



## A Brief Overview of Parent Peer Specialists

Throughout America, there is a growing recognition of the key role peer specialists can play in the recovery of individuals with mental health needs. This document focuses on a particular class of peer specialists who work with families that include children with emotional or behavioral disorders.

### What Is a Parent Peer Specialist?

Parent peer specialists are:

- A parent or caregiver of a child with emotional or behavioral disorders, or other special needs
- Specifically trained for an information, support and advocacy role
- Genuinely understanding and appreciative of the culture of a family living with a child with special needs, because it is also their culture
- Typically employed by an organization other than service-providing agencies

There is a critical difference between support for families and peer specialist support:

#### Family Support

- Delivered by anyone within the system
- All services within a well-balanced system should be supportive
- Therapeutic or professional distance maintained

#### Peer Specialist Support

- Delivered by trained individual with first-person experience
- Must have direct system experience as a family member of someone receiving services
- Use of self and self-disclosure as a means to help

### Theory For the Use of Parent Peer Specialists

Families raising children with special needs, especially those with emotional or behavioral disorders, report significantly higher levels of caregiver strain. Caregiver strain is a term given to describe various stressors affecting the functioning of a family. Caregiver strain may be caused by fear, guilt, anxiety, isolation, hopelessness and exhaustion – all very common traits of families that include children with significant mental health needs.

High levels of caregiver strain have been linked to:

- Decreased likelihood of seeking help for their children
- Child maltreatment (4-10x the incidence of the general population)
- Substance abuse
- Domestic violence
- Fracturing of the family unit (e.g., out-of-home placement, separation/divorce)

Parent peer specialists work directly with the family, targeting the causative factors that increase caregiver strain. They typically employ a non-judgmental approach that fosters listening, learning and lasting solutions.

The model of using someone with a shared experiential background to assist individuals in overcoming the challenges they face is widely-used. One of the more well-known examples is Alcoholics Anonymous.

### **What Does a Parent Peer Specialist Do?**

The specific activities conducted by a parent peer specialist are individualized, based on the strengths and needs of the child and his/her family. In general, they work to break the loneliness, isolation and hopelessness that often grip these families. They teach skills, either directly or through modeling. They identify resources and assist the family in accessing and using those resources. They use relationships they've developed to help the family get their needs met.

Activities provided by parent peer specialists may include:

- Supplying information so families can better understand and participate in the systems serving their children
- Giving emotional support and guidance through a maze of services
- Acting as an objective liaison between families, schools, case managers, care coordinators and service providers
- Advocating for filling gaps in services and supports that can help a child flourish
- Ensuring that school plans are effective and appropriate
- Leading support groups that are confidential and educational
- Sponsoring low-cost social and recreational events for families
- Providing telephone support at times needed by families
- Offering hope and encouragement in times of crisis
- Helping families become better advocates for their children

### **Parent Peer Specialists in Collaborative Systems of Care (a.k.a. Wraparound)**

Wraparound is a collaborative team process designed to ensure strong family involvement and shared decision making. Because of this construct, some may argue that parent peer specialists (PPS) are not necessary in the process. In practice however, not all wraparound teams are adequately prepared and supported to empower parents to drive the team and be informed decision-makers for their children's plan of care. Likewise, not all family members possess the self-advocacy skills required to share in decision-making with their wraparound team (Osher & Penn, 2008). Parent peer specialists can help ensure fidelity to the key wraparound concepts of family involvement and shared decision making.

According to the National Wraparound Initiative (NWI), "the [Parent Peer Specialist] (*Note: NWI refers to PPS as "Family Partners"*) is a formal member of the wraparound team whose role is to serve the family and help them engage and actively participate on the team and make informed decisions that drive the process. [Parent peer specialists] have a strong connection to the community and are very knowledgeable about resources, services, and supports for the family. The [parent peer specialist's] personal experience is critical to earning the respect of families and establishing a trusting relationship that is valued by the family" (Penn & Osher, 2007).

Parent peer specialists help the wraparound process work more smoothly by reminding the team of the importance of the wraparound principles and fostering open communication. As one parent peer

specialist put it, "I can say things to parents that they will listen to because I'm a parent, not a professional. I can also say things to professionals that [the family] can't say, but I can because I'm 'just a parent,' all of which facilitates open communication on teams." Parent peer specialists often report that families will listen to what they say, while ignoring the same exact information when provided by a professional.

Activities provided by parent peer specialists in wraparound settings may include:

- Acting as a mediator, facilitator, or bridge between families and agencies
- Communicating and educating team members on wraparound principles, the importance of family voice and choice, and other key aspects of ensuring wraparound fidelity
- Helping the team understand the parent perspective
- Helping families prepare for and supporting families during Individualized Education Program (IEP) meetings
- Sharing personal experiences that can help teams to develop creative strength-based options
- Taking calls and providing support at times professionals are typically unreachable
- Listening to the family's frustrations and concerns, thereby freeing up time for the Care Coordinator
- Saying things to family members that may have a greater impact because the PPS has experienced some of the same frustrations and challenges as the family
- Conducting program evaluations that are more likely to get honest positive and negative feedback from families

As a general practice, parent peer specialists should serve on wraparound teams only as long as families need their support to effectively speak for themselves. However, they should continue to be available as a resource to wraparound families in times of need.

### **Evidence for Parent Peer Specialists**

#### ***Literature Review***

A large body of research speaks to the unique benefits of parent-to-parent support:

- Parent-to-parent support provides help in seeing hope for the future, feeling less alone, seeing positives in the situation, acceptance of the child's diagnosis, seeing family strengths, and dealing with stress (Santelli et al., 1997).
- Peer support was found to be helpful by over 80% of parents utilizing the services; it increased parents' sense of being able to cope and their acceptance of their situation (Kerr & McIntosh, 2000)
- Parent-to-parent support is a means for helping parents feel less isolated, for providing empathy by those who truly understand, and for providing hope in what may seem a hopeless situation (Shelton et al., 1987).

Some of the conclusions found in the literature review include:

- "The transforming effect of contact with other parents was clearly evident."
- "Parent-to-parent support can exert a powerful stress-buffering influence."
- "Peer support provided ... benefits ... that evidently could not be derived from other sources."
- "Parents of children with special health care needs are uniquely qualified to help each other."

## Research Studies

There are two recent studies of the impact of parent peer specialists.

<b>Study</b>	Parent Support: Building Structures That Support and Assist Children (Davis-Groves, et al., Univ. of Kansas, 2007)	Parent Peer Support and Outcomes for Children with Mental Illness (Ramacher, UW-Stout, 2010)
<b>Method</b>	Mixed-methods approach consisting of focus groups, interviews, questionnaires, and secondary analysis of an existing database	Non-random pilot study with self-administered online surveys with five demographic and eight closed-ended statements, based on the Likert Scale
<b>Key Findings</b>	Children whose parents received peer support specialist services have better outcomes in terms of residential status, law enforcement contact, academic performance, and school attendance. In addition, these children demonstrated fewer externalizing behaviors than children whose parents were not receiving support.	Parents receiving peer specialist services experienced improvement in coping skills, emotional health and confidence, as well as increased knowledge, improved management of children's behavior, and more confidence in advocacy skills. The data do not as strongly support a link to improvement in the children's behavior. However, there is still some indication that improvements for the parents impacted the children, as evidenced by a correlation between parent coping skills and better school grades for their children.

## Evaluation of Wisconsin Family Ties' Services

The following outcomes were determined by a survey of families served by Wisconsin Family Ties (WFT) in 2009.

- 97% feel they now have somewhere to turn when they need information & support
- 84% believe WFT helped them become better advocates for their children
- 88% reported they now know the steps to take when they are concerned about the services their children are or are not receiving

For families that identified prior to receiving services that improvement was possible according to the survey rating scale (i.e., where the "pre-test" was not already at the highest rating on the Likert Scale before receiving parent peer specialist services), respondents reported the following improvements after receiving services from Wisconsin Family Ties:

- 100% felt more capable of dealing with the various systems serving their child
- 84% felt more able to cope with their family situation
- 97% reported having more information regarding their child's diagnosis, treatment options and available community programs
- 86% felt more hopeful about the future

*This document was authored by Hugh Davis, a parent of children with mental health needs and executive director of Wisconsin Family Ties.*