



Barriers to Achieving a System of Care for Children with Mental Health Needs:

Lack of Information and Support for Parents

Parents' Voices:

"It's really hard to find out where to go to get help. There's just not enough information out there about where to go to get help."

"They need a master list of resources. As soon as a parent finds out your kid has [a problem, they should say,] 'here's a master list of resources.' Doctors, therapists, anybody dealing with kids, school nurse, pediatrician, counselor's offices, school [should have a copy]. Those are the places that you go first....they are the ones who say something's not right and we need to talk to you."

"Parents [need to be educated] of how you work within the system and how do you sit in a team meeting and how do you conduct yourself when you're on the verge of breaking down. Because we are. We are desperate and we're upset, and we might be professional people on the outside world but when you're sitting at that table, you lose who you are professionally and you become a parent. It means teaching parents how do you pull through that and strategically write everything out when you go to that meeting and talk to the team. And you *are* part of that team."

"Typically you have to be able to educate yourself as a parent and ask the right questions. So the parent has to have the knowledge base prior to the phone call and when you're in a crisis, you can't always do that. Plus parents aren't pleasantly assertive when they're in a crisis. They're in a crisis. So the knowledge base is really missing across the board. Most people don't know what programs are out there and the ones that are out there are so limited."

"One of the things that we've observed going in for IEP (special education) meetings... I've seen parents sign in ahead of us that literally cannot write. So, can we expect – in order for their child to receive appropriate services – for them to be able to go out and do the kind of research and reading and access the types of people [they need to]? They need more – resources are great for parents who are willing to sit down and can read it and process it and know what to do with it, but not every child who has needs has that family environment."

"The support group [has helped]. Even though it's once a week, we're a very tight group. And we're there for each other, and she [my daughter] noticed a difference within two weeks of me going there."

Research:

- A system of care for children with serious emotional disturbance outlines a comprehensive continuum of services designed to meet the needs of children and their families. One underlying premise of the system is that services are family-focused, meaning that not only does the system respond to the unique needs of individual children, but it also supports families in their roles as caregivers. This philosophy translates into particular family-centered services in the system of care, including family support services, support groups and advocacy.

- Historically, parents have not been included in service planning for their children, partly because they were viewed as the cause of their children's problems. In addition, the stress and overwhelming demands of raising a child with mental health problems make it difficult for families to participate as partners without additional support. The Surgeon General's Report on Mental Health (1999) cites the importance of providing family support services to "strengthen adults in their roles as parents, nurturers, and providers." Two of the most important aspects are *emotional support* and *education* about what services exist and how to advocate for them appropriately.

Policy Recommendation:

The public and private sectors in Virginia should come together to develop a stronger, centralized system of family support and information that encompasses and greatly expands existing efforts. Current programs are helpful for pockets of parents, depending on geographical area or involvement with particular agencies. Also, the Virginia Commission on Youth has developed a very helpful resource guide for best practices in children's mental health treatment. However, there is no central source of parent information, support, and advocacy training. Virginia should consider models of parent support organizations and coalitions that have been effective in other states. **Below are two examples of particularly effective parent organizations.**

Maryland: The Maryland Coalition of Families for Children's Mental Health (www.mdcoalition.org) is "a grassroots coalition of family and advocacy organizations dedicated to improving services for children with mental health needs and their families, and building a network of information and support for families across Maryland."

- Eight family and advocacy organizations joined in 1999 and incorporated as a private nonprofit organization which is governed by a volunteer Board of Directors.
- Funding is provided by the state department of health and mental health and the local Baltimore Mental Health Systems. The organization is a member of the National Alliance for the Mentally Ill (NAMI) and a state chapter of the Federation of Families for Children's Mental Health.
- Through its staff and website, the Coalition provides information and resources for parents by locality, including support groups. It also publishes reports on issues such as custody relinquishment and private insurance, and it hosts a Family Leadership Institute to train parents in advocacy skills.

New Jersey: The New Jersey Parents' Caucus (www.njparentscaucus.org) began in 1990 as a group of families of children with serious emotional disturbance wanting to affect public policy. Its mission is "to ensure that every family who has children with special emotional and behavioral needs is given an opportunity to play a strong and active role in the development and delivery of effective and timely services for their children."

- The organization grew and was incorporated as a private nonprofit. By joining with other child advocacy organizations, it was able to play a major role in making policy recommendations to the Governor and state legislature in 1998. These efforts resulted in the Children's System of Care Initiative, now called the Partnership for Children (www.njkidsoc.org), which is a major state effort to restructure the service delivery system for children.
- Funding is provided through the federal Substance Abuse and Mental Health Services Administration (SAMHSA) and the corporate support of Eli Lilly and Company. The Caucus is a state chapter of the Federation of Families for Children's Mental Health and also a member agency of the Child Welfare League of America.
- The organization provides education, information, advocacy, support and referrals to parents and professionals throughout New Jersey.

Sources: Stroul BA & Friedman RM (1986). *A System of Care for Children & Youth with Severe Emotional Disturbance*. • US Department of Health and Human Services. (1999) *Mental Health: A Report of the Surgeon General*.

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