treatment
- Intervention should begin early and be intensive
- Intervention should encourage family involvement
- Individualized programs should be developed using assessment information
- A comprehensive curriculum should be developed by integrating different therapeutic / educational approaches
- Intervention should employ systematic, planful teaching
- Behavioral methods are the primary mode of treatment

- Applied Behavior Analysis (ABA) is a broad term that includes many effective systematic teaching methods such as discrete trial training, structured teaching, pivotal response training, functional communication training, and incidental teaching; no single ABA approach has been proven more efficacious than another
- Intervention should include periodic monitoring of progress and goals
- Intervention components should include specialized, developmentally-based programming in imitation, communication, play, and social interaction skills
- Intervention should include teaching activities that foster engagement, initiative, and adaptation to transitions
- Strategies should provide a structured and supportive teaching environment
- Programming for generalization to other settings should be included
- A functional and proactive approach to problem behaviors should be applied
- Opportunities for peer interactions should be provided
- Children should be prepared for transitions to future educational settings
- Consistency between service providers

Although these guidelines were established primarily for young children with autism (0-8 years), all of the principles also apply to older individuals.<sup>7</sup> The following types of therapeutic services that are often necessary for children and adolescents with autism spectrum disorders are listed below.<sup>7</sup> These services are provided by various systems including public and private agencies. Public-funded agencies include schools and community mental health centers. Private agencies include private insurance providers, university-based programs or private providers.

- Educational programming
- Speech-language therapy
- Occupational therapy
- Summer programming
- Parent training (e.g., in behavior modification techniques) and counseling
- Medication management
- Individual therapy for child or adolescent
- In-home behavior therapy
- Case management
- Respite care
- Inpatient hospitalization or residential care

This report will revisit the experiences parents and caregivers have had with these services and the funding agency after describing the current system of services available from publicly funded agencies in the state of Kentucky. Chapter 2 reviews the purpose and methods. Chapter 3 includes a structural description of the system as it is designed with information on state agencies, and available treatment for publicly-funded services for children with autism spectrum disorders. Chapter 4 describes parental utilization of services, costs, and outcomes of various funding agencies as related to services use. Chapter 5 describes access to services. Chapter 6 summarizes the findings as well as the strengths and challenges of the current service system. The chapters will cover the following:

- **Rationale for the survey:** Why was this study done?
- **The mode of service delivery:** Which organizations were responsible for implementing the services across the state, what services were available, how do children qualify?
- **Survey participants:** Who were the parents and caregivers who responded to this survey and what were their child's characteristics?
- **Parental and Caregiver Perspectives:** What services, how many services, and what out-of-pocket costs did parents and caregivers incur?
- **Broader issues:** What publicly-funded service organization(s) have responsibility for treating autism across the state?

This report addresses the major question, "What services did parents and caregivers access, what outcomes did these services have on the child and family, and who funded the service."

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## Purpose and Method

The purpose of this study was to assist SIAC, ASDAC, and KY DMHMRS in meeting their objectives and provide needed information for policy planners, program administrators, service providers, advocates, parents and caregivers, researchers, and others to begin to understand the current system of publicly and privately-funded treatment and have a documented basis for making improvements.

### How Was the Study Conducted?

The State of the Services Committee (SOS), one of the subcommittees of ASDAC, identified a lack of descriptive information available regarding services and the organization of services for individuals with ASDs in Kentucky. In particular, information was lacking on the agencies who receive public monies for autism, parental experiences in obtaining services from these as well as private-funded agencies, the financial impact of obtaining services on families, parental satisfaction with services, and child and family outcomes that result from the services. One of the goals of the SOS Committee was to generate a parental survey in order to obtain information that may assist SIAC and the ASDAC in meeting their objectives.

#### Data Sources and Analyses

In order to obtain a nonbiased sample of parents with a child with an ASD (e.g., a community-based sample is more representative than a clinic-based sample of families), several data sources were utilized. Members of ASDAC distributed surveys either by mail, email, or directly to local autism support group members and regional educational coops. David Lane, member of ASDAC, created a web version of the survey to allow respondents to complete an on-line questionnaire. A total of 125 surveys were completed and returned. Seven of these surveys were not analyzed because they were completed by someone other than the parent or caregiver (e.g., a child's teacher) or completed by people who live out of state (e.g., Iowa). Five additional surveys were not analyzed because they represented adults with an ASD who were 22 years or older.



## Primary Questions

1. Who responded to the survey and how representative was the sample compared to residents across Kentucky?
2. What kind of health insurance did the respondents have?
3. How many parents, caregivers, and children with ASDs used behavioral / mental health services?
4. How many children received habilitative services such as speech and language therapy and occupational therapy?
5. How many children were treated with medications and how many of the medications were related to treatment for emotional or behavioral disorders?
6. How many children had comorbid diagnoses and what were they?
7. How many children received public, private, and home school services?
8. How did parents and caregivers rate the program that provided funding for services and who was the most common payor for the service?
9. How many families and children used services related to autism spectrum disorders and how much did families pay out-of-pocket for these services?
10. What service(s) provided the best outcome for the child and the family?
11. What were parental views regarding satisfaction with child's educational program?
12. What services did parents prioritize as high need?
13. Based on reports of family and children needs, what are the gaps in services, and how do these findings relate to needed services for the treatment of autism spectrum disorders?

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## Overview of the Publicly-funded Agencies for Autism Spectrum Disorders in Kentucky

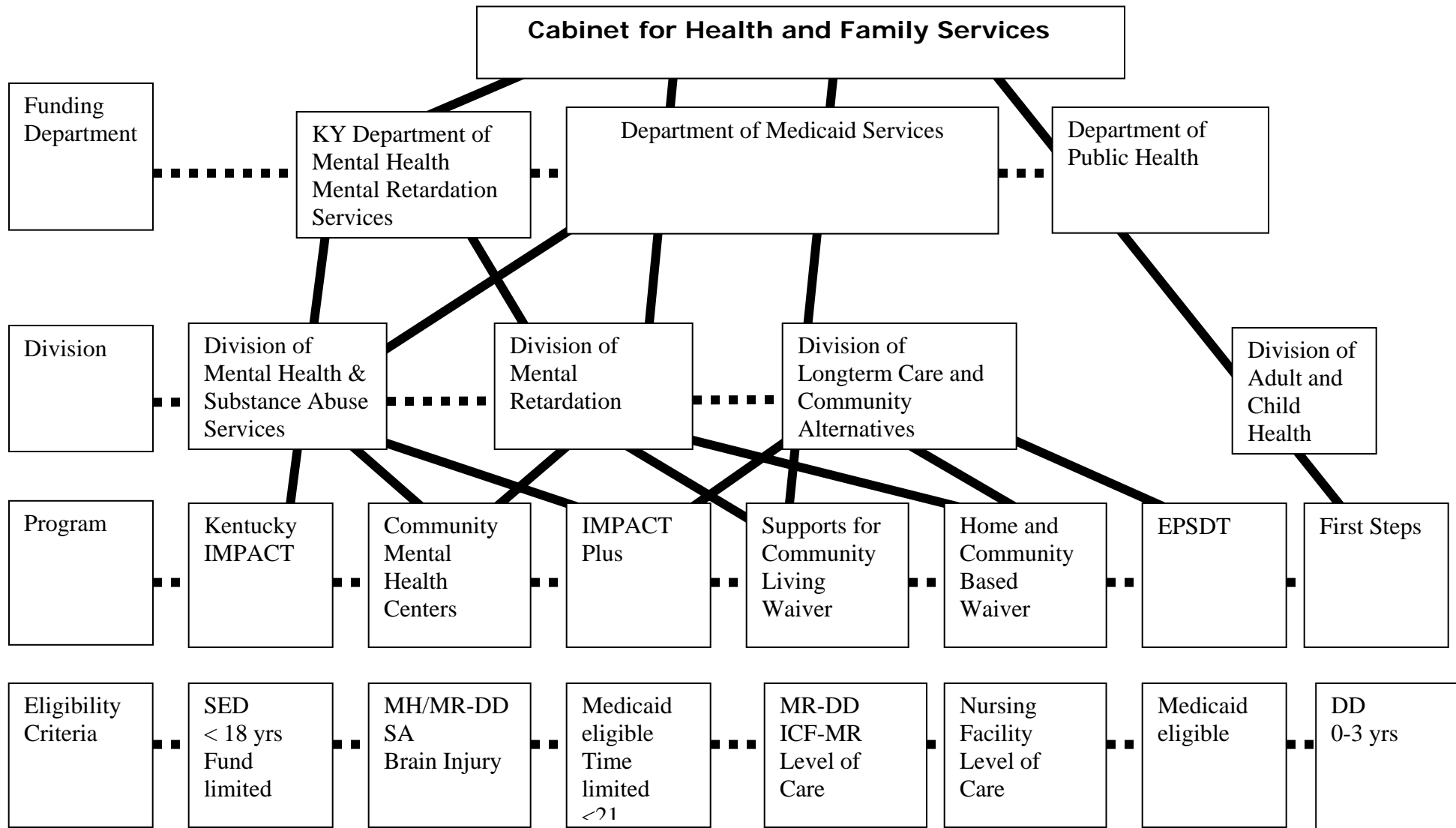
### State and Federal Funding and Administrative Agencies

Figure 1. describes the system for publicly-funded treatment for children and adolescents with ASDs, and shows the agencies and eligibility criteria for receiving services. The types of treatment provided by the agencies are in Figure 2.

Three departments, the Department of Medicaid, the Department for Mental Health and Mental Retardation Services, and the Department for Public Health fund all public-supported services for children, adolescents, and adults with autism spectrum disorders outside of the Department of Education, which provides services through Federal Law PL 105-17, Individuals with Disabilities Education Act.

The types of services funded vary depending on the type of program or waiver. Each program has unique eligibility criteria. No program focuses solely on the needs of children and adolescents with autism spectrum disorders.

Figure 1. Public Funded Programs Responsible for Reimbursement or Provision of Medical and Behavioral Health Interventions for Persons with Autism\*



\*School services are not included in this description

Figure 2. Kentucky Public-Funded Agencies and Types of Services Provided for Autism\*

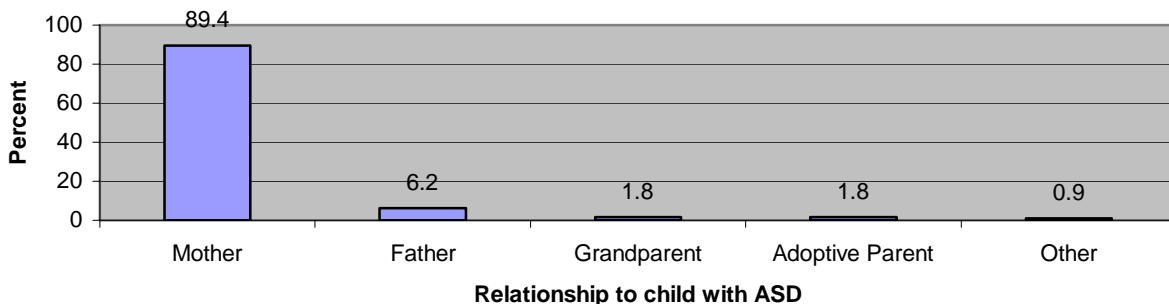
Agency	Purpose	How to qualify	Services							
			Service Coordination	Respite Care	Therapeutic Child Support	Behavior Mgmt	Speech & Language	Occupational Therapy	Advocacy	Early Intervention
First Steps	Provides early intervention for birth to three.	Based on assessment of developmental skills	X	X	X	X	X	X		X
Home and Community Based Waiver	Provides Medicaid coverage and some therapeutic services	Must meet skilled nursing facility level of care to be eligible to participate; must be unable to care for own activities of daily living.	X	X			X	X		
Kentucky Impact	Increase and improve services, coordinate services, reduce dependency on hospitalization, and increase the use of less restrictive community-based services.	Severe emotional disability. Less than 18 years, psychiatric disorder, problems in at least 2 of areas of functioning, have been disabled for at least one year, must require service planning from at least 2 agencies	X	X	X	X			X	X
Impact Plus	Provides community-based supports. Time limited.	A strict eligibility criterion, the child has to be at risk of institutionalization and needs a medical card and a mental health diagnosis	X		X	X				
KY Cabinet for Health and Family Services Ombudsman	Provides advocacy for consumers								X	
Medicaid	Provides medical and behavioral health coverage.	Based on Income Persons with Home and Community based waiver are eligible		X						
Early and Periodic Screening, Diagnosis, & Treatment Program (EPSDT)	Provides range of rehabilitative and habilitative services (medical and behavioral health)	Based on disability Under 21 years	X	X	X	X	X	X	X	X
Protection & Advocacy	Protect and advocate for human and legal rights.	Call and discuss							X	
Supports for Community Living or Kentucky Supported Living	Provides range of home and community based services	Must have mental retardation/DD and meet requirements for residence in an Intermediate Care Facility and MR/DD level of care and other Medicaid requirements.	X	X	X	X	X	X		

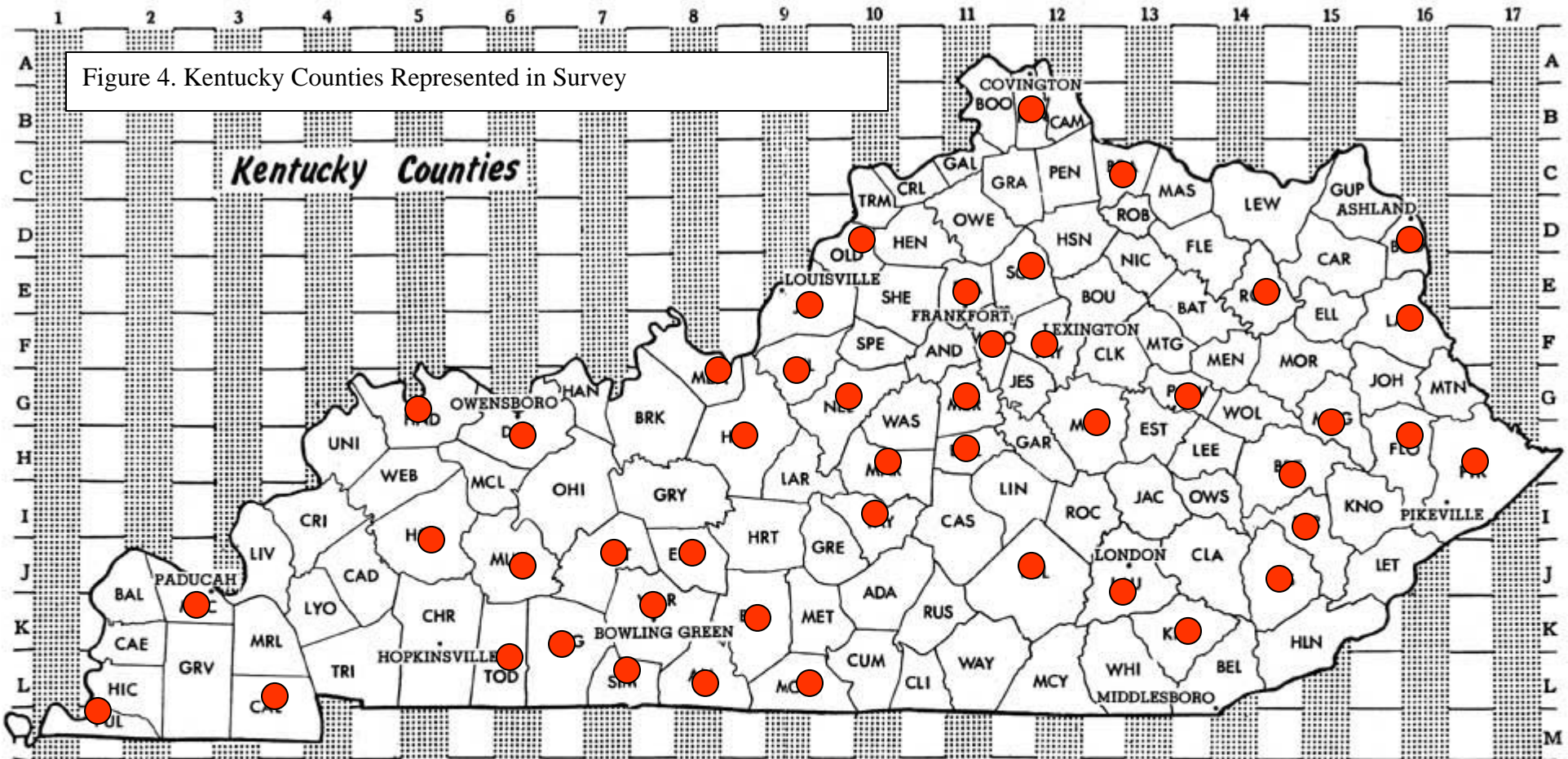
## Detailed Description of the Experiences Reported by Parents and Caregivers Accessing the Treatment System for Autism Spectrum Disorders

### Study Participants

The respondents consisted of 113 parents or caregivers in Kentucky (see Figure 3) from 46 counties in Kentucky (Figure 4). About 90% of the respondents were the mother. Figure 5 shows the educational background of the respondents and compares the percentage of respondents' backgrounds to the Kentucky Census. More than 50% of survey respondents were college graduates or had advanced training in comparison to about 20% identified by the Kentucky Census. The divorce rate of the respondents was similar to the Kentucky Census as depicted in Figure 6. The income level was somewhat higher for the survey respondents (Figure 7). Racial background was similar to the Kentucky Census (Figure 8). Twenty-four of the respondents had Medicaid (Passport, Medicaid, KY Welfare, K-CHIP) listed as their primary health insurance carrier (Figure 9). Seventy-seven parents or caregivers listed private insurance as their primary carrier.

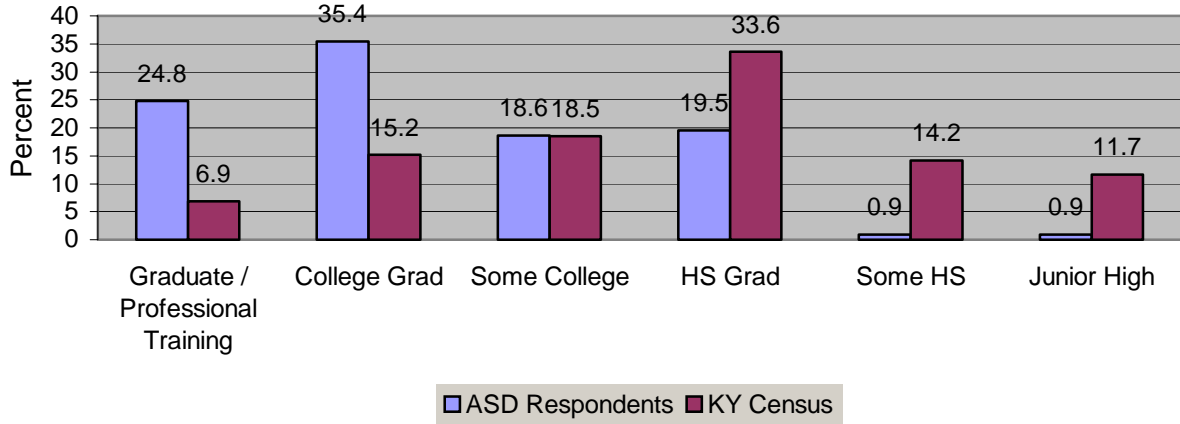
Figure 3. Respondent



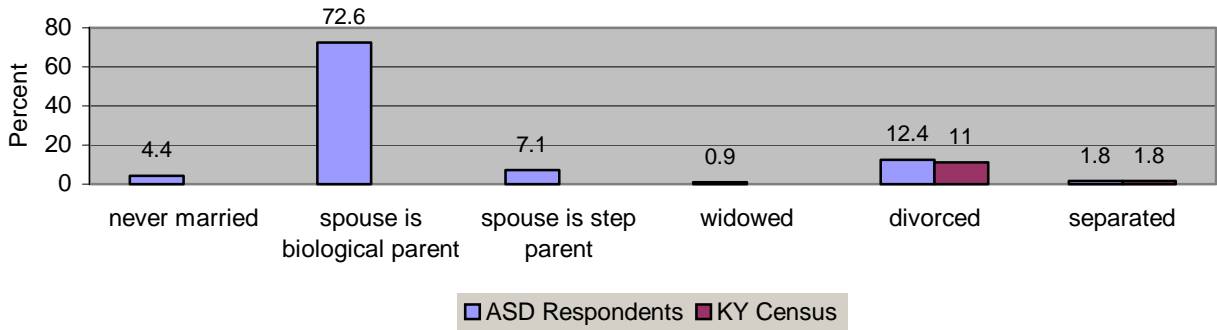


(Reprinted with permission of the Kentucky Geological Survey.)

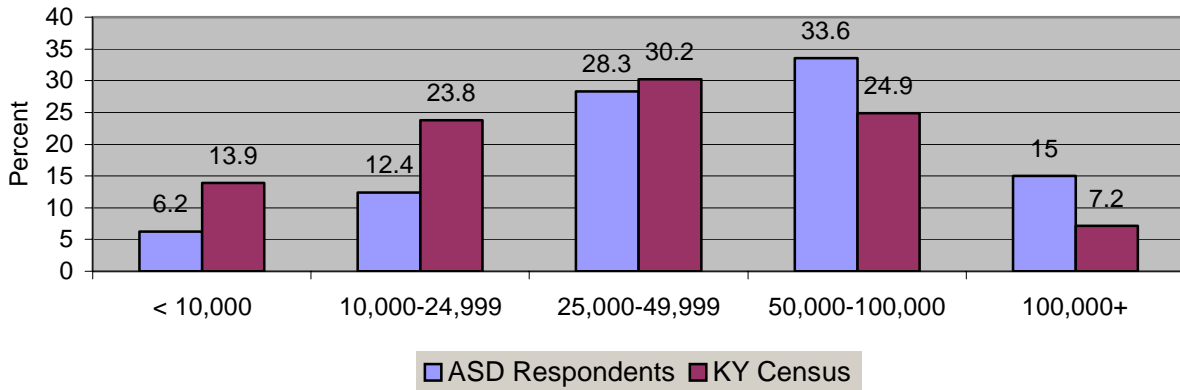
**Figure 5. Educational Background**



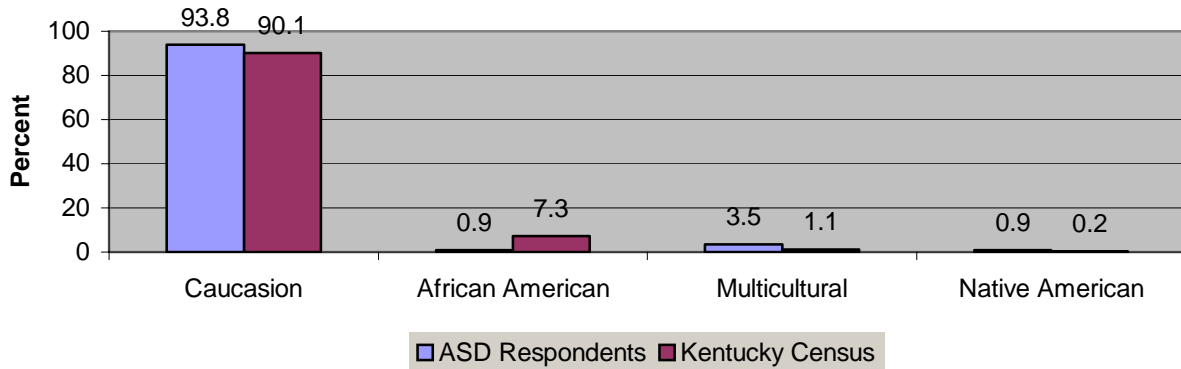
**Figure 6. Marital Status**



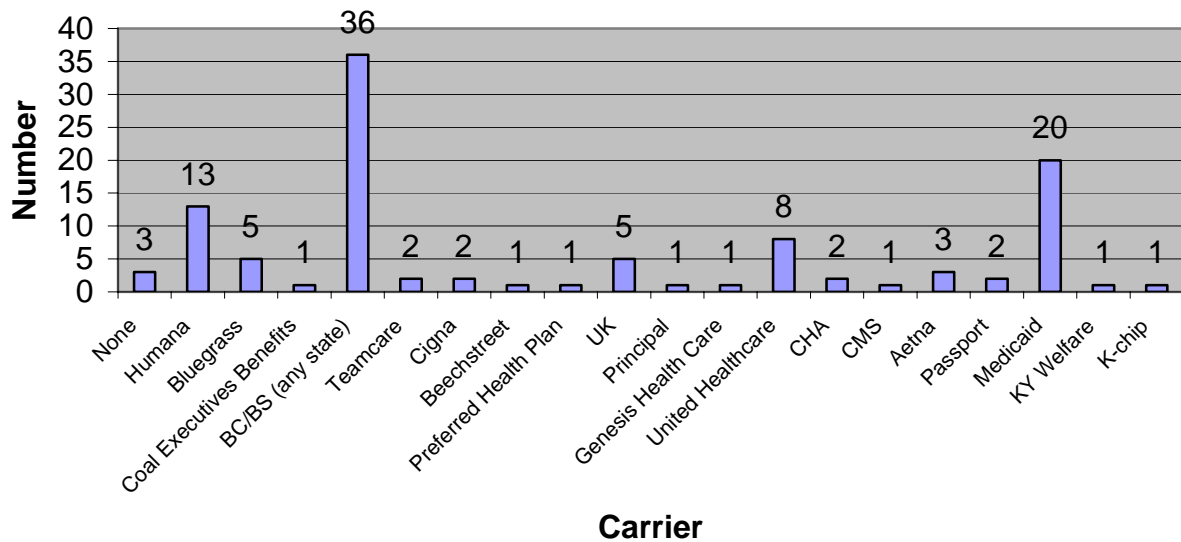
**Figure 7. Annual Income**



**Figure 8. Race**



**Figure 9. Insurance Carrier**



**Description of the Children and Adolescents**

Descriptions of the 113 children and adolescents represented in the study are provided in Table 1 and Figure 10. Most of the children fell between the ages of 6 and 11 years. The average age of the children was 9.9 years. The average age of diagnosis was about 3.7 years; treatment began on average when the children were 3.3 years. Apparently children entered treatment before receiving an ASD diagnosis. Seventy-seven percent of the children had an autism diagnosis (Figure 11); about 86% of the children were in public school programs (Figure 12) and attended a general education classroom (Figure 13).



Table 1. Description of Children

Variable	Response	
Gender	Males	98 (87%)
	Females	14 (12.5%)
Age	Mean	9.9 years (SD: 4.4) range 2.5-21.0 years
Age Diagnosed		3.7 years (SD: 2.7) range 1-16 years
Age TX started		3.3 years (SD: 2.9) range 0-18 years
Number on Medications		71 (62.8%)

Figure 10. Distribution of Individuals with ASDs by Age

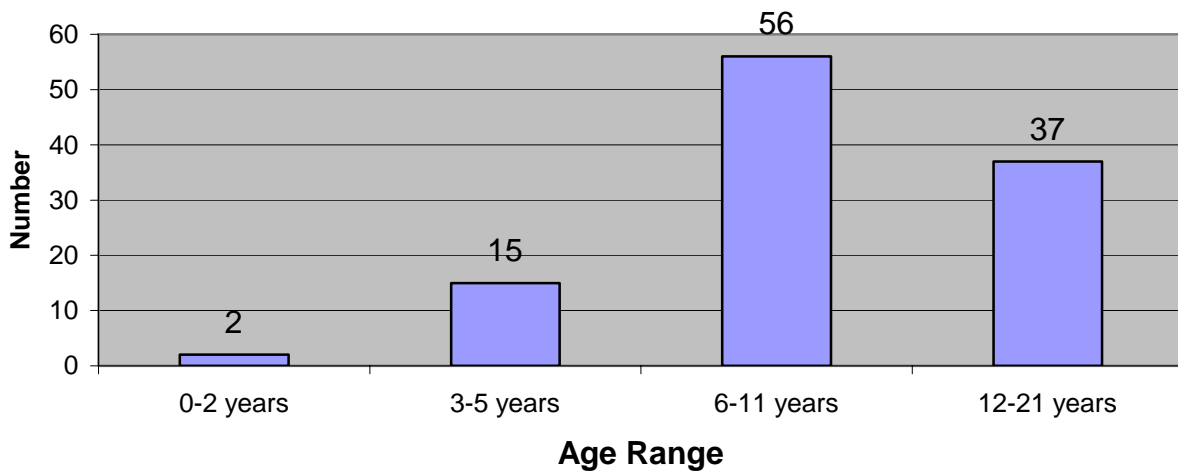
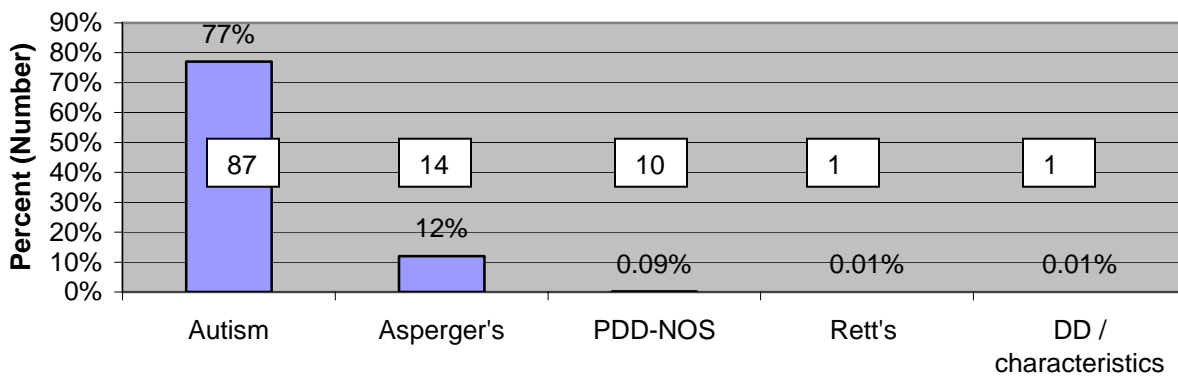
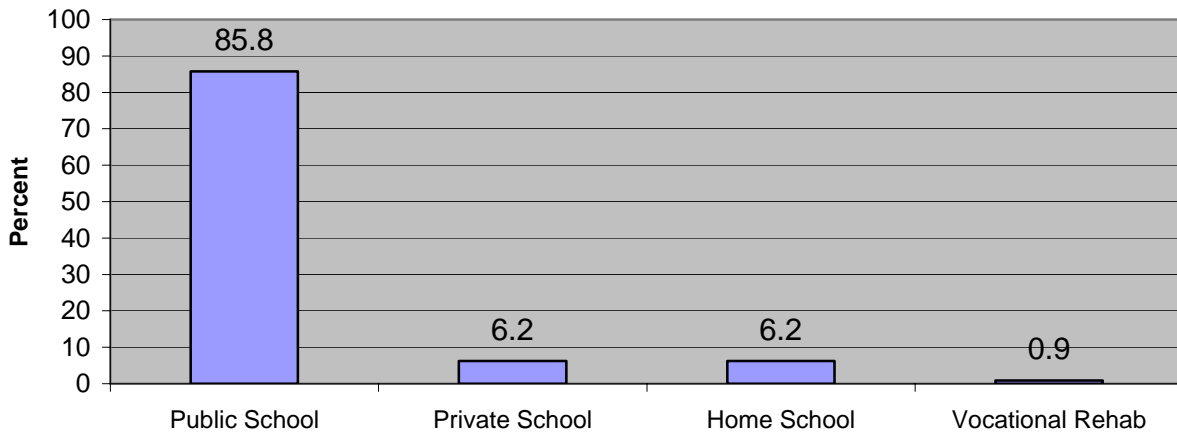


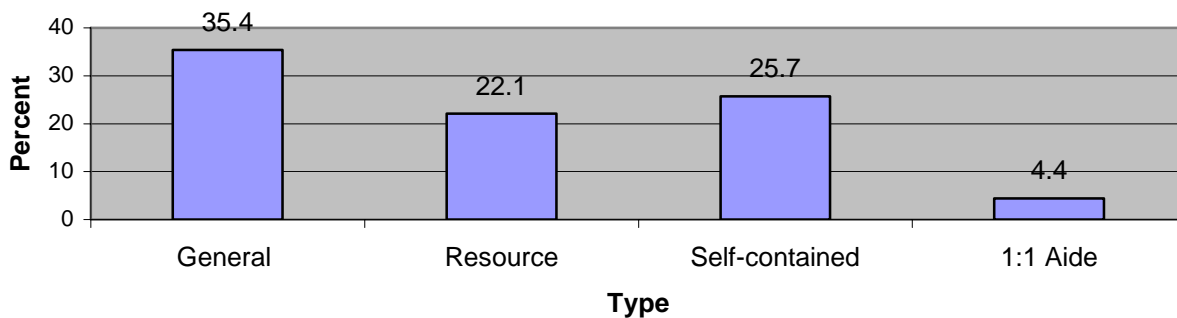
Figure 11. Percent and Number of Children by Diagnosis



**Figure 12. Type of Program**



**Figure 13. Type of Classroom Attended Most of the Day**



**Mode of Service Delivery: What and How Many Services were Utilized and What were the Outcomes?**

Information on services listed in Table 2, utilization, costs, and outcomes was collected. Parents and caregivers were asked to rate only those services that were received in the last **six** months. Parents also rated their level of stress caused by issues having to do with their child. Using a scale from 1 (no problem) to 10 (big problem), parents and caregivers reported an average rating of **7**.

Table 2. Types of Services Surveyed

Type of Service
• Inpatient Hospitalization or Residential Care
• Medication Management
• Parent Counseling or Training
• Individual Therapy for Child or Adolescent
• In-Home Behavior Therapy
• Speech and Language Therapy
• Occupational Therapy
• Case Management
• Respite Care
• Other Services

**Inpatient Hospitalization or Residential Care**

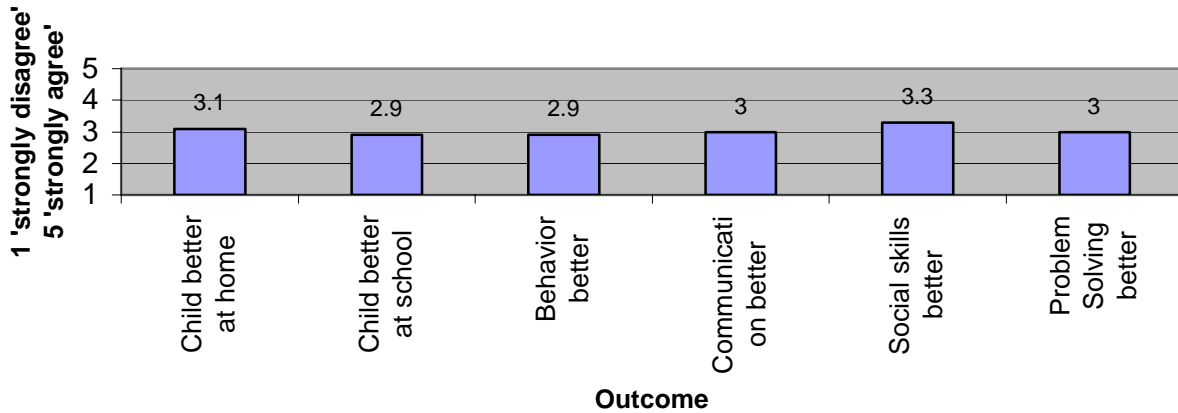
Table 3 lists the payor of the service, who refused to fund the service, if the decision was appealed, and if services were received following appeal. Using a scale from 0 (as bad as a program can be) to 10 (as helpful as a program can be), parents rated the agency that funded the service.

A total of 7 children spent an average of 47 days in psychiatric hospitalization or residential placement. The number of days ranged from 1 to 168. Medicaid was the payor for most children and refused payment for one child, but paid when the decision was appealed. Private insurance paid for 2 children and refused payment for 1 child. Figure 14 shows the outcomes of residential or psychiatric hospitalization on the child, and Figure 15 shows the outcomes on the family, including whether there was less financial stress as a result of the service.

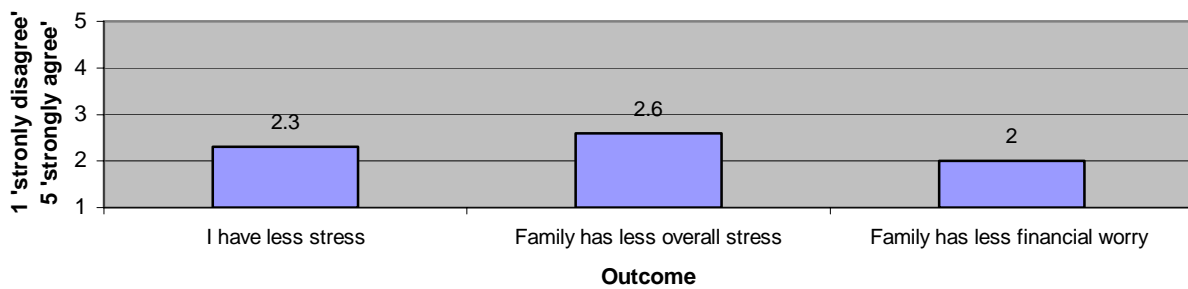
Table 3. Who Paid for Psychiatric Hospitalization or Residential Placement?

Payor of Service	Funded	Refused	Appealed	Received Services
Private Insurance	2	1		
Medicaid	5	1	1	1
Waiver (HCB)	2			
Impact				
Impact Plus	1			
EPSDT				
School system				
Other				
Self pay				
Total self pay amount				
<b>Mean Rating</b>	<b>7</b>			

**Figure 14. Parent-Reported Child Outcomes Following Residential Placement**



**Figure 15. Parent-Reported Outcomes Following Residential Placement**



### Medication Management

A total of 71 children and youth (62.8%) were treated with medications. Reasons for medications are listed in Table 4. In the last six months, 48 or 67.6% of the 71 children received medication management. Also listed is the number of drugs for behavior and total number of medications used.

Table 4. Types, Reasons, and Numbers of Medications Used by Children

Type of Psychotropic Drugs	Number of Children	% of Total
Antipsychotics	24	21.2
Antidepressants	29	25.7
Mood Stabilizers	2	1.8
Stimulants	13	11.5
Sedatives or hypnotics	6	5.3
Antihypertensives	7	6.2
Anticonvulsants	9	8.0
Miscellaneous Other	33	29.2

<b>Number of Drugs for Behavior</b>		
1	20	17.7
2	9	8.0
3	3	2.7
<b>Number of Total Medications</b>		
1	27	23.9
2	24	21.2
3	8	7.1
4	5	4.4
5	3	2.7
6	2	1.8

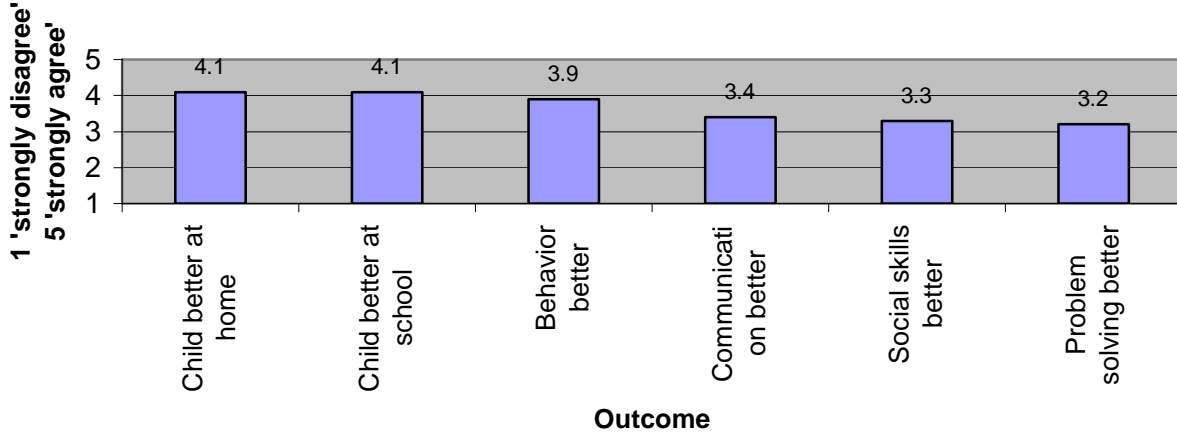
Of the 48 children who received medication management services within the last 6 months, they were seen 3 times on average. The number of trips ranged between 1 and 10 visits. Private insurance was the most common payor, followed by families (Table 5).

Table 5. Who Paid for Medication Management

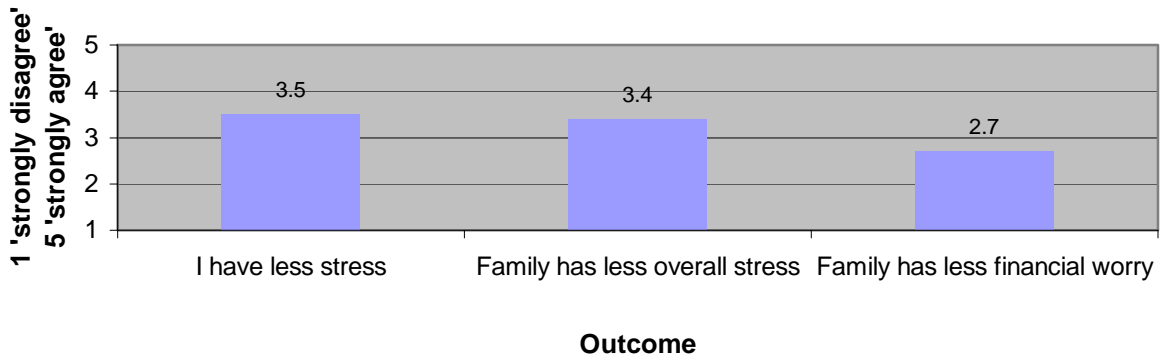
<b>Payor of Service</b>	<b>Funded</b>	<b>Refused</b>	<b>Appealed</b>	<b>Received Services</b>
Private Insurance	21	6	1	
Medicaid	16	1	1	
Waiver (HCB)	1	1	1	1
Impact	1			
Impact Plus	2			
EPSDT				
School system		1		
Other	2			
Self pay	18			
Total self pay	\$1,266.00 (average) and \$4.00 - \$12,000 (range) \$174 (average when \$8,000 and \$12,000 removed) and \$4.00 - \$600.00 (range)			
<b>Mean Rating</b>	<b>7</b>			

Families traveled between 1 and 1200 miles for treatment. Three families traveled 710, 1,000, and 1,200 miles. Excluding these families who traveled extreme distances, the average number of miles traveled was 75 miles roundtrip (range from 1 to 380 miles total). Figures 16 and 17 show the child and family outcomes resulting from medication management.

**Figure 16. Parent-Reported Child Outcomes of Medication**



**Figure 17. Parent-Reported Family Outcomes of Medication**



**Counseling or Training**

Forty-one of the parents and caregivers received counseling or training regarding their child in the past 6 months on average of 7.7 times, with a range between 1 and 30 times. Parents / Caregivers were also the most frequent payor of this service (see Table 6). They paid between \$14.00 and \$1,800.00, with an average of \$389.00. When the two extreme variables were removed (\$1,000.00 and \$1,800.00), the average cost was \$186.00 and the range was \$14.00 to \$700.00 of out-of-pocket expenses. After families, school systems and Impact Plus were the most common payors. Figures 18 and 19 show the child and family outcomes of parent/caregiver counseling or training.

Table 6. Who Paid for Parent/Caregiver Counseling or Training

Payor of Service	Funded	Refused	Appealed	Received Services
Private Insurance	6	3	2	2
Medicaid	7	3		
Waiver (HCB)	3	2		
Impact	1	1		
Impact Plus	9	2		
EPSDT	1			
School system	9	2		
Other	5			
Self pay	16			
Total self pay	\$389.00 (average); \$14.00 to \$1,800.00 (range) \$186.00 (average when \$1,000.00 and \$1,800.00 removed) and \$14.00 to \$700.00 (range)			
Mean Rating	5.8			

Figure 18. Parent-Reported Child Outcomes of Parent/Caregiver Counseling

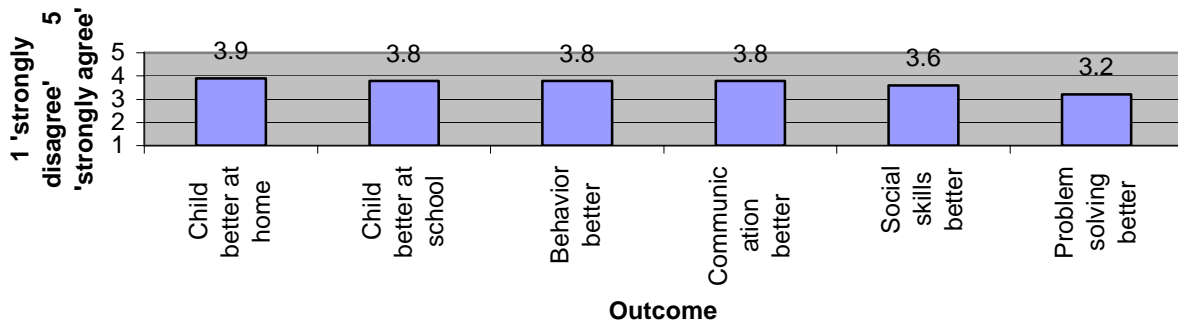
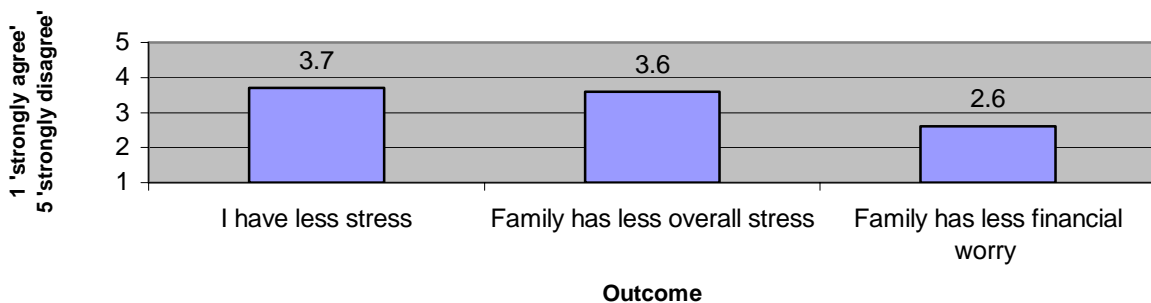


Figure 19. Parent-Reported Family Outcomes of Parent/Caregiver Counseling



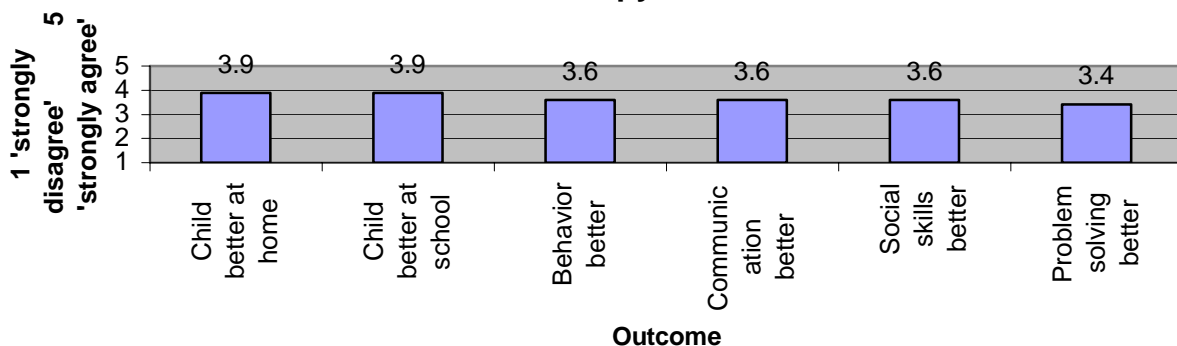
## Individual Therapy

Forty-seven of the respondents reported that their child received individual therapy in the last six months. They reported on average, their child was seen 52 times. Reports ranged from 1 to 168 sessions. Parents were the most common payor, followed by Medicaid. Parents paid on average \$347.00 when extreme values were removed (see Table 7). When these values were included, parents paid \$624.00 for individual therapy. Figures 20 and 21 show child and family outcomes of individual therapy.

Table 7. Who Paid for Individual Therapy?

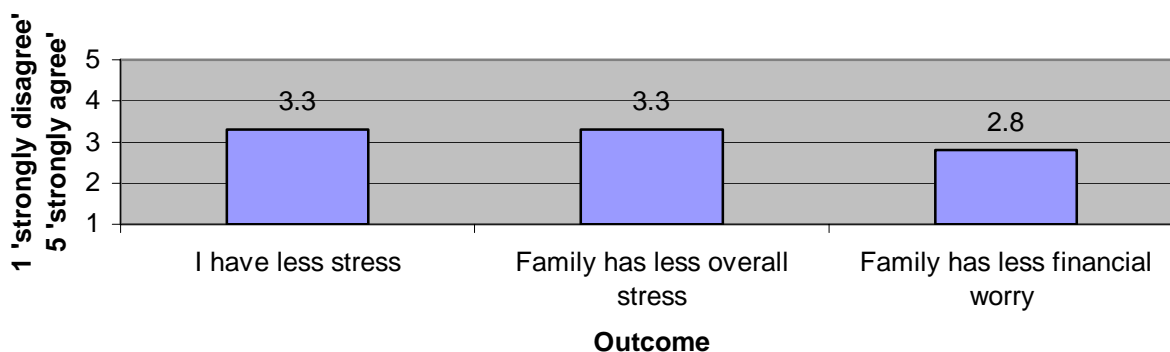
Payor of Service	Funded	Refused	Appealed	Received Services
Private Insurance	11	1		
Medicaid	12	3		
Waiver (HCB)	5	2	1	1
Impact		2		
Impact Plus	11	2		
EPSDT	4	1		
School system	9	1		
Other	1			
Self pay	14			
Total self pay	\$624.00 (average) and \$48.00 - \$2,000 (range) \$347.00 (average when \$1,000, 1,920, and \$2,000 removed) and \$48.00 - \$778.00 (range)			
Mean Rating	7			

Figure 20. Parent-Reported Child Outcomes of Individual Therapy





**Figure 21. Parent-Reported Family Outcomes of Individual Therapy**



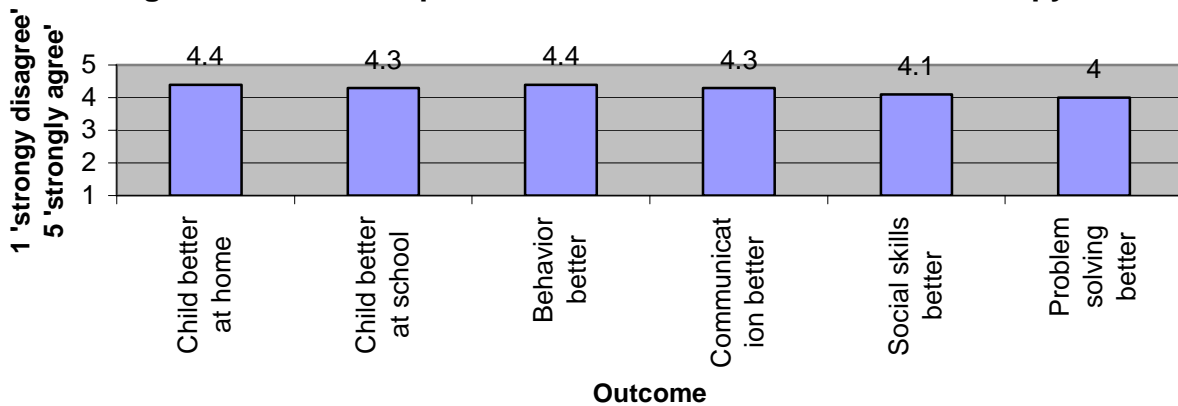
### In-Home Behavior Therapy

Twenty-five of the respondents reported that their child received in-home behavior therapy in the last six months. They reported on average, their child was seen 79 times. Reports ranged from 4 to 180 sessions. Impact Plus was the most common payor, followed by parents and caregivers (see Table 8). Ten parents and caregivers funded services themselves. On average, parents and caregivers paid \$3,734.00 for this service in the last six months. Child and family outcomes are shown in Figures 22 and 23.

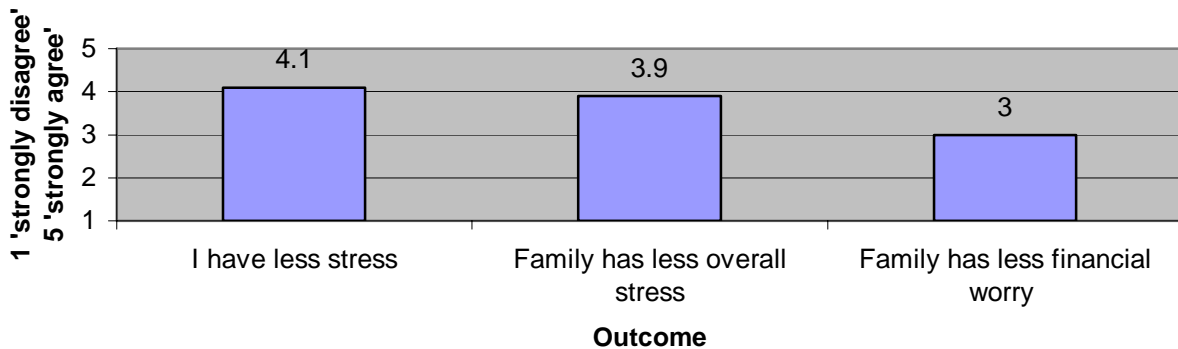
Table 8. Who Paid for In-Home Behavior Therapy?

Payor of Service	Funded	Refused	Appealed	Received Services
Private Insurance	2	5	1	1
Medicaid	4	3		
Waiver (HCB)	4	3	1	1
Impact		2		
Impact Plus	13	3	1	1
EPSDT	1	2		
School system	2	3		
Other				
Self pay	10			
Total self pay	\$3,734.00 (average) and \$500.00 - \$10,000 (range)			
Mean Rating	6.4			

**Figure 22. Parent-Reported Child Outcomes of In-Home Therapy**



**Figure 23. Parent-Reported Family Outcomes of In-Home Behavior Therapy**



### Speech and Language Therapy

Eighty-six of the respondents reported that their child received speech and language therapy in the last six months. They reported on average, their child was seen 42 times. Reports ranged between 4 and 168 sessions. School was the most common payor, followed by families (see Table 9). Family paid out-of-pocket an average of \$493.00. Figures 24 and 25 show child and family outcomes.

Table 9. Who Paid for Speech and Language Services?

Payor of Service	Funded	Refused	Appealed	Received Services
Private Insurance	10	5	1	1
Medicaid	11	1	1	1
Waiver (HCB)	3	1	1	1
Impact				
Impact Plus				
EPSDT	5			
School system	60			
Other	3			
Self pay	13			
Total self pay	\$493.00 (average) and \$90.00 - \$1,920 (range)			
Mean Rating	6.8			

Figure 24. Parent-Reported Outcomes of Speech/Language Therapy

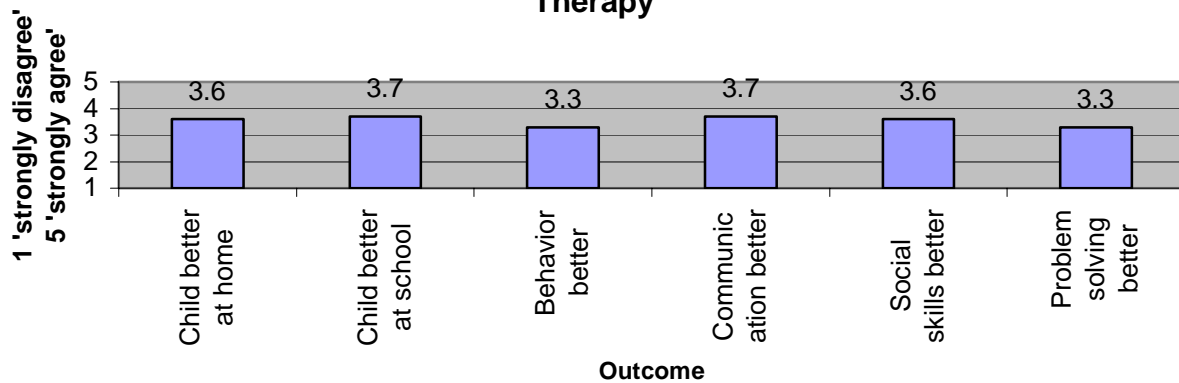
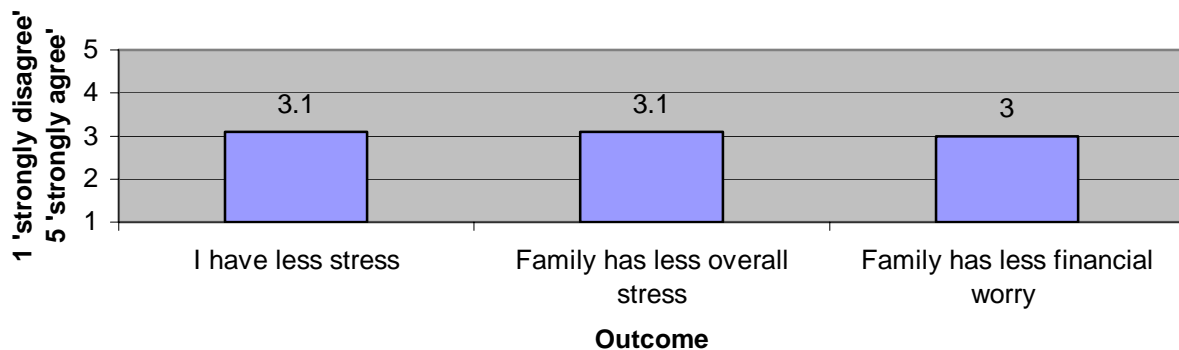


Figure 25. Parent-Reported Family Outcomes of Speech/Language Therapy



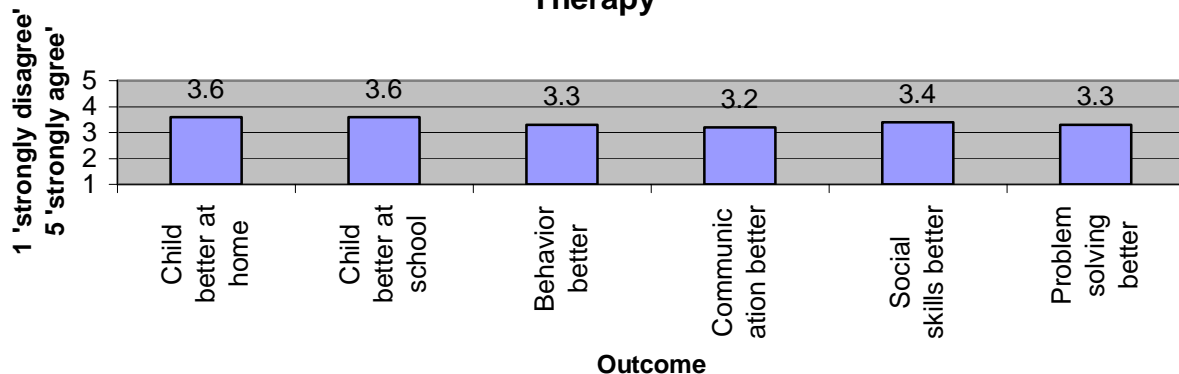
## Occupational Therapy

Seventy-seven of the respondents reported that their child received occupational therapy in the last six months. They reported on average, their child was seen 29 times. Reports ranged from 1 to 168 sessions. Schools were the most common payor, followed by Medicaid and private insurance (see Table 10). Figures 26 and 27 show child and family outcomes of occupational therapy.

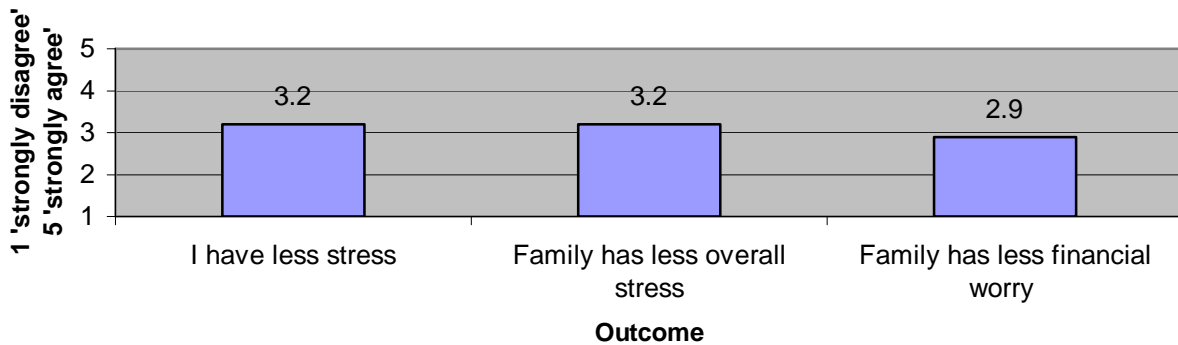
Table 10. Who Paid for Occupational Therapy?

Payor of Service	Funded	Refused	Appealed	Received Services
Private Insurance	13	2		
Medicaid	15			
Waiver	2	1	1	1
Impact				
Impact Plus				
EPSDT	5			
School system	49			
Other				
Self pay	4			
Total self pay	\$560.00 (average) and \$280.00 - \$1,080.00 (range)			
Mean Rating	6.6			

Figure 26. Parent-Reported Child Outcomes of Occupational Therapy



**Figure 27. Parent-Reported Family Outcomes of Occupational Therapy**



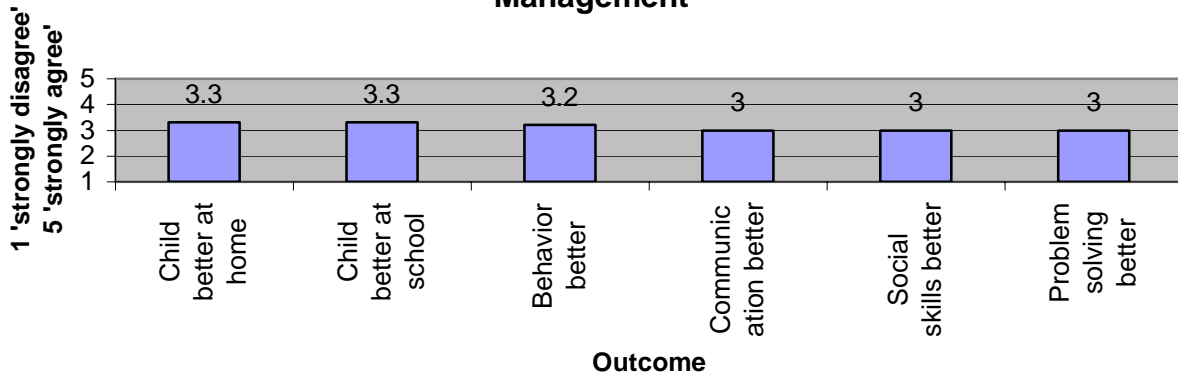
### Case Management

Thirty respondents reported receiving case management in the last six months. They reported on average, their child was seen 11 times. Reports ranged from 2 to 73 sessions. Impact Plus followed by Medicaid and Medicaid Waivers paid for the service (see Table 11). Figures 28 and 29 show child and family outcomes of case management.

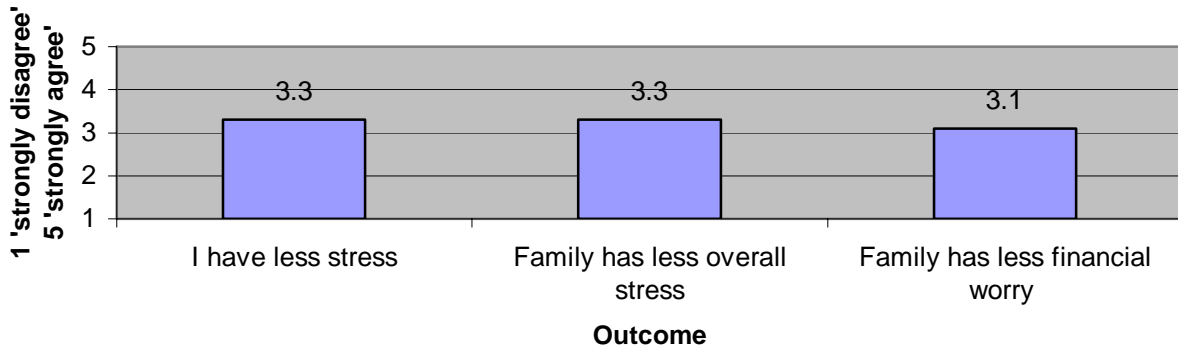
Table 11. Who Paid for Case Management?

Payor of Service	Funded	Refused	Appealed	Received Services
Private Insurance		1		
Medicaid	9			
Waiver (HCB, SCL)	10	1	1	1
Impact	4			
Impact Plus	18			
EPSDT				
School system	1			
Other	1			
Self pay				
Total self pay			0	
Mean Rating			6.7	

**Figure 28. Parent-Reported Child Outcomes of Case Management**



**Figure 29. Parent-Reported Family Outcomes of Case Management**



**Respite**

Thirty-three of the respondents reported that they received respite care in the last six months. They reported receiving an average of 10 visits of respite care. Reports ranged from 1 to 50 visits. The Medicaid Waivers were the most common payor of respite care (see Table 12). Parents and caregivers also listed specific community mental health centers as payors (Communicare, Seven Counties Services, Lifeskills, North Key Community Care). Figures 30 and 31 show child and family outcomes of respite care.

Table 12. Who Paid for Respite Care?

Payor of Service	Funded	Refused	Appealed	Received Services
Private Insurance	2	4		
Medicaid	3	1		
Waiver (HCB, SCL)	13	2	4	4
Impact	1			
Impact Plus	3	1		
EPSDT				
School system		1		
Other	9			
Self pay	2			
Total self pay	\$450.00 (average) and \$10.00 - \$800.00 (range)			
Mean Rating	7.1			

Figure 30. Parent-Reported Child Outcomes of Respite Care

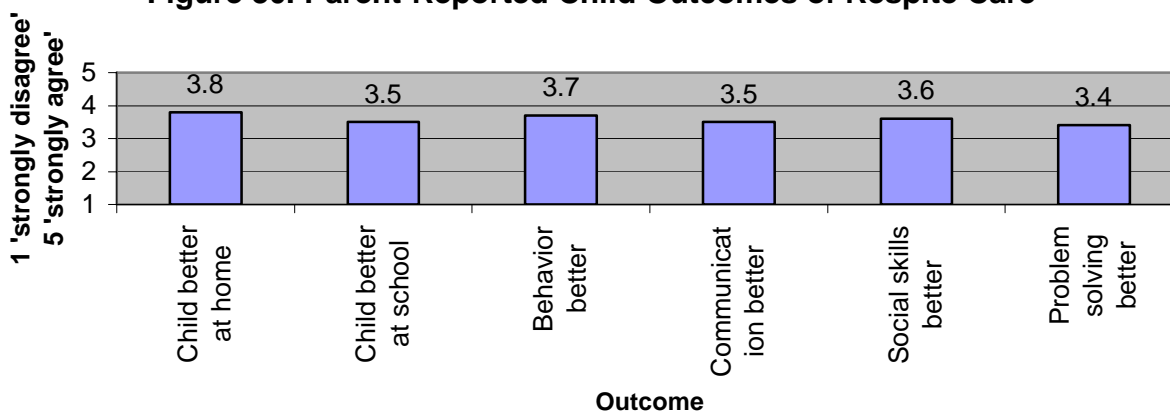
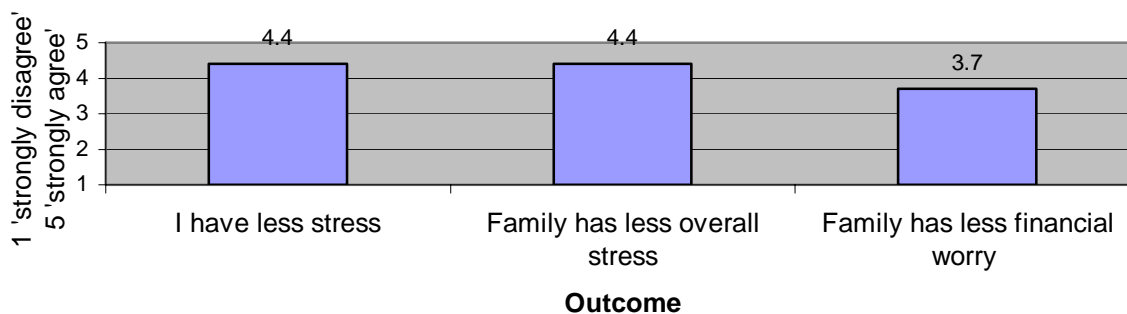


Figure 31. Parent-Reported Family Outcomes of Respite Care



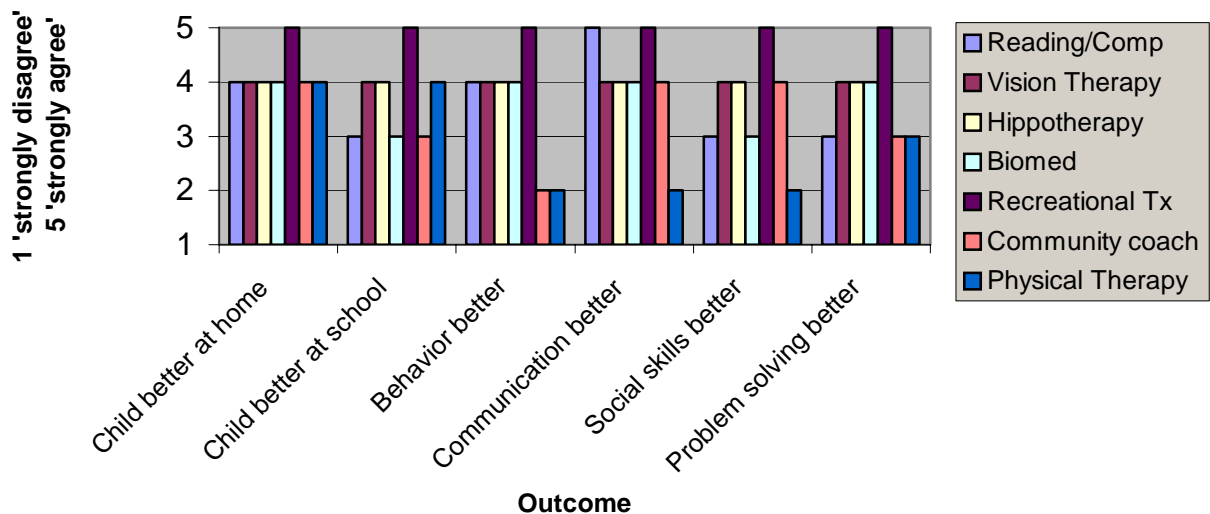
## Other Services

Fourteen parents and caregivers reported additional treatments received, costs for these interventions, and outcomes. Table 13 lists the treatment or intervention. Figures 32 and 33 show the child and family outcomes.

Table 13. Description of Additional Interventions

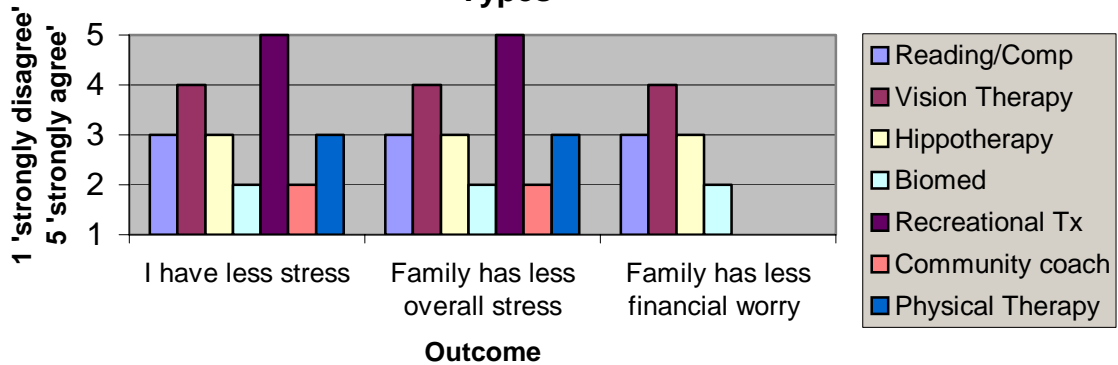
Description of Intervention	Number Reported	# Times Seen	Payor	Out-of-pocket average cost
Reading Comprehension	1		School	
Vision Therapy	1		School	
Hippotherapy	2		Self	\$490.00
Biomedical	1		Self	\$140,000.00
Recreational Therapy	2		EPSDT/ School/ Self	\$355.00
Community Coaching	1	9	Self	\$1,800.00
Physical Therapy	2	48	Medicaid / Other	

Figure 32. Parent-Reported Outcomes of Other Types of Services





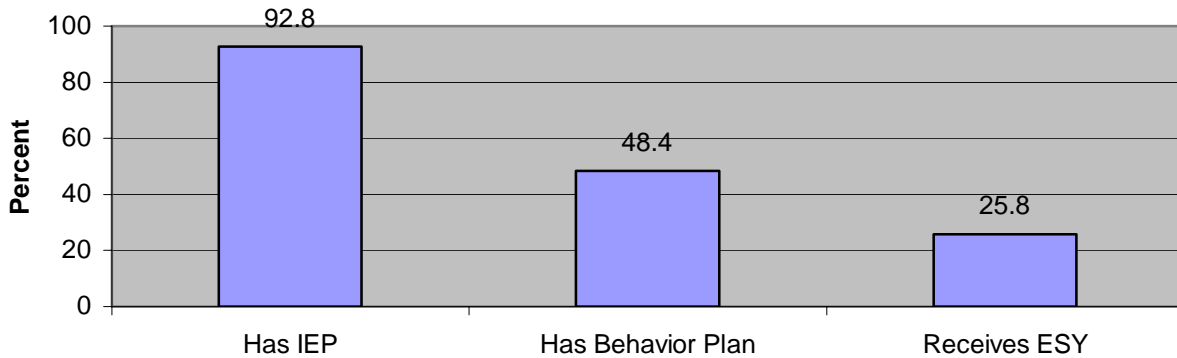
**Figure 33. Parent-Reported Family Outcomes of Other Service Types**



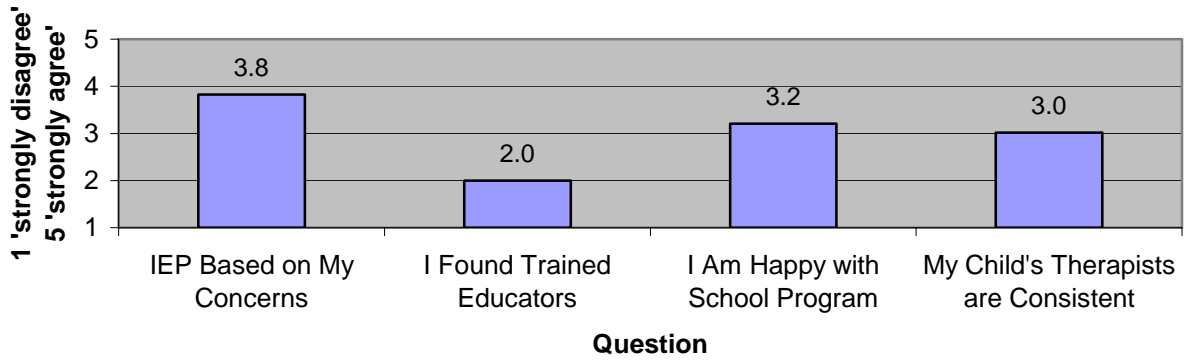
## Educational Services

Ninety-seven (85.8%) of the children and adolescents were served by public school programs. Ninety (92.8%) of these children had an Individual Education Program (IEP). Forty-seven of the children (48.4%) with an IEP had a behavior plan. Twenty-five children with an IEP also received extended school year services (25.8%) (see Figure 34). Figure 35 shows parent and caregiver perceptions of their child’s school program, and figure 36 shows perception of child behavior.

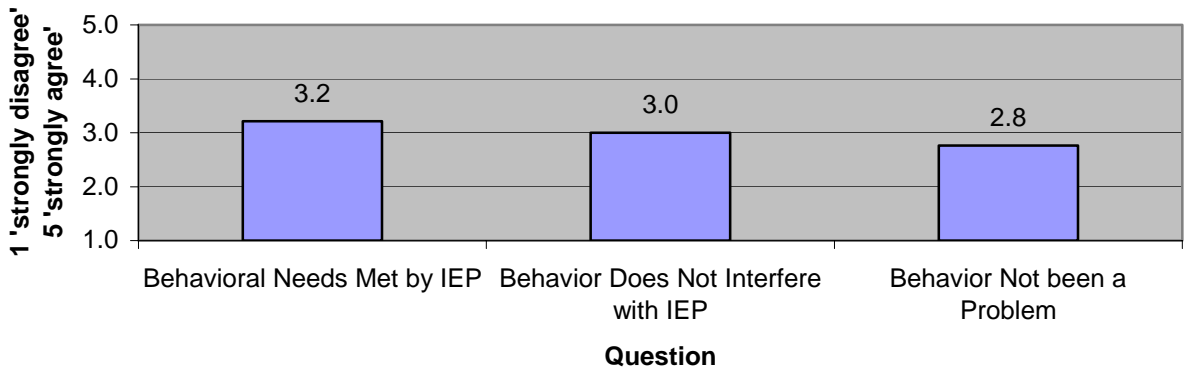
**Figure 34. Description of Educational Supports**



**Figure 35. Parent / Caregiver Perceptions of School Program**



**Figure 36. Parental Perception of Child Behavior and IEP**



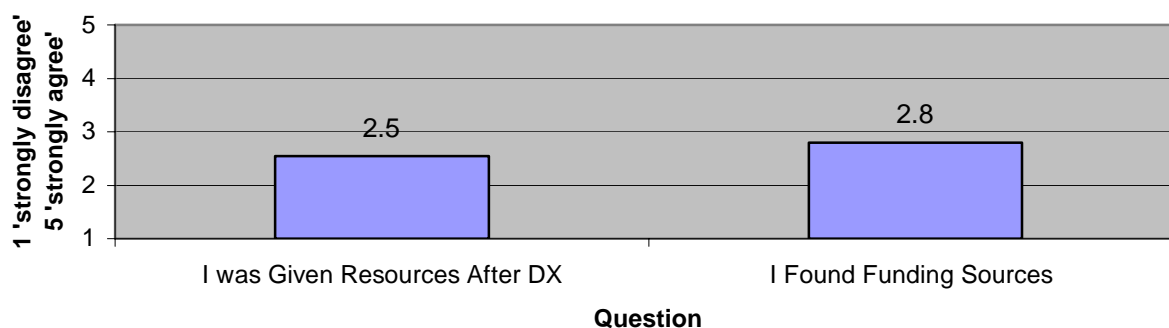
# Chapter 5

## Accessing the Treatment System for Autism Spectrum Disorders

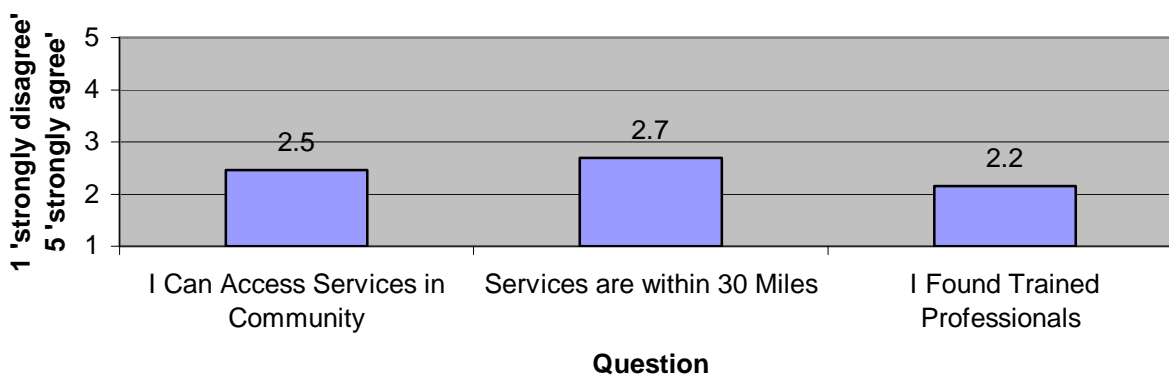
### Referrals to and Access to Services and Trained Providers

Parent and caregivers rated the degree to which they were given information on resources after the child's diagnosis and if they were able to access funding resources (see Figure 37). Figure 38 provides information on how accessible services were within the community and if trained professionals were located. Figure 39 describes parent and caregiver access to childcare within their family and in the community. Figure 40 shows which services parents rated as "highest priority" to obtain or increase.

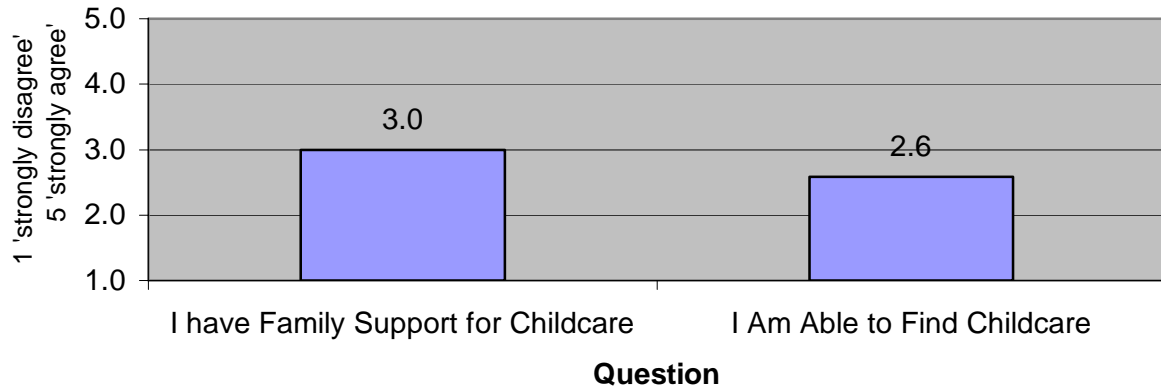
**Figure 37. Parent / Caregiver Report of Referrals to Resources**



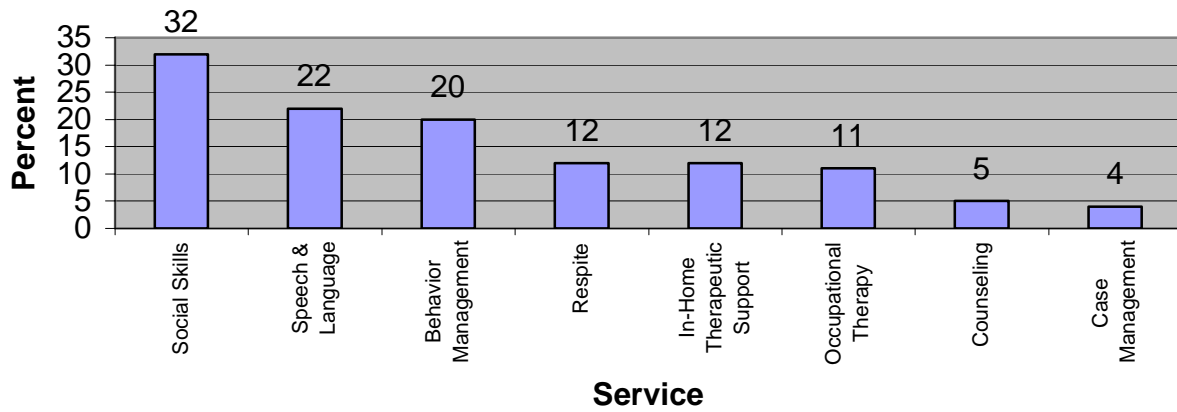
**Figure 38. Parent / Caregiver Report of Access to Services**



**Figure 39. Parent / Caregiver Perception of Access to Childcare**



**Figure 40. Percent of Parents / Caregivers Who Reported Services as "Highest Priority" to Obtain**



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## Summary

### Answers to Primary Questions

Answers to some of the main questions of this study are below:

1. Who was represented by the survey and how representative was the sample compared to residents across Kentucky?
  - The survey participants were generally representative of the demographic characteristics in Kentucky. One hundred and thirteen respondents resided in 46 counties in Kentucky. The marital status and racial backgrounds of the respondents were similar to reports from the Kentucky census; however, income and educational levels were somewhat higher in the sample.
2. What kind of health insurance did the respondents have?
  - Twenty-one percent of the respondents had publicly-funded health insurance (compared to about 25 % of Kentuckians),<sup>8</sup> 76% had private insurance (compared to about 62% of Kentuckians), and 2% had no insurance (compared to about 13% of Kentuckians).
3. How many parents, caregivers, and children with ASDs used behavioral / mental health services?
  - A majority of children and adolescents (52%) used behavioral or mental health services over the last 6 months. These services included in-home behavior therapy, individual therapy, or psychiatric hospitalization. When parent counseling or training was included, an additional total of 15 parents and caregivers were included, resulting in 65% of respondents using a behavioral or mental health service.

4. How many children received habilitative services such as speech and language therapy and occupational therapy?
  - A total of 71 children receive both speech and language therapy and occupational therapy. Six children receive occupational therapy only and 15 children receive speech and language therapy only. Overall, a total of 92 (81%) children received speech and language and / or occupational therapy services.
  - The school system was the most common payor of these services, followed by Medicaid and private insurance for occupational therapy.
  - After schools, parents were the most common payor of speech and language therapy, paying on average \$493.00 during the last six months.
  
5. How many children were treated with medications and how many of the medications were related to treatment for emotional, behavioral, or mental health disorders?
  - A majority of children and adolescents were treated with medications (63%). Forty-five percent of children were treated with medications related to emotional, behavioral, or mental health disorders.
  
6. How many of these children had comorbid diagnoses and what were they?
  - Forty-nine percent of the children had another diagnosis. Of these, 34.5 % was a mental health diagnosis.
  
7. How many children received public, private, and home school services?
  - Most of the children and adolescents were in public school programs (85.8%). About 6% were in private schools or were home-schooled.

8. How did parents and caregivers rate the program that provided funding for services and who was the most common payor for the service?

- On a scale from 1 (as bad as a program can be) to 10 (as helpful as a program can be), parents and caregivers rated funding sources for parent counseling and training as lowest in helpfulness.
- Parents were the primary or secondary payor of several behavioral or mental health services that are considered standard treatments for ASDs.
- Medicaid and Medicaid Waivers were the payor of less traditional services such as case management and respite care.

Table 14. Type of Service, Rating, and Payor

<b>Service</b>	<b>Rating</b>	<b>1<sup>st</sup> Payor</b>	<b>2<sup>nd</sup> Payor</b>	<b>3<sup>rd</sup> Payor</b>
Hospitalization/ Residential	7	Medicaid	Waiver / Private Insurance	Impact Plus
Medication	7	Private Insurance	Self	Medicaid
Counseling	5.8	Self	Impact Plus / School	Medicaid
Individual Therapy	7	Self	Medicaid	Impact Plus / Private Insurance
In Home Therapy	6.4	Impact Plus	Self	Medicaid / Waiver
Speech / Language	6.8	School	Self	Medicaid
Occupational Therapy	6.6	School	Medicaid	Private Insurance
Case Management	6.7	Impact Plus	Waiver	Medicaid
Respite Care	7.1	Waiver	Other	Medicaid / Impact Plus

9. How many families and children used services related to autism spectrum disorders and how much did families pay out-of-pocket for these services?

- Children with ASDs were substantial users of medical and behavioral health services and parents were often the primary payor of services; a majority (71%) of parents or caregivers paid for at least one type of medical or behavioral health service. Table 15 shows the number and percent of parents and caregivers who used a service and their out-of-pocket costs in the past six months.

Table 15. Number of Parents / Caregivers who Used Services, Number who Paid Out-of-Pocket, and Average Out-of-Pocket Costs

Type of Service	# Used (%)	# Self Pay (%)	Average Amount*
Inpatient Hospitalization or Residential Care	7 (6)	0 (0)	0 / 0
Medication Management	71 (63)	18 (25)	\$174 / \$1,266
Parent Counseling or Training	41 (36)	16 (39)	\$186 / \$389
Individual Therapy for Child or Adolescent	50 (44)	17 (34)	\$347 / \$624
In-Home Behavior Therapy	25 (22)	10 (40)	\$3,734
Speech and Language Therapy	86 (76)	13 (15)	\$493
Occupational Therapy	77 (68)	4 (5)	\$560
Case Management	30 (27)	0 (0)	0 / 0
Respite Care	33 (29)	2 (6)	\$450
Overall Total	420	80	\$6,024 / \$7,516
Overall Average	47	11	\$860 / \$1,074

\*The first amount represents the average once the extreme values are removed; the second amount is the average including the extreme values

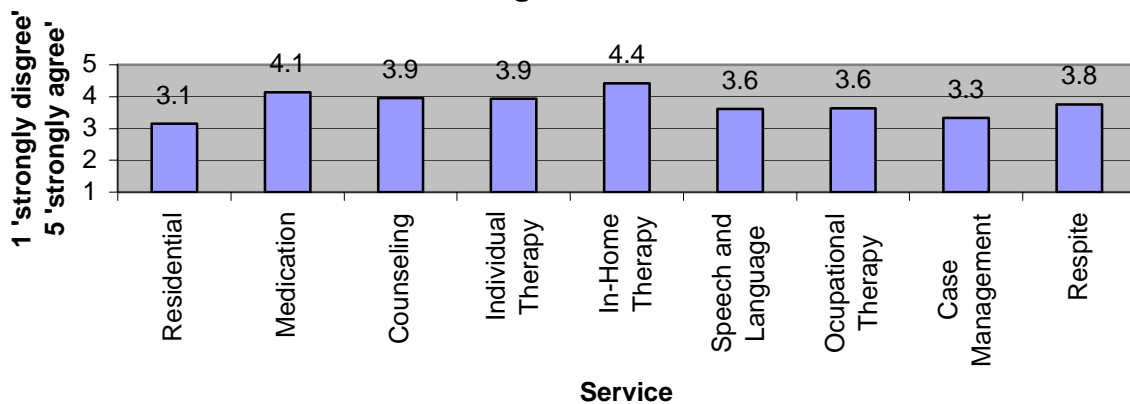
- Using a conservative estimate, the 80 parents who paid out-of-pocket expenses for services paid an average of \$860 (\$6,024 / 7) during the past six months; the actual average amount, which includes the extreme values, was \$1,074.



10. What service(s) provided the best outcome for the child and the family?

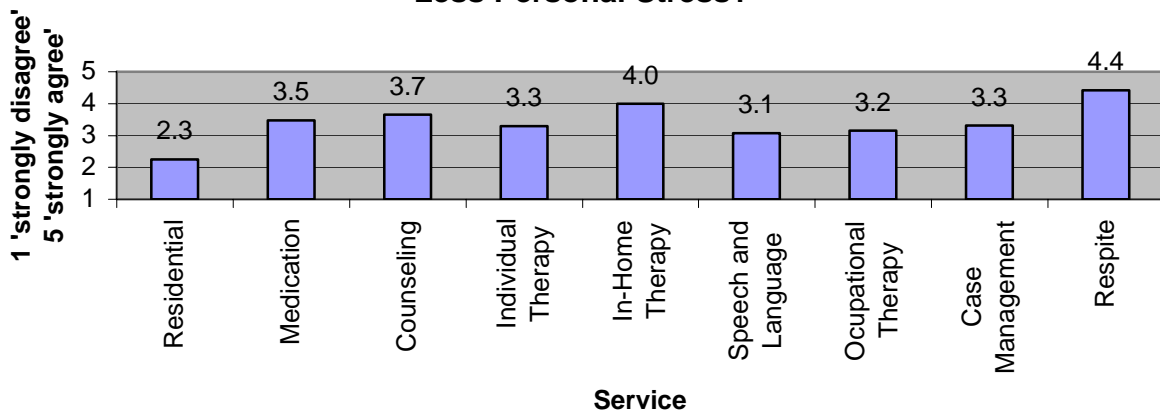
- Figure 41 shows that parents and caregivers indicated that all services were better than neutral (a rating of 3), with the slight exception of residential care. In particular, in-home behavior therapy, medication, parent counseling and training, and individual child therapy helped the child do better at home relative to other services based on parental / caregiver report.

**Figure 41. Parent / Caregiver Report: Does Service Result in Child Doing Better at Home?**



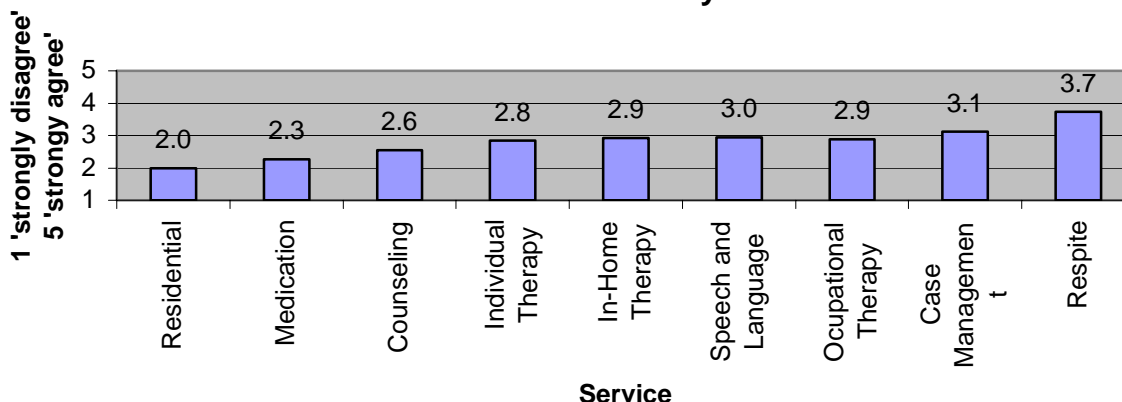
- With the exception of residential treatment, Figure 42 shows that respite care and in-home resulted in less personal stress compared to other services based on parental / caregiver report.

**Figure 42. Parent / Caregiver Report: Does Service Result in Less Personal Stress?**



- Parents and caregivers reported that respite care resulted in less financial worry relative to other services.

**Figure 43. Parent / Caregiver Report: Does Service Result in Less Financial Worry?**



11. What were parental views regarding satisfaction with child’s educational program?

- Of the 85.8% children who were in public school programs, parents and caregivers generally agreed that their concerns were reflected in their child’s educational program. Their report of satisfaction with their child’s program was generally neutral. Parents and caregivers generally disagreed that they were able to find educators trained in the latest methods of teaching children with ASDs.

12. What services did parents prioritize as high need?

- Parents and caregivers prioritized in order social skills, speech and language therapy, and behavior management therapy as the services of highest priority.

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## Recommendations

### Strengths and Gaps in Services

Based on reports of family and children needs, what are the strengths and gaps in services, and how do these findings relate to needed services for the treatment of autism spectrum disorders?

- **Consistency between service providers**  
Parents and caregivers reported that they were “neutral” with regard to the degree of consistency between teachers and therapists.
  - There needs to be more coordination between various service providers.
- **Inclusion of families in treatment / program planning**  
Parents and caregivers reported that they generally agreed that their child’s program included their concerns and input. However, parent training regarding their child is not a service parents report receiving from schools in general.
  - Schools need to provide more training and support to parents and caregivers (Section §300.24 of IDEA).
- **Speech-language therapy**  
About 3 of 4 children and adolescents received speech and language therapy. School was the primary payor, followed by parents and caregivers. Children are getting access to speech and language therapy, primarily through the public school system, rather than other public or private resources. However, parents and caregivers desire more speech and language services and are not getting the desired access to these services through Medicaid, the Waivers, EPSDT, or private insurance.
  - Parents need more access to speech and language therapy services.

- **Occupational therapy**  
 About 2 of 3 of the children received occupational therapy. The school system, followed by Medicaid were the primary payors. Children are getting access to occupational therapy, primarily through the school system.

  - Based on parents' and caregivers' reports, children are getting access to occupational therapy services. It is unclear whether children are receiving adequate access.
  
- **Summer programming**  
 About 1 of 4 of the children received extended school year services. Children are not getting access or continuity in services that will help them maintain skills.

  - Various agencies such as schools and departments of mental health and mental retardation need to work in a more coordinated fashion and provide more consistent programming for children and youth with ASDs.
  
- **Parent counseling or training (e.g., in behavior modification techniques)**  
 About 1 of 3 parents and caregivers received counseling or training and parents were the primary payor.

  - Parent counseling and training is a standard treatment for ASDs.<sup>1,3,6</sup> Funding agencies need to cover this service.
  
- **Individual therapy**  
 About 1 of 10 children and adolescents received individual therapy and parents were the primary payor. Children and adolescents are not getting access to individual therapy, based on parental and caregiver priorities for social skills and behavior management services.

  - Individual therapy is a standard treatment for ASDs and this service should be covered by public and private funding agencies so that parents can access services.
  
- **Medication management**  
 About 2 of 3 of the children were treated with medications and about 2 of 3 of these children were seen in the last six months.

  - Most children and adolescents who are treated with medications are seen every six months; however, there is still a need for more continuity of care.

- **Case management**  
 About 1 of 4 parents and caregivers received case management. Case management was only provided by public-funded agencies; private insurance did not fund case management. Thus, families with private insurance are not accessing this service. It is not clear if parents of private insurance would benefit from this service, although it was not listed as a highly desirable service in comparison.

  - More information is needed if parents and children with private insurance would benefit from this service.
  
- **Respite care**  
 About 1 of 3 parents and caregivers received respite care. Respite care was the service that parents and caregivers report resulted in less personal, family, and financial stress. Only parents and caregivers with access to the Medicaid Waivers were likely to receive respite care.

  - More families, with private and public-funded insurance, need access to trained respite providers.
  
- **In-home behavior therapy**  
 About 1 out of 5 children received in-home behavior therapy. In-home behavior therapy was the service that was most costly to parents. Parents were the second common payor of this service. Parents and caregivers with access to IMPACT Plus used this service more compared to other parents. This was also the service reported by parents and caregivers with the best outcome on the child and on the family.

  - More parents and caregivers need in-home behavior therapy and access to additional funding sources.
  
- **Inpatient hospitalization / residential placement**  
 About 1 out of 15 children and youth received inpatient hospitalization or residential placement. A strength is that there is a continuum of services; however, it is not known if parents have sought residential placement but were unable to receive it.

  - More information needs to be gathered on parent and caregiver's need for inpatient hospitalization or residential placement.

- **Experience with Medicaid**  
Although Medicaid is the most frequent funder of less traditional services such as case management or respite care. No parents or caregivers reported that services were funded by the Early Periodic, Screening, Diagnosis, and Treatment program.
  - Children who have Medicaid need access to services under EPSDT, such services may include but are not limited to standard treatments for autism such as behavior therapy, social skills training, parent training, and speech and language therapy.

## System-Level Strengths and Challenges

- Several potential funding sources appear to be available, yet parents and caregivers are often the primary payor of mental / behavioral health and habilitative services that are recognized as standard treatments for autism.
- Parents and caregivers identified additional behavioral health services such as social skills and behavior management as priority services they would like to increase or access. More information is needed on reasons for the barriers to access.
- Several services had a positive impact on child and family outcomes. But the impact of in-home behavior therapy on the child and family was notable (ratings of 4.4 for child and 4.0 for family). Medication, parent counseling and training, individual child therapy, respite, speech and language, and occupational therapy had positive child outcomes (ratings  $\geq 3.5$ ) for the child, and respite care, in-home behavior therapy, parent counseling and training, and medication (ratings  $\geq 3.5$ ) had positive outcomes for the family.
- Schools are often a primary payor of essential services such as speech and language and occupational therapy and a vital resource for families.
- Medicaid is a primary funder of all publicly-funded services for children and adolescent with ASD, yet many children and adolescents with autism spectrum disorders do not qualify for Medicaid services.
- Parents and caregivers with private insurance had less access to a variety of services such as respite care and case management.

- Children are not receiving a diagnosis until the age of 3.7 years. Autism can be screened at 18 months of age and diagnosed reliably in 2-year-olds.<sup>8-12</sup> Very young children with autism are not receiving the benefit of early intervention services through First Steps.
- Parents and caregivers reported consistently the lack of services within their community and the lack of trained professionals.
- Overall, parents and caregivers reported that they are not coping as well as can be due to issues regarding their child with ASD.
- There is a lack of statewide responsibility or oversight of treatment for children and adolescents with ASDs. Although three agencies provide funding for services, there is a complex arrangement between these agencies and programs. Children receive various services that are not applied systematically or consistently to families. More information is needed about the sources of funding, amounts of funding to public agencies, responsibilities of agencies for ASDs, and direction for the future. Other states such as Tennessee, Indiana, and Georgia have a state-wide plan for autism.

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