

**Family Voice and Family Choice:  
Strategies to Ensure Meaningful Family Involvement**  
Children's System Change Initiative Stakeholders' Group  
Family Workgroup  
March 2004

**Background**

At the December 1, 2003 Children's Mental Health System of Care Initiative Stakeholders' meeting, Bob Nikkel announced that OMHAS would like to create a Family Member and Caregivers workgroup. OMHAS partnered with the Oregon Family Support Network (OFSN) and National Alliance for the Mentally Ill (NAMI) to plan and coordinate three family workgroups. Prior to the work group's scheduled meetings, a survey was developed for family members to respond with information about service needs, experiences, and concerns, providing them an opportunity to express interest in participating in work groups to help define meaningful family involvement in the children's mental health system. Results of the 28 surveys were compiled and provided a starting point for the work of the three family workgroups. The workgroup's purpose was "to prepare recommendations designed to ensure meaningful family involvement within the Children's Mental Health System of Care Initiative."

It was clear from the very first focus group meetings that family participation would need to go beyond "making recommendations". Families feel they have already made recommendations and offers of consumer organization participation at many levels of planning and decision making. There even have been mandates regarding "meaningful family or consumer involvement" that have brought about little or no change in how families of children with mental health disorders are regarded, informed, respected and served. OFSN and NAMI are not interested in participating in an effort that would continue business as usual. Family involvement that does not change the mental health system to better serve families is not "meaningful."

We report back to you nothing so simple or easy to ignore as recommendations. Rather, we report to you goals for system change that will improve services for children and their families. In our limited time, we have begun to think through these changes from the family perspective, and have identified strategies, benefits and action steps for change making at state, county, MHO and provider levels. Change that goes beyond the mental health system because child and family needs do not begin and end with mental health alone. How mental health, schools, juvenile justice, basic needs, health care, child welfare and others interrelate, collaborate, and compliment each other must be a part of the changing picture for children and their families to be served in a horizon of shrinking resources and increasing needs and family stress.

**Workgroup Process**

Two four-hour family workgroups (18 participants) were held in Eugene (with Klamath Falls attending by speaker phone) and Portland, February 3rd and 5th respectfully. A third follow-up workgroup, with some of the same participants and some new participants (for a total of 21), was held in Salem on Saturday, March 6<sup>th</sup>, from 2-5PM. The participants traveled from Triangle Lake, Pleasant Hill, Eugene, Springfield, Cottage Grove, Medford, Klamath Falls, Oregon City, Portland and Beaverton, devoting

7 hours of travel and meeting time to think through the strategies outlined on the accompanying document.

The initial workgroups in Portland and Eugene were asked to describe what meaningful family involvement might look like at each level of the children's mental health system (see attached Parent Focus Group Questions and Responses). The family members generously shared their experiences and perspectives and provided many new thoughts to how family involvement could be meaningful at the state, county, MCE, and provider levels. The experiences that families related in these discussions ranged from outpatient, day treatment, school, psychiatric residential, and hospital settings. There were moving stories of successes, and others about the hurt and harm done to a child and family. Everyone who listened left with a heart that was touched in some way. The ideas that came out of these discussions were creative, practical and hold the promise of system improvement for everyone; those who work in the mental health system as well as those who use it.

### **Key Goals and Strategies**

In the last workgroup, 21 family members convened to develop elicited strategies for ensuring meaningful family involvement based on previous workgroup suggestions. The family members divided up into four smaller groups and developed fourteen system change strategies out of a list of 103 suggestions. Family members agreed that they would like the stakeholder group to consider creating goals and strategies for the remaining suggestions, as well. **And finally, family members expressly requested that the stakeholder group meet with an equal number of family workgroup members at a family-friendly time in order to model and discuss the values of family involvement.**

Respectfully submitted,

Jeanne Schultz  
Executive Director, OFSN

Angela Kimball  
Assistant Director, NAMI Oregon

## **Family Voice and Family Choice: Strategies to Ensure Meaningful Family Involvement**

### **Goal: Expanding Family Voice**

#### **Strategies:**

- Include family members as part of state and MCE-level site review teams
- Create state-level children's mental health ombudsman and children's mental health family advocates at MCE and provider levels. (Advocates are family members)
- Establish uniform statewide grievance procedure
- Hold regular, family-friendly community forums at local and regional levels to elicit informal family input regarding community needs, access, choice, and service delivery
- Establish formal children's mental health inter-agency advisory councils at state and county levels with minimum of 51% representation by family members and foster parents who currently care for or have cared for children with mental health and/or co-occurring disorders. County councils report quarterly to local Board of County Commissioners and Commission on Children & Families.
- Include families as part of any new decision-making bodies, such as local ITS access committees
- Include family members in final level of hiring process for MCE management and for provider personnel
- Establish a mechanism for meaningful youth involvement
- Develop state policy and funding mechanism to provide supports that enhance family participation, including stipends

### **Goal: Expanding Family Choice**

#### **Strategies:**

- Ensure that families help administer flexible funding pools at local level
- Negotiate inter-governmental agreements at state and MCE level to blend funds to serve children with intensive service needs who have multi-system involvement
- Rewrite children's outpatient mental health rule to reflect System of Care principles, including strengths-based, family-driven, child and family teams with involvement of natural supports and other child-serving agencies
- Develop provider contracts that reflect full Title 19 service array, with incentives for continuous care coordination for children with serious mental, emotional, or behavioral disorders
- Ensure access to fully array of Title 19 treatment services for families of children with serious mental, emotional, or behavioral disorders, regardless of whether self-pay or moving in and out of Medicaid eligibility
- Disseminate information about family-serving organizations and full array of services to families at first contact with children's mental health providers
- Expand state mental health website to describe full array of Title 19 treatment services and link website to county, provider, and consumer organization websites. Make same information available in hard copy, alternative formats, and languages for the public. Involve family members in reviewing the information and websites for family friendliness.