

Washington County CATCH Initiative:
Identifying Children's Mental Health Needs

Results of Parent Survey
December 2004

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Acknowledgements

This survey was made possible with funding from the American Academy of Pediatrics through a CATCH (Community Access to Child Health) Planning Grant.

A subcommittee of the Children's Mental Health Advisory Board (established to oversee this planning grant and process) deserves the credit for developing the survey protocol and creating survey questions. Members of this subcommittee included: Laura Jones, Parent/Parent Support Network; Cindy Simpson, Parent/CASSP; Bob Maltz, Narragansett Bay Pediatrics/South County Hospital; and Susan Orban, VNS Home Health Services/Washington County Coalition for Children. Members of this subcommittee logged in many hours developing this survey. David Robinson, Ph.D, of CERCA/MSPCA, and Mia Patriarcha, RI Dept. of Health, provided consultation to the subcommittee regarding survey development.

Parents were recruited to complete surveys through 19 different community partners. Without their assistance, this survey would not have been possible. These community partners included:

- Bradley School
- CASSP
- CODAC
- Family Service of RI
- Family Solutions CEDARR
- Frank Olean Center
- Head Start
- Narragansett Public Schools
- Narragansett Indian Health Center
- Private MD Offices
- Parent Support Network
- South County Community Action
- South Shore Mental Health Center
- South County ARC
- South County Child and Family Consultants
- Thundermist Health Center of South County
- Trudeau Early Intervention
- Westerly School Dept.
- Wood River Health Services

Data entry and compilation was completed by Archer Research under the supervision of statistician, Erik Lind. Louise S. Kiessling, MD, put in countless hours analyzing data results.

The most credit, however, goes to the parents and caregivers who took the time to complete surveys and give us their feedback regarding services in Washington County.

Robert Maltz, MD
 Chair
 Children's Mental Health Advisory Board
 Washington County CATCH Initiative

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EXECUTIVE SUMMARY

In 2003, the Washington County CATCH (Community Access to Child Health) Initiative was established to:

- 1) identify gaps in services for area children with emotional, behavioral and mental health needs and
- 2) make recommendations for change.

The initiative was funded through a grant by the American Academy of Pediatrics and overseen by the Children's Mental Health Advisory Board (comprised of key community stakeholders and parents). In order to identify and understand the mental health needs of children under age 21 and to assess the service and support needs of families in Washington County the initiative has engaged in three data collection activities:

- Key informant interviews
- Survey of parents
- 7 Focus groups (two with parents and one each with pediatricians, Head Start personnel, child care providers, mental health providers, and special education directors).

This report details the significant findings of the parent survey, which was conducted from February through July 2004. Unfortunately, due to funding and HIPAA regulations, a proper epidemiological study could not be conducted. Thus, a convenience sample was conducted with the aid of 19 community partners who invited interested parents to complete surveys. Although the inherent flaws of this survey design are recognized, the insight of 145 Washington County parents cannot be discounted.

This sample cohort consists of 145 parents/caregivers reporting information related to their 194 children (39 families reported having 2 or 3 children) with emotional, behavioral, or mental health problems, including substance abuse. Surveys were obtained from parents living in all 9 towns of the county, with the largest numbers of surveys obtained from parents living in the population centers, i.e. North Kingstown, South Kingstown, and Westerly. The majority of children in this survey cohort were older: only 27 (14%) were in the 0-6 year age group; 73 (39%) were in the 7-12 year age group; and 89 (47%) were in the 13-21 year age group. The cohort of children also consisted of significantly more males 128 (66%) than females 51 (26%). 14.1% of parents reported they have or suspect their child under age 21 has a substance abuse (drug or alcohol) problem. A break-down of the problems/diagnoses of children reported in this survey sample is as follows: 82 with Attention Disorders & Comorbidities; 17 with Anxiety; 63 with Disruptive Behavior; 67 with Depression/Mood Disorders; 24 with PDD/Autism; 15 with Substance Abuse; 12 with Other. The Other category includes: Schizophrenia, Eating Disorders, Cerebral Palsy, genetic anomalies, etc. (Note: Children may have more than 1 problem/diagnosis.)

Key findings include:

- **The lack of qualified local mental health providers** was cited repeatedly by parents in response to several survey questions. Over half (53.8%) of the parents (78 of 145) cited *Lack of providers in area* as a difficulty they have faced when trying to get mental health services for their children. In response to an open-ended question about what would make it easier to get needed mental health services for your child, 35 of 78 (45%) parents cited the lack of qualified mental health providers. Parents noted more providers are needed with the skill and training to deal with a variety of children's mental health and behavioral issues. Because local providers are limited, many parents have been forced to seek services out of the area. As a result, over one quarter (26.2%) of parents (38 of 145) listed *Distance from my home to treatment providers* as a difficulty faced in obtaining services for their children. In addition, 11.7% of parents (17 of 145) cited *Distance too far* as a barrier in transporting their children to mental health appointments.
- **The need for broader insurance coverage** was cited in response to several survey questions as well. 1/3 of parents (46 of 140) surveyed reported their child's health insurance has caused trouble in getting needed mental health services for their children. When queried as to what kind of trouble they have had, 37 (26.2%) parents noted *Finding an approved provider or services with the expertise my child needs*. Almost 20% of parents (27 of 141) cited difficulties in *Getting insurance approval for services*. Another 13.5% of parents (19 of 141) indicated *Cutting through 'Red tape' to get needed services* was an issue. Over 1/4 of parents (39 of 145)

indicated *Insurance limitations* had been a problem for them when asked to specify difficulties they have faced when trying to get needed mental health services for their children. In response to the open-ended question about what would make it easier to get needed mental health services for your children, 25.6% of parents (20 of 78) again cited insurance issues, underscoring the need for broader insurance coverage. Parents noted that Washington County children with private or no insurance (84%) receive less services than those with Medical Assistance (16%). Medicaid funds support services such as HBTS (Home Based Treatment Services), CIS (Children's Intensive Services), and respite care, which are not covered by most private insurance plans. Over half (52.6%) of parents (70 of 133) reported they pay out of pocket for mental health services not covered by insurance. Almost 20% of these parents indicated they must pay out-of-pocket for their children's mental health care because their providers do not accept insurance payments. Of those who are paying out-of-pocket for mental health services, 57% of parents indicated this posed a hardship for them.

- The **need for improved preventive/crisis intervention services** was also highlighted in survey findings. Almost 30% (43 of 144) of parents reported they have had to contact the police because of their child's behavior. This was most common in the 13-21 year age group (55.2%). 29.7% (43 of 145) of parents reported that their children had been seen in the Emergency Room or hospitalized for mental health reasons. Over half (52.5%) of these parents (21 of 40) indicated that this could have been avoided if counseling or other mental health services were available.
- The survey documents the need for mental health providers and schools to better **accommodate the schedules of working parents as well as the need to expand the current capacity of child care and after-school programs to care for children with mental health needs**. 74.8% of parents surveyed (107 of 143) are in the workforce, either part-time or full-time. 62.5% of parents (85 of 143) reported that within the last 12 months they had to miss work to tend to their child's mental health needs, such as service planning, appointments, conferences, school discipline meetings. The median # of days missed was 5. Of those reporting (23 of 70), 1/3 (32.9%) indicated they had missed 9 or more days of work for this reason in the last year. In addition, 20.7% of parents (30 of 145) cited *Work conflicts* as a difficulty they have faced when trying to get mental health services for their children. 30.2% of parents (42 of 139) reported having trouble finding child care because of their child's behavior or mental health issues; 59% of parents of children with PDD/autism reported this difficulty. In addition, 27.9% of parents (39 of 140) reported they have had trouble finding after-school care. Again, parents of children with PDD/autism reported having greater difficulties (63%). When asked what would make it easier to get needed mental health services for your children, 10.2% of parents (8 of 78), noted the need for more convenient office hours (evening and weekend appointments) for services.
- **Parents are being heard and respected during the creation of service plans.** One of the most positive findings of this survey related to parents' perceptions of their role in service planning for their children. 75% of parents surveyed (105 of 140) indicated that they have some type of service plan (i.e. Early Intervention IFSP, IEP, 504 Plan, CEDARR Family Service Plan, or CASSP Family Service Plan). Of these parents, 84% reported they felt they had an ***equal voice in the creation of service plans***.
- **Waiting lists were highlighted as a problem.** Over 1/3 of parents (37.9%) cited difficulties with Waiting Lists (55 of 145) in accessing services for their children. Many parents commented on the 1-2 year waiting lists for HBTS (Home-Based Treatment Services), the limited availability of respite care, and their need for additional timely support services. These needs are reflected in the following three remarks:
 - "Families with kids who have 24/7 care issues are isolated and exhausted. We need respite. We need in-home services. We need child care."*
 - "The state of RI will pay for HBTS, but the waiting lists are 1-2 years long and there is an extreme shortage of HBTS workers because of low pay so children who need these services never receive them."*

"Parents need support/respice funds. The divorce rate (lack of support) is so high amongst parents of special needs kids. We need help. We burn out despite extraordinary efforts to care for our children..."

In conclusion, results of this parent survey document that children's mental health needs in Washington County are not being adequately met. Significant gaps in services exist. The issues facing families as well as mental health providers in Washington County are complex and will require a coordinated and multi-faceted approach to improve service delivery. Key to these efforts is the need to address underlying policy issues, such as parity (comparability between insurance benefits for physical and mental health services), insurance coverage, and reimbursement rates. The current capacity of mental health services must be expanded in our community to meet the needs of families with children with emotional, behavioral, mental health, and substance abuse issues. It is in the interest of these children, their families and our community that we begin addressing these needs now. For the cost of our inaction. . . unnecessary psychiatric hospitalizations, residential placements, arrests, school failure, family disruption. . . is considerable.

BACKGROUND

Parents and professionals in Washington County, Rhode Island have had increasing concern about the mental health services available to children in their community. In an Issue Brief published by Rhode Island Kids Count in October 2002, concerns about services nationally and statewide were documented. They reported “there is an inadequate system of preventive services and supports for children and families at risk. In addition, there is an inadequate system of specialized services and supports for children with diagnosed mental illness or other special mental health needs”.

Data from the 1999 Surgeon General’s Report on Mental Health summarize a number of studies that conclude that 20% or one child in five between the ages of 9 and 17 has a diagnosable mental, behavioral or addictive disorder. The data are probably more complex than that. One of the best recent epidemiological studies of childhood psychiatric disorder has been the Great Smokey Mountain Study of Youth, which began with a large random sample of youth age 9-13, (over 11,000 in all) in 11 counties of North Carolina and then followed a cohort of 1420 children through age 16 (Costello, EJ et al., 1996, *Arch. Gen Psychiatry* 53: 1129-1136; Costello, EJ et al., 2003, *Arch Gen Psychiatry* 60:837-844). In the first study, the three month prevalence of a psychiatric diagnosis was 20.3%, similar to the other studies.

However, when they followed the subsample of 1420 children for 4 to 7 years, they found the 3 month prevalence dropped to 13.3% and that the 9 year old group had the highest number of diagnoses, but the number of diagnoses dropped to a low point at age 12 and then started up again to reach the 13.3 figure for a 3 month prevalence period at 16. Of note, a number of disorders decreased in frequency- enuresis, tics, separation anxiety, ADHD, while others increased- social anxiety, panic, depression, and substance abuse. That pattern is not surprising since a number of these “psychiatric disorders” are really developmental (enuresis) or neurological (tic) disorders which become less frequent with maturation. This points up the importance of another point made by the 2002 Issue Brief by RI Kids Count, namely that there needs to be parity between “physical” and “mental” health where insurance is concerned because the disorders are all really physical! Parity means there are no differential co-pays, for instance 20% for physical illness, but 50% for mental illness.

The Great Smokey Mountain Study also noted that once a child had one psychiatric diagnosis, they were three times more likely than the other children to acquire another one, especially if they were a girl. This was true despite the fact that girls were much less likely than boys to have an initial diagnosis. Another finding was that the severity of the disorders increased with age, and a larger percentage of both boys and girls with a psychiatric diagnosis qualified as Significantly Emotionally Disturbed at 16 than at age 9, suggesting either a move to a more severe disorder, little or no treatment, ineffective treatment or a lack of services and unresponsiveness of their environments so that the youth became less likely to succeed with increasing age, family, and/or school difficulty. The diagnoses tended to change as indicated above, often going to a more complex or severe diagnosis- ADHD to Oppositional Defiant Disorder, anxiety to depression, from anxiety to Conduct Disorder to substance abuse etc. With adolescence the severity of the disorders increased. We have no knowledge what kind of services, if any, these children had since this was not an interventional study, but the multiple year outcome is disturbing. Ultimately more than the 20% of the children had had at least one diagnosis by age 16.

We know that early recognition of children at risk for behavioral, developmental or mental health problems is crucial. The effective methods to do this, as well as the methods to train parents and educators to respond to these needs, are well documented in ***From Neurons to Neighborhoods, The Science of Early Childhood Development*** (Jack P. Shonkoff and Deborah A. Phillips, Eds. National Academy Press, Washington, DC, 2000). In summary, they note “The scientific evidence- ranging from behavioral genetics and neuroscience to policy analyses and intervention research- on the significant developmental impacts of early experiences, care giving relationships, and environmental threats is incontrovertable.----The question today is not whether early experience matters, but rather how early experiences shape individual development and contribute to children’s continued movement along positive pathways.” (p. 388) Integration of our knowledge into our services is critical.

The RI Kids Count Issue Brief mentioned above summarizes what else research tells us is necessary for a comprehensive program of mental health services for children, namely a continuum of treatment and intervention opportunities for the children identified with a mental health problem and support for the parents and families. Documenting the needs of this community as seen by the parents is a first step to improving services.

METHODS

The goal of this parent survey was to obtain information regarding:

- Service needs for families with children with behavior and mental health problems
- Gaps in existing services
- Barriers that prevent use of existing services

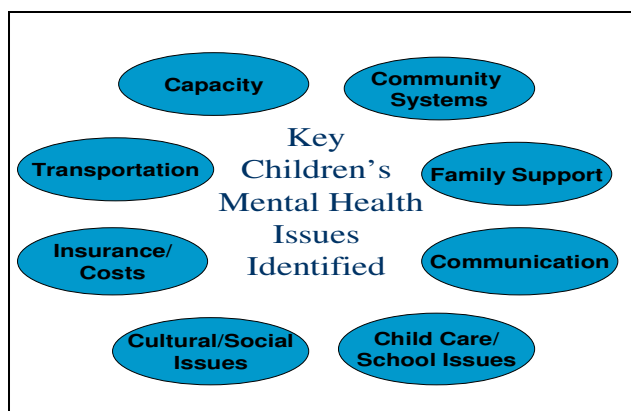
The target population for this survey was Washington County parents/caregivers of children < 21 years with behavioral or mental health problems. Unfortunately, due to funding and HIPAA constraints, a feasible approach for conducting a statistically valid random sample could not be developed. Instead, community agencies and providers, who had on-going relationships with Washington County parents, were utilized to identify and recruit parents to complete surveys. Although this methodology had inherent flaws, important information from 145 Washington County parents was still garnered.

The survey was administered over a 6-month period from February through July 2004. Parents were recruited to complete the self-administered written questionnaires by pediatricians' offices, schools, and social service agencies. 19 different community partners assisted in survey recruitment efforts, including:

- | | |
|-------------------------------------|---|
| • Bradley School | • Private MD Offices |
| • CASSP | • South County ARC |
| • CODAC | • South County Child and Family Consultants |
| • Family Service of RI | • South County Community Action |
| • Family Solutions CEDARR | • South Shore Mental Health Center |
| • Frank Olean Center | • Thundermist Health Center of South County |
| • Head Start | • Trudeau Early Intervention |
| • Narragansett Public Schools | • Westerly School Dept. |
| • Narragansett Indian Health Center | • Wood River Health Services |
| • Parent Support Network | |

In addition, a few parents requested surveys by phone in response to a press release that was issued about the survey. The survey was self-administered to allow parents the opportunity to speak frankly without fear of jeopardizing their relationships with service providers/recruiters. Although the survey was meant to be self-administered, survey recruiters were available to assist those parents with low-literacy skills if needed. Surveys were completed anonymously and placed in sealed envelopes by parents upon completion. Incentive coupons (for a free cup of coffee and muffin or Del's Lemonade and cookie) were given to parents by recruiters once surveys were completed. Survey envelopes were then mailed to Archer Research for data entry and analysis.

Survey questions were developed by a small sub-committee (with both parent and professional representatives) in collaboration with an outside consultant. The sub-committee met numerous times from September 2003 through January 2004 to design the ***Children's Mental Health Needs Survey***. Questions were created to explore issues that had been identified through key informant interviews as part of this CATCH initiative. These key issues are depicted in the diagram below:



The survey was reviewed and revised numerous times during development. Because the survey was to be self-administered, the length of the survey was limited to 4 pages (in an 11X17" booklet format). Before implementation, the survey was piloted with 5 parents at a local support group meeting. The survey was also reviewed and approved by the Children's Mental Health Advisory Board overseeing the CATCH initiative prior to administration.

A cover letter from Robert Maltz, MD, Chair of the Children's Mental Health Advisory Board, and flier regarding parent focus groups was part of each survey packet. Every community partner received detailed instructions as to how to administer the survey, numerous survey packets, mailing envelopes to Archer Research, and incentive coupons. Because they had infrequent in-person contact with parents, some partners mailed surveys to parents with another cover letter from them encouraging completion. Response rates to these mail surveys were surprisingly high.

Survey recruitment was initially planned for a 1-month period, however was extended over a 6-month period in order to solicit more parent surveys. Survey recruitment was ended when the number of surveys collected had diminished to less than 10 in the month of July. Information regarding the number of surveys collected with a break-down by age group, town, and agency was communicated to partners on a monthly basis throughout the survey fielding period.

CHARACTERISTICS OF SURVEY RESPONDENTS & THEIR CHILDREN

Total Surveys Submitted:	156
Countable Surveys:	145
Surveys Not Counted:	11

A Total of 156 surveys were collected from parents/caregivers. Of these, 145 were determined to be countable. 11 surveys could not be counted. The reasons why these surveys had to be discounted were: 5 were not residents of Washington County; 3 were duplicate responses; and 3 indicated that their child did not have an emotional, behavioral, mental health, and/or substance abuse problem or diagnosis.

The 145 families represented in this survey sample were recruited through 19 different sources. The recruitment source of the surveys clearly impacted the characteristics of the survey cohort. A break-down of countable surveys by recruitment source is as follows:

Recruitment Source	#(%) of Surveys
Bradley School	21 (14.5%)
South County Child & Family Consultants	19 (13.1%)
Frank Olean Center	18 (12.4%)
Parent Support Network	15 (10.3%)
CASSP	14 (9.7%)
Westerly School Dept.	8 (5.5%)
Wood River Health Services	8 (5.5%)
Private MD Office	7 (4.8%)
South County ARC	6 (4.1%)
Thundermist Health Center of South County	6 (4.1%)
Head Start	5 (3.4%)
CODAC	3 (2.1%)
Family Solutions CEDARR	3 (2.1%)
Narragansett Indian Health Center	3 (2.1%)
Trudeau Early Intervention	3 (2.1%)
Family Service of RI	2 (1.4%)
Phone Request	2 (1.4%)
South Shore Mental Health Center	1 (0.7%)
Narragansett Public Schools	1 (0.7%)

Surveys were obtained from families living in all 9 towns in Washington County. Towns with the greatest populations (i.e. North Kingstown, South Kingstown, and Westerly) garnered higher numbers of surveys. A break-down of surveys by town of residence is as follows:

Town of Residence	# (%) of Surveys
Charlestown	10 (6.9%)
Exeter	5 (3.4%)
Hopkinton	4 (2.8%)
Narragansett	12 (8.3%)
New Shoreham	1 (0.7%)
North Kingstown	29 (20%)
Richmond	9 (6.2%)
South Kingstown	43(29.7%)
Westerly	32 (22.1%)

Of the surveys in this sample:

- 127 (87.6%) were completed by biological parents
- 10 (6.9%) were completed by adoptive parents
- 6 (4.1%) were completed by grandparents, relatives, or other
- 2 (1.4%) were completed by foster parents.

The majority of surveys (93.1%) were completed by women: 135 women and 10 (6.9%) men completed surveys.

It should be noted that because this survey was self-administered, not all respondents answered every question.

Reflective of Washington County demographics, survey respondents were overwhelmingly White. Of those who reported their race on surveys:

- 119 (97.5%) indicated they were White or Caucasian
- 2 (1.6%) indicated they were Black
- 1 (0.8%) indicated they were Native American.

Survey respondents who reported Marital Status listed the following:

- 76 (60.8%) indicated they were Married
- 30 (24%) indicated they were Divorced
- 19 (15.2%) indicated they were Single.

Survey respondents were more likely to be over age 35. A break-down of surveys by age of respondents is as follows:

- Under Age 21 = 3 (2.1%)
- Age 21-34 = 24 (16.6%)
- Age 35-44 = 68 (46.9%)
- Age 45-54 = 42 (29.0%)
- Age 55 or Older = 8 (5.5%).

Survey respondents tended to be well educated. Most survey respondents reported they had continued their education after completion of high school. A break-down of surveys by respondents' educational status is as follows:

- Less than some high school = 2 (1.4%)
- Some high school = 4 (2.8%)
- High school diploma = 20 (13.9%)
- Some college = 50 (34.7%)
- Graduated from college = 37 (25.7%)
- Some graduate school education = 12 (8.3%)
- Graduate degree = 15 (10.4%)
- Technical certificate or specialized technical training = 4 (2.8%).

Annual household incomes of survey respondents tended to be greater than \$30,000/year. A break-down of surveys by income is as follows:

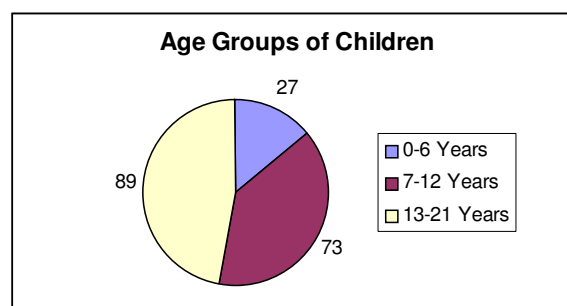
- Less than \$20,000 = 26 (18.6%)
- \$20,000 to less than \$30,000 = 23 (16.4%)
- \$30,000 to less than \$50,000 = 30 (21.4%)
- \$50,000 to less than \$75,000 = 29 (20.7%)
- \$75,000 to less than \$100,000 = 21 (15%)
- \$100,000 or more = 11 (7.9%)

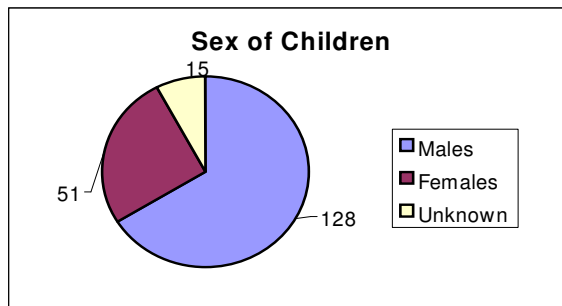
As to be expected, single and divorced parents were both more likely to report incomes <\$30,000/year. In addition, parents who reported using Community Health Centers generally had less than <high school education and made <\$30,000.

The median number of children under age 21 living in respondents' homes was 2.

The 145 families represented in this survey sample reported they had 194 children with mental health needs. 39 families indicated they had 2 children and 10 families reported they had 3 children in their families with mental health needs.

Children in this survey cohort tended to be older. Of those children for whom age was listed, only 14% (27) were in the 0-6 year age group. 39% (73) of the children were in the 7-12 year age group; and 47% (89) of the children were in the 13-21 year age group.





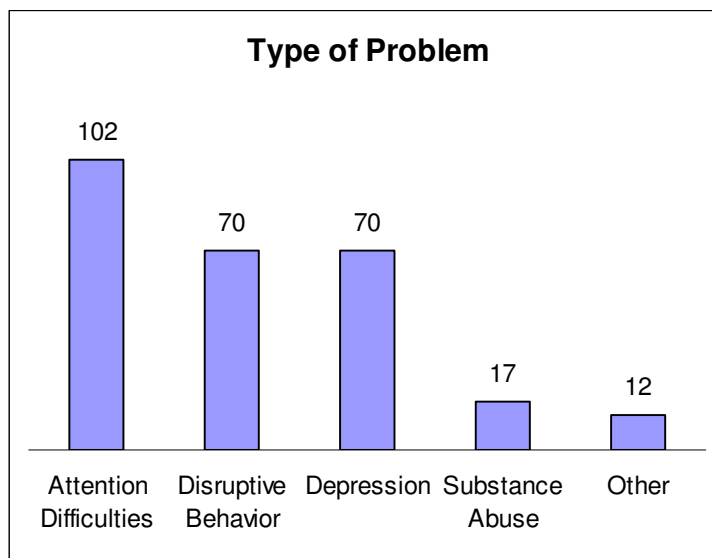
Significantly more males than females were reported with mental health needs in this survey cohort. 128 (66%) males compared with 51 (26%) females were reported. Note: sex information was not listed for 15 (8%) children in cohort. In the 0-6 age group, 20 of 21 are boys identified with problems while in the 7-12 age group it drops to 78%, and then 66% in the 13-21 year age group. Girls with mental health needs are significantly older than boys.

138 (97.2%) survey respondents indicated they have or suspect that their child under age 21 has attention difficulties, disruptive behavior, depression, or other mental health problem.

20 (14.1%) respondents indicated they have or suspect that their child under age 21 has a substance abuse (drug or alcohol) problem.

Respondents were asked to identify the type of problems their child has using the following designations:

Attention Difficulties *Disruptive Behavior* *Depression* *Substance Abuse* *Other*
 Parents could check more than one category if appropriate. Space was also provided on the survey to list their child's diagnosis, if any. A break down of the designations listed by parents is as follows:



Since children could display more than one type of problem, a break-down by the number of problems listed is useful in providing an indication of the severity of problems facing children in this cohort:

Children with 1 problem listed = 78

Children with 2 problems listed = 44

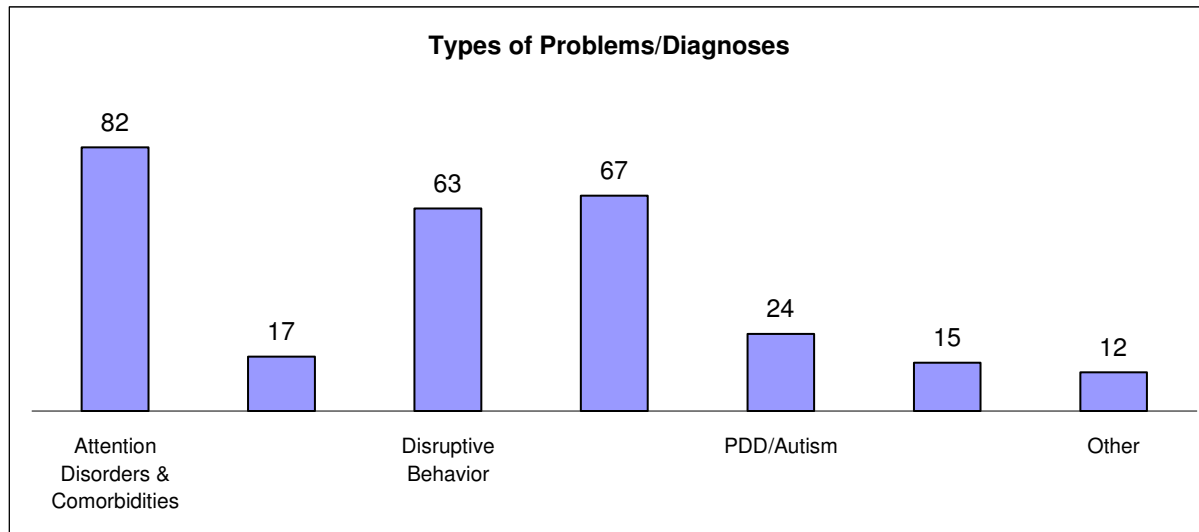
Children with 3 or more problems listed = 34.

Children with multiple, more severe mental health problems tend to be in the 13-21 year age group. 2/3 (15 of 21) of the parents surveyed from the Bradley School had children with 3 or more problems.

The problem categories above were selected by the survey sub-committee because they are non-clinical and easy-to-understand. For children for whom parents might suspect a problem and not yet have a formal diagnosis, the sub-committee thought these categories would have the most meaning for parents. However, few parents that were not

already involved in treatment services were recruited to complete surveys and 106 formal diagnoses were listed by parents on surveys. Given the availability of this data, a more refined analysis was conducted of the types of problems using the following categories:

- **Attention Disorders & Comorbidities** (including attention problems, ADHD, ADD, tics, Tourette Syndrome)
- **Anxiety** (including PTSD, Attachment Disorders, OCD)
- **Disruptive Behavior** (including ODD, Conduct Disorder)
- **Depression/Mood Disorders** (including Bipolar Disorder)
- **PDD/Autism** (reflecting the complete autism spectrum including Asperger's Syndrome)
- **Substance Abuse**
- **Other** (including Schizophrenia, Eating Disorders, Cerebral Palsy, genetic anomalies, etc.)



Using these problems/diagnoses to assess our survey cohort, we found:

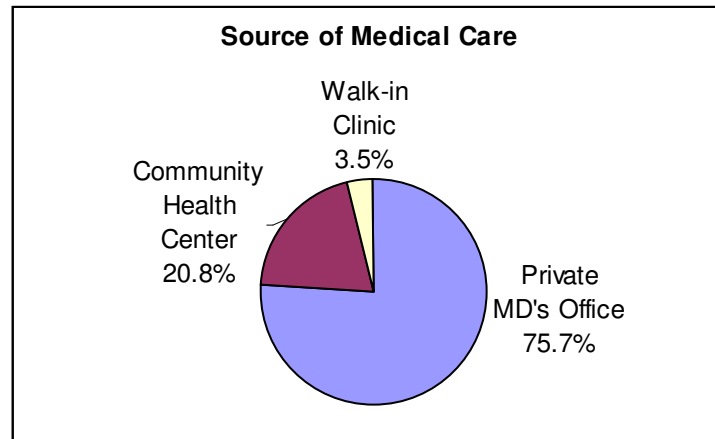
- All problem categories have a 3 or 4 boys to 1 girl ratio split, except depression and anxiety where the split is 2:1.
- Attention difficulties are highest among children ages 7-12 years.
- Children with anxiety are more likely to be in the 13-21 year age group than in the 0-6 year age group.
- Anxiety and substance abuse were more prevalent in the 13-21 year age group.
- Depression/mood disorders are significantly more prevalent (54.4%) in the 13-21 year age group than in the younger 2 groups.
- Children with PDD/autism are more likely to be younger and have Katie Beckett coverage.

SURVEY QUESTION RESULTS

Medical and Mental Health Resources

1. Where do your children usually go for their medical care?

The majority (75.7%) of children in this cohort receive their medical care in private doctors' offices. Children who have Medicaid are seen by private providers at a similar % as those seen by overall respondents. Almost 21% of children reported in this survey receive their care through Community Health Centers. 40% of the children surveyed using Community Health Centers have RIte Care.



2a. Does your child require medication to help manage his/her behavior or functioning?

69% Yes

31% No

A majority of the parents surveyed (98 of 142 reporting) reported their children require medication to manage their behavior or functioning. The most severely involved children (those with 3+ problems identified) are more likely to take medication. Children with attention difficulties, disruptive behaviors, or depression/mood disorders are significantly more likely to take medication than children with PPD/Autism (80+% vs. 56%).

2b. If Yes, who prescribes your child's medication?

70.7% Psychiatrist

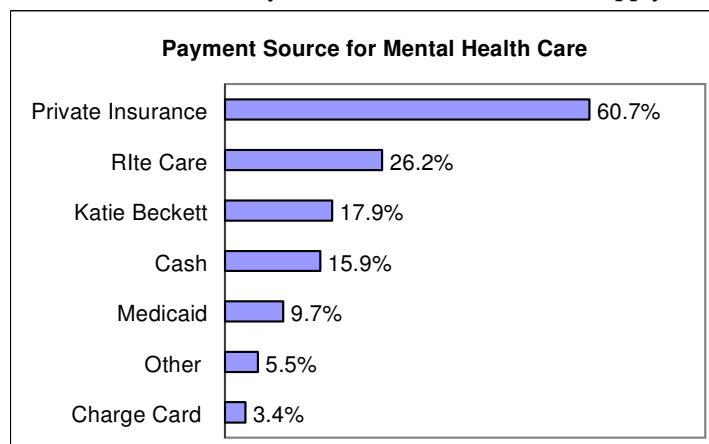
15.9% Pediatrician

11.0% Family Practice Physician

2.4% General Practice Physician

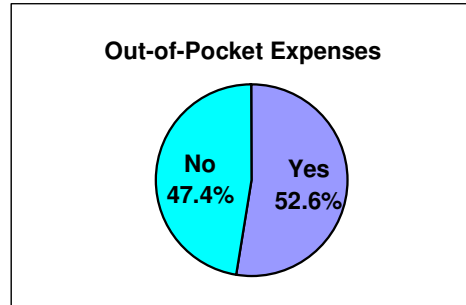
Despite the statewide shortage of child psychiatrists, almost 71% of the children requiring medication have it prescribed by a psychiatrist.

3. How do you pay for *mental health care* for your children? *Check all that apply*



Since only 16% of the county's children are covered by some form of Medical Assistance (i.e. RIte Care, FIP, SSI, or Katie Beckett), it is not surprising that the majority of parents (88 of 145 respondents) surveyed indicated their children's mental health expenses are paid for through private insurance. (Please note parents could have more than one source of payment/coverage.) 62.5% of those parents with children identified with PDD/autism reported having Katie Beckett Medical Assistance. Being involved with a CEDARR Family Center correlated with having Katie Beckett Medical Assistance.

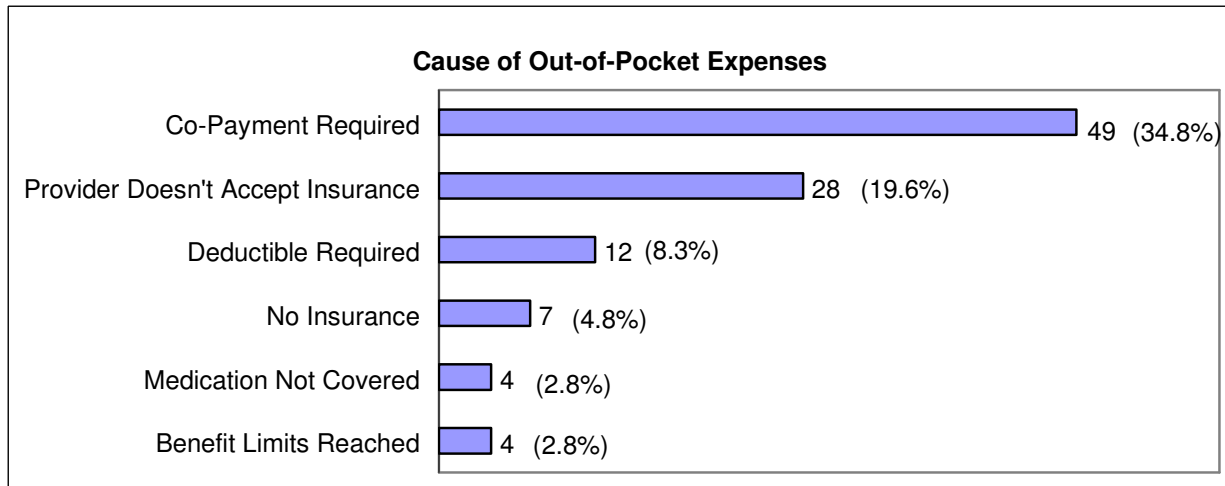
4a. Have you had to pay out of your pocket for *mental health* services not covered by insurance?



Over half of the parents surveyed (70 of 133 reporting) indicated that they had to pay out-of-pocket for *mental health* services not covered by insurance. Parents who work part-time are more likely to have to pay out-of-pocket for *mental health* services (62.5% or 25). Parents who are college educated and who have higher incomes are also more likely to have to pay out-of-pocket for *mental health* services. Children with PDD/autism are less likely to have co-pays required (given their Katie Beckett coverage). Parents of children with substance abuse problems are more likely to have a provider who accepts insurance and less likely to have to pay a deductible.

4b. If Yes, Why? Check all that apply

Parents cited the following reasons why they were paying out-of-pocket for their children's mental health care:



Other causes cited by parents for out-of-pocket expenses included:

- "Therapy services not covered"
- "Dr's do paperwork wrong"
- "Insurance does not cover certain lab work;" "Lab for medicine level check not covered."

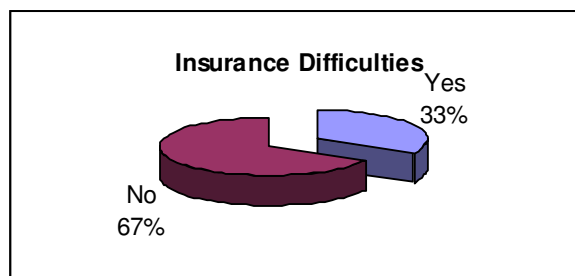
4c. Did you have difficulty paying for these *mental health* expenses?

- 49 (57%) Yes
- 37 (43%) No

Of those who had to pay out-of-pocket for *mental health* services, 57% of parents (49 of 86 responding) indicated this posed a hardship for them. Parents who were less educated reported more problems paying out-of-pocket for mental health services.

5a. Has your child's health insurance ever caused trouble getting needed *mental health* services for your child?

Almost 1/3 of survey respondents (46 of 140 reporting) indicated they had trouble getting needed mental health



services for their child related to insurance. 67.1% of respondents (94 of 140 reporting) denied any difficulties.

5b. If Yes, what kind of trouble have you had? Check all that apply

Parents checked off these difficulties on the surveys:

37 (26.2%) ***Finding an approved provider or services with the expertise my child needs***

27 (19.1%) ***Getting insurance approval for services***

19 (13.5%) ***Cutting through "Red tape" to get needed services***

Parent listed these Other difficulties as well:

"Providers don't accept insurance"

"Can't find a doctor in the area who accepts insurance and is taking new patients"

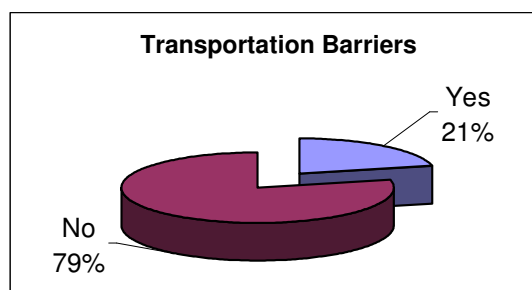
"We don't have health insurance"

"Now 19, her neurologist is too expensive so her family Dr. is seeing her next week. I do not know if she will be able to prescribe meds."

"Paid out of pocket with minimal reimbursement for many years because of provider we chose"

"Getting the right level of services. I did not find out about Katie Beckett until my child was 17 years old. My child could have benefited from CIS or HBTS, which I didn't know about, but would have qualified for."

6a. Do you ever have trouble transporting your child to *mental health* appointments?



Although the majority of parents denied transportation posed a barrier, over 1/5 of the parents surveyed (31 of 145) indicated they have had trouble transporting their children to mental health appointments.

6b. If Yes, Why? Check all that apply

17 (11.7%) ***Distance too far***

8 (5.5%) ***No public transportation available***

8 (5.5%) ***Must rely on others for a ride***

6 (4.1%) ***Car in poor working order***

4 (2.8%) ***No car***

3 (2.1%) ***Bus service inconvenient***

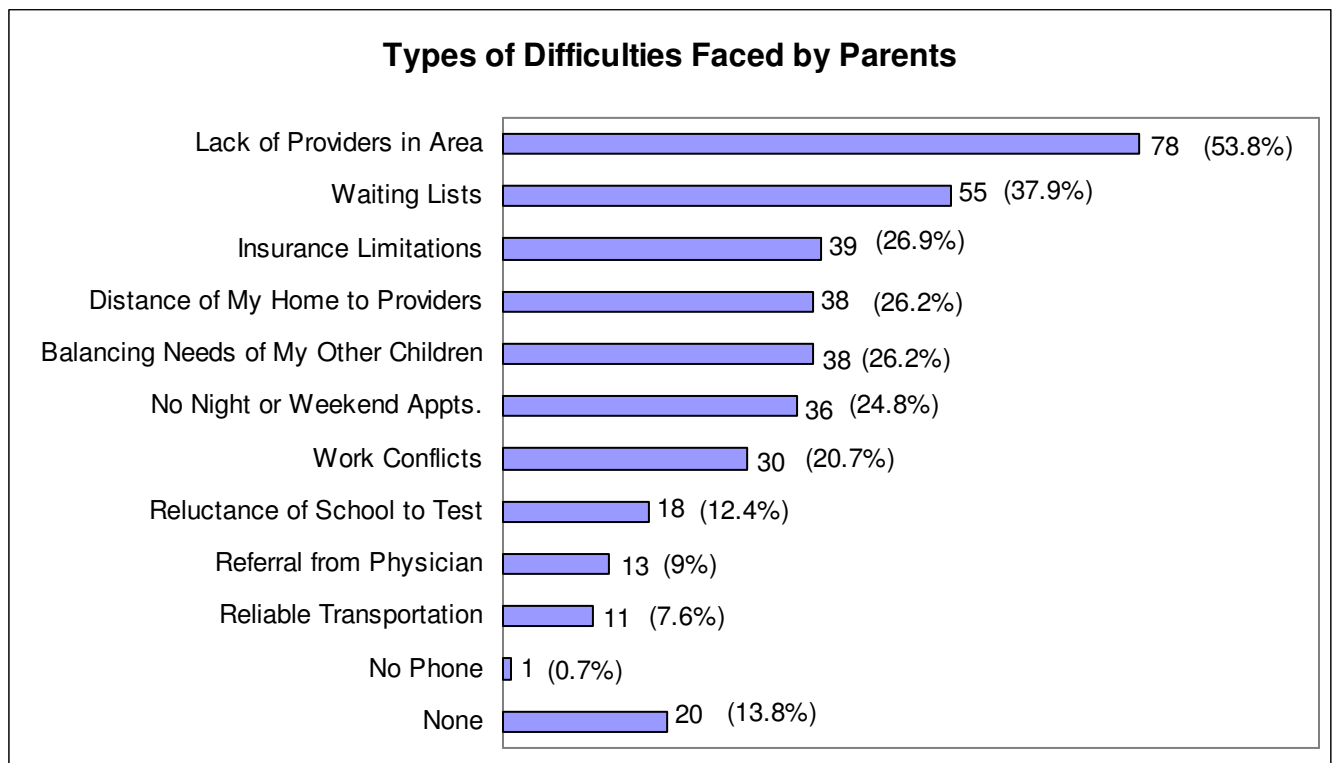
2 (1.4%) ***Taxi inconvenient***

Almost 12% of respondents (17 of 145) indicated *Distance too far* as a barrier in getting their child to mental health appointments.

7. What difficulties have you faced when trying to get *mental health* services for your child? *Check all that apply*

Parents reported facing a variety of difficulties when trying to access mental health services for their children:

- Over half (53.8%) of the parents (78 of 145) cited *Lack of providers in area* as an issue. Parents of children with anxiety problems cited the lack of providers as their primary difficulty in accessing services. Parents of children with 2 or more problems also had significantly more trouble finding providers.
- Over 1/3 of parents (37.9%) listed *Waiting lists* (55 of 145) as factors in accessing services for their children. Waiting lists were significantly more of an issue for those with Katie Beckett and Medicaid coverage and CEDARR plans. 69.2% of parents with Katie Beckett coverage for their children cited waiting lists as a barrier in getting needed services. 75% of children with PDD/autism experienced problems with waiting lists for services.
- Over 1/4 of the parents (26.9%) surveyed noted some difficulty getting needed mental health services because of *Insurance*. This was highest for families with children in the 13-21 year-old age category.
- *Balancing the needs of my other children* was cited as an issue by 26.2% of survey respondents. 60% (9 of 15) of parents of children with substance abuse and 46.7% (21 of 45) of parents of children with more severe mental health problems (3 or more problems) reported difficulties in balancing the needs of other family members.
- 1/5 of parents noted *Work conflicts* posed a difficulty in getting services for their children.
- *Reluctance of the school to have child tested* was cited as more an issue for children ages 13-21 rather than ages 0-6. And, it was an issue for over half (53.3%) of the children with substance abuse problems. Reluctance to test was also an issue for almost 1/4 of parents (24.4%) whose children had 3 or more problems.
- Only 13.8% of parents (20 of 145) reported they experienced no difficulties.



8. What would make it easier to get needed mental health services for your child(ren)?

Of the 78 parents who responded to this open-ended question:

-35 (45%) cited the need for **more qualified mental health providers** in the area as reflected in this sample of parent comments:

"More providers in our area, preventive services, providers who accept insurance and Medicaid"

"More help closer to home. More Doctors who accept insurance."

"More psychiatrists in our area whom work with children specifically"

"Doctors with needed expertise and counselors, too"

"Providers with expertise in my child's autism"

"More mental health providers who are truly in touch with teen issues-Anger management"

- "More qualified providers in Washington County who accept all forms of insurance"*
"There is no specialist in ADHD/ADD in this area"
"More child psychologists"
"More child therapists"
"More local providers"
"More experienced care providers near my home"
- 20 (25.6%) noted the need for **broader insurance coverage** as noted in some of these parent comments:
"If place would accept all Insurances from state"
"Affordable insurance"
"I find the hardest part the cost. Most agencies do not accept both insurances."
"If more services would be covered and more products in the area of alternative medications and services were provided and covered"
"Better health insurance coverage by Blue Cross"
"Being able to pick and choose the doctor you want without having to get referrals for everything"
"More options for parents with Private Insurance..."
- 9 (11.5%) expressed the need for **more services**, including group therapy, social skills training, home-based treatment, etc., in the area
- 8 (10.2%) listed the need for **more convenient office hours** (evening and weekend appts.) for services
- 7 (8.9%) requested a **directory of services**, citing the need for more information regarding what services are available and how to obtain them
- 5 (6.4%) cited the need to address lengthy **waiting lists** for services as noted by these comments:
"No Waiting Lists"
"Local providers without waiting lists"
"If there wasn't such a long waiting list for HBTS"
- 4 (5.1%) listed **quality** of care issues, such as:
"People correctly doing their job"
"Better coordination of care"
"An acceptance that mental health is part of a teen's physical health"
"More attention paid to medications and effects."
- 3 (3.8%) noted the need for **respite services** as commented by this parent:
"I've been told there is not respite or money for my son to get services. It took 3.5 years"
- 2 (2.6%) cited the need for better **preventive and emergency services** as recommended by these parents
"Easier access to emergency services when in crisis"
"Preventative services"
- 2 (2.6%) listed **transportation** as an issue
- 2 (2.6%) requested additional **school supports** including:
"Having more professionals, part of school where most of these problems start would make sense to me"
"More support from school system. More willingness of staff to speak up and get involved."
- 1 (1.2%) cited the need to eliminate **red tape**:
"Less red tape! Sometimes time limit programs do not get to be looked at on individual basis"

Communication

9. Have you discussed your child's emotional, behavioral, or mental health problems with your medical provider or Doctor?

- 133 (91.7%) Yes
 12 (8.3%) No

10. Has being afraid to ask for help or concern about what others may think ever prevented you from seeking mental health help for your child?

- 22 (15.4%) Yes
 121 (84.6%) No

11. Has insensitivity by service providers (i.e. teachers, therapists, doctors, etc.) to your spiritual or cultural beliefs interfered with you seeking mental health help for your child?

- 17 (11.8%) Yes
 127 (88.2%) No

12. Can you talk honestly regarding your child's problems with your child's service providers (i.e. teachers, therapists, doctors, etc.)?

130 (92.9%) Yes
10 (7.1%) No

13. Do your child's service providers explain things to you in a way you can understand?

131 (94.9%) Yes
7 (5.1%) No

14. Do you feel you get enough information from service providers (i.e. teachers, therapists, doctors, etc.) regarding your child's progress?

89 (64.5%) Yes
49 (35.5%) No

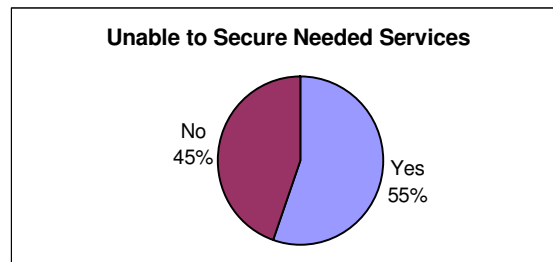
Parents of children grouped in the Other problem/diagnoses category (with more classical medical diagnoses, such as schizophrenia, eating disorders, CP, genetic anomalies, etc.) feel they are better informed from service providers regarding their child's progress- 82% as compared to 46 % for ADHD and 57% for substance abuse.

15. Do you understand how your child's medication works?

81 (87.1%) Yes
11 (11.8%) No
1 (1.1%) Does not take medication

Community Resources

16a. Have you ever felt that your child needed services, but you could not obtain them?



Over half (55.4%) of the survey respondents (77 of 139) indicated that at one time they were unable to secure needed services for their children. For parents with middle incomes, this was even more true. 71% of parents with incomes between \$30,000 and \$75,000 reported they felt their child needed services and they were not able to obtain them.

16b. If Yes, what kind of help did your child need and not receive?

56 Parents responded to this open-ended question. Some of the specific services parents noted they thought their child needed, but could not obtain were:

- Crisis intervention - *"During crisis didn't know where to take her. Unable to get in to see doctor or therapist."*
"During an emergency we had to rely on the local police."
"Needed immediate service identified by school, but no real help (24 hour) from community."
"depressed, suicidal-had a breakdown that required hospitalization at Butler"
"Emergency services when in crisis due to waiting lists."
- HBTS - *"We are still on waiting list for HBTS."*
"HBTS workers to fill hours allotted by DHS."
- Child Care - *"Daycare that can handle him"*
- Counseling - *"Counseling, no insurance"*
"PTSD treatment for sexual abuse"
- Group therapy
- Social Skills Group
- School Support Services - *"Preschool transportation. There was a program available, but school dept. said they did not have to bus him.."*
"Additional tutoring and academic supports at school"

- Therapeutic Recreation/Horseback Riding
- Behavior Specialist
- Mentor/Big sister Program
- Medical Insurance
- Psychiatric evaluation
- Anger Management
- More Intensive Services - *"When you HAVE insurance, you are not able to get some of the more intensive services"*
- Respite - *"Respite Care, nothing available."*

17. Have you had trouble finding child care because of your child's behavior or mental health problems? (Example: not allowed in child care because of behavior problems)

- 42 (30.2%) Yes
- 71 (51.1%) No
- 26 (18.7%) Not Applicable

30.2% of parents (42 of 139) reported having trouble finding child care because of their child's behavior or mental health issues; 59% of parents of children with PDD/autism reported this difficulty.

18. Have you had trouble finding after-school care because of your child's behavior or mental health problems? (i.e. not allowed in program because of behavior problems)

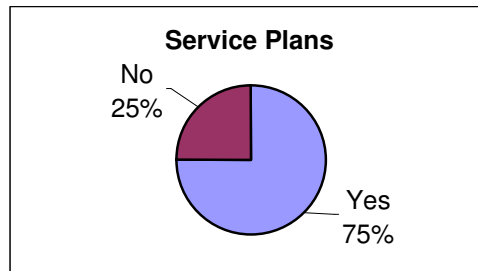
- 39 (27.9%) Yes
- 64 (45.7%) No
- 37 (26.4%) Not Applicable

Almost 28% of parents reported they have had trouble finding after-school care. Again, parents of children with PDD/autism reported having greater problems (63%). Parents of children with disruptive behavior (37%) and ADHD (35%) had significantly more problems finding after-school programs than those with children with depression/mood disorders. Some comments from parents include:

- "There are not enough therapeutic child care centers."*
- "This has been one of our biggest challenges to find industrial strength sitters."*
- "My child is now 12 and child care subsidy is cut off, however, he cannot stay alone-developmental delay."*
- "was kicked out of YMCA summer camp and others"*
- "People do not understand it's a mental health issue. They are not just out of control brats."*
- "Never get a break because we can't afford an appropriate caregiver."*
- "She was kicked out of her first preschool because of her behavior and was told not to come back. We have never had a baby sitter except for a family member."*

19a. Does your child have a service plan?

75% of parents surveyed (105 of 140) reported their children have service plans.



19b. If Yes, what type of plan do you have?

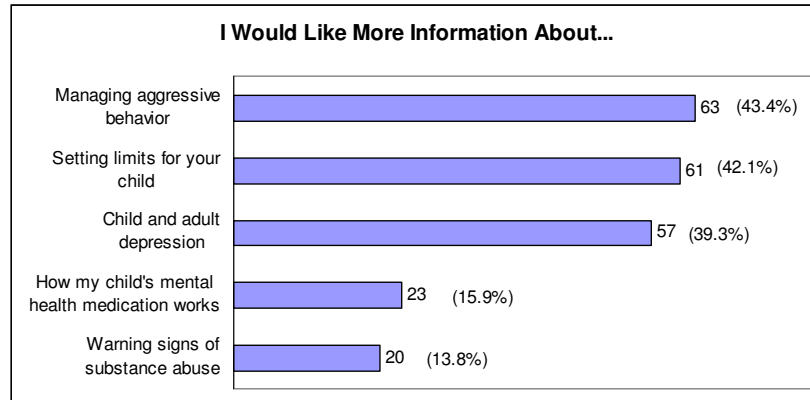
- 25 (17.2%) CEDARR Family Service Plan
- 11 (7.6%) CASSP Family Service Plan
- 2 (1.4%) Early Intervention IFSP
- 94 (64.8%) IEP
- 9 (6.2%) 504 Plan

Of those parents surveyed, Community Health Center patients were less likely to have CEDARR Family Service Plans in place. Those diagnosed with substance abuse are less likely to have service plans (53% vs. 75%). Those with more severe problems are more likely to have service plans. 100% of those with Katie Beckett coverage have service plans.

19c. Do you feel you had an equal voice in the creation of this plan?

- 84 (84.8%) Yes
15 (15.2%) No

The vast majority 84.8% of parents (84 of 99) indicated they feel they **do** have a voice in creating their children's service plans.

20. I would like more information about... *Check all that apply*

Other topics suggested by parents included: eating disorders, self esteem, vocational info, support groups, options, system management, and group therapy. 60% of the parents interested in substance abuse information had a child with a substance abuse problem

Employment**21. Do you work?**

- 44 (30.8%) Part-time
63 (44.1%) Full-time
36 (25.2%) I am not employed

74.8% of parents surveyed (107 of 143 reporting) are in the workforce, either part-time or full-time.

22a. In the past 12 months, have you had to miss work to tend to your child's mental health needs, such as service planning, appointments, conferences, school discipline meetings?

- 85 (62.5%) Yes
51 (37.5%) No

62.5% of parents (85 of 136 reporting) indicated they had missed work in the past 12 months to tend to their child's mental health needs.

22b. If Yes, what is the total number of days you have missed?

- 1-4 days = 27 (38.6%)
5-8 days = 20 (28.6%)
9 or more days = 23 (32.9%)
Median # of days missed = 5

Almost 1/3 (32.9%) of parents (23 of 70) reported they had missed 9 or more days of work to tend to their child's mental health needs.

23. Have you had to quit or reduce the # of hours you work because you cannot obtain adequate child care to meet your child's mental health needs?

- 34 (25.6%) Yes
99 (74.4%) No

1/4 (25.6%) of parents (34 of 133) reported they had to quit or reduce the # of hours they work because they could not obtain adequate child care to meet their children's mental health needs.

Information About You and Your Child to Help Us Plan

25. Have you ever had to contact the police because of your child's behavior?

43 (29.9%) Yes

101 (70.1%) No

Almost 30% of parents (43 of 144) reported they had to summon the police to their home because of their child's behavior. This is most common in the 13-21 year-old age group (55.2%). 18.3% of parents with children ages 7-12 years old reported they contacted the police because of their child's behavior. 87% of parents (13 of 15) with a child with a substance abuse problem reported they had summoned the police. Parents of children with PDD/autism had significantly less need to call the police than parents of children with other diagnoses.

26. Has your child ever had "psychological" or educational testing about his or her behavior or mental health problems?

122 (85.9%) Yes

20 (14.1%) No

Most of the children (85.9%) in this cohort (122 of 142 responding) have undergone psychological or educational testing. 14% of the children have **never** been tested, including 7% with an IEP.

27a. Has your child ever been seen in the Emergency Room or hospitalized for mental health reasons?

43 (29.7%) Yes

102 (70.3%) No

Almost 1/3 (29.7%) of the children (43 of 145) in this sample have either been seen in the Emergency Room or hospitalized for mental health reasons.

- Significantly more 13-21 year olds have been seen in the Emergency Room or been in the hospital for mental health reasons than children in the younger age groups.
- Significantly more children with depression/mood disorders than ADHD, disruptive behavior or PDD/autism have been seen in the Emergency Room or hospitalized.
- Children with ADHD, disruptive behavior, and PDD/autism are significantly less likely to be seen in the Emergency Room or hospitalized.
- Children with substance abuse problems were more likely to be seen in the Emergency Room or hospitalized than children with PDD/autism.

27b. If Yes, could this have been avoided if counseling or other mental health services were available?

21 (52.5%) Yes

19 (47.5%) No

Over half (52.5%) of the parents (21 of 40) whose children were seen in the Emergency Room or hospitalized reported they felt this could have been avoided if counseling or other mental health services were available. Parent comments included the following:

"If a child psychiatrist were available to diagnose my child with Bipolar to receive the appropriate help and medication, we could have avoided hospitalization."

"If I could have had a competent therapist at that time, I believe she would have been a lot better off. I did not realize I wasn't seeing someone who could actually help her."

"I believe one ER visit was in fact caused by a lack of knowledge and proper handling of my child's problem by mental health professionals."

"I am interested in potential counseling to reduce/avoid any future issues."

37. Are there any other issues about your child's mental health needs that we have not asked about and are important to you?

26 (20.5%) Yes

101 (79.5%) No

If **Yes**, please explain:

-"Sometimes trying to get information is like going on a wild goose chase not only do I have a child dealing with SSMHC, but also an adult and it has some good programs but the rest seems to need a complete overhaul."

-"I have a very artistic child that relies on this gift to sort through his feelings, anger, sadness, aggression etc. but what is available is far too expensive."

-"The state of RI will pay for home based therapy but the waiting list are 1-2 years and there is an extreme shortage of HBTS workers because of low pay so children who need these services never receive them."

- "Support for parents that are middle class. I have some money in savings therefore I do not qualify for help paying for health and mental health."

- "Our greatest concern is the future, what is available for our son and the process we need to go through."

- "My 10 yr. old has never been accurately diagnosed."

- "Not enough family help when you have a child with special needs."

- "Social opportunities to interact with age appropriate peers, this can be isolating."

- "A support group. Having a child with mental health issues is very draining."

- "If drug abuse in H.S. were caught earlier- mental issues could have been treated sooner."

- "My child did not have the proper testing, diagnosis or services until he was 14 despite seeing a psychiatrist and psychologist from age 7. I feel he has been cheated by the school and not been given services due to out lack of knowledge about available services."

- "Families with kids who are 24/7 care issues are isolated and exhausted. We need respite. We need in-home. We need child care."

- "Due to cost of additional staffing needed for enrichment programs, our children are missing out on a much needed social skill building experience."

- "Parents need support/respite/funds. The divorce rate (lack of support) is so high amongst parents of special needs kids. We need help. We burn out despite extraordinary efforts to care for our children. Some of us have mental health issues ourselves."

- "Social groups- my child is aching for friends."

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