

NASMHPD

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Assessment #7

The Role of Family-Run Organizations in Systems of Care: How Partnerships with States Can Achieve Shared Goals

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Acknowledgments

The roles of family-run organizations highlighted in this document are based on the experience of more than 30 organizations that play a critical role in supporting the families of children, youth, and young adults with behavioral health challenges. They provide invaluable services to assist families to navigate complex services systems and to develop the knowledge and skills they need to improve their lives and the lives of their children. They also have developed partnerships with state and local systems that have incorporated “family voice” into system and policy decisions to ensure that services and supports meet the needs of youth and families. Their impact has been enormous, and their work has created a paradigm shift in children’s behavioral health towards family-driven, youth-guided systems.

The activities of six family-run organizations are highlighted in this document based on information provided by their leaders. Much appreciation is due to: Sandy Bumpus, Executive Director of the Oregon Family Support Network; Regina Crider, Executive Director of the Youth & Family Peer Support Alliance in Illinois; Anne Geddes, Public Policy Director of the Maryland Coalition of Families for Children’s Mental Health; Candy Kennedy-Georgen, Executive Director of the Nebraska Federation of Families for Children’s Mental Health; Lisa Lambert, Executive Director of the Parent/Professional Advocacy League in Massachusetts; and Paige Pierce, Executive Director of Families Together of New York State. Gratitude is also due to the state leaders who contributed their perspectives on the roles of family organizations and the benefits of partnerships – Amy Baker, Child and Family Mental Health Manager of the Oregon Addictions and Mental Health Division; Lisa Betz, Associate Deputy Clinical Director of the Illinois Division of Mental Health, Child and Adolescent Services; Donna Bradbury, Associate Commissioner of the New York State Office of Mental Health; Sheri Dawson, Director of the Nebraska Department of Health and Human Services, Division of Behavioral Health; and Al Zachik, Acting Executive Director of the Behavioral Health Administration of the Maryland Department of Health and Mental Hygiene.

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Executive Summary

This paper describes the roles that family-run organizations fulfill within systems of care, and how family-run organizations and states can collaborate to achieve their shared mission of improving services and outcomes for children, youth, and young adults with behavioral health challenges and their families. The system of care approach was introduced in the mid-1980s to address well-documented problems in service systems for this population (Stroul & Friedman, 1996). One of the many issues was the failure to involve families in partnership roles, either in the delivery of services for their own children or in the development of policies and service systems. Family partnerships were central to systems of care from the outset, and the approach has evolved to embrace the core value of “family-driven, youth-guided” services (Stroul, Blau, & Friedman, 2010).

The partnerships with families in systems of care contributed to the creation of national, state, and local family-run organizations that have used their collective voices to impact child-serving systems (Bryant-Comstock, Huff, & VanDenBerg, 1996). Federal support for family-run organizations has been provided through grants from the Substance Abuse and Mental Health Services Administration (SAMHSA) to family groups to create statewide family networks, and grants through the federal Children’s Mental Health Initiative have required partnerships with family groups and support for the development of state and local family-run organizations. State agencies have also supported the development and operation of family-run organizations through grants, contracts, and other strategies.

Currently, these organizations play a wide range of pivotal roles in systems of care at both the policy and service delivery levels. The role of family-run organizations has been defined as “active support,” at two levels – advocacy focused on individual children and families and advocacy to achieve broader systemic and policy goals (Osher, Penn, & Spencer, 2008). These two levels provide a framework for categorizing the roles of family-run organizations, and a typology was created that details family organization roles at the child and family level and at the system and policy level within their states and communities. These roles are described in this paper, with brief examples from over 30 family-run organizations.

Roles of Family-Run Organizations at the Child and Family Level	Roles for Family-Run Organizations at the State and/or Local System and Policy Level
<ul style="list-style-type: none"> ▪ Provide information and referrals ▪ Provide hotline/helpline services ▪ Provide parent peer support services ▪ Provide youth peer support services ▪ Provide system navigation services ▪ Provide respite services ▪ Provide support groups for families and youth ▪ Provide education and training programs for families and youth ▪ Provide services for families and youth in partner child-serving systems ▪ Provide social and recreational activities for families and youth ▪ Provide community outreach and social media outlets to provide information and support to families and youth 	<ul style="list-style-type: none"> ▪ Identify needs and initiate advocacy for children’s behavioral health services and systems of care ▪ Participate in the development of policies and processes ▪ Participate in the design and implementation of services and supports ▪ Participate in the development of financing for services and supports ▪ Participate in the evaluation of policies, services, and supports, and participate in research ▪ Recruit, educate, and support family members and youth to participate at the system/policy level ▪ Develop family and youth leaders to participate at the system/policy level

Roles of Family-Run Organizations at the Child and Family Level	Roles for Family-Run Organizations at the State and/or Local System and Policy Level
	<ul style="list-style-type: none"> ▪ Train and certify parent peer support providers and youth peer support providers ▪ Provide training to professionals, families, and youth related to children’s behavioral health and systems of care ▪ Conduct conferences for families and professionals related to children’s behavioral health and systems of care ▪ Participate in the development and delivery of strategic communications related to children’s behavioral health and systems of care

To further illustrate the roles of family-run organizations, leaders from six family-run organizations were interviewed to obtain detailed descriptions of their activities. Three organizations were selected based on their strong activities at the child and family level, and three were selected based on their strong activities at the system and policy level. All of the organizations are statewide, with the exception of the YFPSA, which was initiated as part of a county system of care, has expanded to a four-county area, and is in the early stages of becoming a statewide organization. The work of these six organizations in each area of the typology is described in the paper.

Family-Run Organizations Interviewed	
Child and Family Level	System and Policy Level
<ul style="list-style-type: none"> ▪ Youth and Family Peer Support Alliance, Champaign Illinois (YFPSA) ▪ Nebraska Federation of Families for Children’s Mental Health (NFFCMH) ▪ Oregon Family Support Network (OFSN) 	<ul style="list-style-type: none"> ▪ Maryland Coalition of Families for Children’s Mental Health (MCF) ▪ Parent/Professional Advocacy League (PPAL), Massachusetts ▪ Families Together in New York State (FTNYS)

In addition, the paper includes the perspectives of state children’s mental health leaders about their partnerships with family-run organizations and the benefits for service systems. State leaders from five states were interviewed and provided examples of activities that they have found particularly important. These clustered in the three major categories of family voice, peer support, and identifying system needs.

Family organizations and their members bring arguably the most important perspectives to systems of care. In some cases, family organizations may question and challenge states and communities to improve policy and services, while in others they will be staunch supporters of state systems. Their role ranges from advocacy and services for individual children and families, to participation in the highest-level policy discussions and decisions, to identification of issues and advocating for solutions. In all of these situations, family-run organizations can collaborate with state and community leaders to work together toward their shared mission of providing the most effective services and supports for children, youth, and young adults with mental health challenges and their families.

Family Partnerships in Systems of Care

This paper describes the roles that family-run organizations fulfill within systems of care and how family-run organizations and states can collaborate to achieve their shared mission of improving services and outcomes for children, youth, and young adults with behavioral health challenges and their families. The concept of a system of care for children and youth with serious mental health conditions emerged in the mid-1980s in response to the many reports and studies that documented the lack of effective and appropriate services for them and their families. At that time, children's mental health systems suffered from a lack of federal or state leadership, few community-based services, little collaboration among child-serving systems, and little or no advocacy on behalf of these children and adolescents (Stroul & Friedman, 1996). A significant flaw across child-serving systems was the failure to involve families in partnership roles, either in the delivery of services for their own children or in the development of policies and service systems.

Family partnerships were integral to the system of care approach from the outset. Initially the approach called for "family-focused" systems and services, based on the premise that the families and surrogate families of children with mental health conditions should be full participants in all aspects of service delivery and policy making. The approach evolved to strengthen this value by embracing the need for "family-driven" systems and services. The updated definition of a system of care specifies meaningful partnerships with families and youth, as well as core values that include family-driven and youth-guided services (Stroul, Blau, & Friedman, 2010).

The partnerships with families in systems of care helped to spur the development of a family movement in children's mental health, and supported the creation of national, state, and local family-run organizations that have used their collective voices to impact child-serving systems (Bryant-Comstock, Huff, & VanDenBerg, 1996). Currently, these organizations play a wide range of pivotal roles in systems of care at both the policy and service delivery levels. These roles are described in this paper, using examples from over 30 family-run organizations. The activities of six organizations are highlighted in greater detail. In addition, the paper includes the perspectives of state children's mental health leaders about their partnerships with family-run organizations and the benefits for systems of care.

Development of Family-Run Organizations

Although family groups for children with developmental disabilities have been effective advocates since the 1960s, organizations of families of children with mental health conditions were created more recently. The roots of family-run organizations for children's mental health can be traced to early federal efforts to promote the development of systems of care. The Child

System of Care Definition

*"A spectrum of **effective community-based services and supports** for children, youth, and young adults with or at risk for mental health and related challenges and their families that is organized into a **coordinated network**, builds meaningful **partnerships with families and youth**, and addresses their **cultural and linguistic needs** in order to help them **function better** at home, in school, in the community, and throughout life"*

System of Care Philosophy

Values:

- Community Based
- Family Driven, Youth Guided
- Culturally and Linguistically Competent

Principles:

- Broad Array of Effective Services and Supports
- Individualized, Wraparound Practice Approach
- Least Restrictive Setting
- Family and Youth Partnerships
- Service Coordination
- Cross-Agency Collaboration
- Services for Young Children
- Services for Youth and Young Adults in Transition to Adulthood
- Linkage with Promotion, Prevention, and Early Identification
- Accountability

and Adolescent Service System Program (CASSP), launched in 1984, provided grants to states to reform children’s mental health systems, and required grantees to address family involvement (Bryant-Comstock, Huff, & VanDenBerg, 1996). National and regional conferences followed (referred to as “Families as Allies” meetings), and provided a vehicle for parent-professional

Although the participation of individual family members is valuable, family-run organizations offer a collective voice that increases both credibility and impact.

partnerships and for families to connect and organize. The roles of parents and other family members evolved to encompass, not only involvement in planning and delivering services for their own children, but also advocacy and support for other families, involvement in policy making, participation in the development and evaluation of services, and serving as providers of services themselves. Family support and advocacy organizations began to emerge at

state, regional, and local levels as family members came together to increase their impact through their collective voices (Koroloff, N.M., Friesen, B.J., Reilly, L., & Rinkin, J., 1996).

Federal support for family-run organizations continued through grants from the Substance Abuse and Mental Health Services Administration (SAMHSA) to family groups to create statewide family networks. Since its initiation in 1988, the Statewide Family Network Grant Program has provided funds to assist state family-run organizations, along with technical assistance through a national technical assistance center. Further support for family-run organizations has been provided through SAMHSA’s Children’s Mental Health Initiative (CMHI) that was launched in 1992 and continues to provide grants to states, tribes, territories, and communities to implement, sustain, and expand the system of care approach (SAMSHA, 2015). These grants have included increasingly strong requirements to employ family leads, establish partnerships with family groups, and support the development of state and local family-run organizations. State agencies have also played an influential role in supporting the development and operation of family-run organizations through grants, contracts, and other strategies.

A significant milestone was the formation of a national voice through the National Federation of Families for Children’s Mental Health (NFFCMH) in 1989 as an organization focusing on children with a variety of emotional, behavioral, or mental health conditions. NFFCMH assumed a national advocacy role, helped organize family-run organizations in states and communities, and formed a network of state and local chapters advocating for improved services. At the same time, another national organization (the National Alliance on Mental Illness – NAMI), created its Children and Adolescent Network, emphasizing both research and service system improvements for children with serious mental health conditions. State and local NAMI chapters also began focusing on children and adolescents.

Most recently, the Family-Run Executive Directors Leadership Association (FREDLA) was formed to build the leadership and organizational capacity of state and local family-run organizations focused on the well-being of children, youth, and young adults with mental health, emotional, or behavioral challenges and their families. FREDLA was incorporated in 2013 and provides training and consultation to family-run organizations and to others to ensure that family-run organizations have a strong voice and fulfill their critical role in improving services and supports.

As of 2015, it is estimated that there are approximately 40 statewide family-run organizations and over 70 local family-run organizations focusing on children, youth, and young adults with mental health challenges (Walker, Nicolson, Bruns, & Sweeney, 2014). These family-run organizations typically have parents or primary caregivers as 51 percent or more of their governing boards and leadership (Mendoza, 2012).

As family-run organizations have grown, they have had increasing influence on systems of care, and they have been instrumental in fostering a family-driven approach in which *“families have a primary decision making role in the care of their own children, as well as the policies and procedures governing care for all children in their community, state, tribe, territory, and nation”* (Osher, Penn, & Spencer, 2008).

Roles of Family-Run Organizations in Systems of Care

The overarching role of family-run organizations is to ensure that the voices of families are heard at all levels of service systems. The role of family-run organizations has been

characterized as advocacy, defined as “active support,” at two levels – advocacy focused on individual children and families and advocacy to achieve broader systemic and policy goals (Osher, Penn, & Spencer, 2008). These two levels provide a framework for categorizing the roles of family-run organizations. Accordingly, a typology was created that details family organization roles at the child and family level and at the system and policy level within their states and communities.

In 2014, a FREDLA initiated a national data collection project, in partnership with the Technical Assistance

Roles of Family-Run Organizations at the Child and Family Level

- Provide information and referrals
- Provide hotline/helpline services
- Provide parent peer support services
- Provide youth peer support services
- Provide system navigation services
- Provide respite services
- Provide support groups for families and youth
- Provide education and training programs for families and youth
- Provide services for families and youth in partner child-serving systems
- Provide social and recreational activities for families and youth
- Provide community outreach and social media outlets to provide information and support to families and youth

Network for Children’s Behavioral Health led by the Institute for Innovations and Implementation at the University of Maryland’s School of Social Work. The project is designed to systematically collect information from family-run organizations, including information on their roles. An initial survey of 31 statewide family-run organizations found that nearly all fulfill various roles at the child and family level. For example, between 90% and 100% of the statewide organizations reported providing one-to-one support, training, and information and referral services for families. At the system and policy level, 80% indicated that they are involved in public policy analysis and advocacy and 86% in training for child-serving professionals.

Roles for Family-Run Organizations at the State and/or Local System and Policy Level

- Identify needs and initiate advocacy for children’s behavioral health services and systems of care
- Participate in the development of policies and processes
- Participate in the design and implementation of services and supports
- Participate in the development of financing for services and supports
- Participate in the evaluation of policies, services, and supports, and participate in research
- Recruit, educate, and support family members and youth to participate at the system/policy level
- Develop family and youth leaders to participate at the system/policy level
- Train and certify parent peer support providers and youth peer support providers
- Provide training to professionals, families, and youth related to children’s behavioral health and systems of care
- Conduct conferences for families and professionals related to children’s behavioral health and systems of care
- Participate in the development and delivery of strategic communications related to children’s behavioral health and systems of care

A subsequent survey of 45 statewide family-run organizations collected more detailed information about roles (FREDLA, 2014). Examples of roles at each level are described in the table below, organized according to the typology. Although many additional family-run organizations fulfill these roles, the examples in the table reflect those reported by family-run organizations through the FREDLA survey. They demonstrate how the activities of family organizations enhance state and local systems of care.

EXAMPLES OF ROLES OF FAMILY-RUN ORGANIZATIONS	
Roles of Family-Run Organizations at the <i>Child and Family Level</i>	
Provide information and referrals	<ul style="list-style-type: none"> ▪ Delaware Family Voices holds a monthly call for parents to ask questions about their Medicaid coverage for their children or about issues with the children’s mental health system. ▪ Iowa Federation of Families for Children’s Mental Health provides information to parents and youth on diagnosis, medications, services, and understanding and exercising their rights.
Provide hotline/helpline services	<ul style="list-style-type: none"> ▪ Nebraska Federation of Families for Children’s Mental Health is an active partner in a Family Helpline for children’s behavioral health. ▪ Rhode Island Parent Support Network developed and implemented a Peer Mentor Program that provides a toll free helpline for families in need of support, information, and referral that is staffed by parents with lived experience.
Provide parent peer support services	<ul style="list-style-type: none"> ▪ Maryland Coalition of Families for Children’s Mental Health provides parent peer support to families caring for a child with mental health needs; peer support services are Medicaid billable. ▪ Michigan Association for Children’s Mental Health provides parent peer support services that are Medicaid reimbursable (Parent Support Partner Project). ▪ Nebraska Federation of Families for Children’s Mental Health provides parent peer support and family navigator services to support families experiencing challenges. ▪ Nebraska Federation of Families has a contract with the state child welfare agency to provide parent peer support services to families involved with the child welfare system. ▪ Tennessee Voices for Children contracts with the three Medicaid managed care organizations in the state to provide parent peer support services that are Medicaid billable.
Provide youth peer support services	<ul style="list-style-type: none"> ▪ Georgia Parent Support Network provides youth peer support services through a Youth Transition Peer Center.
Provide system navigation services	<ul style="list-style-type: none"> ▪ Maine Parent Federation initiated a program called “Family Support Navigators” who help families identify their needs, develop family support plans, and gain the skills and knowledge needed to effectively navigate systems on their own in the future. Family support parents are provided additional training to become navigators. ▪ Maryland Coalition of Families for Children’s Mental Health has a Military Family Navigator who specializes in supporting military families caring for a child with mental health needs.
Provide respite services	<ul style="list-style-type: none"> ▪ Georgia Parent Support Network provides respite homes serving over 300 youth per year. ▪ Oregon Family Support Network provides respite services to families.
Provide support groups for families and youth	<ul style="list-style-type: none"> ▪ D.C. Total Family Care Coalition provides support groups including a group for families with a child currently or previously placed in a psychiatric residential treatment facility. The group provides support, information, and resources to assist youth to transition back to their homes and community successfully.

EXAMPLES OF ROLES OF FAMILY-RUN ORGANIZATIONS

Provide education and training programs for families and youth	<ul style="list-style-type: none"> ▪ Maryland Coalition of Families for Children’s Mental Health provides educational programs including Navigating the Transition Years and Active Parenting. ▪ Montana Family Support Network provides a 12-week training program in the evidence-based Nurturing Parenting Program that addresses areas including developmental stages of children, empathy, appropriate discipline techniques, building self-worth, etc. ▪ Nebraska Federation of Families for Children’s Mental Health was contracted by the managed care organization to pilot the Targeted Parenting Assistance Program that makes online parent education modules available for families of children with behavioral health challenges. ▪ Utah Allies with Families developed an educational program with four components – From Hope to Recovery for parents/caregivers, Sibshops for siblings, Kid Power for the identified child, and Childcare for young children. ▪ Virginia Family Network developed a training program to teach parents skills for advocating for their child.
Provide services for families and youth in partner child-serving systems	<ul style="list-style-type: none"> ▪ Kansas Keys for Networking provides a Targeted Parent Assistance Program, a program to assist youth in state custody graduate from high school and pursue post-secondary educational opportunities. ▪ Massachusetts Parent/Professional Advocacy League has partnered with the juvenile justice system to provide assistance to families who turn to the court to obtain services. Juvenile judges have requested that this service be expanded.
Provide social and recreational activities for families and youth	<ul style="list-style-type: none"> ▪ Rhode Island Parent Support Network hosts social events bringing hundreds of children and families together to create natural support communities.
Provide community outreach and social media outlets to provide information and support to families and youth	<ul style="list-style-type: none"> ▪ D.C. Total Family Care Coalition holds outreach activities to increase mental health awareness and engage family members and youth in system of care activities, including presentations at health fairs and other community events on mental health stigma and how to access mental health resources. ▪ Idaho Federation of Families for Children’s Mental Health uses technology and social media to connect and provide educational opportunities to families, including webinars and interactive video programs available statewide. ▪ Idaho Federation of Families for Children’s Mental Health held a suicide awareness “Bowl a Thon” with over 150 youth. ▪ Montana Family Support Network hosts a wellness festival for high school and middle school youth through Youth MOVE.

Roles of Family-Run Organizations at the State and/or Local System and Policy Level

Identify needs and initiate advocacy for children’s behavioral health services and systems of care	<ul style="list-style-type: none"> ▪ Wisconsin Family Ties addressed the lack of a state-level organizational focus on children’s mental health and was instrumental in establishment of the state Office of Children’s Mental Health.
Participate in the development of policies and processes	<ul style="list-style-type: none"> ▪ Alabama Family Ties has representation on a large number of state-level committees and works closely with the state’s protection and advocacy organization. ▪ Idaho Federation of Families for Children’s Mental Health advocated for language added to pending legislation establishing children’s mental health committees in all seven regions of the state. ▪ Michigan Association for Children’s Mental Health worked to include a formal “Family-Driven, Youth-Guided Policy” in the state plan. ▪ Nebraska Federation of Families for Children’s Mental Health participated in the creation of legislation to develop and implement a statewide system of care. ▪ Nebraska Federation of Families for Children’s Mental Health was appointed by the Governor to the Children’s Commission, a high-level leadership body to create a statewide strategic plan for child welfare reform. The organization was also

EXAMPLES OF ROLES OF FAMILY-RUN ORGANIZATIONS

	<p>appointed as one of the three tri-chairs of the system of care expansion planning initiative to develop a comprehensive strategic plan to expand and sustain the system of care approach.</p> <ul style="list-style-type: none"> ▪ New Hampshire Granite State Federation of Families is a lead partner in all children’s behavioral health policy and planning in the state, providing family perspectives and experience-based expertise, including the system of care expansion initiative, Safe Schools Healthy Students initiative, and Children’s Behavioral Health Collaborative. ▪ Texas Federation of Families for Children’s Mental Health and Alamo Area Youth MOVE have participated in planning and developing the statewide system of care expansion initiative. ▪ Wisconsin Family Ties led a six-year advocacy effort that resulted in legislation regulating the use of seclusion and restraints in schools.
<p>Participate in the design and implementation of services and supports</p>	<ul style="list-style-type: none"> ▪ Kentucky Partnership for Families and Children created regulations for parent and youth peer support providers (Family Peer Support Specialists and Peer Support Specialists) with the Dept. of Behavioral Health; peer support is now Medicaid billable. The organization is working to include regional and state-level peer support coaches. ▪ Massachusetts Parent/Professional Advocacy League has surveyed families and helped develop training and tools for support to primary care physicians to provide behavioral health services. ▪ Montana Family Support Network certified workers in the evidence-based practice Triple P that teaches parenting strategies to address current parenting issues and concerns and prevent future problems. ▪ Nebraska Federation of Families has been a key partner in the development and implementation of a new service, Alternative Response, for early intervention and prevention of involvement in the child welfare system for families. ▪ North Carolina Families United standardized and expanded the development of parent peer support services (Family Partners) statewide, increasing providers from 6 to 390 by 2013. ▪ North Carolina Families United developed early childhood and infant mental health support by developing and training parent peer support providers that specialize in working with families of young children. ▪ Oregon Family Support Network developed goals and strategies to create a consistent array of family support services throughout the state, including support groups, respite services, social activities, advocacy training, one-on-one parent peer support, coaching and supervision of parent peer support providers, and systems navigation services. ▪ South Carolina Federation of Families participated in the implementation of Positive Behavior Intervention and Support (PBIS) programs in schools, early intervention services for youth at risk of entering the juvenile justice system, and substance use services. ▪ Wisconsin Family Ties worked with the state to expand the state’s wraparound initiative to all 72 counties and 11 tribes.
<p>Participate in the development of financing for services and supports</p>	<ul style="list-style-type: none"> ▪ Families Together in New York State participated in the design and implementation of Medicaid managed care to ensure financing for family support, respite care, and other services to reduce the use of hospitalization, emergency rooms, and residential facilities. ▪ North Carolina Families United assisted the state transition mental health services to a managed care approach with managed care organizations, without losing system of care values and principles and family and youth voice and choice. ▪ Oregon Family Support Network has served on state advisory committees and task forces to ensure that health care reform planning, service delivery, and evaluation

EXAMPLES OF ROLES OF FAMILY-RUN ORGANIZATIONS

	<p>are relevant and meaningful to the families and youth served in the state's behavioral health system.</p> <ul style="list-style-type: none"> ▪ Utah Allies with Families developed a curriculum, training, and supervision model for parent peer support providers that were accepted by Medicaid, and parent peer support services are now Medicaid billable. ▪ Wisconsin Family Ties played a key role in state budget initiatives resulting in a \$29 million increase in mental health funding for 2013-2015.
<p>Participate in the evaluation of policies, services, and supports, and participate in research</p>	<ul style="list-style-type: none"> ▪ Kansas Keys for Networking completed a multi-year study (using randomized control groups) with a consulting firm that demonstrated the effectiveness of a Targeted Parent Assistance program developed by the organization. The program provides parent and youth peer support, information, and training, and it is being replicated statewide through six regional family-run organizations. ▪ Maryland Coalition of Families for Children's Mental Health participates in research programs supporting families whose children are taking anti-psychotic medication and supporting families whose children are discharged from psychiatric hospitals. ▪ Oregon Family Support Network developed an evaluation tool to demonstrate the effectiveness of parent peer support services.
<p>Recruit, educate, and support family members and youth to participate at the system/policy level</p>	<ul style="list-style-type: none"> ▪ Kentucky Partnership for Families and Children identifies and trains parent and young adult leaders. ▪ Maryland Coalition of Families for Children's Mental Health holds a Family Leadership Institute to train families to become effective advocates. ▪ Iowa Federation of Families for Children's Mental Health coaches families to develop advocacy and negotiation skills. ▪ Virginia Family Network launched a statewide youth network, including recruiting and training young adults with personal experience to lead youth groups in communities.
<p>Develop family and youth leaders to participate at the system/policy level</p>	<ul style="list-style-type: none"> ▪ Colorado Federation of Families for Children's Mental Health developed a toolkit for family and youth organizations to increase business management and leadership skills. ▪ Florida Family Café created and supports a Change Agent Network of volunteers throughout the state. ▪ Massachusetts Parent/Professional Advocacy League has assisted youth to speak at grand rounds, schools, and conferences to use their own experiences to improve care for children and youth. ▪ North Carolina Families United trains youth and emerging adults in youth leadership. ▪ North Dakota Federation of Families for Children's Mental Health held a youth leadership training conference for transition-age youth to develop advocacy skills; the training was planned and led by youth. ▪ Rhode Island Parent Support Network developed and implemented training curricula on family and youth leadership. ▪ Virginia Family Network is providing leadership training to parents and youth.
<p>Train and certify parent peer support providers and youth peer support providers</p>	<ul style="list-style-type: none"> ▪ Colorado Federation of Families for Children's Mental Health created a curriculum for family advocates and family system navigators. ▪ Massachusetts Parent/Professional Advocacy League provides training to parent peer support providers (Family Support Specialists) who help families to access services and gain skills to help their children. ▪ Nebraska Federation of Families for Children's Mental Health is developing a parent peer support certification program in partnership with the state behavioral health agency and the University of Nebraska. ▪ North Carolina Families United developed and delivers a comprehensive training

EXAMPLES OF ROLES OF FAMILY-RUN ORGANIZATIONS

	<p>program for parent peer support providers to become nationally certified.</p> <ul style="list-style-type: none"> ▪ Oregon Family Support Network developed a certified training program for peer support specialists based on an extensive set of skills. Trained peer support providers have the ability to bill Medicaid. The organization also developed and implemented a curriculum and training for coaches and supervisors. ▪ Tennessee Voices for Children developed and conducts training for certification of parent peer support providers statewide, including a manual and competency tests. ▪ Utah Allies with Families developed a curriculum to train parent peer support providers (Family Resource Facilitators) and provides training statewide.
<p>Provide training to professionals, families, and youth related to children’s behavioral health and systems of care</p>	<ul style="list-style-type: none"> ▪ Maryland Coalition of Families for Children’s Mental Health provides Mental Health First Aid training. ▪ New Hampshire Granite State Federation of Families serves as co-lead for the development and implementation of the New Hampshire Behavioral Health Training Network and provides direct training and mentoring to professional staff working with youth and families. ▪ North Carolina Families United provides services to transition-age youth using the RENEW model and trains other youth-serving professionals on how to use this best practice model. ▪ Utah Allies with Families provides training on the impact of mental illness on families, professionals, paraprofessionals, and social work students. ▪ Wisconsin Family Ties developed a curriculum on trauma-free crisis intervention and provides training to child-serving professionals on this and other effective approaches to working with children with behavioral health challenges and their families.
<p>Conduct conferences for families and professionals related to children’s behavioral health and systems of care</p>	<ul style="list-style-type: none"> ▪ Delaware Family Voices held a conference addressing the needs of children with mental health challenges for families and providers; U.S. Senator, Lt. Governor, and Secretary of Health were speakers. ▪ D.C. Total Family Care Coalition held a family conference focused on increasing awareness of available resources, with the participation of a city council member and behavioral health agency officials. ▪ Florida Family Café hosts an annual Youth Summit as an activity of the Florida Youth Council. ▪ Maryland Coalition of Families for Children’s Mental Health holds an annual REACH Retreat for Families and a statewide Connections Conference for families. ▪ New Hampshire Granite State Federation of Families co-sponsors annual conferences including the Children’s Behavioral Health Collaborative Summit and the New Hampshire Summit on Transition. ▪ Virginia Family Network holds statewide conferences for families, youth, and professionals on family-driven, youth-guided policies and services.
<p>Participate in the development and delivery of strategic communications related to children’s behavioral health and systems of care</p>	<ul style="list-style-type: none"> ▪ Maryland Coalition of Families for Children’s Mental Health partners with the Mental Health Association of Maryland to conduct a statewide Children’s Mental Health Awareness Campaign. ▪ Maryland Coalition of Families for Children’s Mental Health hosts an annual day in the state capital for families to meet with their legislators to educate them on the need for services and supports for children and families. ▪ North Carolina Families United organizes statewide campaigns to reduce stigma for families and individuals struggling with mental health issues as part of Children’s Mental Health Awareness campaigns. ▪ Texas Federation of Families takes a leadership role during Children’s Mental Health Awareness Day and hosts events, such as a music fest with over 35 Texas singer songwriters.

Highlights of Family-Run Organization Roles

In order to illustrate the roles of family-run organizations, six family-run organizations were interviewed to obtain more detailed descriptions of their activities. Three organizations were selected based on their strong activities at the child and family level, and three were selected based on their strong activities at the system and policy level. All of the organizations are statewide, with the exception of the YFPSA. This organization was initiated as part of a county system of care, has expanded to a four-county area, and is in the early stages of becoming a statewide organization. The work of these six organizations is described in each area of the typology below.

Child and Family Level

Provide Information and Referrals

YFPSA provides information and referrals through a process described as “linkage and engagement.” Typically, these services are provided to families that will not necessarily need formal parent peer support services, but would benefit from information and linkage with other types of services that may be helpful. Families are referred to the organization by the various child-serving systems, the managed care organization (MCO), or by other families. Families may also find YFPSA on their own and reach out for information. Additionally, YFPSA works with the juvenile detention center to provide information and referrals to families coming into contact with the juvenile justice system. Weekly staffings are used to review youth entering detention, and YFPSA reaches out to their families to engage them prior to or at the youth’s court hearing. Some of these families may ultimately receive parent peer support services if necessary.

NFFCMH has created a network of eight family-run organizations throughout the state, including one Native American family organization. Families can contact these organizations at any time for informational and referral. When families contact the central office via email or phone, they receive the resources the request, and frequently are also connected with their regional organization for assistance that may include parent peer support. The state’s MCO for behavioral health services refers families to NFFCMH if they receive a denial for services to explore their needs and the alternative services and supports that they may be able to access.

PPAL provides information and referrals to families, connecting them to informal supports or resources in addition to formal services. In addition, PPAL noted that about one in five of the calls received requesting information come from providers who are also seeking information and resources.

Provide Hotline/Helpline Services

NFFCMH works with a state-funded hotline currently operated by Boys Town, an agency providing residential treatment and community-based services to youth with behavioral and emotional challenges. The 800 number is active 24-7 and responds to families and youth who reach out during crises. Through a partnership with this hotline, families are referred to NFFCMH for family navigation services that offer eight hours of face-to-face assistance to

Family-Run Organizations Interviewed

Child and Family Level

- Youth and Family Peer Support Alliance, Champaign Illinois (YFPSA)
- Nebraska Federation of Families for Children’s Mental Health (NFFCMH)
- Oregon Family Support Network (OFSN)

System and Policy Level

- Maryland Coalition of Families for Children’s Mental Health (MCF)
- Parent/Professional Advocacy League (PPAL), Massachusetts
- Families Together in New York State (FTNYS)

determine the family's needs and link them with services and supports. Some will subsequently receive parent peer support. OFSN has a toll-free line that families can call at any time for information and assistance.

Provide Parent Peer Support Services

YFPSA provides parent peer support services under a contract with the MCO and is paid on a fee-for-service (FFS) basis. These services are available to families of Medicaid-eligible children who meet criteria for having serious and complex behavioral health conditions. Referrals come from the MCO, other community-based agencies, or from families themselves. YFPSA also provides parent peer support services to families that do not meet the criteria for MCO involvement, including those that are not Medicaid-eligible. These services are financed by the local mental health board. YFPSA hires only family members with the “lived experience” of having children with behavioral health challenges and who have navigated multiple systems. Peer support providers receive in-house training and ongoing supervision and coaching from the organization. One-on-one peer support is driven by an assessment using instruments such as the Family Journey Assessment, the Child and Adolescent Needs and Strengths (CANS), or Developmental Asset Profile. The assessment leads to goal setting and development of a written “family care plan.” The focus of the parent peer support provider is to provide emotional support to parents and caregivers, to model and teach them how to advocate for their child, and to develop the skills they need for navigating specific child-serving systems. The process also has a component of leadership development that helps family members to develop the skills needed for system- and policy-level advocacy.

OFSN has contracts with community mental health agencies in approximately 15 of the 36 counties in Oregon to provide parent peer support. Because the state is expanding systems of care with Wraparound statewide, the organization has doubled its peer support staff over the last year to meet the increased demand for parent peer support services. OFSN currently employs about 20 providers. Peer support services are Medicaid billable in the state, but family organization cannot directly bill Medicaid unless they become a fully licensed provider. The state requires certification for peer support providers, and OFSN has a state-approved

curriculum. The training for certification is provided by OFSN for its own parent peer support providers and to peer support providers employed by other agencies. The organization is developing a peer coaching curriculum and will coach peer support providers to achieve increasing levels of competency.

NFFCMH uses its statewide network of eight family-run organizations to provide parent peer support. The central umbrella organization has contracts with each of the regional behavioral health authorities, and in turn, contracts with the regional organizations to provide the services. The contract dollars that go to the central NFFCMH office are for “network management” functions, with the majority of funds going to the regional organizations for service delivery. By having a central network management function, parent peer support services are standardized statewide. NFFCMH provides training for peer support providers statewide, including annual retreats for refresher courses, and the training meets and exceeds national standards. Parent peer support is not currently Medicaid billable in Nebraska and is financed primarily with

state general revenue funds. The organization is working with the state to explore certification for parent peer support providers and possible Medicaid financing. A centralized, standardized

“Evaluations have documented the helpfulness of parent peer support services, where families get help from someone who has walked in their shoes. They help families to access services, connect with resources, improve family functioning, and keep children in their homes and communities.” (Sheri Dawson, Nebraska Division of Behavioral Health)

data system is used for peer support services that is used to identify goals, strengths, protective factors, challenges, and areas to work on in service delivery.

Provide Youth Peer Support Services

YFPSA currently has two youth peer support providers who work on child and family teams that are organized by the MCO. The organization hires, trains, supervises, and mentors them. Leadership development for the youth peer support providers is provided in partnership with the local Youth MOVE chapter. YFPSA is in the early developmental stages of expanding youth peer support services. The organization is using standards developed by Youth MOVE National to shape and guide its youth peer support services.

“Family peer support is a valuable resource to families, systems of care, and the state. With legacy families helping other families and supporting them through what they’re experiencing with their child, improves the system of care.” (Al Zachik, Maryland Behavioral Health Administration)

Provide System Navigation Services

OFSN provides system navigation services that are distinct from parent peer support. The organization has small contracts with the hospital system to provide peer support to families that present at emergency rooms for possible hospital admission for their children. Peer support is used during the crisis to connect families with needed services and supports. Referrals may come from psychiatric inpatient units or from emergency room personnel. These services are being provided by OFSN in two counties, with a view toward potential expansion.

NFFCMH provides family navigation services, typically following a crisis. These services may be initiated following contact with the hotline, but can be accessed through family organization network as well. Family navigation is defined as a time-limited service – eight hours of face-to-face services within a 60-day timeframe to assist families through the crisis and help them to access services and supports. Following this period, families can transition to parent peer support services if necessary. The organization has made a commitment that the same person who has provided the family navigation services will continue to work with family to provide longer-term parent peer support.

Provide Respite Services

NFFCMH is involved in a new pilot project that allows the use of state respite funds for “parent’s day out.” Although this is not a considered true in-home or out-of-home respite service, it does provide parents with some relief and support. The pilot also involves training respite providers, with the ultimate goal of providing respite for 72 hours in response to crises while the needs of the child and family are being determined.

OFSN offers a “youth respite night” once a month, whereby families can drop their children off to enable them to have some time for themselves. The organization provides food and activities for the youth. At this time the program is limited, but it has been well received and opportunities to expand the approach are under exploration.

Provide Support Groups for Families and Youth

YFPSA provides two support groups specifically for families. These are open to families referred by the MCO, as well to families from the community that express interests. One is called “Women Supporting Women,” and focuses on decreasing isolation, providing support, increasing self-awareness, and increasing coping skills for women who are managing their children’s behavioral health challenges. The second is “Parents Promoting Presence,” that

focuses on self-advocacy skills and education about children’s mental health, in addition to decreasing isolation and providing support. The organization provides transportation, dinner, and child care for all support group meetings. In addition, incentives are offered by providing “bucks” for participating in support groups and other meetings (such as community stakeholder meetings) that can then be redeemed for a variety of products in a P3 “store.” The local Youth MOVE chapter holds its meetings on the same night, with youth and families starting their meetings together and then going to their separate group meetings. The local mental health board funds these support groups.

OFSN provides support groups that meet once or twice a month. The organization hired a facilitator to connect with families and build these groups. In addition to general support, the groups may focus on a particular topic identified by families. NFFCMH provides support groups through each of its regional organizations. Facilitator training is provided to individuals who lead support groups in communities across the state. Parents receive a stipend to lead the groups, and the central office provides assistance when needed. At this time there are no specialized groups, but the need for a support group for youth with substance use disorders has been identified and is under consideration.

Provide Education and Training Programs for Families and Youth

OFSN provides training in Collaborative Problem Solving (CPS), which is an approach to understanding and helping children with behavioral health challenges. The organization has a staff member who is a certified CPS instructor and delivers the training curriculum statewide. Funded with Block Grant dollars, the training is provided through a contract with the state. The organization also provides education and training on such topics as how to share your story, how to participate in policy-level advocacy, how to cope with holiday stress, transitioning children from summer to fall, and others. New curricula are continually being developed in response to identified needs and interests.

NFFCMH offers two evidence-based educational programs through the regional organizations, including Parent Skill Building the teaches parents how to manage their child’s behavior, and Circle of Security, which is an early intervention program designed to enhance attachment between parents and children. A trauma-related training program was piloted in one area, and parents have elected to continue the work through support groups and chats on the NFFCMH website.

Provide Services for Families and Youth in Partner Child-Serving Systems

YFPSA provides direct services for families of youth entering the juvenile detention center. As noted, weekly staffings are a vehicle for identifying families that may benefit from linkage and engagement services, parent peer support, or youth advocacy. YFPSA reaches out to these families before or at the youth’s court hearing. The organization is also beginning to work with the child welfare system to determine how they can support youth and young adults of transition age who are involved with the child welfare agency. Efforts are also underway to establish relationships with the education system and truancy board to increase collaboration and incorporate peer support services for youth and families.

NFFCMH has a contract with the child welfare agency to provide peer support to families involved with the child welfare system. A contract is being negotiated with the juvenile justice system to offer parent peer support; the

“Based on interaction at policy tables, NFFCMH has taught our system partners about the value of family voice, the services provided through systems of care, and parent peer support. System partners are now considering providing peer support, and the child welfare system is already purchasing the service.” (Sheri Dawson, Nebraska Division of Behavioral Health)

central office would provide network management and the regional organizations would provide the services.

Provide Social and Recreational Activities for Families and Youth

YFPSA organizes and sponsors a variety of social and recreational activities designed for both families and youth. Quarterly family events offer opportunities for family activities, with the goal of reconnecting with each other. Examples include a family and youth dinner dance, magic show, picnic and pool party, and others. All of these activities are also seen as vehicles for disseminating information about children’s mental health through literature and other resources. YFPSA also sent 11 young people to a 5-day leadership camp program at a local university to develop the skills needed to become emerging leaders. The organization is exploring additional social and recreational options for youth, such as plays, concerts, dinner, movie night, or events at the local university.

Provide Community Outreach and Social Media Outlets to Provide Information and Support to Families and Youth

YFPSA uses social marketing strategies to address broad community issues related to youth mental health, such as the impact of violence on youth and families and the importance of being trauma informed. The organization reaches out to the faith-based community by working with church leaders, presenting to church members, and providing literature and resources. By participating in a cross-agency coalition including the police (Walk as One), YFPSA members walk through the community, knock on doors, and provide information on children’s mental health. Areas with higher rates of shootings have been targeted where families have not typically connected with the organization or other resources to ask for help. Throughout Children’s Mental Health Awareness Week, YFPSA organizes activities including luncheons with stakeholders and community members, state or national speakers on children’s mental health, and trainings on cultural competence. T-shirts, green ribbons, and wrist bands for children’s mental health are widely distributed, and agencies and individuals show their support by posting pictures on YFPSA’s Facebook page. The events culminate in a dinner dance.

NFFCMH organizes numerous special events in observance of Children’s Mental Health Awareness week. Many are funded by private entities, as well as state general funds of federal Block Grant dollars. An example is a pony express ride with motorcyclists riding across the state to increase awareness around children’s behavioral health. Many community events and activities are tied to this ride. All eight regional groups in NFFCMH’s network are involved.

System and Policy Level

Identify Needs and Initiate Advocacy for Children’s Behavioral Health Services and Systems of Care

MCF has a strong history of identifying problems through surveys, focus groups, and other interaction with families, and using documents (“listening and learning from families”), along with other advocacy strategies, to spur systemic responses. An example is the practice of families having to relinquish custody of their children in order to obtain needed behavioral health services, an issue raised particularly by families with private insurance that did not cover the intensive services needed by their children. MCF held focus groups and conducted a study on custody relinquishment that ultimately resulted in state legislation and policies that created a voluntary placement agreement so that

“The family organization is an incredible resource to the state. The family leaders allow us to learn what’s really happening in communities and what the next steps should be to address it. (Amy Baker, Oregon Addictions and Mental Health Division)”

families could access services, including residential treatment, without losing custody of their children.

FTNYS has identified systemic issues and initiated action, often in partnership with other advocacy groups. A particularly significant example with far-reaching effects occurred nearly 15 years ago when the organization identified the lack of parity in insurance coverage between physical health and mental health. In partnership with other advocates, the statewide “Timothy campaign” (named after a boy who took his own life) was formed to advocate insurance parity, with the director of FTNYS serving as the chair and representing family voice. Press conferences, rallies at the capital, petitions, and marches were part of a six-year process culminating in the enactment of a parity law – one of the first states to do so. The organization currently is initiating action to address the placement of youth ages 16 and 17 in adult prisons.

PPAL has used surveys with as many as 500 respondents to identify and collect information from families about system problems. Surveys have explored such areas as access to care, medication use, and privacy and electronic health records. After identifying a system problem related to children waiting in emergency rooms for acute psychiatric inpatient beds, information gathering was initiated through a survey and collection of anecdotal stories. The issue was raised with the state with a request for additional acute care beds, at the same time that increased capacity for home- and community-based services was being created, and for improved intake procedures to address this problem. PPAL testified at a legislative hearing of the mental health and substance use committee and has used media strategies such as talks on local public radio and blogging. An emerging issue that PPAL has identified is the need for services for youth with co-occurring mental health and substance use conditions, and is beginning advocacy activities to fill this gap.

Participate in the Development of Policies and Processes

MCF has representatives serving on numerous committees, work groups, and task forces in the state and, as such, is highly involved in the development of policies and the design of processes, services, and supports. One example is MCF’s representation on the state’s behavioral health advisory body that is responsible for informing state-level policy, guiding the state’s Block Grant applications, and providing direction for the behavioral health agency’s annual plan.

“Family-run organizations have brought family voice to the system of care expansion process. They are part of the team and allow us to see what their struggles are and how to address them.” (Lisa Betz, Illinois Division of Mental Health)

FTNYS has brought family voice to innumerable committees and policy decision making bodies. A current policy issue is the potential merging of the state offices of mental health and substance use services which are now separate agencies. A steering committee was created to deliberate the potential merger, and FTNYS is serving on the steering committee. The organization is ensuring that family members go to hearings related to this merger in

their areas to bring family voice to the discussion. In addition, FTNYS was recently asked to serve on the board of the children’s health home in upstate New York, an opportunity to bring family voice to these new structures created by the Affordable Care Act (ACA).

PPAL has also participated in major policy initiatives in the Massachusetts. The organization was a part of the executive committee for the implementation of the new children’s behavioral health system resulting from a lawsuit. Through this mechanism, the organization brought family

voice to the highest decision making levels and had input into both the design and early implementation of the new system. PPAL noted that good working relationship with the state is essential, and that to maintain a strong partnership with the state, family-run organizations should communicate their concerns and strategies on an ongoing basis, even when the organization is advocating for state reforms.

Participate in the Design and Implementation of Services and Supports

MCF worked closely with the state as the system of care approach was being implemented to include family navigation in the service array. More recently, the organization worked with the state to define and implement parent peer support services that would be covered by Medicaid.

FTNYS has served on committees and work groups charged with defining behavioral health services. In particular, the organization worked with the state to define parent peer support services, how it would be provided, and who would provide it. FTNYS also helped to design the credentialing for parent peer support that the state adopted.

PPAL was integrally involved in the development of family support and training services that were included in the reformed children's behavioral health system in Massachusetts. The organization gathered definitions and job descriptions from other states, and recommended a definition to the state and that parent peer support services be connected to family-run organizations.

Participate in the Development of Financing for Services and Supports

MCF served on the workgroup that developed the Medicaid 1915(i) State Plan Amendment (SPA), a mechanism to expand home- and community-based services to youth with serious and complex behavioral health conditions. During the planning for the SPA, MCF successfully advocated for higher reimbursement rates for parent peer support and payment for services provided by telephone, among other financing issues.

FTNYS is participating in the Medicaid redesign in New York by serving on the redesign team that was created to provide input. There is a behavioral health subcommittee, as well as a committee for children's behavioral health. FTNYS is working to ensure that appropriate children's behavioral health services are included in the 1115 Medicaid Managed Care Waiver that the state will apply for, and that credentialed peer support is a reimbursable service. FTNYS also testifies regularly at legislative budget hearings.

PPAL is represented on the strategic design committee for payment reform in the state and for moving towards integrated care and Health Homes. The organization conducted a survey of over 400 families on integrated care and is bringing the results to the committee's discussions, so that decisions will not be driven solely by cost.

Participate in the Evaluation of Policies, Services, and Supports, and Participate in Research

FTNYS has a staff member who developed the Family Assessment of Needs and Strengths (FANS) that is used to assess outcomes for families before, during, and after services in order to demonstrate the efficacy of peer support. Training is being provided statewide on how to implement the assessment. The New York State Office of Mental Health has been providing resources through a grant for the development of the assessment, pilot testing, and training.

Recruit, Educate, and Support Family Members and Youth to Participate at the System/Policy Level

MCF has recruited family members to serve on various policy making bodies. The Family Leadership Institutes held by MCF are vehicles for identifying family members who are ready and prepared to fulfill policy roles. In one case, MCF was asked to identify a parent of a young child with behavioral health challenges to serve on the behavioral health advisory board. The organization was able to identify and recruit a parent for this role at one of the mini-Family Leadership Institutes that are held around the state.

“The family organization finds potential leaders within communities and provides professional development so they can be effective advocates at the system level.” (Amy Baker, Oregon Addictions and Mental Health Division)

FTNYS has been immersed in work at the system and policy level for a long time, and has developed specific strategies to prepare family members to be effective system-level advocates. The organization has over 40 staff members, with about 10 parent advisors across the state and 5 regional youth partners. There are also 11 chapters in the state’s various regions, each serving a group of 2-9 counties. All of these individuals comprise a network that can be recruited for various system- and policy-level functions both at the state and regional levels. FTNYS has a public policy coordinator who provides public policy and advocacy training around the state, particularly prior to the state’s legislative session. Chapter leaders participate in monthly calls that provide updates on policy issues. Through the calls and a listserv, information about current issues and advocacy needs is disseminated to these leaders. Further, assistance is provided to help family members and youth arrange meetings, write remarks for events such as press conferences, and practice in advance.

“With a contract with the family organization, we have peace of mind that we will have family leaders who are prepared and supported to participate in meaningful ways based on their own personal experience. (Amy Baker, Oregon Addictions and Mental Health Division)

PPAL states that one of its “products” is family leaders. Monthly statewide meetings of family partners are used as a vehicle for identifying potential leaders for policy level advocacy, and the organization provides training on how to become involved, as well as coaching and mentoring to family members who assume this role. PPAL makes a concerted effort to identify and engage leaders from diverse cultures to participate to ensure that diverse family voices are involved at

the system level. A youth group is under PPAL’s umbrella and will likely become a subsidiary of some type. This provides a mechanism for PPAL to foster the development of youth leaders and to assist them to participate at the system/policy level.

Develop Family and Youth Leaders to Participate at the System/Policy Level

MCF holds an annual Family Leadership Institute that trains 20-25 individuals with two-day weekend sessions over a period of six weeks. The program teaches parents how to be leaders, how to advocate for their child, and how to advocate at the system level. Some of the individuals who completed this training were eventually hired as MCF employees, serving in advisory roles for local behavioral health management boards and other entities. Mini-Family Leadership Institutes are also held periodically around the state. The youth organization in MD is under the umbrella of MCF and its staff members are MCF employees (a supervisor and two youth outreach coordinators). The youth organization holds leadership training to prepare youth and young adults for system and policy roles.

FTNYS conducts a week-long program for skill building, called the Parent Empowerment Program (PEP) Training. PEP is a basic training program designed for peer advocates based on a training protocol, *Improving Children's Mental Health through Parent and Community Empowerment*. Central office staff, parent advisors, chapter leaders, and other family members participate in this training to develop peer support, leadership, and advocacy skills. Although the program focuses on the individual child and family level, it embodies a basic philosophy about how to use family voice to influence systems.

Train and Certify Parent Peer Support Providers and Youth Peer Support Providers

FTNYS, in partnership with the state, developed the credentialing process for parent peer support providers (referred to as family peer advocates) and conducts five trainings per year. There are trainers across the state who went through a “train-the-trainers” process. FTNYS is currently the only certifying entity in the state, and all peer support providers must complete the training program and be credentialed by the organization. Parent peer support providers are employed by various provider agencies and some family-run organizations; FTNYS's role is the training and certification.

“The state family organization gets most of the credit for the work of defining the role of peer support specialists and how to do it effectively, designing the training curriculum, and training for professionals on how to work with peer support specialists.” (Amy Baker, Oregon Addictions and Mental Health Division)

Provide Training to Professionals, Families, and Youth Related to Children's Behavioral Health and Systems of Care

PPAL conducts a six-hour training program for providers, including residential and group home providers. Based on the Building Bridges approach, the training is focused on strategies to engage families, which is now required contractually for many providers. Training for professionals on how to engage with youth is also being developed by Youth MOVE Massachusetts, which is under the PPAL organizational umbrella. MCF often presents at conference on a variety of issues related to children's behavioral health, as does FTNYS.

Conduct Conferences for Families and Professionals on Related to Children's Behavioral Health and Systems of Care

MCF conducts an annual conference that is attended primarily by families. In addition to providing information, the conference also provides networking opportunities for family members. The organization is working to boost participation in this event, which is held on a weekend and has a low registration fee as well as the availability of scholarships.

FTNYS holds an annual conference attended by approximately 450 people, primarily family members and youth. Tracks provide training in areas such as learning to be part of a larger movement, leadership training for chapter leaders and board members, billing Medicaid, partnerships between youth and adults, a youth track, and others.

PPAL conducts an annual conference in the spring as the culmination of Children's Mental Health Awareness Week. Over 450 families typically attend, as well as some state and local agency representatives who are able to interact and dialogue with families. Provider agencies and MCOs are among the sponsors of the conference, and there is a nominal cost for families and youth.

Participate in the Development and Delivery of Strategic Communications Related to Children’s Behavioral Health and Systems of Care

MCF has a website, a monthly newsletter, and an email distribution list of over 2,500 recipients. The organization hired a social marketing expert who is working to increase the use of social media and other strategies to get the message out. These communications mechanisms are used for purposes such as policy alerts. One alert was sent when the state was going to cut the behavioral health budget. Due to the advocacy efforts of MCF and other organizations, the proposed cut was rescinded. MCF’s social marketer works with the state to create materials and organize events related to Children’s Mental Health Awareness Week.

PPAL has a large social media presence, including a blog that is posted every other week discussing a variety of issues related to children’s behavioral health from the family perspective. A newsletter, Facebook, Twitter, and other platforms are used for strategic communications to inform and build support.

State Perspectives

The state representatives interviewed were asked to share their perspectives on the benefits of partnering with family-run organizations and examples of what these partnerships have accomplished in their respective states. Several themes emerged from these conversations about areas that are particularly significant to state leaders – family voice, peer support, and identifying system needs. Each is discussed below.

Family Voice

Among the many contributions of family-run organizations to systems of care, they all emphasized the value of partnering with these organizations to bring family voice to policy making. They noted that the goal of state agencies is to make sure that families and youth are getting the best possible services with the best possible outcomes. Given this goal, the participation of families and youth at the system and policy level is critical to know with confidence their needs and preferences for services and their feedback on what works and what doesn’t. They also observed that working with family-run organizations is the most effective way to accomplish this. Although it is helpful to involve individual family leaders, partnering with family-run organizations brings not only their own lived experience to the discussion, but also knowledge of and access to many families and young persons throughout the state. They can take issues to a larger community of families and youth and bring feedback to the state.

*“To create systems from a policy perspective may sound good, but from a practical perspective, it doesn’t work without hearing from families and youth about whether what you’re trying to create will meet their needs.”
(Lisa Betz, Illinois Division of Mental Health)*

Some of the states have contracts with a family-run organization that support the organization’s infrastructure and ensures that family leaders will be available for participation at the system level. This was described as a particularly effective vehicle to ensure family voice – the organization identifies appropriate family members for the particular role, prepares them for involvement through training and mentoring, and supports them in the role. In Oregon, a contract with the family organization pays for policy-level participation, and family members are involved in roles including helping to write Requests for Proposals, reviewing proposals, and developing contracts with providers and MCOs. In Illinois, family organizations are helping to define a set of services needed by youth and families that are not currently covered by Medicaid for potential inclusion in the state Medicaid plan or a waiver.

OFSN, and other family-run organizations, have developed and conduct family leadership training programs that teach family members the skills needed to fulfill roles at the system and policy levels. One state representative described the family organization as “a great resource

we can count on” to bring family voice to the system. It is noteworthy that family organizations are often able to identify and bring youth voice to the table as well through their affiliation and/or sponsorship of youth leaders and youth organizations.

“FTNYS parent advisors are invited to the children’s division quarterly meetings. We look to them for advice and guidance. They are an active part of the division, and they are widely accepted and valued at the state and local levels.” (Donna Bradbury, New York State Office of Mental

To identify family members for policy-level participation, some states benefit from having a network of family organizations throughout the state that enables diverse family voices to be infused throughout all of their system planning and implementation activities. For example, NFFCMH has developed a network of family organizations that correspond to the state regions, allowing partnerships at the regional level as well as at the state level. NFFCMH has been fully involved in all aspects of the state’s system of care expansion efforts, with representatives from all of the regions participating, as well as representatives from the central state office.

Similarly, FTNYS has parent advisors in the state’s five regions who work as close partners with the children’s coordinators in each region and also assist the organization’s central office to address policy issues with state agencies. Oregon is rolling out systems of care with Wraparound care coordination in 13 of its 16 MCOs. The family-run organization helps to identify family leaders to participate on the steering committees in each of these communities. The ability to keep abreast of concerns statewide and to broaden family input into decision making is attributed largely to the structure of the family-run organization in the state.

Peer Support

Parent peer support services are a central component of the work of many family-run organizations, and the state leaders acknowledged their instrumental role in making this service available to families. In Nebraska, family navigation and peer support services have been evaluated, and positive outcomes have been documented. These services help to engage families and build trust, especially when they are initiated at the early stages of service delivery. In many states, parent peer support services are now Medicaid billable, and a growing number of family-run organizations are becoming Medicaid providers.

Beyond providing the peer support services, the state leaders emphasized the pivotal role of family-run organizations in defining, designing, and implementing peer support services, as well as training and credentialing parent peer support providers. A primary part of Oregon’s contract with OFSN is to provide statewide training and professional development for peer support providers, using its state-approved curriculum. It was noted that because of OFSN’s leadership in peer support and involvement at state policy tables, the child welfare system is now purchasing parent peer support and other system partners are considering adding this services. In addition, the state is exploring formalizing peer support further and potentially including it as a Medicaid covered service.

“One of the most important things the organization has done is to help initiate and grow peer support and the credentialing process. They took the bull by the horns and helped to get this off the ground.” (Donna Bradbury, New York State Office of Mental Health)

The state leader from New York indicated that FTNYS was the centerpiece of a workgroup on credentialing peer support, which is now covered through a Medicaid Home and Community-Based Services Waiver and with state funds. The state is now working on a benefit package in anticipation of the transition to Medicaid managed care, and peer support will likely become covered by Medicaid. The Illinois state leader noted that the state is looking to the family-run organization to determine what infrastructure is needed for peer support and to advise the state in this area.

“Family organizations can bring new issues to the attention of the state that are important to families and that can be addressed to improve the lives of children and families.” (Al Zachik, Maryland Behavioral Health Administration)

Identifying System Needs

The state leaders agreed that it is enormously valuable to have strong family-run organizations that can raise issues that the state may not be aware of and that need to be addressed. They have the unique ability to gather information from families through their statewide networks, surveys, focus groups, and the like to both identify and learn about gaps and systemic problems needing attention. In

Maryland, for example, MCF raised the problem of parents relinquishing custody of their children to obtain mental health care, ultimately leading to the implementation of a voluntary placement agreement. Another issue raised in Maryland focused on the poor school outcomes for children with Individualized Education Plans (IEPs) for social-emotional concerns. Collaborative efforts with the education system and grant funds to address this resulted. With strong partnerships, states can also request that family-run organizations reach out to families in their network to gather information about specific issues, such as the needs of families of youth with substance use disorders and youth in the juvenile justice system in Maryland.

Conclusion

For these states, working with family organizations as partners in systems of care at all levels is part of the culture. It is recognized that these partnerships are mutually beneficial to family organizations and to states, and that they improve service systems and outcomes for children and families.

“With their lived experience, families have a working knowledge of systems and are invaluable partners....Family organizations can continue to hold systems accountable as they evolve.” (Donna Bradbury, New York State Office of Mental Health)

Family organizations and their members bring arguably the most important perspectives to systems of care. In some cases, family organizations may question and challenge states and communities to improve policy and services, while in others they will be staunch supporters of state systems. Their role ranges from advocacy and services for individual children and families, to participation in the highest-level policy discussions and decisions, to identification of issues and advocating for solutions. In all of these situations, family-run organizations can collaborate with state and community leaders to work together toward their shared mission of providing the most effective services and supports for children, youth, and young adults with mental health challenges and their families.

“The true value of involving families who have experienced challenges can hardly be articulated, particularly when new opportunities emerge. We know we can turn to the family organization.” (Sheri Dawson, Nebraska Division of Behavioral Health)

“You get immersed in the policy environment and become hyper-focused, so when you have people with lived experience, it helps to remind us why we’re doing this work and what is really important.” (Donna Bradbury, New York State Office of Mental Health)

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