



The Campaign for Children's Mental Health

Virginians Speak Out: A Report from the Campaign for Children's Mental Health July 2010

The purpose of this report, the first in a series from the Campaign, is to summarize citizen opinion on the current state of children's mental health services. Future reports will focus on policy recommendations for improving access to care. In Virginia, the child mental health "system" is really a complex patchwork of public and private services that are regulated and funded by multiple state agencies across three secretariats: Health and Human Resources, Public Safety, and Education. The feedback below includes comments on all aspects of this system: services funded through any means – including Medicaid, private insurance, and the Comprehensive Services Act – and provided by both public community services boards and private providers.

Four hundred parents and professionals across the Commonwealth attended public forums to voice their opinions about the children's mental health system during a listening tour held by the Campaign for Children's Mental Health. The clear message from participants at every forum was that Virginia's child mental health system is in crisis. The array of mental health services needed by children and families is not available, and access to the care that exists is complicated by the fragmented service delivery system. The result is that many children with mental health problems and their families are left largely on their own, unable to access services until problems have become crises.

The Campaign, sponsored by Voices for Virginia's Children and launched in December 2009, hosted the forums in April and May 2010 to learn more about the specific challenges faced by families and providers and to highlight these issues for the McDonnell administration, General Assembly members and other policy makers. Ray Ratke, Special Advisor for Children's Services to the Secretary of Health and Human Resources (now retired), served as the administration's official "listener" on the tour.

The Campaign reached out to citizens at eight forums across the Commonwealth: Lynchburg, Roanoke, Richmond (two forums), Loudoun, Fairfax, Williamsburg and Norfolk. Providers and parents from other localities in the state, including far southwest Virginia, southside Virginia, and Charlottesville, attended these forums as well. Participants were largely service providers, both public and private, and those working in related child-serving fields (e.g. schools). Parents or other

family members of children with mental health challenges were present at all but one of the forums.

In conjunction with the forums, the Campaign surveyed Virginians about the children's mental health system. All individuals (approximately 500) on the Campaign's email listserv, including forum participants, were invited to complete a brief electronic survey. Surveys were completed by 147 people, a 29% response rate.

This report provides information about the feedback received from both the forums and the surveys.



Forum Feedback

Identification of Needed System Reforms

Participants were asked to identify issues that need to be addressed in their region, as well as to recommend state and local policy changes that

would increase the quality of or access to children's mental health services in their region.

Create Comprehensive Array of Quality Services

Recommendations about the **array and quality of services** available were extensive. With the recent growth in the number of in-home and other community-based providers, participants expressed grave concern over the lack of quality oversight and monitoring of these services. Also, participants in all forums identified significant gaps in the array of services; long waiting lists for services or having to travel to access psychiatric care were frequently mentioned. Participants in all areas called for an increase in prevention and early intervention services. They expressed frustration that the system is geared toward children in crisis, who must be served with high-intensity and expensive services, leaving no way to pay for less intensive services that could prevent crises. Participants also cited a need for non-medical services, such as after-school activities, mentoring, and parent education and support, to help children with mental health challenges and their families. Both parents and providers called for more school-based prevention and intervention efforts. Participants also noted that despite improvements in some localities in involving parents in decision-making, much work remains to be done to make families true partners in the child mental health system.



Achieve Consistency Across Virginia

The **need for greater consistency in the services available statewide** was cited at every forum. The disparity among localities in services offered and policies for accessing them is particularly frustrating for parents. It is also difficult for private providers who are trying to develop new services in a multi-jurisdictional area. Participants called for greater leadership from the state and greater collaboration within regions to increase the consistency of services available.

Increase System Coordination

Extensive discussion occurred at each forum about the **fragmentation of the overall system** at both the state and local levels. At the state level, responsibility for funding, licensing and regulation of child mental health services is divided among multiple agencies within three secretariats. Several participants cited the state's demand for local collaboration as part of the Children's Services System Transformation but noted that it was not demonstrated amongst the various agencies and secretariats at the state level. As examples, they cited contradictory regulations being sent to localities from various state child-serving agencies. This lack of cohesiveness leaves local child-serving agencies at odds with one another and causes children to go without services. Parents report being overwhelmed and confused about how and where to access services, and many participants cited the need for a centralized resource to help parents navigate the system.

Strengthen Workforce

Comments about the child mental health **workforce** largely centered on how the training of the workforce affects the quality of services. Across the board, participants called for quality assurance. Participants also wanted the qualifications of providers to be transparent to parents. Many comments were made about the shortage of child psychiatrists, and thus the related need for increased training of pediatricians and other primary care providers. Increased training in children's mental health was also suggested for school personnel. Participants in several areas cited the need for greater cultural competence of providers to help them work with diverse populations of families.

Address Insurance Barriers

Finally, participants raised a number of issues related to both **public and private insurance**. Overwhelmingly, parents attending the forums expressed frustration that private insurance covers very few mental health services for children and that paying out of pocket for services is cost-prohibitive. This leaves a significant number of children without needed treatment. Providers and parents expressed challenges with Medicaid's medical model of reimbursement, meaning that only the child with the diagnosis can be treated rather than addressing underlying problems in the family or addressing the effect of a child's mental health problem on other family members. Providers expressed significant concerns about the new

Medicaid managed care vendor and the perceived inconsistency of pre-authorization decisions. Again, they expressed frustration that the reimbursement system is geared toward serving children in crisis. Providers were also concerned about the possible implementation of Medicaid managed care in behavioral health. They fear that limiting the duration and availability of services will actually lead to greater use of high-end placements, such as residential care, costing more money and reversing the progress made as a result of the Transformation.

Recent Improvements

Participants were asked to comment on any improvements to the children's mental health system made in their region during the last two years. Attendees at all forums were able to identify some positive changes, which were largely attributable to the Children's Services System Transformation. These included:

- An increase in certain types of community-based services
- Increased collaboration among local child-serving agencies
- Increased family involvement in service delivery in some areas
- Additional workforce training around the Transformation's practice model

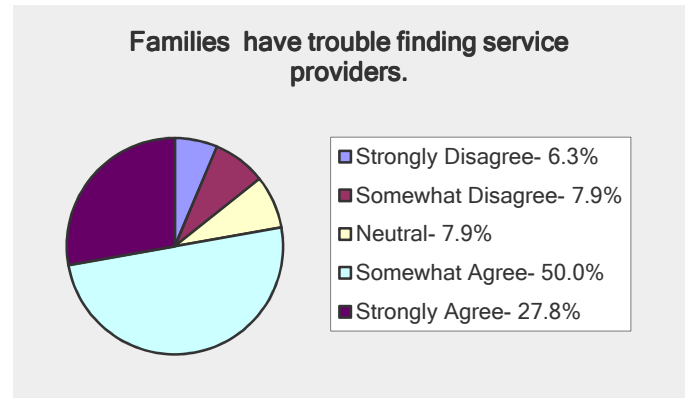
Service growth was most prevalent in intensive in-home services, therapeutic day treatment in schools, and intensive care coordination by community services boards. The combination of more community-based options and increased collaboration among child-serving agencies with the goal of maintaining children in the community led to fewer children in residential placement. Positive comments about the increased number of services, however, were tempered by serious concerns about the quality of some new services.

Increased family involvement in the delivery of children's services was primarily due to training of the workforce on the new practice model of Transformation. Child-serving agencies, particularly departments of social services, are reported to be involving families as partners in determining the best services for their children using national models of family engagement.

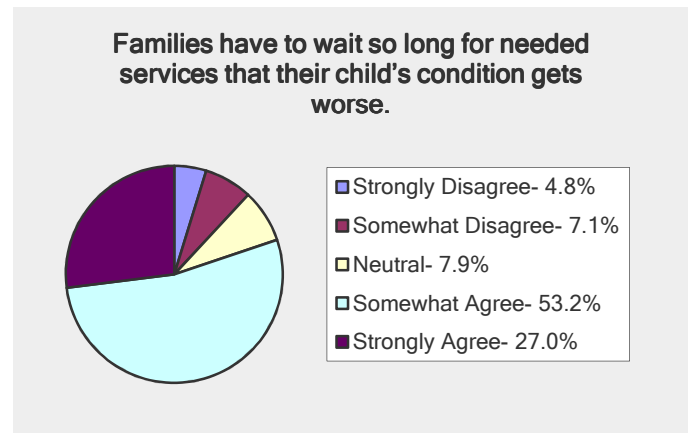
Statewide Survey Results from Professionals

The Campaign conducted brief online surveys of providers and parents in May and June 2010. Survey respondents were asked a series of five questions about access to children's mental health services in their region. As only twenty responses were submitted by families, the Campaign will conduct additional outreach to families to increase the number of respondents. The following results are from the 127 surveys completed by professionals.

78% of professionals from around the state agreed that "families have trouble finding service providers." These responses are consistent with the qualitative feedback from the forums that the system is fragmented and confusing for families and that the availability of services is inadequate.

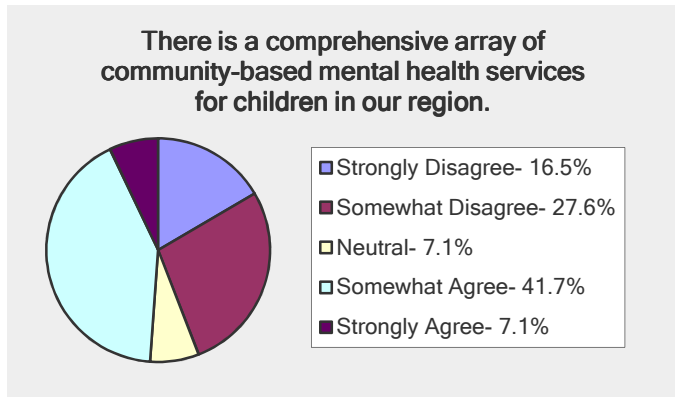
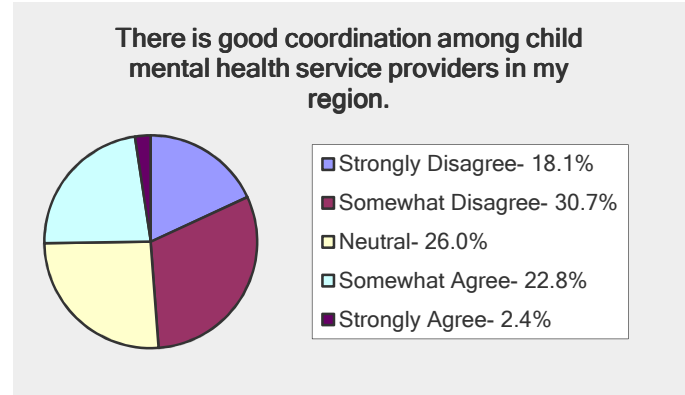


80% of respondents agreed that "families have to wait so long for needed services that their child's condition gets worse." These data confirm that a shortage of providers has dire consequences for the children who are seeking treatment and unable to find it.



49% of respondents agreed that “there is a comprehensive array of community-based mental health services for children in our region.” The responses to this question are mixed, possibly indicating the geographic difference in the array of services offered. A report by the Office of the Inspector General in 2008 confirmed that the availability of children’s services at community services boards varies widely from one area to the next. In addition, it should be noted that this question merely asks about the array of services, not the capacity of the system. Thus, a region could have a wide array of mental health services but still have long waiting times to access some or all of those services.

work remains to be done to create a more cohesive system.

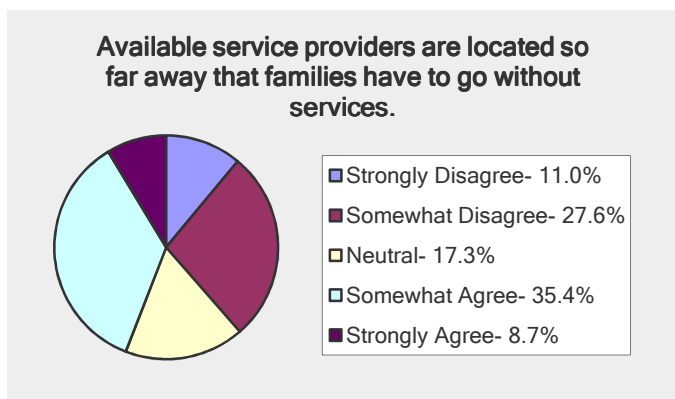


Conclusion

The forums and survey results provide important opportunities for the Campaign and policy makers to learn about the most current concerns across the Commonwealth. The overwhelming message was that the fragmented and inadequate system that exists now creates significant problems for children and families. In addition to the unnecessary human suffering caused by the troubled system is the financial cost of delivering services in this manner. The inescapable conclusion of this community feedback is that the children’s mental health system must be reformed not only to provide the children of Virginia with the mental health treatment they need, but also to make the most effective and efficient use of the system’s current and future resources.

44% of respondents agreed that “available service providers are located so far away that families have to go without services.” The responses to this question were mixed, possibly indicating a geographic difference in the availability of service providers. Forum participants from rural areas indicated that travel to access services was a barrier.

The Campaign for Children’s Mental Health is a three-year advocacy initiative sponsored by Voices for Virginia’s Children. The Campaign is led by a Steering Committee comprised of Mental Health America- Virginia, National Alliance on Mental Illness (NAMI) Virginia, and the Virginia Association of Community Services Boards. Funding for the Campaign is generously provided by Consumer Health Foundation, Bon Secours Virginia Health System, HCA Virginia Health System, Carilion Foundation, and Inova Health System.



For more information about the Campaign, visit www.1in5kids.org or contact Margaret Nimmo Crowe, margaret@vakids.org

25% of respondents agreed that “there is good coordination among child mental health service providers in my region.” These data indicate that despite recent progress toward greater collaboration in some areas of the state, much



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