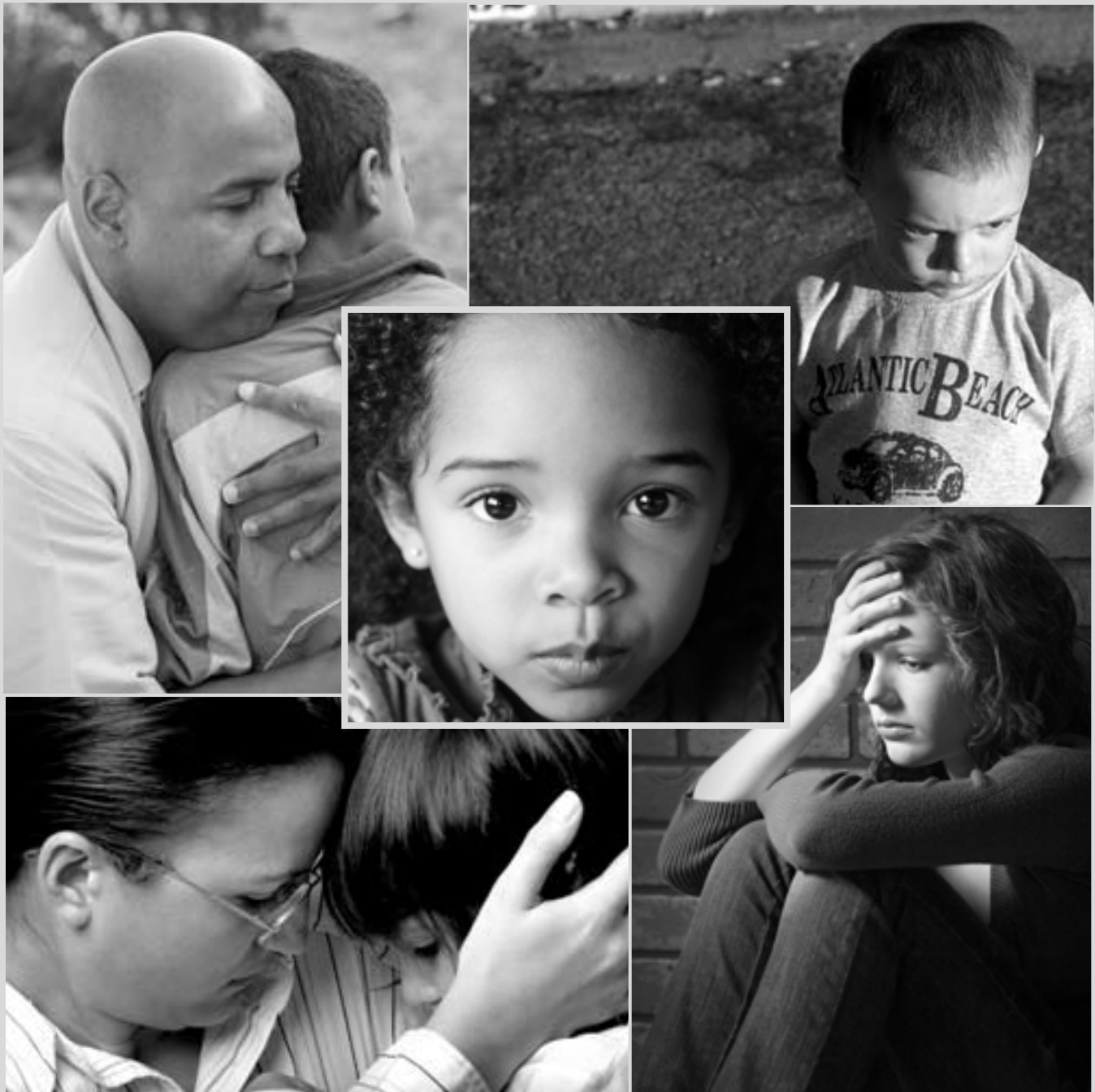


The Arkansas Mental Health System for Children

...A Family Perspective



Introduction

When new children come into the world, they bring a sense of hope and anticipation for their family. Families view this child as their hope for the future. For most families this anticipation culminates in the achievement of important milestones as the child grows up and moves into adulthood as a productive member of society.

For an ever growing number of families, however, the anticipation turns into hopelessness and frustration when their child demonstrates abnormal behavior or other signs of developmental delays. Families seeking help for their child often become frustrated as they attempt to weave their way through a maze of encounters with their child's school, the legal system, and a complex social service system that too often produces dead end referrals, limited choices, and services that are inappropriate. In the end, many families lose hope. Their children "age out" of the system with little or no mechanism for coping with their mental illnesses.

In the summer of 2006, Arkansas embarked on a journey to develop a better system of care for children with mental illnesses by assembling a group of stakeholders and charged them with the task of identifying solutions. A system of care is defined as a coordinated network of community-based services and supports that is organized to meet the challenges of children and youth with serious mental health needs and their families. The current mental health system consists of a variety of providers, including schools, outpatient providers, residential treatment, and acute care facilities. These services, however, are not necessarily coordinated to ensure that children and their families are receiving the best possible services to meet their needs or to ensure availability of those identified services.

The first priority of this group was to ensure that parents and families were engaged in the process. As part of the stakeholders' work, the Arkansas General Assembly passed legislation to begin the process of improving the children's mental health system. The Children's Behavioral Health Care Commission was formed and new First Lady Ginger Beebe led a listening tour throughout the state to gain valuable insights from the experiences of parents. This report is a compilation of the information collected during the tour and includes suggestions from parents to the Commission for improving the children's mental health system.



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About the Listening Tour

The purpose of the listening tour was to give parents an opportunity to share their experiences, both positive and negative, about the Arkansas children's mental health system. We hoped to glean new insights from their stories about what families need to provide better care for their children and to identify ways the system could better meet their needs. Key ground rules for the visits were laid down at the beginning of the project, including:

- The listening tour would focus on families and children. There would be other opportunities to hear from providers and institutions.
- The visits with the First Lady would be intimate and comfortable. They would be held at non-clinical, non-threatening locations.
- Participation in the visits would be limited to parents/caregivers, Mrs. Beebe, and her staff.
- Experienced parent advocates were used as facilitators and recorders. The same facilitators and recorders were used at each session to ensure consistency.
- Press was not allowed at the visits to protect the family and children's privacy.

The ground rules were followed during each visit and valuable input was received from every parent.

Logistics and Demographics

The visits were strategically planned to ensure every area of the state was covered. The list on page 3 reflects the locations and dates of the visits.

During the listening tour, 85 families shared their stories and experiences with the Arkansas mental health system. Many of these families had more than one child with a mental illness. The children discussed ranged in age from 5 to 19.

The following medical diagnoses were mentioned during the visits:

- ADHD
- Autism
- Bi-Polar
- Depression
- Pervasive Developmental Delay
- Schizophrenia
- Obsessive Compulsive Disorder
- Anxiety
- Post Traumatic Stress Syndrome
- Sensory Disorder
- Oppositional Defiance Disorder
- Gender Identity Disorder
- Mood Disorder
- Mental Retardation
- Traumatic Brain Injury

A majority of the children discussed during the visits had multiple diagnoses. Many had both a developmental disability and a mental health diagnosis. Most of the children were being served by multiple systems, including the mental health system, the juvenile justice system, and the education system. Out of the 85 families, 10 were led by grandparents raising their grandchildren, 2 were aunts raising their nieces or nephews, 2 were foster families, and 2 were adoptive families. Of the families that provided information concerning their ethnicity, 46 were Caucasian, 20 were African-American, 4 were Native American, and 1 was Hispanic.

The First Lady Listening Tour

<u>Date</u>	<u>City</u>	<u>Location</u>
<u>May 8, 2007</u>	Paragould	Chamber of Commerce
	Jonesboro	Godsey's Restaurant
	Blytheville	Methodist Church
<u>May 15, 2007</u>	Morrilton	University of Arkansas at Morrilton
	Conway	Antioch Baptist Church
<u>May 22, 2007</u>	Fort Smith	Private Home
	Springdale	The Jones Family Center
	Huntsville	Senior Adult Center
<u>May 29, 2007</u>	Hope	Southern Bancorp Community Room
	Texarkana	Cattleman's Steak Restaurant
	Arkadelphia	Ben Elrod Center
<u>June 12, 2007</u>	Camden	First United Methodist Church
	El Dorado	Healthworks Fitness Center
	Pine Bluff	Don W. Reynolds Community Center
<u>June 21, 2007</u>	Benton	First United Methodist Church
<u>June 26, 2007</u>	Forrest City	East Arkansas Community College
	Helena	Delta AHEC
	Marianna	Community House
<u>July 3, 2007</u>	Little Rock	NAMI-Arkansas

The Results

There are approximately 60,000 children in Arkansas receiving some type of mental health services. The majority of the children are suffering from adjustment disorders, temporary delays, or behavioral issues that are being adequately addressed with school-based mental health services, early intervention services, or outpatient therapy. The families participating in the listening tour represent a much smaller sub-set of families who have children with severe disturbances and are in very fragile states. Even though they represent a smaller number, they are “high need” families with children who are the most vulnerable and who pose major challenges to the systems that serve them. These families need and deserve a true system of care and supportive environment that can both help stabilize their child’s mental health condition and provide more effective treatment options. The input gathered from families during the listening tour provides tremendous insight into the weaknesses of the system and ways that it must be improved.

The visits were free flowing and lasted about an hour and a half. The conversation was prompted by three questions:

1. Tell us about your child and their illness.
2. Tell us about your experience with the children’s mental health system.
3. What could you use/have used to help you with your child?

The utilization of these questions and skilled parent facilitators resulted in very meaningful discussion between the First Lady and family members. Several children with a mental illness attended and added a richness and depth to the conversation. Although the visits were held at various locations throughout the state and included a diverse group of families with a wide range of mental health diagnoses, the issues identified were very similar at all the visits. Three major themes emerged throughout the discussions: the Role of Schools, Fragmented Supervision of Care, and Lack of Family Support.

The Role of Schools

Across the board, the issue that families voiced the most concerns about was dealing with the education system. Illustrative comments included:

- “I know they are trying as hard as they can but they do not know how to deal with children with mental illness.”
- “I have a IEP but it is not followed.”
- “I can’t work because I have to go to the school everyday to help them deal with my child.”

In general, the stories and examples shared by families fell into the following themes:

Utilization of Best Practices in the School Setting for Dealing with Children with Mental Illness:

Several parents provided examples about inappropriate methods of disciplining and teaching children with mental illness. One parent shared her experience that her kindergarten age daughter was being tied to her chair to keep the child in her seat. Another mother shared that her son was forced to sit with his back to the class and teacher, with his head touching the white board. Another parent told a story about arriving at the school after receiving a call to come pick her child up. The child was five years old and she found him face down on a table with his hands tied behind his back.

Many of the children discussed during the visits suffer from extreme symptoms, exhibit disruptive behavior, and are difficult to manage. However, based on the stories told, there is apparently a lack of knowledge and skills among school personnel about how to deal with children exhibiting these symptoms. While the stories above are just three examples, nearly 80% of the parents recounted stories about receiving calls from their child’s school requesting that the parents come to the school because the school was unable to deal with their children.

Utilization of Alternative Learning Environments:

Alternative Learning Environments (ALE) have traditionally been used to separate delinquent students from the rest of the student population in an effort to retain them in a tailored educational environment that will help them finish school. Several parents reported that although their child has a mental illness, they were placed in the school district's ALE program rather than a special education class that would have been more appropriate given their child's condition. While in the ALE class, their children experienced excessive bullying and did not perform well. At least one parent said they had tried to have their child removed from the ALE class, but was unsuccessful.

Transportation Issues:

There were numerous experiences concerning public school transportation. The environment on school buses seems to exacerbate the symptoms of mental illness. At least two stories were shared involving a child with mental illness becoming distraught because they had been taught to use seat belts and the bus did not have seat belts. In several instances, their children had been bullied and goaded into inappropriate reactions by other students. One situation actually escalated into a student attacking the bus driver. According to the parents relaying their experiences, the school personnel involved lacked the knowledge about how to deal with children with mental illness.

School Based Mental Health Services Vary from School to School:

Arkansas Medicaid and the Department of Education have worked together for the past five to ten years to bring mental health services into the schools. According to stories from the parents, there appears to be little consistency in how the schools are providing Medicaid-based mental health services. Several parents told stories of schools changing providers and having to get a new provider when they were happy with the previous provider. Others told stories of not having access to services on school campus because their school did not provide it. Several also stated that they were to

receive services on campus but the therapist never showed up or the sessions were always canceled for various reasons. Parents cited three variations of how services are provided in the schools:

- The school district allows all providers to come into the school and see the child on campus.
- The school contracts with a specific provider and they are the only one allowed on campus. If you choose to see another provider you must do so on your own.
- The school district does not allow any providers on campus and the only counseling available on campus is by school staff.

Fragmented Supervision of Care

The second major category of parental concerns involved issues around supervision of care. Sample comments included the following:

- "I couldn't get my physician to see that my child had a problem."
- "My child has been in the system for twelve years and he is always getting a different therapist."
- "We were forced to change providers and they changed my child's medications. My son was all messed up."
- "My child has been kicked out of several placements and told there is nothing we can do. I can't find anyone who will help us."

Achieving an accurate diagnosis and consistent quality treatment are difficult to achieve in a system that lacks trained providers and care managers. Additionally, Arkansas seems to lack expertise in dealing with the severely emotionally disturbed. The extremely volatile child needs the most intense treatment, yet many facilities and providers do not feel capable of handling them and do not want to assume the risk.

According to the experiences shared by some parents, their children may be extremely volatile or aggressive and are often discharged from facilities and not allowed to return. Others are threatened

with placement in Division of Youth Services facilities as a remedy for their behavior. Parents and providers alike seem to be at a loss as to how to treat these extreme cases. The few providers in the state that are qualified to deal with these cases have waiting lists for up to a year. This results in many children who are dangerously aggressive moving from provider to provider in an attempt to find treatment and care coordination. Both of which are rarely achieved.

Three areas of concerns emerged when talking about supervision of care. They are briefly discussed below:

Difficulty in Obtaining an Adequate Diagnosis:

One concern raised by parents has been the difficulty of obtaining an accurate mental health diagnosis for their child. While research shows that it is difficult to diagnose children at an early age, it is not impossible. Some parents expressed that they have been seeking a diagnosis for as many as twelve years. Their child is clearly exhibiting behaviors that indicate an illness, but local providers are unable to determine specific conditions. Some parents felt their provider was applying the best guess method with a diagnosis. Diagnosing a child's illness is the first step in obtaining treatment for their child.



Primary Care Physicians are Inadequately Trained in Children's Mental Illness:

The child's primary care physician is often the first step to receiving a diagnosis or further assessment of their child's condition. Unfortunately, most primary care physicians are not trained in the specialty of childhood mental illness and are unequipped to effectively treat these conditions. Many parents expressed frustration with physicians who told them their child would grow out of the behavior they were exhibiting or suggested that the parent needed to improve their parenting skills. One parent shared how she had become so frustrated that she called her physician for his home address so she could deliver her child to him so he could care for her son for a week to see if his behavior was truly "normal." Another parent shared that her physician continued to raise her daughter's medication dosage to the point that it was life threatening.

Lack of Child Psychiatrists:

While a medical home for these children is vital, the child's primary care physician must be able to work with a child psychiatrist who can work hand in hand with the child's primary care physician to ensure a child is accurately diagnosed and sufficient treatment is recommended and followed. Child psychiatrists are the hub of care for children with severe mental illness. They have the most expertise and training for diagnosing and treating mental illness. They can prescribe medications and provide appropriate counseling. The experiences relayed by parents during the listening tour, however, clearly indicate that many children had never seen a psychiatrist much less seen a child psychiatrist. Several parents reported "I have yet to actually meet my child's physician" or "I try to contact my physician but he is never available."

According to the Arkansas Medical Society there are 23 child psychiatrists in the state and 15 of those are located in Central Arkansas. Many adult psychiatrists are supervising the care of children but lack any specific pediatric training. Primary care physicians who are not trained to assess or treat mental illness are on their own because there are

insufficient numbers of child psychiatrists available for referrals or consults.

Lack of Family Support

In addition to schools and the supervision of care, the third major issue raised by parents was the lack of family support. The social service systems in most states are very complex and difficult to navigate. Families with children in crisis are often involved with multiple systems that require the parent to educate themselves in order to determine how to access the best services. In Arkansas, families who need help often turn to the Department of Human Services for advice and for access to Medicaid to pay for the services. Many parents mentioned the lack of response by the Department of Human Services as a barrier to care. Parents reported calling their local unit to find out about available services and being turned away with little or no information. Repeatedly, parents shared information during a visit and another parent would reply with “I wish someone would have told me about this earlier,” or “When I asked about this I was told I couldn’t get it.” Almost every parent mentioned struggles with finding information, locating providers/resources and lacking knowledge about the supports available to them and their rights concerning the service.

Parents also talked about the need for respite care or help with caring for their child. Parents told stories of not sleeping for several nights because their child would often get up in the middle of the night and possibly cause harm to themselves or others. Others just needed a break from the constant stress of dealing with a difficult child. Parents talked about not being able to go to the grocery store because their child acted out. Several parents relayed stories of being banned from stores and restaurants because of their child’s behavior. Parents under this type of stress are unable to respond adequately during a crisis and are less able to deal with day to day recovery and treatment. Several parents told us they had financial means to pay for a respite provider, but could not find anyone to provide the respite service in their local area.

One benefit of the listening tour was that parents connected with each other during the visits and not only shared experiences but shared information. Many visits ended with parents sharing contact information and promising to stay in touch with each other. One parent ended a session in tears stating “It is so good to know I am not all alone.” When asked during the visits what they could use to help them they asked for a 1-800 number for resource and provider information and for parent support groups.

Since the beginning of the First Lady’s involvement, a steady stream of e-mails have come to her website requesting information, asking for help with their child, or just wanting a chance to share their story. It is very clear that parents are searching for a support network and information. Parents and families want to be able to help themselves but most lack the resources and knowledge to navigate the current system.

Parental Suggestions

Several potential solutions were gleaned from the parent visits and the information and insights they provided. As part of the visit parents were given the opportunity to provide suggestions that would help improve the system. A compilation of these ideas and suggestions along with possible strategies are listed below and have been grouped into the same categories as the concerns raised by parents.

Suggestions for Improvements in Schools:

- “School personnel need to know more about children with mental illness.”
- “I wish they would put seat belts on buses and have staff ride the bus.”
- “If they just had a place my child could go and calm down it would help.”

Potential Strategies

Training for Teachers and School Personnel.

The state should review professional development curriculums that have already been developed and are being utilized in other states. The curriculums can be made available to teachers as part of their professional development requirements. Additionally, professional development requirements related to dealing with children with mental illness should be considered. Developing and including coursework concerning children with mental illness as part of the higher education requirements for educators would be another possible opportunity for providing additional support for school personnel.

Seat Belts/Monitors on School Buses.

Several parents suggested the use of seat belts or assigned seats on school buses as a way to help control children on school buses. Adding bus monitors to ride on school buses and help maintain control was also suggested. While schools now have the ability to video tape activity on school buses, several parents mentioned being denied the ability to view the tape of their child's questionable activity. Placing a monitor on board will provide immediate intervention for students with bad behavior. Video surveillance can be helpful as a punitive measure, but it does little to help defuse volatile situations that can arise in a school bus setting.

Quiet Rooms.

Several schools in the nation utilize "quiet room areas" to help children calm down during a manic or aggressive episode. These rooms do not have to be extreme, but they should have maximum safety features and be non-threatening to the child. Areas such as this could be used to defuse a situation and keep a child in school rather than sending them home.

Suggestions for Improved Supervision of Care:

- "We need more child psychiatrists to help treat children."

- "I need someone to tell me what is wrong with my child."
- "We need to catch these problems sooner."
- "My child's doctor and the therapist need to work together so everyone will know what is going on."



Potential Strategies

Develop Policies to Increase the Number of Child Psychiatrists in Arkansas.

Arkansas must develop policies to recruit and encourage child psychiatrists to locate in the state. Traditional strategies include loan forgiveness and incentives for residencies and other reimbursement incentives. The state should examine these methods as well as the possibilities of taking advantage of technologies like tele-medicine to provide opportunities for physicians to consult with experienced mental health professionals.

Training for Pediatricians and Family Physicians Concerning Mental Illnesses.

Physicians are always seeking Continuing Education Units (CEUs) to maintain their licensure. A series of CEUs could be developed around children with mental illness that could help pediatricians and

family physicians learn more about diagnosing and treating children with mental illness. Additionally, course work could be added to physician graduation requirements to give pediatricians and family practice physicians a basic understanding of children's mental health.

Improved Screening Methods for Child Care Providers, Schools, and Physicians Can be Used to Identify Problems Sooner.

With half of the children in Arkansas receiving health insurance coverage through Medicaid, the EPSDT program could be used as a means to improve screening children for mental illness. Efforts to improve screening in the Pre-K population are already underway. Experts in the state are conducting a review to develop an approved list of tools for providers to use. This effort should be expanded into school based efforts to provide screening for school age children.

Electronic Medical Records for Children with Severe Emotional Disturbances Can Help Physicians and Providers Better Manage a Child's Care.

Several efforts have been launched in Arkansas to test the feasibility of electronic medical records. Children with serious emotional disturbances being served by multiple systems would be a natural subset to utilize as a pilot group for electronic medical records.

Suggestions for Improving Family Support:

- "I want someone to call that will help answers my questions."
- "I need someone to give me a break, but I can't afford it and I don't have anyone to call."
- "When my child has an episode I need someone to help me right then."

Potential Strategies

Develop a Family Support Network that Includes a Web-Based Resource Directory, Parent Training, and Support Group Development.

One model, Keys for Networking, utilized in Kansas, is recommended as a possible solution for Arkansas. This model not only provides information to parents, but seeks to develop the parent's advocacy skills so they may become self-sufficient and engaged in helping other parents with children with mental illness.

Provide Respite Care and Crisis Intervention Services.

Having a child with a mental illness is very stressful and often results in a parent or care giver being available 24 hours a day 7 days a week. Providing respite care and crisis intervention will support families in their day-to-day life and will help them avoid situations that may escalate into a crisis due to fatigue and stress. There are two specific challenges with this type of intervention. One is funding to increase access to respite and crisis intervention services. It is always challenging to find ways to fund respite as it does not fit into the Medicaid model as a clinical service. It may require utilizing state general revenues for funding. There is the possibility of funding crisis intervention services through Medicaid and this should be analyzed further. The second barrier to providing these services is the lack of available providers. There is no registry of respite providers and they are very difficult to find on your own. The same holds true for crisis intervention. There are very few providers that provide this type of care. However, most experts feel that providers will step up to the plate if funding is made available for these services.

The Department of Human Services Should Develop Strategies to Improve Local Unit Responses to Parent Needs and Questions.

This may include customer service training, availability of local resource directories, identification and training of personnel within the local unit to serve as experts on specific areas.

Conclusion

It is very clear from visiting with parents that the current system is inadequate to meet the needs of children with serious mental health issues. Families are very frustrated and often feel abandoned and misguided. If the purpose of the system is to treat children with mental illness and prepare them to become a productive member of society, then we must develop a system that involves, treats and rehabilitates the entire family. Continuing the cycle of removal, treatment, and reinstatement in the system will not provide healing for the family or the child.

The input we received from families can help guide the transformation of the current system and will provide the newly established Children's Behavioral Health Care Commission with a beginning list of solutions that families will embrace. While other strategies will be necessary for a complete transformation, it is vital that we deal with the issues raised by families and provide them with resources and support to meet the mental health needs of their children.



A very special thanks goes to the follow people who worked on the First Lady Listening Tour Team. The information gathered from families, which was compiled in this report, would not have been possible without their dedication and expertise.

- **First Lady Ginger Beebe and staff, Michaela Hill, Candace Martin, and the Arkansas State Police**
- **Parent Facilitators:**
 - Pam Marshall and Georgia Rucker-Key, Arkansas Federation of Families for Children’s Mental Health**
 - Joyce Soularie, the Arkansas Mental Health Planning and Advisory Council**
- **Parent Recorder: Missa Hollis-Hatfield, NAMI Arkansas**
- **Youth Advisor: Ayla Soularie**
- **Coordinator and Report Compiler: Rhonda Sanders, Arkansas Advocates for Children & Families**

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