

Mississippi Families' Experience with Seeking Mental Health Care for Their Children



Background: Families as Allies is the only statewide organization run by and for families of children with mental health challenges. We support each other and work together to make things better for our children.

For the past three years, as part of our goal to make things better for our children, we have enhanced our capacity to gather data about our own work and also Mississippi's child-serving systems .

In July 2016, the Mississippi Department of Mental Health contracted with Families as Allies to gather data and information from families about their experiences accessing services for their children in the mental health and education systems.

Three parent-to-parent approaches were used to gather data between July 2016 and June 2017 (TH=Town Hall; ●=Surveys)

- 1. Telephone interviews** with 320 parents statewide focused on demographics and experiences in finding help for their children.
- 2. Paper and Pencil Surveys** of 150 parents from 29 counties regarding what systems they had accessed and how helpful and responsive those systems were.
- 3. Ten Town Hall Meetings** throughout the state with 120 parents who were asked **"What's Working, What's Not Working and What's Needed?"** in the Mental Health and Education Systems.



Initial Findings:

1. Telephone interviews

- A substantial number of children with mental health challenges have not come to the attention of the formal mental health system.
- School issues, often related to special education, are families' most pressing concern.
- Families have not heard of most of the mental health services mandated by state law.

2. Paper and Pencil Surveys

- There appear to be possible methodological problems with the survey, leading to inconsistent response patterns and indications of response bias.
- These methodological problems may be related to the survey not being clearly identified as by and for families.

"...School issues, often related to special ed, are families' most pressing concern..."



3. Town Halls

- Issues with school are the greatest challenge families identified
- Communication and collaboration within and between systems are lacking and sometimes non-existent
- Parents want to be partners in all aspects of their children’s care, including planning programs and policy, but often feel they are not included or wanted
- There are issues with the availability, expertise and reliability of providers and services
- The types of services available don’t align with the needs families identify
- There is a need for more support during crises
- “Nothing” was a common response to “What’s working?”

“...parents want to be partners in their children’s care, including policy...”

IMPLICATIONS FOR PLANNING AND REFORM

<p>Think in terms of <u>a system of care for mental health</u> rather than a mental health system.</p>	<p>Families and people receiving services must have a primary role in directing their own care as well as designing and evaluating services, programs and policies.</p>	<p>To decrease stigma, increase access and make mental health care more responsive, put services where people already are – in schools, for example.</p>	<p>Family and consumer run organizations are an effective, cost-efficient way to provide peer to peer support and gather and disburse reliable and helpful data about mental health care.</p>
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Next Steps for Families as Allies

1. **Expand** these efforts to include other systems as well as broader populations of families whose children are affected by mental health challenges
2. **Ensure** we evaluate our own work as well as families’ experiences with systems.
3. **Update** what we focus on as we learn more about what is relevant and important to families.
4. **Identify** partners and resources to enhance our evaluation capacity.

Next Steps for the Department of Mental Health

1. **Support** collaboration between the education and mental health systems.
2. **Prioritize** training for mental health providers and peer support specialists about special education and other practical education issues.
3. **Continue** to enhance relationships with family and consumer run organizations.

Mental Health and Education Town Hall Findings*



What's WORKING?	What's NOT WORKING?	What's NEEDED?
<ul style="list-style-type: none"> • Parental Involvement • Community Mental Health Centers' visibility in the schools • Therapists in the schools • Local advocacy groups • Informal school services such as tutoring and ROTC • Compassionate school counselors and special education teachers • Some specific services cited by specific families. <ul style="list-style-type: none"> <i>"One-on-one support"</i> <i>"Individual Therapy"</i> <i>"Support from case managers"</i> <i>"Day treatment for part of school day"</i> • "Nothing" was a common answer. 	<ul style="list-style-type: none"> • Families do not get the information they need <ul style="list-style-type: none"> <i>"They don't tell you what's going on with your child's treatment."</i> <i>"I don't understand the mental health diagnosis."</i> • Issues with the availability, expertise and reliability of providers, including inappropriate diagnoses <ul style="list-style-type: none"> <i>"My child has a hard time adjusting to a new therapist."</i> <i>"The medications are not helping with my child's behavior."</i> <i>"My child has been on 16 different medications."</i> <i>"The doctor sees my child for 8 minutes then changes the medication."</i> • Parents not feeling "a part of" the treatment and services. <ul style="list-style-type: none"> <i>"I have three children receiving services and I have three different case managers. And, I only communicate with one of the case managers for one of my children."</i> <i>"The school is pressuring me to medicate my child."</i> 	<ul style="list-style-type: none"> • Information about Crisis Response in Mississippi and access to crisis line. • Parents having more input into decision making for their child's treatment and services. • More input from families on the way services should be provided. • Parent involvement with policy • In-Service for the Community Mental Health Center and the school for better coordination of services. • Increased support for parents. • Trained and skilled therapists. • One case manager per family. • Better treatment plans for behavior disorders. • Careful observation of children before medication is prescribed. • Parent education on medications and the side effects, mental health diagnoses and treatment.

What's WORKING?

What's NOT WORKING?

What's NEEDED?

- Cost/distance to access mental health services
- Length of Services
- Poor communication and collaboration between the Community Mental Health Center and the school.
- Lack of Services, including respite and services for children with autism
- Not knowing about crisis services and how to access them
- *"I call 911 when my child is disruptive at home"*
- Parents not knowing where to find resources for children
- *"What services should I have?"*
- Taking away social opportunities for children with disabilities (behavior related disabilities) at school
- Inappropriate services for children with ADHD
- Children being "labeled as bad" for their behavior related disability
- Parents don't have the opportunity to be involved in policy.
- Multiple school issues with special education & Individual Education Plans (IEPs)

"The only time I'm asked about the IEP is to sign it"

"Inclusion children are included but not educated. They just sit there."

"My child gets suspended for his disability."

- Increased services for children with Autism Spectrum Disorder (ASD) that are family centered so that the child can remain at home.
- Increased Respite Services.
- Resource guide for parents
- Parent support group
- Access to more therapists
- Appropriate services for children with ADHD
- *"Appropriate medications for ADHD"*
- Highly qualified special education teachers
- For the child to be educated in their "own school" and not a "day school" away from peers

**Collected in Parent Town Hall meetings throughout the state by Families as Allies from July 2016 – June 2017*