



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

Focus Group Results
December 2004

Background

Between April and December 2004, seven focus groups were held with Parents, Pediatricians, Child Care Providers, Head Start Staff, Mental Health Providers, and Special Education Directors to explore issues related to children's mental health services in Washington County, RI. These focus groups were designed to provide more qualitative data to information already gathered through interviews with 40 key informants and a survey of 145 parents conducted earlier this year. Issues addressed during focus groups included:

- the most significant challenges facing children with mental health needs in Washington County
- barriers faced in obtaining needed mental health services for children
- identification of services that are most helpful
- identification of services that are needed, but are not currently available
- identification of supports needed by parents
- ideas to improve services for children with mental health needs in Washington County

The groups were facilitated to elicit open, honest feedback from participants relating to each of these points as well as to probe new areas of interest raised spontaneously in the group interview setting.

These focus groups were conducted between February and December 2004. Parents were recruited for focus groups through our parent survey process. Parents who completed surveys were given flyers about the focus groups in their survey packets. Those interested were asked to complete a written form indicating times they may be available to participate in a focus group. Parents were then contacted and two parent focus groups were scheduled in two different locations in the county, one in the town of Wakefield and one in Westerly. In an effort to assure participation by the other provider groups, efforts were made, where possible, to incorporate focus group discussions into other regularly scheduled group meetings, i.e. South County Hospital Pediatric Meeting, Head Start Staff Training Date, etc. Because the focus group with Special Education Directors had to be cancelled and rescheduled due to poor attendance, a survey was circulated prior to the second meeting to garner some information from them, if the second attempt failed as well. Thus, findings from this group include both oral and written comments.

Results

Four consistent themes emerged from the focus groups, reinforcing the information obtained through key informant interviews and parent surveys. These four themes were:

Access to Services

Quality of Services

Parent Advocacy

Funding

Two themes dominated the discussion in every focus group: ***Access to Services*** and ***Quality of Services***. Of the 243 total number of focus group comments, 98 or 40% related to Access to Services and 89 or 37% related to Quality of Services. A broad array of specific issues was identified under each of these two themes. 37 or 15% of focus group comments related to ***Parent Advocacy*** and the remaining 19 or 8% of comments related to ***Funding*** issues.

Access to Services

Focus group participants noted that services must be accessible and available (meaning no waiting lists, convenient hours to accommodate the needs of families, and transportation not an issue) if

children and their families are expected to benefit. *"Access to services is limited"* in Washington County noted Head Start staff.

In every focus group conducted, participants cited the need for additional mental health providers, i.e. child psychiatrists, therapists, behavioral specialists, or specialists with certain age groups or specific disorders. *"More providers/more options for treatment"* are needed. In 5 of the 7 focus groups, the limited capacity of child psychiatry services was noted. (This issue was not raised by child care providers or Head Start staff.) *"South County is dismally lacking in child and adolescent psychiatry."* Participants reported that local psychiatrists have very limited appointment availability or don't accept insurance due to poor insurance reimbursement rates. One parent commented, *"There is not enough help out there. . .We can't find a child psychiatrist."* A mental health provider commented *"Timely access to pediatric and adolescent psychiatry...Timely...Resources aren't here to begin with...It's almost a joke to say patients need a psychiatric referral because the wait is 2, 3, or 4 months out."* Pediatricians and mental health providers noted the lack of readily available advice from psychiatrists as another concern. A mental health provider commented, *"None are able to provide consultation to therapists. We should be working together on these difficult cases."* Head Start Staff, Child Care Providers, and Special Education Directors noted the need for more mental health providers who have expertise working with young children. *"Few have the qualifications to work with young children."* Parents and Child Care Providers also cited the need for more behavioral specialists in the area. Parents reported the need for more mental health providers with expertise in specific disorders, such as ADHD, PDD, cutting, etc. *"It is hard to get services for my son because few understand his disorder."* Another parent stated, *"As far as local therapists for my kids, I've not found one."* Special Education Directors reported the need for local mental health providers with expertise in sexual trauma and treatment as well as with specialization in all 3 age groups (0-6 years, 7-12 years, and 13-21 years). Mental health providers acknowledged that the number of mental health providers in the area is limited. And, as a result, the needs of children and their families frequently outstrip the capacity of mental health providers to fill them. Thus, parents must either travel out of the area to obtain services for their children or endure waiting lists/delays in seeking services. As one mental health provider described, *"I have a real schedule crunch because the time that is best for families is already taken by other families...Families must call multiple providers to find providers with appointments available when they need them."*

Another issue that surfaced in several focus groups was the need for a local resource directory, referral phone line, or *"informational road map"* regarding available mental health services for use by both parents and providers. As one Mental Health Provider commented, *"As long as I've been in this community, I've never known all the services available. There is no central way to know it."* This issue was raised in focus groups with Child Care Providers, Head Start Staff, Mental Health Providers, and Parents. *"There may be resources available that we are not aware of,"* noted several providers. *"I wish when my children were young, I knew where to go,"* noted a parent.

The need for more inpatient psychiatric resources for children was highlighted in focus groups with Pediatricians and Mental Health Providers. *"There are not enough psychiatric hospital beds for kids who need them. It's a real crisis."* Pediatricians explained that pediatric beds in psychiatric hospitals are frequently not available promptly, requiring that children remain in local hospitals receiving no treatment for acute psychiatric disorders until a psychiatric bed becomes available. After discovering letters from her 14-year-old threatening death, one parent noted, *"My daughter was in the hospital ER for 24 hours and then was discharged home as there were no beds available."*

Pediatricians and Parents cited the need for crisis services. Pediatricians reported that although children in severe crises can get their needs met through hospitalization and children with mild problems can wait for services to begin, kids with impending crises highlight one of the most glaring gaps in services and their availability in Washington County. The need for clinical staff on site at schools to deal effectively with crises and clinical emergencies was noted by a parent. In order to access crisis services, some parents reported they have had to involve the police. *"to get her help, we had to call the cops. I feel like we were pushed in that direction...There had to be a better way,"* another parent reported.

The need for more home-based services, including Home-Based Treatment Services (HBTS) and respite care, was underscored by Parents and Head Start Staff. The limited availability of these needed services is a major problem. *"Every 6 months, we must justify and lie on these forms in order to keep services...HBTS are now being discontinued for my son because he supposedly doesn't need it anymore'...With limited respite care options available, families have few resources other than HBTS..."The bottom line is: the system is failing these kids,"* said one parent.

The importance of intervening early was also raised in multiple focus groups. Parents commented, *"We need to intervene early"* and *"More community-based diversionary programs are needed, not enough out there."* Better parent education and support programs were recommended by Mental Health Providers, Head Start Staff, and Parents. Child Care Providers and Head Start Staff cited the difficulties of obtaining services for children ages 3-5 through the schools. They noted that *"Public schools are not interested... They choose to deal with the behavior issues once the children enter Kindergarten"* missing an important opportunity to intervene early in the lives of these preschoolers. One child care provider commented, *"Schools need to develop a preventive rather than reactive model"* for young children with behavioral issues.

Lack of access to the following specific services or programs were identified in focus groups:

- Anger Management Classes for Youth
- Group Therapy for Teens
- Social Skills Groups for Children
- Longer Range Treatment and Supports (beyond the time limits of CIS - Children's Intensive Services - and HBTS)
- Enrichment Programs for Children with Special Needs
- After-School Programs for Children with Behavioral or Mental Health Challenges

In addition, a family approach to treatment was recommended. *"It is important to get everyone in the family to get help or support...because siblings need support, too...the needs of these children are often left out,"* a parent noted.

Quality of Services

The lack of care coordination or case management services is a source of frustration to providers and parents alike. The issue was raised in focus groups with Pediatricians, Head Start Staff, Child Care Providers, and parents. The parent comments below best describe this frustration and need.

"The whole system is like a big board game and no one is giving us the rules"... "And we're playing with our child's life"... "by the seat of our pants."

"We've needed someone to tell us what to do...where to take our son to get him the services he needs...We feel like we've been playing 'hit or miss'. We had to find everything on our own...We never felt like there was anything out there to help us."

"A seamless, cohesive stream of help is needed."

The need for better after-care plans and services was highlighted in focus groups with Pediatricians and Parents. Pediatricians noted a lack of communication and follow-up from psychiatric hospitals in RI after children are hospitalized. Pediatricians indicated they tend not to be notified when children have been discharged and discharge planning and counseling needs are not commonly discussed with the child's pediatrician. One parent commented, *"When kids get into Bradley or Butler, they don't stay long enough to get the help they need and no follow-up plans are made."* Another parent reported, *her 14-year-old daughter was discharged after 3 days because she refused to take meds. No counselor was lined up to provide follow-up care after her discharge."*

Communication issues were raised by Child Care Providers, Pediatricians (as noted above), and Parents. These issues relate both to how service providers communicate with each other and with parents. As several parents described:

- *"I must educate the professionals all the time...services are fragmented...I must prompt communication between them...I must do a lot of advocating...I feel like we're a picture with lots of dots and no one to connect them."*
- *"I want the psychiatrist to educate me about how I can help my sons. I must force the issue, otherwise it wouldn't happen."*
- *"There was a lack of communication with my son's counselors. We never felt like we were on the same page with our son and the counselors."*
- *"Clinicians need to ask parents what they need rather than tell them what they need."*
- *"It's important for therapists to check in with parents because kids don't always tell the truth and they need to treat the whole family. Not all therapists do that and it's a sin not to."*
- *"I get so confused by providers because they don't speak in laymen's terms."*

Child Care Providers noted that many schools won't communicate with them or allow them to participate in IEP meetings. They reported school systems have difficulty recognizing the expertise of child care providers. Special Education Directors expressed their interest in having outside service providers more involved in team meetings.

Satisfaction with services provided by schools varied among focus groups and participants. Some were pleased with services, many were not. School related issues were raised in 5 of 7 focus groups (all but Pediatrician and Mental Health Provider focus groups). The issues raised are complex as reflected in this comment from a parent:

"There are significant problems with how the schools deal with our children. Contributing factors include: Class size, Focus on Testing, Limited Funds, and Limited Teacher Training. Even Special Education teachers don't understand the details of all the mental health disorders. Schools are quick to blame the children and label them as 'not trying hard enough.' High achievers are also not served well by schools. These high functioning kids have self-esteem issues and don't get the services they need."

Special Education Directors also raised the issue of meeting the mental health needs of children who have long bus rides to clinical day programs.

Child Care Providers, Head Start Staff, Special Education Directors, Pediatricians, and Parents all cited the need for more training for direct service workers (including child care providers, after-school programming staff, recreation staff, etc.) and teachers regarding children's behavioral and mental health issues. One parent relayed this story about her 11-year-old son:

"Teachers need to be taught how to handle children with mental health needs. When my child was hospitalized after a suicide attempt, the teacher and students were instructed by the principal not to send cards"

or visit so as not to reinforce his attention-seeking behavior. This speaks volumes about their lack of understanding about suicide."

Some Pediatricians felt their training was inadequate to do some of the prescribing of psychotropic medications that they were feeling pressured to do. There was consensus regarding the need for guidance from psychiatrically trained personnel in the prescribing of psychotropic medications by Pediatricians.

Staff turnover was an issue raised in focus groups with Head Start Staff and Parents. They explained low pay for CIS and HBTS workers result in frequent staff turnover and disruptions in services. As one parent commented, *"Stability is key to my son's management and success...With HBTS, there's always staff leaving and new staff coming."*

Parent Advocacy

The need for additional parenting supports (i.e. parenting classes, support groups, one-on-one peer support, etc.) came up in focus groups with Child Care Providers, Head Start Staff, Mental Health Providers and Parents. Parents indicated:

- *"There are few supports for family members. We get depressed, stressed...We had to go out of this town for parental support as well."*
- *"No one understands when I try to get some help...You must be doing something wrong, because he's doing okay at school. There is no support for parents down here."*
- *"If we don't get the kind of support we need, we won't be able to keep her" (foster child)... There's no support group for parents like myself."*
- *"We need to be able to connect with other parents."*
- *"Parenting classes often don't have content that is applicable."*

In addition, the need for advocacy support was stressed. *"Many parents are not able to access services on their own...Parents need coaching and mentoring as to how to obtain needed services for their children,"* suggested Head Start Staff. *"Most parents don't know what to ask...Schools don't share info about what services are available,"* indicated Child Care Providers. *"Schools engage in willful deceit, keeping information from parents,"* said one parent. *"You must be an advocate and be vigilant with the schools all the time...You must be a pain in the butt to get needed services for your children,"* added another parent.

Funding

Insurance issues were raised in 6 of the 7 focus groups (every group except Child Care). Lack of insurance coverage can be a major barrier for children in need of mental health services. *"Despite having two parents working, we can't afford counseling as it is not covered by our insurance...only so many sessions are covered and prescriptions are expensive, costing \$45.00 per month,"* noted one parent. *"My son with Asperger's needed a social skills group, but private insurance wouldn't pay for it,"* said another mother. Insurance in families with multiple members in need of services can also be a barrier, noted a mental health provider. *"Someone does without, usually the parent or the Mom."* In addition, families with private insurance do not qualify for services such as CIS. *"We don't qualify for CIS because of our insurance,"* said one parent. *"If you have good insurance, you are unable to get services."* Another parent indicated, *"Because of financial problems, we've been referred to our Pediatrician to continue prescribing her meds., rather than a psychiatrist."* Insurance coverage for those ages 19-21 can be an issue, too. *"Because my 19-year-old daughter has no health insurance, her PCP (Primary Care Provider) is providing medication management."* In cost saving measures, Pediatricians noted insurance companies may require Pediatricians to refer to psychologists or therapists with whom they are not familiar or in whom they may not have confidence.

A substance abuse treatment provider reported, *"DCYF won't pay for medical services (for those dually diagnosed)...As a result, we have stopped accepting DCYF clients. If they have depression or some other disorder, DCYF won't reimburse us for treating them...which doesn't make a lot of sense to me. But DCYF will pay for urinalysis and counseling."* Lack of reimbursement for substance abuse treatment groups was also noted. *"We end up putting kids in individual treatment instead of groups, because we can't get reimbursed."*

Two other funding issues raised by child care providers include: 1) transportation from school to all child care sites could avoid unnecessary disruptions in placements for children and 2) funding for a behavioral consultant. *"Child care centers or homes don't have the financial resources to hire a behavioral consultant like Head Start Programs do."*

Focus Group Profiles

Pediatrician Focus Group

This focus group was conducted as part of the monthly meeting held with Pediatricians who have privileges at South County Hospital in Wakefield, RI. The meeting was held in February 2004 and was facilitated by Robert Maltz, MD. Primary issues raised during this focus group centered around crisis management (including need for psychiatric hospitalization, prompt evaluations, and discharge planning), medication issues, psychiatric consultation and care coordination.

Head Start Staff Focus Group

This focus group was held in conjunction with a day of in-service training for staff. The group was conducted in April 2004 and was facilitated by Linda Cardillo, LICSW. Primary issues raised during this focus group included: the lack of mental health providers in the area, impact of stigma and understanding of mental health issues in children upon parents' ability to seek help for their children, transportation and insurance barriers, reluctance of schools to service children ages 3-5 with behavioral problems, and parents' need for coaching and mentoring as to how to obtain needed services for their children.

Parent Focus Groups

Two parent focus groups were held with parents in June 2004. They were held in two opposite parts of the county to allow for greater parent participation. 10 parents participated in the focus group held at Bradley School in Wakefield; and 6 parents participated in the focus group at Westerly High School in Westerly. Both groups were facilitated by Linda Cardillo, LICSW. As described above, parents were recruited for participation through a flyer that was included in parent survey packets. Stipends were provided to parents as incentives and included reimbursement for travel and child care expenses. Issues raised by parents ran the gamut of all the issues identified through the other focus groups and in addition identified the need for greater parenting supports and communication with providers. Parents in both groups spoke openly and honestly regarding their experiences. Their experiences with the mental health services in Washington County make a compelling case for change.

Child Care Provider Focus Group

This focus group, which was facilitated by Susan Orban, LICSW, was held as part of the September 2004 meeting of the Child Care and After-School Programming Work Group (a subcommittee of the Washington County Coalition for Children). The goal of this work group is to expand the current capacity of child care and after-school programs in caring for children with special needs in Washington County. Primary issues raised during this focus group included: the need for training

and consultation for child care providers regarding how to deal effectively with behavioral issues in the classroom, difficulties accessing services from the schools and easing transitions for children ages 3-5, training for child care providers regarding how to deal with parents' denial about their children's problems and empower them to seek appropriate treatment for their children, and an "informational road map" for parents outlining area resources. Child care providers felt strongly that access to consultation from a behavioral specialist in child care settings could greatly impact the trajectories of young children displaying problems. As a result of this focus group discussion, this work group submitted a proposal to the United Way of RI to fund a behavioral specialist position at South Shore Mental Health Center to provide consultation and training to all licensed child care providers in Washington County.

Mental Health Provider Focus Group

Local mental health providers were invited to participate in a focus group facilitated by Jeff Brusini, LMHC, held in November 2004 at the offices of South County Child and Family Consultants. The group, which consisted of psychologists, social workers, licensed mental health providers, and an MD, included 7 private practice providers and 9 providers associated with various counseling and social services agencies in the area. The high participation in this focus group appeared to underscore the importance deemed to this effort by providers. Primary issues discussed during this focus group were: capacity needs (including the long waits and delays in securing psychiatry services, the lack of inpatient resources, and the limited # of mental health providers in general), insurance limits and reimbursement issues, and the need to develop a "central registry" of available services. Placing pressure on the main insurance companies in the state (i.e. Blue Cross/Blue Shield, United Behavioral Health, and Neighborhood Health Plan of RI) was suggested as a way to begin resolving identified difficulties and cobbling information to develop a detailed mental health resource directory.

Special Education Director Focus Group

The focus group with Special Education Directors was held in conjunction with a monthly meeting of the Special Education Directors in the South Region in RI. The first attempt was made in April 2004, however, since only 2 Directors were present the group was rescheduled for December 2004. Since attendance is voluntary and attendance was again uncertain, a written survey was circulated to area Special Education Directors prior to the second focus group. Information was gathered from 4 of the 8 Special Education Directors in the region and the information here reflects both their verbal and written comments. Special Education Directors cited the need for additional mental health providers in Washington County, noting especially the need for child psychiatrists and local providers with expertise in sexual trauma. The need for mental health providers with experience with specific age groups (i.e. 0-6, 7-12, and 13-21) was also noted. Staff development on children's mental health needs (including infant mental health), managing aggressive behavior, and helping families apply for Katie Beckett MA benefits, as well as new programs for school-based mental health services were suggested. Determining better ways to meet the mental health needs of children who experience long bus rides to clinical day programs was also cited as a need by Special Education Directors.