

**Highlight: Preliminary Findings of F.A.C.T. Family Support Program for Families with
Members with Developmental Disabilities Pilot**
Prepared for F.A.C.T. by
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Summary: The Family Support Partner program for families with developmental disabilities, housed within F.A.C.T., a family-run organization, is uniquely positioned to meet the needs across the lifespan of families living in St. Charles County. Their longstanding commitment to families, receiving supports and staff who are families experiencing disability, provides an element not offered by many other professional organizations.

Consistent with research on family support programs with peer-professional staff, preliminary findings from this report indicate that families have the information they need and are better able to advocate and navigate the supports within medical, educational and long-term services and supports. Additionally, they have increased problem solving skills enhancing their ability to function throughout the day and maintain a stable housing. As a result, families showed signs of decreased stress and caregiver isolation, which presented itself through findings showing families were able to participate more in the community, maintain employment, or meet basic needs. Although there are limitations to the preliminary findings, in terms of the methodology and sample size, F.A.C.T. is committed to designing their program in a manner allowing for stronger outcome data and evaluation purposes. F.A.C.T. continues to define the core components of the program to ensure fidelity of implementation consistently within the program and for replication in other organizations.

The F.A.C.T. Family Support Program is especially relevant in the current state of long-term services and supports for people with developmental disabilities (DD). The positive benefits of opportunities and expectations for an inclusive quality of life in the community for people with DD, as all other American citizens, also brings a different set of demands and skills on the parents and family members. They are accessing and coordinating not only the formal services and supports for their loved one, but also for themselves within communities with extraordinary resources among its members, societal viewpoints and risks. This coupled with higher demands and limited funding of the DD service system oftentimes leaves parents without the needed support to navigate life. As identified in the literature, providing peer professional support within a family-centered and family-run organization could serve as an efficient and cost-effective strategy that has immediate and long-term implications.

Need: Families providing support at home to their loved ones with IDD must meet the daily demands that these conditions present, while facing other unique challenges, including: (a) extra financial costs tied to meeting the needs of their loved one, (b) unemployment or missed vocational opportunity resulting in lost family income, (c) difficulties with completing normal household routines or chores, (d) chronic stress, social isolation and overall changes in lifestyle, and added responsibilities for negotiating multiple social service systems (Reynolds et al., 2015; Vanegas & Abdelrahim, 2016; Bailey, Golden, Roberts, & Ford, 2007; McCann, Bull, & Winzenberg, 2015; King, Teplicky, King, & Rosenbaum, 2004).

Families have long embraced the responsibility of caring for their members who have disabilities (Rothman, 1971) and continue this responsibility, as exhibited in current national data. It is estimated that only 25% of people with DD receive formal disability supports with more than half that receive those support receiving them in the family home (Braddock et al., 2015; Larson et al., 2014).

Additionally, it is estimated that families currently provide \$335 billion worth of caregiving annually for their members with disabilities (Feinberg, Reinhard, Houser, & Choula, 2011).

Role of FACT: Since 1998, F.A.C.T. has provided the Partnership With Families (PWF) program for families with children with behavioral health needs, an evidenced based intervention that is integrated into the Systems of Care framework developed by SAMSHA. Specifically, F.A.C.T. has provided Family Support Partners who are parents who also have children with behavioral health needs, which allow them to provide peer support to the families in the PWF program. At least half of the children served through PWF were also diagnosed with a DD; however, children only diagnosed with DD could not receive F.A.C.T. services due to funding restrictions.

In response, with funding from the Developmental Disabilities Resource Board of St. Charles County and Missouri Division of Developmental Disabilities, F.A.C.T. piloted the Family Support Program to serve families of individuals with DD. As parents of children with a variety of disabilities, F.A.C.T. staff knows that all families need support regardless of diagnosis. All families with members with disabilities are likely to be involved with the same systems, are at risk for isolation, and experience significantly more stress than parents of typically developing children.

Preliminary Impacts: Sixty-seven survey respondents (23% response rate) provided feedback to a survey about their family outcomes and the impact of their Family Support Partner. Support Partners help families:

- Get needed information (86%)
- Teach families to advocate for their child, family, and self (79%) and teach them to problem solve and plan for day-to-day situations (77%)
- Help families identify someone they trust, who listens and talks when needed (75%)
- Link families to community activities (84%)
- Connect to services and supports to meet their physical and mental health needs not accessible previously (81%)
- Encourage connection with friends and community members (82%)
- Encourage family relationships (80%)

Family Support Partners were most helpful in:

- **Teaching respondents to advocate for themselves** and their families
- **Identifying a trustworthy person** with whom respondents could talk, who would listen when needed.
- **Serving as a reliable source for help** when needed.
- **Providing** frequent communication that meets the diverse communication styles and cultures of families served.

This support is:

- **Unique** since Family Support Partners bring experience, understanding, and empathy to their interactions with families allowing them to provide relatable, practical support to families.
- **Valuable** because Family Support Partners understand the experience of families and help them *not to feel so different and alone*.
- **Helpful**, because they have experienced situations similar to the families supported. They have experientially navigated the resources they are providing and can help families understand the systems, which they are navigating.

Faculty contracted to conduct evaluation and assessment are encouraged to report their findings and conclusions freely. Points of view and opinions are not official positions of the University of Missouri-Kansas City, F.A.C.T., or any of their funding sources. Please contact Michelle Reynolds for full findings reynoldsmc@umkc.edu or 816-235-1759