Summary of Calls with SAMHSA Regional Administrators

The Family Run Executive Director Leadership Association (FREDLA) facilitated calls with eight Regional Administrators throughout the months of February and March. Thirty-five family organizations participated on the calls. The following provides a summary of the major points that were discussed on many of the calls. FREDLA wishes to thank all of the Regional Administrators for their time and interest in supporting family-run organizations.

Overview of Family-Run Organizations

Family-run organizations were started more than 25 years ago as a result of National Institute of Mental Health (NIMH) Child and Adolescent Service System Program (CASSP). Family voice is a cornerstone of the Children's Mental Health System of Care and grants to states and local jurisdictions were required to fund family organizations. Additionally, in 1988, SAMHSA began to award Statewide Family Network (SFN) grants to family-run organizations. The amount of the award has been $60,000 with an option for an additional $10,000 for youth programs. In 2015 the SFN award was increased to $95,000. Currently there are SFNs in 35 states. Family-run organizations are characterized by four distinct factors:

- Mission focused on supporting families caring for a child with mental health needs
- Governance at least 50% family members with "lived experience."
- Executive Director and direct service staff all family members with lived experience
- Family voice and choice evident in every aspect of the organization

"Lived experience" is defined as having the experience of being the primary caregiver for a child with mental health needs.

Topics Discussed

1. Family voice is critical to the system and equal to youth and consumer voice. All three are needed to make the system viable system for all.

2. Parent peer support can only be provided by parents with "lived experience." There is concern that mental health providers are providing what may be termed peer support, but it may not be a parent with "lived experience" providing the services.

3. "Parent peer support" is very different from adult consumer peer support. There is concern that peer support is being viewed as a homogeneous and the complexity of parent peer support is not recognized. The developmental stages of children from infancy to young adulthood can present mental health challenges that are manifest in different ways at each stage and involve different treatment modalities, programs, agencies, eligibility criteria and laws. This makes parent support a service that requires a unique set of skills, experience navigating numerous service systems and knowledge of multiple resources.

4. Family-run organizations are the cornerstone of systems of care for children, but often cannot fulfill that roll due to lack of adequate resources.

5. Statewide Family Networks (SFNs) provide direct services to families through information and referral, one-to-one support, training, and support groups. Additionally, SFNs provide public awareness, bring family voice to public policy tables and advocate through legislative processes. Many SFNs also facilitate the development of youth and young adult programs that may stay under the umbrella of family-run organizations or may spin off and become independent organizations.

6. Sustainability is a major concern for family-run organizations
   a. Budgets for family-run organizations range from $70,000 to over $2 million; however, the average budget is less than $500,000.
   b. Private funding is becoming more challenging. Foundations want to fund new projects for a limited period of time making it difficult to support the infrastructure.
   c. Many states are moving to Medicaid reimbursement for parent peer support. Rates for the service may only support the actual service and are not adequate to increased administrative functions as a result of billing for services.

Recommendations

1. There is a need for a statewide family network in every state/territory and the need for adequate funding available to make this a possibility.

2. Funding for Statewide Family Networks has been consistently at a low level since its inception. Increase in the amount ($95,000 from $60,000- $70,000) in the most recent RFA was much appreciated and is in the direction of adequate funding; however, the need to fully fund these statewide networks at an adequate rate remains.

3. It was strongly suggested that the current national definition of "family member" (*below*) be updated and/or revised in the RFA for Statewide Family Network Grants to eliminate the requirement for the young adult to be served by an Individual Service Plan. Many young adults do not want to be in a program or to have a service plan. The voices of these families are not "counted" as authentic family voice when it comes to a SAMHSA-funded SFN grant. This overlooks a major voice for families caring for transition-age youth or young adults over age 18, as well as omits a significant number of family members with lived experience that are valuable in family-run organization governance and support.

   > *"family members, who have primary daily responsibility for the raising of a child, youth, adolescent or young adult with a serious emotional disturbance up to age 18, or 21 if the adolescent is being served by an Individual Education Plan (IEP), or up to age 26 if the young adult is being served by an Individual Service Plan (ISP) in transition to the adult mental health system"* Appendix J – Certificate of Eligibility
   >
   > <u>Suggested language to eliminate the age limit when defining "family member":</u>
   > *"family members, who have/have had primary daily responsibility for the raising of a child, youth, adolescent or young adult with a serious emotional disturbance served by an Individual Education Plan (IEP), an Individual Service Plan (ISP) in transition*

to the adult mental health system to eliminate the age limit when defining "family member."

4. Often a state may have multiple SAMHSA grants that work in silos and do not connect as part of a coordinated system. Exploring ways to coordinate efforts among SAMHSA grants within states and territories would maximize the use of available funds and efforts, leading to a system at the state level that is aligned as a full system of care for children, youth and families.

5. Although the CMHI (System of Care) RFAs include the importance of family-driven care and involvement of family-run organizations, there continues to be a struggle in implementation to consistently implement this practice. It was suggested that the RFA include more emphatic language regarding implementation of family-driven care throughout RFA, including specific expectation that states and local jurisdictions connect to statewide family organizations as these organizations are the vehicle to bring family voice to all aspects of the system.

6. As a means of further embedding the system of care philosophy at the national level, it was suggested that SAMHSA explore the possibilities of coordinating funding between federal agencies, such as OJJDP and Child Welfare, to maximize available funds and impact for children, youth and families.

7. Family-run organizations are very pleased that peer workforce and development is a SAMHSA priority. They have an enormous amount of expertise regarding parent/family support providers in terms of hiring, training, supervising and supporting this workforce. Family-run organizations ask that SAMHSA encourage states to use this expertise as the peer workforce grows, and they request ongoing support and guidance through Technical Assistance on certification and Medicaid reimbursement for these services.

8. SAMHSA support was requested by the family-run organizations nationally in continuing to support meaningful family involvement at the state level and in strengthening expectations for documenting the variety of ways families are involved in policy-making, service development and evaluation, and service delivery. The most common method of documentation currently is attendance to meetings which does not capture the many other ways that families are and should be involved.

9. At the state level, there tends to be a disproportionate amount of mental health block grant monies focused on adult services than children's services. Family-run organizations are often in a position annually to advocate for more equality in mental health block grant funding for children and youth. It was requested that SAMHSA offer more guidance to states in this area, as well as encouragement to examine more equal disbursement of mental health block grant funds across populations within the state.

10. There are ongoing challenges around the interpretation of Medical Necessity at the state level for parent support services. Guidance from SAMHSA for both family-run organizations and state authorities is needed.

Family-Run Organizations Participating on the Calls

The following family-run organizations participated on the calls:

Region 1 – Katherine Power –

NAMI Connecticut
Paloma Bayona
Granite State Federation of Families for Children's Mental Health
Kathleen Abate, Linda Thomas
Parent Support Network of Rhode Island
Lisa Conlan, Executive Director
Parent/Professional Advocacy League (Massachusetts)
Anne Silver, Director of Operations

Note: Region 1 calls were facilitated by a member organization of FREDLA, the Parent Professional Advocacy League in Massachusetts.

Region 2 – Dennis O. Romero, M.A.

Family Based Services Association FSO of Monmouth County
Ann Goldman
New York State Families Together
Paige Pierce
Puerto Rico
Millie Court

Region 3 – Jean Bennett, Ph.D.

Delaware Voices for Families
Wanda Ford, Statewide Family Network Project Coordinator
Delaware Department of Behavioral Health
Barbara Messick, Family Liaison
Maryland Coalition of Families for Children's Mental Health
Jane Plapinger, Executive Director
Pennsylvania System of Care Partnership
Dianna L. Brocious - Family Involvement Specialist
Allegheny Family Network
Ruth Fox, Executive Director
National Alliance on Mental Illness of Virginia
Stephany Melton Hardison, Family Network Director
Total Family Care Coalition
Gail Avent, Executive Director

Region 4 – Stephanie McCladdie, MPA

The Family Café
Lori Fahey, Executive Director
Georgia Parent Support Network
Sue Smith, Executive Director
Kentucky Partnership for Families and Children
Carol Cecil, Executive Director
Mississippi Families as Allies
Joy Hogge, Executive Director

North Carolina Families United
Gail Cormier, Executive Director
Tennessee Voices for Children
Kathy Rogers, Program Director

Region 5 - Capt. Jeffrey Coady, Psy D.
Wisconsin Family Ties
Hugh Davis, Executive Director
Association for Children's Mental Health
Jane Shank, Executive Director
Indiana Federation of Families
Brenda Hamilton, Executive Director
Youth & Family Peer Support Network
Regina Crider, Executive Director
Illinois Division of Mental Health-Child & Adolescent Services
Judy Hutchinson, Family Consumer Specialist

Region 6 - Michael Duffy, RN/BSN
Lee and Phillips County Families Moving Toward Excellence
Pam Marshall, Executive Director
Nebraska Federation of Families for Children's Mental Health
Candy Kennedy-Georgan, Executive Director
Brain Injury Awareness of New Mexico
Monica Miura, System of Care Director
Texas Federation of Families for Children's Mental Health
Patti Derr, Executive Director

Region 8 - Charles Smith, Ph D.
Federation of Families – Colorado Chapter
Thomas H. Dillingham, Executive Director
North Dakota Federation of Families
Carlotta McCleary, Executive Director

Region 9 - Capt. Jon Perez, Ph. D.
Family Involvement Center
Jane Kallal, Executive Director
United Advocates for Children and Families
Michaele Beebe, Director, Research and Public Policy
G.I.F.T.S., Inc.
Mary-Therese Edgerle, Executive Director
Nevada P.E.P., Inc.
Karen Taycher, Executive Director

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