

# Family and Youth Peer Support Literature Review

SEPTEMBER 2013

## INTRODUCTION

Family and youth peer support (FYPS) is an essential component in serving youth and families through a Care Management Entity (CME) approach. While there is variability in how the relationship between FYPS providers and CMEs is structured and funded (e.g., direct hire of the family partners by the CME as in Massachusetts versus contracting with a family run organization as with Wraparound Milwaukee), the key elements of FYPS include advocacy, education, training, and peer-to-peer support. In many instances the providers of these services are individuals with lived experience in caring for a child with behavioral health or special health care needs. The National Federation of Families for Children's Mental Health and family run organizations have been strong proponents of the benefits of FYPS for many years, advocating for the recognition and funding of these services through state and federal dollars, and their inclusion and sustainability as part of the broader array of children's services funded through Medicaid.

FYPS providers, as well as families and youth receiving peer support, stress that these services are an essential enhancement to formal services to promote the health and well being of children and families. FYPS providers are not only a critical component of the teams serving children and youth with behavioral health challenges, but they are essential natural supports to caregivers and the entire family. Though evidence of their effectiveness is still emerging, the existing research suggests positive outcomes for those receiving FYPS. The literature also emphasizes the need for more in-depth research on this topic to develop a more substantial evidence base.

This review summarizes much of the existing research on FYPS, focusing predominantly on the literature relevant to peer support for children and youth with significant mental health and/or physical health challenges. It was developed as a resource to support states in strengthening their CME approach through the development and implementation of FYPS across child and adolescent serving systems.

## BENEFITS OF FAMILY AND YOUTH PEER SUPPORT

### **Peer support provides benefits of experiential learning and helps to connect families with each other.**

- A.F. Hartman, M.B. Radin, and B. McConnell. "Parent-to-Parent Support: A Critical Component of Health Care Services for Families." *Issues in Comprehensive Nursing*, 15 (1992), 55-67.

**Peer support programs help parents who have children with special needs find and become reliable allies for each other.** They provide parents with the opportunity to connect with and support each other through informational and emotional support, and through reciprocity.

- B. Santelli, A. Turnbull, J. Marquis, and E. Lerner. "Parent-to-Parent Programs: A Resource for Parents and Professionals." *Journal of Early Intervention*, 21, no.1 (1997), 73-83.

**Parent-to-parent support programs are valued by parents and may improve the emotional functioning of parents who have children with disabilities and help them improve their coping skills.**

- V. Robbins, J. Johnston, H. Barnett, W. Hobstetter, K. Kutash, A.J. Duchnowski, and S. Annis. The Louis de la Parte Florida Mental Health Institute, Department of Child and Family Studies. "Parent to Parent: A Synthesis of the Emerging Literature." (Tampa, FL: University of South Florida, 2008). (p.6)

**The self-efficacy and empowerment of families can be enhanced by providing family support, and this has been associated with a variety of improved outcomes such as service initiation and completion; increased knowledge about the youth's condition and relevant services; satisfaction; and youth functioning at discharge.**

- L. Bickman, C. Heflinger, D. Northrup, S. Sonnichsen, and S. Schilling. "Long Term Outcomes to Family Caregiver Empowerment." *Journal of Child and Family Studies*, 7, no. 3 (1998a), 269-282.
- L. Bickman, M.S. Salzer, E.W. Lambert, R. Saunders, W.T. Summerfelt, C. Heflinger et al. "Rejoinder to Mordock's Critique of the Ft. Bragg Evaluation: The Sample is Generalizable and the Outcomes are Clear." *Child Psychiatry and Human Development*, 29, no. 1 (1998b), 77-91.
- C. Heflinger, L. Bickman, D. Northrup, and S. Sonnichsen. A Theory-Driven Intervention and Evaluation to Explore Family Caregiver Empowerment." *Journal of Emotional and Behavioral Disorders*, 5, no. 3 (1997), 184-191.
- M.G. Resendez, R.M. Quist, and D.G.M. Matshazi. A Longitudinal Analysis of Family Empowerment and Client Outcomes." *Journal of Child and Family Studies*, 9, no. 4 (2000), 449-460.

**There is encouraging initial evidence of the value of family education and support (FES) in reducing child symptoms and improving child functioning. Furthermore, there is evidence of some benefits to the parents and caregivers, including a reduction of stress, improved mental health and well-being, increased self-efficacy, perceived social supports, and increased treatment engagement.** FES is commonly delivered through clinician-led, peer-to-peer or professional-parent team mechanisms. In their review of the family support literature, Hoagwood (2010) identified 50 studies that met criteria for inclusion that had evaluation data. Clinician-led programs (33) were the most numerous, followed by family-led (11) and team-led (6) programs. Although there were differences in the rigor or methodology among the three types of programs, the contents of the components were similar with some differentiation of emphasis across the three types.

- K. Kutash, L.G. Garraza, J.M. Ferron, A.J. Duchnowski, C. Walrath, and A.L. Green. "The Relationship between Family Education and Support Services and Parent and Child Outcomes Over Time." *Journal of Emotional and Behavioral Disorders*, published online, August 2012.

**The findings in the Family Experience Study suggest a need to increase contact with, and access of families in wraparound to, other families who experience similar problems with their children.** Future research should compare differences in short- and long-term outcomes based on different treatment conditions, such as a facilitator condition to assess the effect of having a facilitator who was also a parent of a child with a mental health problem, a peer mentor condition to assess the presence or absence of a peer mentor, and a support group condition to assess the presence or absence of a family support group.

- K. Painter, J. Sean Allen, B. Perry. "Families' Experiences in Wraparound: A Qualitative Study Conceived and Conducted by Families Through a Professional-Family Collaboration." *Journal of Emotional and Behavioral Disorders*, 19, no. 3 (2011), 156-158.

**Parents in the Parent Connectors group displayed a greater increase in hopefulness from baseline to follow-up than parents in the comparison group.**

- J. Duchnowski, J. Ferron, A. Green, and K. Kutash. "Supporting Parents Who Have Youth with Emotional Disturbances Through a Parent-to-Parent Support Program: A Proof of Concept Study Using Random Assignment." *Administration and Policy in Mental Health Services Research*, 38, no. 5 (2011), 412-27.

## INCREASED USE OF FAMILY AND YOUTH PEER SUPPORT

**The use of formal peer supports or advocates to increase family involvement in children’s mental health services appears to be increasing.** For example, numerous accounts of programs are made in children’s mental health systems of care publications, conference agendas and workshops. In addition Jensen and Hoagwood (2008) edited a book written by parents to teach other parents to become formal supports for parents with children experiencing mental health challenges, and Miles (2008) describes models that systems of care have used in hiring “family partners” as staff and integrating them into their wraparound processes. More recently, Munson et al. (2009) examined how parent advocates operating within a federally supported system of care framework describe their role in working with families.

- T. Davis, S. Gavazzi, S. Scheer, R. Uppal. “Measuring Individualized Parent Advocate Services in Children’s Mental Health: A Contextualized Theoretical Application.” *Journal of Child and Family Studies*, 20, no. 5 (2011), 669-684.

## ROLES OF FAMILIES

**A large majority (over 90 percent) of agency directors believe the most important roles for families are educating other families, advocating for mental health services, and peer-to-peer support. Other key roles identified by over 79 percent of the directors include leading support groups, training other families, serving as a direct liaison with mental health providers, and direct advocacy on behalf of individual families.** Noting the lack of advocacy-related research, Hoagwood et al. (2008) conducted a national survey study of 226 directors of family advocacy, support, and education organizations affiliated with children’s mental health and collected information on the types of services provided by the family advocacy organizations and their perceived impact on outcomes. The literature consistently reflects a general sense that peer support providers serve an important role.

- T. Davis, S. Gavazzi, S. Scheer, R. Uppal. “Measuring Individualized Parent Advocate Services in Children’s Mental Health: A Contextualized Theoretical Application.” *Journal of Child and Family Studies*, 20, no. 5 (2011), 669-684.

## FAMILY SATISFACTION WITH PEER SUPPORT

**Parents who participated in peer support groups were overwhelmingly satisfied with their experiences.** Participants in the Parent Connectors group who participated in the follow-up interview were asked three satisfaction questions. In regards to satisfaction with the Parent Connector assigned to them, parents were overall very satisfied, with 98 percent stating that they were very satisfied with their Parent Connector.

When asked what they found most useful about having a Parent Connector, 97 percent of the responses were positive and described the Parent Connector as relaying information and connecting them to resources, being a good listener, and caring.

- J. Duchnowski, J. Ferron, A. Green, and K. Kutash. “Supporting Parents Who Have Youth with Emotional Disturbances Through a Parent-to-Parent Support Program: A Proof of Concept Study Using Random Assignment.” *Administration and Policy in Mental Health Services Research*, 38, no. 5 (2011), 412-27.

## WORKFORCE/SUSTAINABILITY

**Given shortages in the mental health work force, there may be opportunities to expand the role of families and service capacities within family organizations.** Fiscal sustainability however was a major concern of these organizations (Hoagwood et al, 2008). Creating stable support for family advisors, comparable to the Medicaid coverage for adult consumer-provided services, could address both workforce shortages and fiscal sustainability. The message that evidence is critical to such policy change is articulated in a guide for family peer-to-peer support programs (FFCMH, 2008a).

- P. Gyamfi, C. Walrath, B. Burns, R. Stephens, Y. Geng, and L. Stambaugh. "Family Education and Support Services in Systems of Care." *Journal of Emotional and Behavioral Disorders*, 18, no. 1 (2012) 14-26.

## NEED FOR MORE RESEARCH

**Family or peer support providers have the potential to effectively help alleviate some of the noted gaps in children's mental health services; however, scant research literature exists to provide detailed documentation of the services rendered by peer support providers and their impact.**

- T. Davis, S. Gavazzi, S. Scheer, R. Uppal. "Measuring Individualized Parent Advocate Services in Children's Mental Health: A Contextualized Theoretical Application." *Journal of Child and Family Studies*, 20, no. 5 (2011), 669-684.

**Although family education and support is growing in availability within the children's mental health field, it has been the advocates and leaders in public policy, not researchers, who have led the way in developing and facilitating their implementation in communities across the country.** It is important that researchers become involved in examining these services so that the discussion on refining and improving these services for a high-need group of children and their families are informed by empirical investigations.

- K. Kutash, L.G. Garraza, J.M. Ferron, A.J. Duchnowski, C. Walrath, and A.L. Green. "The Relationship between Family Education and Support Services and Parent and Child Outcomes Over Time." *Journal of Emotional and Behavioral Disorders*, published online, August 2012.

**With the passage of the Mental Health Services Act in 2004 in California, support for the provision of services to include peer providers identified as consumers and family members has been on the rise.** Many California counties have, in some way, included employees with lived experience as consumers and family members into the workforce either through direct hire or through community based organizations. As California operates on a county-based system, these efforts have very little consistency across the state with regard to hiring practices, qualifications, necessary skill sets, job duties, and supervision. Significantly, there is no statewide standardized statement regarding the value, significance, or role of these peer providers in the mental health system.

- Working Well Together, Training and Technical Assistance Center. "Certification of Consumer, Youth, Family and Parent Providers: A Review of the Research." (2012). Available at: [http://inspiredatwork.net/uploads/WWT\\_Peer\\_Certification\\_Research\\_Report\\_FINAL\\_6.20.12\\_1\\_.pdf](http://inspiredatwork.net/uploads/WWT_Peer_Certification_Research_Report_FINAL_6.20.12_1_.pdf).

### **About the CHIPRA Care Management Entity Quality Improvement Collaborative**

This resource was developed by the Center for Health Care Strategies (CHCS) through its role as the coordinating entity for a five-year, three-state Quality Demonstration Grant project funded by the Centers for Medicare & Medicaid Services under the Children’s Health Insurance Program Reauthorization (CHIPRA) Act of 2009. The multi-state grant is supporting lead-state Maryland, and partner states Georgia and Wyoming, in implementing or expanding a Care Management Entity approach to improve clinical and functional outcomes, reduce costs, increase access to home- and community-based services, and increase resiliency for high-utilizing Medicaid- and CHIP-enrolled children and youth with serious behavioral health challenges.

### **About the Center for Health Care Strategies**

The Center for Health Care Strategies (CHCS) is a nonprofit health policy resource center dedicated to improving health care access and quality. We work with state and federal agencies, health plans, providers, and consumer groups to develop innovative programs that better serve low-income Americans, especially those with complex and high-cost health care needs.

Visit [www.chcs.org](http://www.chcs.org) for additional resources and tools for improving the quality and cost-effectiveness of care for Medicaid beneficiaries with complex needs.