

Needs Assessment and Recommendations on Children's Mental Health in Alabama

Alabama Chapter-American Academy of Pediatrics Mental Health Coalition

Partners

Alabama Family Ties Alabama Department of Public Health

- Bureau of Family Health Services
- ALL Kids
- Office of Primary Care and Rural Health

Alabama Department of Mental Health and Mental Retardation Alabama Department of Rehabilitation Services Alabama Department of Human Resources Medical Association of the State of Alabama National Alliance on Mental Illness (NAMI)-Alabama

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Background and Statement of Values

"The burden of suffering by children with mental health needs and their families has created a health crisis in this country. Growing numbers of children are suffering needlessly because their emotional, behavioral and developmental needs are not being met by the very institutions and systems that were created to take care of them." (Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda, January 2001)

Brought together to conduct the first of two American Academy of Pediatrics (AAP) grants to improve access to care for children's mental health services, the Alabama Chapter-AAP Mental Health Coalition was created in 2005. Since then, the coalition has conducted roundtable networking and educational sessions in eight local areas of Alabama to improve communications and linkages between primary care pediatricians and the mental health community. In addition, the 2007 Open Forum on Children's Mental Health in Alabama, held January 27, 2007 in Montgomery, Alabama, convened more than 80 pediatricians, family physicians, and other primary health care providers, mental health providers, parents, and representatives from state health and human service agencies to promote children's mental health needs as a top-priority item on the state's agenda to improve the healthcare and quality of life for Alabama's children. All of these meetings have provided forums for discussion among a diverse cross-section of disciplines to explore the current and desired systems of care to improve quality of care, access to care, and adequate funding of children's mental health services in Alabama.

Currently, 27,000 children are served in the public mental health system in Alabama; approximately 25 percent of these are on psychotropic medications (serious psychiatric medications, excluding ADHD medication). Only a third of these children are estimated to have access to a child psychiatrist. According to the Surgeon General's report on "Children and Mental Health," one in five children has a diagnosable mental health issue that may need attention. Thus, approximately 280,000 of the 1.24 million children living in Alabama are likely to have a disorder at some point in childhood. Of these, one in 10 can be estimated to have a serious emotional disorder and require mental health services.

According to Kid's Count Databook 2008, Alabama ranks 47th among the 50 states, with higher rates of infant mortality, teen pregnancy, and teen deaths by accident, homicide and suicide than the national average. In addition, 70 percent of children in Alabama whose symptoms "warrant at least a psychological evaluation" have not received any mental health services within the last 12 months, according to the Research and Training Center for Children's Mental Health at the University of South Florida (December 2003).

Clearly, children are falling through the cracks of the current system. Based on the above facts, coupled with resounding opinions expressed at the roundtables and Open Forum, three overriding principles have emerged as universal values of the partnering organizations: Access, Quality and Financing.

- Rates of early detection and intervention for developmental, behavioral, and mental health challenges in young children must be improved in Alabama in order to ameliorate, reverse prevent the impact of mental illness across the lifespan, from infancy throughout adult life;
- Substantially improved access to appropriate mental health services—within a reasonable physical distance and time frame--must be achieved to assist the growing number of children and their families in Alabama with mental health needs;
- Mental health disorders must be perceived as a legitimate aspect of human health if we are to achieve parity of both public perception and the policy of employers and financers of healthcare.

The following pages detail the specific problems/needs, our values and recommendations for solutions.

Early Screening, Assessment/Diagnosis and Intervention for Early Childhood Mental Health Issues

Problem: The mental health, social-emotional and behavioral needs of the very young child, birth to five years of age, are not comprehensively addressed within the existing service delivery systems. Use of standardized screening tools for developmental, behavioral and mental health risks is not routine practice, thus compromising detection, early intervention, diagnostic, and treatment referrals. In addition, the continuum from screening to treatment lacks cohesiveness.

Statement of Values: Supporting and promoting mental/emotional health and well-being are critical elements of child health care. Rates of early detection and intervention for developmental, behavioral, and mental health challenges-in young children and their primary caregivers-must be improved in order to ameliorate, reverse, or prevent the progression of these conditions from childhood into adulthood.

Summary: "Childhood is a vital period for healthy social and emotional development, and early intervention and prevention efforts can affect health outcomes, school readiness, and health costs." (NASHP: Building Better Systems for Child and Adolescent Mental Health, Jan. 2007).

Primary health care services hold great promise as settings in which developmental problems, including mental health issues, can be detected and addressed.

A much stronger collaborative effort is needed to build a better system for the promotion of social and emotional health and development, prevention, early intervention, and care for mental health conditions affecting the very young child. Addressing the emotional, mental wellness and behavioral needs of the young child requires a continuum of services and must be a shared responsibility of public and private entities, providers, families, and the community.

Some current complementary efforts in the state include:

- The Alabama Partnership for Children, Early Childhood Comprehensive of Care, and Alabama: Assuring Better Child Health and Development Screening Academy (AABCD) initiative promotes policy and practice improvements to support and spread the use of standardized developmental screening tools in pediatric practice settings throughout the state.
- The Child Abuse Prevention and Treatment Act (CAPTA) requires Child Protection Services to make referrals to IDEA, Part C, Early Intervention for findings of abuse and/or neglect for children from birth to three years of age. Standardized developmental or social-emotional screening is not routinely performed for these high-risk children.
- Referrals of children from birth through two years of age to Alabama's Early Intervention System, under the Individuals with Disabilities Education Act (IDEA), Part C₇ require that the five developmental areas, including social and emotional development, be assessed for delays and intervention.
- Early Head Start and Head Start encompasses the ideals of developmental and behavioral screening and the provision of disability and mental health services to children in these programs.
- IDEA, Part B, Preschool Special Education, Section 619, provides services to eligible children from three to five years of age through the public school system. Primary care physicians cannot refer directly, but can encourage parents to request an Individual Education Plan (IEP) evaluation from which an IEP can be developed and services within the IEP provided.

- The Office of School Readiness coordinates pre-K programs throughout the state; the Alabama Chapter-AAP endorses the state's current efforts to increase these services that improve behavioral, emotional and cognitive development to prepare children for school.
- Substance Abuse and Mental Health Services A few community mental health centers provide services to children as young as two years of age, but, overall, are not equipped to address prevention, early identification and treatment of emotional, behavioral, and mental health problems of the very young child and family.
- The Alabama Chapter-AAP's own Reach Out and Read early literacy program provides new books to children from six months to five years of age in pediatric office settings so that children grow up with a love of books and parents learn the basics of reading aloud from their pediatric providers.
- There are, additionally, other related state and local efforts that are, or can be supportive of children's mental health issuers—the Children's Policy Councils, Family Resource Centers, Child Care Resources, The Alliance for Drug Endangered Children, and the Alabama Autism Task Force/Interagency Autism Coordinating Council, among others.

Suggested Strategies:

- Share "Facts on this Issue" (see end of this section) with peers, key stakeholders, critical partners, and decision-makers.
- Host forums to inform and promote a well-coordinated system of care, including pediatric screening, early intervention, related and specialty services, and mental health services.
- Develop a pathway for health, developmental, child welfare, mental health professionals, and other critical stakeholders to partner with one another other to develop and implement a model of family-centered, community-based care, addressing critical mental health issues affecting the very young child and family.
- Promote effective and efficient learning/CME opportunities to familiarize physicians and appropriate staff with administration of standardized screening tools (general developmental, inclusive of social-emotional development and autism-specific screeners) and how to set up office processes to support screening, billing, and tracking of referrals.
- Promote the adoption and spread of the medical home as the ideal setting for developmental surveillance and screening of children and adolescents.
- Support concrete avenues to reduce perceived and real communication barriers between physicians, referral resources, and families.
- Follow up with the recommendations of the Alabama Autism Task Force and the new Interagency Council to promote public awareness, screening and early identification of autism, develop new funding streams for services; increase state university awareness for research on autism spectrum disorders; create comprehensive case management services; foster independent advocacy to meet the needs of individuals with autism and their families.

Facts on This Issue:

- 16 percent of children have developmental disabilities; only 20 percent to 30 percent are detected prior to school entrance.
- Clinical judgment detects fewer than 30 percent of children who have developmental disabilities. (Hix-Small H, Marks K, Squires J, Nickel R. "Impact of Implementing Developmental Screening at 12 and 24 Months in a Pediatric Practice." *Pediatrics 2007*; 120:381-389;

Rosenberg SA, Zhang D, Robinson CC. "Services for Young Children: Prevalence of Developmental Delays and Participation in Early Intervention." *Pediatrics* 2008;121: e1503-e1509;

Schonwald A, Huntington N, Chan E, Risko W, and Bridgemohan C. Routine Developmental Screening Implemented in Urban Primary Care Settings: More Evidence of Feasibility and Effectiveness. Pediatrics, Feb 2009; 123: 660 – 668;

Pinto-Martin JA, Dunkle M, Earls M, Fliedner D, Landes C. "Developmental stages of developmental screening: steps to implementation of a successful program." *American Journal of Public Health.* 2005; 95:1928-1932.)

- Research over the past decade has clearly documented high rates of emotional and behavioral problems among children removed from their homes and placed into out-of-home care ("Relationship Between Entry Into Child Welfare and Mental Health Service Use" by L. Leslie, M. Hurlburt, S. James, J. Landsverk, D. Slyment, and J. Zhang.)
- Some children are "above cut-off" on general developmental screens, but still have a behavior disorder.
- Postpartum mood disorders correlate to personal-social delays, cognitive delays, and future behavioral disorders in the child.
- There is an emerging evidence base for the role of early intervention services in improving outcomes for children with developmental and mental health problems in the general population that heavily relies on accurate and appropriate screening and assessment practices.
- The American Academy of Pediatrics has developed a policy of Developmental Surveillance and Screening of Infants and Young Children, recommending the use of standardized developmental screening tools at the 9-, 12-, 24- or 36-month well-child visits, and autism-specific screeners at 18 and 24 months.
- Two-thirds of physicians in a 2000 AAP survey felt that they were not adequately trained to conduct developmental assessments.
 (Sices L. 2004. "How Do Primary Care Physicians Manage Children With Possible Developmental Delays? Pediatrics 2004; 113: 274-282; Silverstein M, Sand N, Glascoe FP, Gupta B, Tonniges
 - T, O'Conner K. "Pediatricians' reported practices regarding developmental screening: Do guidelines work? And do they help?" Pediatrics 2005; 116:174-179.
- Findings from the AABCD pilot data indicate an increase from 4 percent to 78 percent in use of standardized developmental screening tools, resulting in a 138 percent increase in referrals to Early Intervention, compared to the same period in the previous year before implementation of standardized screening.

2 Mental Health Parity and Payment

Problem: Insurance coverage for mental health is extremely limited in Alabama. According to the AAP Policy Statement, "Insurance Coverage of Mental Health and Substance Abuse Services for Children and Adolescents: A Consensus Statement," it is currently estimated that at least 13 million children are in need of mental health or substance abuse services, yet attempts to restrain healthcare costs have resulted in decreased availability of mental health and substance abuse services for children and adolescents. Third-party payors and employer plans "carve out" mental health benefits, placing mental health coverage at a vastly lower priority than physical health coverage. According to the AAP, among the primary obstacles to appropriate access to mental health care for children are managed care and insurance systems that provide lower benefits for mental health care than for medical care. This often takes the form of higher co-payments, deductibles, and limits on visits and days of coverage. There also exists a lack of payment of primary care providers for ADHD and other psychosocial diagnoses by private insurers.

Statement of Values: Private insurers should cover all mental health disorders at the same level as physical illness. Services provided by clinicians in all settings—primary care clinics, centers, schools—must be paid for in order to assure sustainability and quality of services.

Strategies/Recommendations:

- Mental Health Parity Legislation Legislation recently passed Congress (October 2008) to remedy this problem by requiring insurers and employers to guarantee that these and other treatment limitations on mental health care are no more stringent than similar restrictions on medical and surgical care. The proposed laws also contain provisions to ensure that small businesses are not overly burdened by these requirements. Clarification of the impacts of the federal law at the state level should be addressed.
- Work with all child-serving agencies in Alabama, i.e. Medicaid, Department of Public Health, Department of Mental Health and Mental Retardation, Department of Human Resources, Department of Youth Services, Department of Children Rehabilitation Services, and Department of Children's Affairs, to develop a strategy for the blending and braiding of state programmatic funds to provide more mental health services and eliminate duplication of services for children at risk.
- Recommend full implementation of Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) so that children receive the full range of mental health services.
- Work under the auspices of the Alabama Chapter-AAP's newly formed Pediatric Council to initiate dialogue with private insurers to advocate for mental health as part of pediatric health access issues to increased coverage of children's mental health services in the medical home setting.
- Evidence-Based Prevalence Data for Third-Party Payors Work with Blue Cross Blue Shield of Alabama to gather one year's worth of data on the prevalence of ADHD and other mental health-related disorders seen and diagnosed in primary care.
- Approach employers with data on the cost of adult mental health issues not addressed in childhood, costs of medications for teen and adult psychotropics, and work days lost due to mental health issues.
- Engage other stakeholders in an awareness campaign to improve access to children's mental health services, i.e. PTA, Alabama School Nurses, State Department of Education, Department of Public Health, United Voices for Children, etc.
- Approach local employer groups to expand mental health coverage to full parity for children and adolescents.
- Advocate for appropriate implementation of mental health parity at the state level develop a unified legislative push to build on current success of the Children's Mental Health Roundtable projects.
- Advocate for improvements in payment to primary care physicians by private insurance companies such as BCBS, UnitedHealthcare, TRICARE, etc.

Facts on This Issue:

- The financing of children's mental health services are extremely complex and should involve efforts to improve financing systems in both the private and public sectors.
- Children with mental health needs are at greater risk for poor quality of care due to use of multiple providers such as pediatricians, psychiatrists, case managers and other mental health care providers.
- Although 70 percent of children are privately insured, private health insurance pays for less that half of the costs for children's mental health services. Parity between physical and mental health services is key to increasing access to care for children with serious emotional disorders.



Problem: Of the 1.24 million children living in Alabama, it is estimated that 1 in 5 children or approximately 280,000 Alabama children will have a diagnosable mental health issue at some point in their childhood. However, many of these children will not have access to a practicing child and adolescent psychiatrist. Like may states, Alabama faces a critical shortage in mental health professionals. It is estimated that there are less than 3.9 child and adolescent psychiatrists per 100,000 people in the state.

Due to the shortage of psychologists and psychiatrists within the state, pediatricians can provide an immediate extension of the mental health workforce by identifying potential problems via pediatric clinical encounters. The lack of coordination and communication between the various providers that work with children – mental health professionals, child welfare and primary care physicians – creates an environment that lacks continuity of care and promotes less than adequate diagnosis and treatment of young children.

Statement of Values: The number of qualified child mental health providers should be increased through support for training programs, better recruitment into these programs, job incentives, and improved communication and coordination of services.

Strategies/Recommendations:

- Enhance communication and coordination of services by offering joint training opportunities for primary care providers and mental health professionals. Pediatricians and family physicians are able to use basic diagnostic screening tools to identify mental health issues during regular well-child check-ups. Joint training will allow providers to define the service integration framework so that primary care providers can handle simple cases and work with the mental health professionals to manage the more complex cases. An integrated approach will help alleviate the overwhelming caseloads faced by master's-level social workers, psychologists and psychiatrists.
- Consistent use of screening tools for diagnosis Communication and coordination of services between primary care physicians and mental health professionals can be enhanced by using the same screening tools.
- Co-locate physicians and mental health professionals Have multiple services offered in one location for busy families. Allowing master's-level social workers or therapists to "moonlight" in pediatric offices will enhance the opportunities for coordinated treatment and improved communication. It also expands the opportunities for consultation.
- Creation of a state loan repayment program and development of community incentives for mental health professionals who agree to practice in rural communities in Alabama. Stipends should be available during last year of residency or master's-level program.
- Promote opportunities in mental health professions to students in rural communities. Research has shown that in the first nine years of life, rural living is imprinted on an individual, so if we can "raise our own" from a rural community, it is much more likely that they will stay in a rural community.
- Develop "career ladders" in mental health, providing financial and professional incentives for mental health professionals to obtain advanced degrees.

- Use advanced nurse practitioners in pediatric practices to provide mental health services.
- Expand the use of video communications to deliver telepsychiatry to the rural underserved areas.

Primary Care and Mental Health Integration and Communication

Problem: Communication between primary care providers and mental health professionals needs to be improved. Lack of timely communication and coordination of treatment often hampers access to mental health services and leads to duplication of services and inefficiencies in care for Alabama's children. The dichotomy between physical and mental health care contributes to the stigma associated with mental illness.

Statement of Values: Children's overall health and well-being is inclusive of their emotional and mental health needs and should be screened, evaluated, treated and/or referred as part of typical primary health care practices. Meaningful communication and service integration must be established by primary care providers and mental health professionals in order to create much-needed efficiencies and access to care for children with mental health needs.

Strategies/Recommendations:

- Sustainable local networks or alliances/discussions develop university-affiliated child and family psychiatry center as a central coordinator for child psychiatric needs, seamless system/integration between primary care providers and psychiatry, Child and Adolescent Psychiatric Institute, standardized forms, service environment assessment as beginnings of communication.
- Continue and improve the relationship and work begun through the AL-AAP Mental Health Coalition by sharing information about the public/private mental health systems, partnering on professional educational opportunities, and developing of legislative and fiscal strategies to improve mental health services. Promote and support initiatives that integrate mental health services with primary care providers. Co-location of services would increase coordination and communication of treatment, reduce stigma, and improve access. For many families, it would help them with missed school, work and transportation issues. Develop universally accepted guidelines that are compliant with federal regulations that facilitate the exchange of information for treatment coordination and monitoring of children with mental health needs.
- Expand the Annual Child and Adolescent Psychiatric Institute to include policy-makers and the need and goals for transformation in the mental health system.
- Create email groups at the local level through which pediatricians and children's mental health providers can interact to staff children and share resource information.
- Develop a public education plan to address children's mental health advocacy issues.
- Develop a timeline for an advocacy push linking with or building upon the momentum of current related issues: autism, developmental screening, and telemedicine for children's mental health initiatives.
- Reach out to the school systems to provide better linkages between children and mental health providers.
- Create a system for the pediatric referral coordinators to communicate with all service providers and share information with their peers
- Invite community mental health center Child and Adolescent Coordinator to attend the hospital staff meetings to provide information and linkages with the hospital and the community mental health center

Facts on This Issue:

- The majority of prescriptions of psychotropic medications for children are written by pediatricians, not psychiatrists.
- Alabama has a few primary care practices that are co-located with mental health services.
- Most parents and families would rather receive their services in locations that are designed to serve children, such as pediatrician's offices, schools, etc.
- Co-location and "one-stop shops" are models of service-delivery that is increasing in popularity across the country and especially in rural areas of states.

5 Mental Health Education for Primary Care

Problem: Primary care physicians do not receive adequate training in medical school and residency to handle the breadth of mental health problems facing children today. However, many children do not have access to or cannot afford specialist mental health care and need to rely on pediatricians to provide that care and/or locate additional resources for them.

Statement of Values: Pediatricians and other primary care physicians and clinicians need to play a central role in the prevention, identification and treatment of mental health problems in children. They can help promote children's mental health and learn to screen, diagnose and in many cases provide treatment for children with mental illness. Therefore, they must be adequately educated on mental health screening, diagnosis, and treatment, as well as how to make appropriate referrals to local specialist services.

Current Efforts

- The Alabama Department of Mental Health and Mental Retardation's Child and Adolescent Psychiatric Institute (CAPI), co-sponsored by the Alabama Department of Public Health Children's Health Insurance Program, is an annual meeting that has brought together primary care and mental health providers for the purposes of establishing better communication, developing ongoing strategies to improve delivery of mental health care in the state, and providing mental health continuing medical education (CME).
- Alabama Chapter-American Academy of Pediatrics roundtables have initiated the process of developing collaborative efforts between local pediatricians and mental health providers at the local and regional levels.
- The Alabama Chapter-AAP and member pediatricians are in the process of beginning comprehensive assessment of local service environments.

Strategies/Recommendations:

- Ongoing CME for primary care physicians by child and adolescent psychiatrists.
- Intensive proficiency course in mental health for primary care pediatricians, such as through yearly CAPI as well as self-study opportunities similar to the North Carolina sexual abuse certification program, which includes reading materials and self-assessment exercises.
- Education to include mental health screening, diagnosis, and management when appropriate
- Identification of local referral processes and resources.
- Ready access of primary care physicians to information on those processes and resources, such as through mental health service directories.
- Availability of local and/or distance specialist consultation by mental health providers for specific educational needs of primary care physicians.

- Consultation letters from mental health providers to be used as an ongoing form of primary care physician education.
- Local identification of specific educational needs and opportunities, such as through existing pediatrician and mental health specialist meetings and Grand Rounds.
- Reformat the Children's Mental Health Resource Directory created in the 2008 Roundtable Project to link by specific diagnosis and insurance plan and include flowchart to guide mental health care categorized by special services.
- Provide training on HIPPA issues to pediatricians to increase the sharing to children's mental health needs with providers
- Follow up with the Children's Policy Council at the local level to educate the stakeholders on children's mental health needs.
- Invite the Family Resource Centers, if available at the local level, to host children's mental health forums and update the Children's Mental Health Resource Directory so that it becomes a fluid resource.

Facts on This Issue:

- The state of Alabama has a serious shortage of specialist mental health providers, resulting in crowding and excessive waiting times for existing services.
- The lack of mental health parity in health insurance policies means that specialist services are inaccessible to many children for financial reasons.
- Primary care physicians are in an ideal position to provide a medical home for children with mental illness, by becoming better educated in screening, diagnosis, treatment and referral.
- If primary care physicians learn to manage milder cases of mental illness independently, such as ADHD and uncomplicated depression, this would reduce crowding and improve access to specialist services.
- Pediatricians are extensively trained and experienced in normal child behavior and development and thus have a strong base for further education in mental illness.
- Primary care pediatricians can provide continuity of care and have known their patients and families in many cases since birth. With further training, this continuity puts them in an ideal position to recognize and manage mental illness early in the course.

6 Connecting with Families

Problem: Families often feel hesitant to reveal their child's mental health issues due to stigma. Families are often ignored as the resource and primary caregiver to their child. Families of youth with mild-to-moderate mental heath needs are often only seen by their primary care providers.

Statement of Values: Families and youth are equal partners in care decisions. Families and youth are valued as experts on the child needing care. Trust is an essential part of mental health care. Care is strength-based, not symptom-based. Each youth is an individual and each care plan should be created individually.

Strategies/Recommendations: There are two ways pediatricians can connect with families: on an individual level through the services provided and at the state level through helping to create policy change.

On the individual level, strategies to connect with families would include:

- Take time to listen to the family and the youth.
- Recognizing that parents are the best resource for their children. Health care providers see children on a limited basis, but parents are constant.
- Find out which family members are key caregivers and realize their family make-up may be *different* (not better or worse) from what the providers are familiar with.
- Ask open-ended questions to learn about behaviors, symptoms, and family routines.
- Value what the family is saying about their child so they can value what you are teaching them about how to care for their loved one.
- Involve the family and the youth in creating a care plan that focuses on strengths, concerns, needs and resources.
- Know what is available in the community and being ready to refer the family to these resources.
- Let families know if they are not familiar with a diagnosis, medication or treatment.
- Refer families to support services they need, such as local support groups or "warm lines," events, or trainings from a family organization. Warm lines offer readily accessible, heart-to-heart support with informed and resourceful mentors skilled in day-to-day parenting issues.
- Ask families for active participation in the care of their child.
- Help to advocate for their child by being an example or referring them to an organization that can show families how to advocate.
- Assist families with maintaining and organizing information about their child so families can be good care coordinators.
- Help families to realize the value of networking with other families; isolation does not help the parents or the youth involved.
- Expect to have a continuing relationship with the youth and family when they are referred to specialty care.

At the state level:

- Help create policy change by partnering with family organizations, (examples: Alabama Family Ties, NAMI Alabama) and organizations that care about children's issues overall and have a stake in transforming children's mental health. (Examples: VOICES for Alabama's Children, Alabama PTA, Alabama Network for Children with Disabilities, Family Voices of Alabama, and Alabama Disabilities Advocacy Program)
- Participate in state and local-level task forces and work groups and request that family members be an equal and present partner at each meeting. Lead by example and have families train other stakeholders.
- Survey parents and youth on what they need and share the results at the local and state level. Insist on a flexible, culturally competent, responsive, health care system.