Family Peer-to-Peer Support Programs in Children’s Mental Health

A Critical Issues Guide

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Family Peer-to-Peer Support Programs in Children’s Mental Health: A Critical Issues Guide

Table of Contents

Acknowledgements ................................................................................................................................3
Introduction and Background................................................................................................................. 3
The Parent Partner Assessment Workgroup ....................................................................................... 4
Purpose of the Guide .......................................................................................................................... 5
Organization of the Guide .................................................................................................................. 5
Part I: The Backbone: Evaluate Family Peer-to-Peer Support!............................................................... 5
Defining Family ................................................................................................................................... 5
Defining Family Peer ........................................................................................................................... 6
Defining Types of Support and Developing Outcomes for your Program .......................................... 6
Sample outcomes from the PPAW .................................................................................................. 7
Part II: Then, Design the Program .......................................................................................................... 8
Job Descriptions and Job Titles ........................................................................................................ 8
Hiring Agency and Location of Family Peer-to-Peer Support Programs ........................................... 8
Samples of hiring agency and location structures from the PPAW ................................................... 9
Training, Supervision and Support ..................................................................................................... 9
Sample training and supervision structures from the PPAW ............................................................. 10
Ensuring a culturally and linguistically competent program ............................................................ 10
The question of certification ................................................................................................................ 10
Sample certification approaches from the PPAW ............................................................................. 11
Part III: Finally, Seek Funding ............................................................................................................. 11
Medicaid .............................................................................................................................................. 11
Sample of funding sources from the PPAW ....................................................................................... 12
Part IV: Summary Conclusion ............................................................................................................ 12
Appendix A: The Parent Partner Assessment Workgroup ................................................................. 14
History ................................................................................................................................................ 14
Members ............................................................................................................................................. 14
Endnotes ............................................................................................................................................ 15
Acknowledgements

Several types of parent support have emerged as strategies for improving, if not transforming, the children’s mental health care system. They include three in particular. One is the “parent partner” as used in the context of wraparound teams and as documented in The Resource Guide to Wraparound (NWI, 2008). Another is one that sees parents who have systems and life experience as excellent candidates to be paraprofessionals, augmenting the role of clinical health service providers. This second type includes some degree of clinical training and supervision and may be developed, even promoted by professionals and clinicians. The third type is what we are talking about in this resource guide. It is the basic provision of information, support and advocacy from one parent to another parent going through similar circumstances with their own child. A significant point of clarification that needs to be made here is that the type of “parent partner” about which this guide is written specifically requires a parent who has a child with serious mental health needs. (There is more about this criterion on page 5.) These three types of “parent partner” may overlap in many situations and may even compete in others. We want to express respect for the contributions made to the field by those programs developing and promoting all variations.

This document is the result of numerous collaborative relationships. The National Federation of Families for Children’s Mental Health (National Federation) is indebted to Brigitte Manteuffel of ORC Macro, Inc. and Gary Blau and Sylvia Fisher of the Substance Abuse and Mental Health Services Administration (SAMHSA) for seeing the value in convening a group of parent-evaluator teams to expedite their work and to gather lessons learned. These teams, from system of care communities in various stages of developing, implementing and evaluating their own parent-to-parent support programs are the Parent Partner Assessment Workgroup (PPAW), convened and facilitated by the National Federation. Their individual and collective commitment, passion, and leadership have moved us one giant step forward and have informed the contents of this guide. We thank the following PPAW members: Eve Bleyhl, Susan Bredice, Maria Delmoro, Beverly Wilkinson, Norin Dollard, Connie Hammitt, Bill Hobstetter, Teresa King, Gisela Lawson, LuAnn McCormick, Malisa Pearson, Vestena Robbins, Brooke Schewe, Dianne Shaffer, Marya Sosulski, Chris Stormann, Carolyn Sullins, and Amy Winans.

The National Federation also would like to thank experts who met with us, advised us, questioned us, and encouraged us. They include Eric Bruns, Al Duchnowski, Barbara Friesen, Kimberly Hoagwood, and Krista Kutash. Finally, we acknowledge our debt to the numerous workshop and listserv participants as well as those individuals who have called the National Federation for technical assistance.

Introduction and Background

Family peer-to-peer support is the most fundamental element of the children’s mental health family movement (hereafter referred to simply as the family movement) and has been for more than 20 years. Families have always intuitively known that sharing information, support and advocacy with one another is a key to overcoming the challenges of raising and supporting a child with emotional, mental or behavioral disorders.

Family peer-to-peer support, a core function of most family-run organizations, has been poorly documented, inconsistently funded, and even less well evaluated. The result is that the family movement is now at a critical crossroads. “We” know that family peer-to-peer support is of great value, but current context requires more than intuitive knowing.
Current context requires scientific knowledge to claim the value of peer-to-peer support. The concept of evidence-based has emerged as a requirement to fund services and supports in many situations. Thirty years of increasing portions of funding for mental health services coming from Medicaid, coupled with looming budget deficits are among the most important factors in today’s environment. These challenges mandate the children’s mental health family movement to clearly define and systematically demonstrate the value of family peer-to-peer support. It must be defined, documented and demonstrated in a language common to funders, policy makers and decision makers. That language – that way of knowing – is through participatory program evaluation processes.

In addition to the above mentioned funding issues, workforce issues such as cultural and linguistic competence and underserved geographical regions have intersected with a changing research agenda to grab the attention of numerous academicians and researchers. State entities have begun creating, funding, and filling internal positions for family advocates. For example, a recent survey of state mental health directors, the National Federation found 13 states out of 22 reporting employment positions for family members within their state agencies. (National Federation, 2008) As researchers, state agencies, and other stakeholders seek to solve system wide work force deficits and to improve outcomes, they have become interested in the potential of family peer-to-peer support. Questions such as the following are emerging in the field. Does family peer-to-peer support improve child and youth outcomes? Is it a way to get clinical services into rural areas by training and supervising para-professionals? It is critical that the family movement take a stand in defining and directing the future course of family-to-family support work.

The family movement is in danger of losing that which evolved as an effective and essential strategy for families raising children with emotional, mental or behavioral disorders – peer-to-peer support. The movement is in danger of having others define core elements of family peer-to-peer support. There is danger of being held accountable to outcomes never intended to result from family peer-to-peer support. And, all of this, while there is a significant threat to the fiscal sustainability of family-to-family support programs.

The National Federation strongly believes that these concerns and questions need to be answered by families in their communities. No doubt, state wide consensus will be necessary for issues like certification, funding, and evaluation. But, we believe that consensus comes from local dialogues. And, the experiences, the values and the collective wisdom of families must be driving local decisions up to the state and national levels.

The Parent Partner Assessment Workgroup

In early 2007, the National Federation identified and recruited family-driven teams from four SAMHSA funded system of care communities and one state funded adult consumer organization that were independently exploring ways to assess family peer-to-peer programs. Representing various program designs and stages of development, these teams were convened as a workgroup to collectively share information and address needed problem solving. Named the Parent Partner Assessment Workgroup (PPAW), the group embarked on a series of listening sessions at national conferences and meetings with researchers and academicians doing related work. In 2008, with additional support from SAMHSA, the group grew to include teams from seven SAMHSA funded system of care communities. (See Appendix A for more information and a member list.) At the time this document is being written, the group has convened for monthly teleconferences, shares an on-line work space for written collaboration, and has met twice for two-day work sessions.

As a result, each of the teams has received in-depth peer-to-peer technical assistance to advance their own projects. PPCW is committed to sharing their learning through conference presentations and written documents, as resources permit. PPCW members also participate in the National Federation’s
Parent Partner Program Listserv intended to expedite dialogue and information sharing across communities. Listserv members may pose questions directly to PPAW members via that listserv.

The National Federation has been supported by ORC Macro, Inc., the American Institutes of Research, and SAMHSA to convene and facilitate the PPAW. Throughout the guide, there are sections devoted to sharing examples from the PPAW, although the contents of this guide are the voice of the National Federation and not members of the PPAW.

**Purpose of the Guide**

This guide is intended to provide an overview of critical issues related to the progress and sustainability of family peer-to-peer programs in children’s mental health. It will indicate important decision points for the design and implementation phases of family peer-to-peer programs.

**Organization of the Guide**

The Guide is divided into three sections focused on

- evaluation
- program design
- funding

The order of these three sections is intended to underscore the following principle.

*Outcomes drive program design & the program drives financing.*

Many organizations make the mistake of first seeking funding and then determining the elements of their programs. Program evaluation too often becomes an afterthought – if a thought, at all. This guide aims to keep the reader focused on first deciding what to do, then deciding how to do it, and only then deciding how to pay for it. Mission driven programs that are well documented and reasonably evaluated are far more likely to be successful and to sustain than those who choose to “follow the money.”

**Part I: The Backbone: Evaluate Family Peer-to-Peer Support!**

The first step in evaluating any program is to clearly define what is being assessed and the criteria being used to assess it. Therefore, the highest priority for the family movement must be to *explicitly define family peer-to-peer support* and then to build the evidence base demonstrating its value. When terms are not clearly defined, families and other stakeholders sometimes find themselves in conflict simply because they are not “meaning the same thing”. To ensure that family peer-to-peer support programs are not co-opted, that everyone understands what they are, what they do, and what they accomplish, explicit definitions must be developed and consistently used.

**Defining Family**

A recent scan of chapters and State organizations of the National Federation revealed huge disparities in how the term “family member” is defined, when it is defined at all. As the family movement advocates for family involvement, for family-driven care, and for family peer-to-peer support, we cannot afford to leave this term vague. Absent a clear definition and common meaning, hard won progress will be eroded.

The point of “family member” designation is perhaps as simple as a person who is raising or has raised a child or youth with [same disability]. Depending on the context, the category of disability may
be as specific as ADHD or as broad as “emotional, behavioral or mental health challenges”. There have been communities in which a disability indicator was not specified at all. This situation permitted a “family member” – with or without special needs or even similar needs -- to represent the experience of families about which he or she had no direct knowledge.

For the purpose of defining family for the family peer-to-peer programs in children’s mental health, perhaps the PPAW’s definition is the most useful.

**Defining Family Peer**

In May 2008, the PPAW agreed upon the following definition for “family peer.”

- **Currently raising or has raised a child or youth with emotional, behavioral or mental health challenges**
- **Current knowledge of the [children’s mental health] system**
- **Experience with and consciousness of the struggle, recognizes the standpoint of the parent**

Standpoint, as used in the third bullet, refers to the unique perspective a person has based on their life experience which in this case is that of raising a child with mental health challenges.

Some have suggested expanding the second bullet to include all child, youth and family serving systems. That type of specificity, however, can be captured in job descriptions and included in training curricula as they will vary from community to community. This definition was intentionally kept basic and simple as minimum criteria that might work across all communities. The important thing is to get a simple definition that clearly identifies who the program intends.

**Defining Types of Support and Developing Outcomes for your Program**

Developing outcomes for your program requires first defining the support to be provided. What does the program seek to provide? What is meant by support?

Important questions with which to grapple include the following. Why do we do this? What are we accomplishing? What are we trying to change? Is this change important enough to fund?

Outcomes are the things the program causes to change. Programs are held responsible for their outcomes.

Some have suggested that family peer-to-peer support should improve the child’s clinical outcomes. For example, family peer-to-peer support might reduce the child’s symptoms or improve his behavior. As Barbara Friesen of the Research and Training Center on Family Support and Children’s Mental Health at Portland State University has said, “...there is a very long causal chain between [family support] and outcomes for children and families.” (Friesen, 2004, p.1) There are many things that impact a child’s emotional, mental or behavioral disorder and support to the family by other family members can not alone create improved clinical outcomes.

Barbara Friesen further provides a warning to family-run organizations. “...family support organizations should not be held responsible for outcomes over which they have little or no direct control (i.e., child outcomes). And, as family organizations move forward in doing evaluation to learn more about what the outcomes of family support, education and advocacy activities might be, they should not over-estimate what they can cause to happen, placing themselves in a position where it looks as if they have not met goals.” (Friesen, 2004, p.2)

And yet, one recent study found that among family members receiving family-to-family peer support, their youth age 11 and older decreased their alcohol and other substance use. (Kaufman, 2008, p.3)
The desired outcomes should drive program design just as an organization’s mission should drive what it does from day to day. So, a program that is being developed should start with clearly identifying the outcomes it intends to accomplish and then build the program – essential job tasks and activities, the job descriptions, the training, support and supervision, etc. – to support those outcomes.

If evaluation is being added to an already existing program, it will be important to discover the outcomes being achieved. The Tapestry System of Care in Cuyahoga County, Ohio documented family peer support activities. They did this to identify additional training needs as well as their unanticipated outcomes.

An examination of the literature search conducted by Vestena Robbins and others finds outcomes such as the following being assessed.

- reduced parental stress, insecurity, and helplessness
- improved motivational levels, patience, and tolerance
- increased sense of empowerment

Outcomes need to be realistic, do-able, and measurable. Without a set of commonly agreed upon core outcomes to guide all family peer-to-peer program evaluations, each program will have to carefully identify and measure their own outcomes.

Sample outcomes from the PPAW

<table>
<thead>
<tr>
<th>COMMUNITY</th>
<th>INDIVIDUAL OUTCOMES</th>
<th>SYSTEM OUTCOMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>OHIO: Tapestry System of Care</td>
<td>Caregiver strain is reduced</td>
<td>Access, Capacity, Location (community based services), timeliness of services, length of stay, collaboration, fidelity to the wraparound process, attendance and systems representation on family teams.</td>
</tr>
<tr>
<td></td>
<td>Progress in made on family member goals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Academic attendance and performance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Employment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Engagement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amount of services accessed</td>
<td></td>
</tr>
<tr>
<td>NEBRASKA: Family Support Network</td>
<td>Families have enhanced capacity to provide for children’s needs</td>
<td>Program Manager takes referral which provides basic information on the family / identifies immediate needs ... and then assigns Family Partner to work with the family.</td>
</tr>
<tr>
<td></td>
<td>Child and family involvement in case planning and treatment is enhanced</td>
<td>Family Partners collect/record data on the following: * # of Face to Face contacts</td>
</tr>
<tr>
<td></td>
<td>Families are helped to keep their children safely maintained in their homes whenever possible and appropriate</td>
<td>* Specific Services/Support Provided – i.e. budgeting, housing, utility assistance, help with case plans/court orders...* Family Team Meetings * Court Hearings * Number and Nature of Referrals Made * Phone Calls made/received on behalf of family - we count pretty much anything we do for/with families.</td>
</tr>
<tr>
<td></td>
<td>Families are assisted in accessing appropriate services/support to meet their child’s educational needs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Families have identified that as a result of NFSN services/support they * Feel more confident/better equipped to stand up for themselves in the professional service realm * Understand their rights better * Feel more hopeful</td>
<td></td>
</tr>
<tr>
<td>MICHIGAN: ASK &amp; Kalamazoo Wraps</td>
<td>Initial: Families will increase their knowledge of mood, behavior and emotional disorders. Relevant to their children’s needs.</td>
<td>Organizations in the System of Care for children’s mental health become more family-driven and youth-guided in their systems and practices.</td>
</tr>
<tr>
<td></td>
<td>Intermediate: Families will be able to advocate for their children, with the help of a Family Support Partner.</td>
<td>ASK promotes agency and governmental policies that support families that work with ASK.</td>
</tr>
<tr>
<td></td>
<td>Longer-term: Families will advocate for their children’s needs without a Family Support Partner.</td>
<td></td>
</tr>
<tr>
<td>NEW YORK: Families Together in Albany County</td>
<td>Reduced caregiver strain</td>
<td>Keep children in home/home community Improved family perception of systems -child welfare, social services</td>
</tr>
<tr>
<td></td>
<td>Increased knowledge and understanding of MH, systems, services, meds</td>
<td></td>
</tr>
</tbody>
</table>
In addition, during a meeting with members of the PPAW in May of 2008, Kimberly Hoagwood, PhD of Columbia University suggested four core outcomes while acknowledging the absence of any good measures at this point in time.

- Decreased isolation
- Decreased (internalized) blame
- Increased realization of importance of self care for parents
- Increased ability to take action (through gaining knowledge and learning how to take action)

**Part II: Then, Design the Program**

With definitions and outcomes in place, the program is more easily operationalized.

### Job Descriptions and Job Titles

There is a great deal of diversity in the position titles for people providing family peer-to-peer support, varying greatly from one community to another. Generally, the first words in the title are *family, parent* or *peer*. Most titles also include one of the following: *liaison, specialist, advocate, partner, support[er], officer, coach, advisor, mentor, contact, navigator,* or *coordinator.*

Once more, it is important to point out that these terms are also used to describe paraprofessionals supporting families. Also, the National Wraparound Initiative uses the term “parent partner” for the person facilitating the wraparound team. (For more information on the National Wraparound Initiative, see [www.rtc.pdx.edu/NWI](http://www.rtc.pdx.edu/NWI).) Neither of these two situations is being described here. And, while many people who are providing peer-to-peer support have additional responsibilities in their roles, the focus in this document is limited to the family-to-family peer support work.

In May 2008, members of the PPAW agreed upon the following list as the common core tasks of a family member providing peer-to-peer support:

- Provides information, support and advocacy
- Helps the family navigate through the system(s)
- Helps family member understand all possible options and make informed decisions
- Promotes productive partnerships between parents and professionals

### Hiring Agency and Location of Family Peer-to-Peer Support Programs

A concern expressed by numerous family leaders is family peer-to-peer workers being located within the agencies that serve children, youth and families. Does such location impair a parent partner’s ability to advocate objectively? Can it interfere with the ability to provide full and unbiased information about choices? These questions are unstudied. Concern and thought should be given to them when designing your program.
Samples of hiring agency and location structures from the PPAW

<table>
<thead>
<tr>
<th>COMMUNITY</th>
<th>HIRING AGENCIES</th>
<th>LOCATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>OHIO: Tapestry System of Care</td>
<td>Neighborhood Collaboratives, dispersed throughout the county and some more than 100 years old, receive contracts from the System of Care to hire Parent Advocates.</td>
<td>Neighborhood Collaboratives housing the Parent Advocates are located throughout the city and Parent Coaches are county wide.</td>
</tr>
<tr>
<td>KENTUCKY: From System of Care to Statewide expansion</td>
<td>Currently: Family Liaisons are hired by Community Mental Health Centers across the state (usually one per region – this is optional) Family liaisons specializing in substance abuse and early childhood mental health are employed by the statewide family organization. Planned: Family Peer Support Specialists will be hired by the Community Mental Health Centers (CMHC) across the state, while their coaching will be provided by the statewide family run organization.</td>
<td>Currently: Family Liaisons are located in Community Mental Health Center settings; KEYS (system of care) Family Liaisons are school based. Planned: The location of Family Peer Support Specialists is yet to be determined but will likely be in the Community Mental Health Centers. They will work in homes, schools, and the community based upon the wishes of the family.</td>
</tr>
<tr>
<td>MICHIGAN: Advocacy Services for Kids (ASK) &amp; Kalamazoo Wraps System of Care</td>
<td>Advocacy Services for Kids, private, non-profit family organization</td>
<td>Embedded in other agencies: 9th District Court; Goodwill Industries; Center-based school for youth with emotional impairments and an alternative High School; Kalamazoo Community Mental Health and Substance Abuse Services; Advocacy Services for Kids</td>
</tr>
<tr>
<td>MICHIGAN: Association for Children’s Mental Health (ACMH) &amp; IMPACT System of Care</td>
<td>Association for Children’s Mental Health, the Statewide Family Network</td>
<td>Clinton-Eaton-Ingham County Community Mental Health Authority, the County mental health provider</td>
</tr>
<tr>
<td>FLORIDA: One Community Partnership System of Care in Broward County</td>
<td>Mental Health Association of Broward County, Florida</td>
<td>The Parent Partners office is located in the city of Fort Lauderdale, but the Parent Partners work in homes, schools and in the community depending on wishes of the family.</td>
</tr>
<tr>
<td>NEW YORK: Families Together in Albany County</td>
<td>Families Together in NYS, Inc., the state organization of the National Federation of Families for Children’s Mental Health</td>
<td>Community-based Family Resource Center-urban, rural, suburban Parsons Child and Family Center, the largest child serving agency in the area And, Satellite Offices in County MH Clinic and a Pediatrician’s office</td>
</tr>
</tbody>
</table>

Training, Supervision and Support

The successful peer-to-peer support program will be able to provide thorough high-quality training that is specific to this unique role. Family members hired to provide peer-to-peer support need training, supervision, and support to ensure they have the opportunity to access information and to develop skills needed to be successful in their roles.

Existing peer-to-peer support programs have numerous approaches to training, but most are using a mix of existing training curricula from various sources, updating them with local issues, regulations and resources. Note in the matrix below that training sources include the National Federation’s Family Driven Care training, various wraparound curricula, and the Hand to Hand training from the National Alliance on Mental Illness (NAMI).

Pat Miles, a consultant from Oregon, makes a critically important point about training and supervision of family peer supporters. While her focus is on family partners in the context of
wraparound projects, her point is applicable to the focus of this document – family peer-to-peer support programs. She discusses the importance of clearly defined expectations, roles and responsibilities, and supervision that manages skills and not personalities. Her case for specialized training is well made. Most important is the following statement by Pat Miles.\textsuperscript{vi}

\textit{Family partner boundaries are different than boundaries for people who have been professionally trained for their roles. Supervisors have to join with family partners in order to establish helpful limits and structures to manage their personal stories.}

Certainly, documentation of training and on-going supervision is critical to any peer-to-peer support program and as part of assessing the value of the program. One (Jan 2007) workshop participant called for the evolution of a new kind of supervision, suggesting that typical employee supervision does not completely provide the kind of oversight and support needed by parents providing this service.

**Sample training and supervision structures from the PPAW**

<table>
<thead>
<tr>
<th>COMMUNITY</th>
<th>TRAINING</th>
<th>SUPERVISION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>OHIO: Tapestry System of Care</strong></td>
<td>Wraparound Parent Partner, Wraparound Vroon VanDenBurg, NAMI's Hand to Hand Train the Trainer, Federation of Families Family Driven Care Train the Trainer, Family Leadership Academy Train the Trainer, Skill Building</td>
<td>System of care supervisors or individuals named by the directors at the Neighborhood collaborative supervise the Parent Advocates. Parent Coaches currently are supervised by a coordinator at the Community Care Network. All parent partner supports are overseen by Teresa King, Family Lead at the system of care administrative services organization.</td>
</tr>
<tr>
<td><strong>MICHIGAN: Association for Children’s Mental Health (ACMH) &amp; IMPACT System of Care</strong></td>
<td>Parent Partner Core Skills, Parent Partner Essential Skills, Wraparound, Special Education Law, Positive Behavior Interventions and Supports, Additional trainings as needed</td>
<td>Supervision by Impact Lead Family Contact-who is employed by ACMH, statewide family organization. Weekly face-to-face individual supervision. Every other week group supervision with all advocates and lead family contact, non clinical</td>
</tr>
</tbody>
</table>
necessary because Tennessee’s managed care contract includes language mandating providers be certified. Again, however, from one State to another, there is a great deal of variation.

Sample certification approaches from the PPAW

<table>
<thead>
<tr>
<th>COMMUNITY</th>
<th>CERTIFICATION?</th>
</tr>
</thead>
<tbody>
<tr>
<td>OHIO: Tapestry System of Care</td>
<td>We try to use advanced “train the trainer” programs wherever possible towards sustainability and many of these courses have a type of certification. There is no official certification for Parent Advocates and Coaches though we do require completion of the training modules in a timely manner.</td>
</tr>
<tr>
<td>KENTUCKY: From System of Care to Statewide expansion project</td>
<td>Currently: There is no formal certification process in place. Planned: Family Peer Support Specialists will be required to attend a state-approved training and pass a family peer support core competency post test.</td>
</tr>
<tr>
<td>NEBRASKA: Family Support Network</td>
<td>This is not something that is currently on our radar. We are not adverse to the concept of credentialing, but we don’t think a cookie cutter approach is desirable. The most essential qualities our family partners possess are their personal experience – both the challenges of their family situation and the positive outcomes they achieved; their insight into the system of service and family dynamics; their passion for system change and helping others; problem solving ability; communication skills; tenacity...if a credential could effectively capture/enhance these characteristics that would be great, but a credential without the qualities that make our family partners the incredible advocates they are would be pretty meaningless.</td>
</tr>
<tr>
<td>MICHIGAN: Advocacy Services for Kids (ASK) &amp; Kalamazoo Wraps System of Care</td>
<td>The State of Michigan is currently working toward the certification of family to family support providers</td>
</tr>
<tr>
<td>MICHIGAN: Association for Children’s Mental Health (ACMH) &amp; IMPACT System of Care</td>
<td>No goal to certify our family advocates</td>
</tr>
<tr>
<td>FLORIDA: One Community Partnership System of Care in Broward County</td>
<td>Planned: Family Support Partners will be required to undergo a state-approved certification process.</td>
</tr>
</tbody>
</table>

**Part III: Finally, Seek Funding**

With outcomes defined and the program designed, if not implemented, appropriate funding sources can be matched. It is beyond the scope of this Guide to provide technical assistance in matching and securing appropriate funding; however there is hope to be shared in the variety of known funding streams.

Family peer-to-peer programs have been funded through numerous sources including Medicaid, Federal Mental Health Block Grants to States, child welfare agencies, as well as local, state and federal grants and cooperative agreements. Corporate America should also be interested in funding programs that can demonstrate a reduction in employee absenteeism due to reduced stress or improved ability to advocate for needed services and supports. Careful planning is important to maximizing use of the numerous funding strategies that can be used to support family peer-to-peer programs in children’s mental health.

An excellent fiscal planning tool is **A Self-Assessment and Planning Guide: Developing a Comprehensive Financing Plan**. A technical assistance tool produced by a five-year study, **Financing Structures and Strategies to Support Effective Systems of Care**, the planning guide is available for free download at [http://rtckids.fmhi.usf.edu/study03.cfm](http://rtckids.fmhi.usf.edu/study03.cfm).
Medicaid

States have a wide array of options for dealing with Medicaid-funded mental health services. What is likely to work best in an individual State inevitably will be a reflection of the history, current context, organizational structure, policy priorities, and leadership goals in that state. While Medicaid recently announced that peer-to-peer support services for adult mental health consumers would be a covered service, the same has not held in children’s mental health. A few states have overcome this with waivers and others have broken their services into categories already recognized and supported by their Medicaid plans. For example, if peer-to-peer support is not covered, perhaps family support/education is.

As stated earlier, technical assistance specific to securing funding for peer-to-peer support is beyond the scope of this Guide. Simple funding variations among peer-to-peer programs have been described and an assessment and planning guide has been cited and recommended. The final word of advice in this section is to assume no limitations and be vigilant in exploring possibilities, but always keep in mind that programs will need to demonstrate their ability to do what they claim. Family peer-to-peer programs must develop evidence – must infuse evaluation throughout.

Sample of funding sources from the PPAW

<table>
<thead>
<tr>
<th>COMMUNITY</th>
<th>FUNDING SOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td>OHIO: Tapestry System of Care</td>
<td>SAMHSA dollars and the Board of County Commissioners (BOCC) currently provide all funding for both Parent Advocates and Parent Coaches. The BOCC has committed to provide sustainable funding after the grant.</td>
</tr>
<tr>
<td>KENTUCKY: From System of Care to Statewide expansion project</td>
<td>Currently: Family Liaisons are funded with state and federal monies provided by the Department for Mental Health, Developmental Disabilities, and Addiction Services to the Community Mental Health Centers. KEYS (system of care) Family Liaisons are grant funded. Proposed: Family Peer Support Specialists would be funded with state monies, grant monies, as well as third-party payor funds (e.g., Medicaid, private insurance).</td>
</tr>
<tr>
<td>NEBRASKA: Family Support Network</td>
<td>NFSN operates per an annual budget of $400,000 through Nebraska’s public funds: 1. Region Six ICCU 2. HHS Safety and Protection Division. ICCU funding pays for the Executive Director, Office Manager, Program Manager and 4 Family Partners who work only with ICCU families in Region Six – capacity for these positions is about 120 families at any given time. HHS funding pays for two Family Partners, one full-time and one part-time, who work with other Region Six families in crisis per referrals from CPS, Professional Partners, Therapists, community organizations and self referrals. Capacity for these positions equals a total of 50 families.</td>
</tr>
<tr>
<td>MICHIGAN: Advocacy Services for Kids (ASK) &amp; Kalamazoo Wraps System of Care</td>
<td>SAMHSA Kalamazoo Community Mental Health and Substance Abuse Services Greater Kalamazoo United Way</td>
</tr>
<tr>
<td>MICHIGAN: Association for Children’s Mental Health (ACMHI) &amp; IMPACT System of Care</td>
<td>Annual Case rate per family – Childcare fund dollars from DHS (child welfare) and Court (family division)</td>
</tr>
<tr>
<td>NEW YORK: Families Together in Albany County</td>
<td>SAMHSA SOC grant funds and donations</td>
</tr>
</tbody>
</table>

Part IV: Summary Conclusion

This guide’s intention was to explore the critical issues and essential elements of family peer-to-peer support programs in Children’s Mental Health. Through examining major points in evaluation, program design and funding we have walked through many of the issues faced in establishing strong and prosperous family peer-to-peer programs. Family peer-to-peer support is a key element in the many
family-run organizations across the country. It has been regarded as one of the most powerful and motivational tools to help families in overcoming the challenges of raising and supporting children with emotional, mental and behavioral disorders.

Remember, when developing family peer-to-peer support programs it is important to access all elements of the program; evaluation peer-to-peer support as a whole. What does it mean in your community? What should it look like? How will you define it? In designing the program, develop clear and concise job descriptions. Be transparent about your expectations and requirements. Take time to thoroughly explore the pros and cons of certification before making a decision on whether or not it will work in your community. Finally, in seeking funding, do your research. Assess your resources and move from there. Think creatively and be sure to consider what documentation and evaluation process are best at showing your program’s worth.

The National Federation of Families for Children’s Mental Health believes in the importance of family peer-to-peer support programs. It has been stated that “the parent to parent support field is in need of conceptual and theoretical refinement" (Robbins et al., 2008. P6). While we see the undeniable worth of these programs in our family run-organizations across the nation, we also see the need to place a stronger investment in enhanced documentation, improved evaluation processes and more funding being provided to these programs. Lack of evidence that these programs improve the lives of families raising children with emotional, mental or behavioral disorders will compromise the future of the family movement. It is time to take action.
Appendix A: The Parent Partner Assessment Workgroup

History

The National Federation convened the Parent Partner Assessment Workgroup (PPAW) for the family–evaluator teams on the PPAW currently represent seven systems of care communities in varying stages of developing, implementing and evaluating their own local Parent Partner programs. Their work represents family-driven processes - that is families have primary decision making roles.

The PPAW workgroup is a coalition of families of children and youth with mental health needs and evaluators providing peer to peer support. This workgroup intends to share resources among themselves, and eventually to find and share common elements of parent partner program models and their assessments with the larger children's mental health community. The workgroup began as four communities, but three additional communities have been added since. The communities are from all over the country, and the workgroup is comprised of groups from various walks of life. The national Federation of Families for Children's Mental Health initiated this workgroup and supports its ongoing work through a subcontract from ORC Macro, Inc.

The funding to support this workgroup came from the federal Substance Abuse and Mental Health Services Administration, ORC Macro, Inc. and the American Institutes for Research.

Members

This workgroup is composed of seven communities:
1. Tapestry System of Care (Cleveland, Ohio)
2. IMPACT (Lansing, Michigan)
3. One Community Partnership (Broward County, Florida)
4. Kentuckians Encouraging Youth to Succeed (Frankfort, Kentucky)
5. Advocacy Services for Kids (Kalamazoo, Michigan)
6. Nebraska Family Support Network (Omaha, Nebraska)
7. Families Together of Albany County (Albany, New York)
Endnotes


iv Ibid.


