

F.A.C.T. Family Support Program for Families with Members with Developmental Disabilities

**Family Support Partner Participants July
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Executive Summary

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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.

Preliminary Findings of F.A.C.T. Family Support Program for Families with Members with Developmental Disabilities Pilot

Need for Supporting Families with Members with Developmental Disabilities

Families are a core unit of our society, serving as a source of support for all its members. For people with disabilities, the role of family is central to providing emotional and physical support across the lifespan. Family members, with or without disabilities and regardless of age, bring joy and cause for celebration to their families. Family members with IDD also require support due to the nature of their disabilities. While some individuals with IDD have difficulties in only one area of everyday functioning, many face multiple challenges cutting across more than one life domain. They may face challenges related to health impairments, learning problems, difficulties with behavior or social interaction, or mobility impairments.

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 developmental disability receive formal disability supports with more than half that receive those supports 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).

History of F.A.C.T and Supporting Families

F.A.C.T. is a freestanding, non-profit family organization that has been serving families of children with disabilities in St. Charles County for 30 years. F.A.C.T. serves approximately 1075 families each year who have a family member with a developmental disability or behavioral health issues. Families receive information, navigation, emotional support and advocacy through the different programs offered. Using a peer mentoring approach in all of its programs, F.A.C.T. staff are able to offer supports building on the “lived experience as a parent of child with a disability” coupled with extensive training and coaching for their role as an Educational Advocate or Parent Support Partner. This approach enables F.A.C.T. to provide individualized and responsive supports that are truly family-driven, strengths-based and culturally competent.

Since 1998, one of F.A.C.T.'s core programs has been the Partnership With Families (PWF) for families with children with behavioral health needs, which is an evidenced based intervention integrated into the Systems of Care framework developed by SAMSHA. In this program, Family Support Partners, all of whom have a child with behavioral support needs, help families navigate the systems, find and utilize community resources, and ultimately give families the tools they need to become empowered and resilient. By mentoring and modeling a Family Support Partner hopes to teach families how to handle any situation that might arise regarding their children, impart knowledge that gives families hope for the future, and to ensure that all families have the information they need in order for their children to be fully included in the community as they so choose.

As F.A.C.T. provided supports to over 600 families of children with behavioral health needs it became evident that more than half of these children also had a developmental disability. It was during this time that F.A.C.T. began to recognize that the Family Support Partner evidenced-based approach would be applicable to families raising children with developmental disabilities because the needs of the families were the same even if the diagnosis and the service system was different. Families of children with a developmental disability needed assistance with accessing and navigating educational supports, medical supports, community integration and other quality of life areas. Parents also needed the emotional support that comes from talking to another parent that has been there and has experiences for which to draw from when problem solving.

In October 2013, F.A.C.T. successfully secured funding from the Developmental Disabilities Resource Board of St. Charles County (DDRDB) to pilot the Family Support Program with families that include a person with a developmental disability, allowing them to hire one Family Support Partner. Through their relationship with the St. Charles County Coalition of Service Providers, F.A.C.T. was able to secure additional funding from the Missouri Division of Developmental Disabilities for four additional staff in 2015.

In July 2015, F.A.C.T. launched its pilot of the Family Support Partners program and has provided supports to over 374 families with members with developmental disabilities living in St. Charles County. Specifically involving parents (192 mothers, 84 fathers, 3 stepparents) as well as other family members such as siblings, extended family, and foster parents. Families were providing care and supports to members with disabilities that ranged between the ages of newborn to 65 years old, with the majority (73%) being school aged between 6 to 21 years old and 20% representing early childhood (birth to 5 years old).

To better understand the impact of the pilot, F.A.C.T. contracted with UMKC Institute for Human Development, UCEDD in 2015 to implement a results-based evaluation strategy that would identify the core components unique to the population of families with developmental disabilities and begin developing and collecting outcome data on those initially being served by the program. This report provides an overview of the results of focus groups with families and staff, as well as

the initial survey of participants who are either receiving or had received supports from a Family Support Partner.

Initial Evaluation Findings of the Parent Support Partners for Families with Members with Developmental Disabilities (DD) Pilot

Identifying Core Program Components and Outcomes

UMKC focused on understanding the core components and outcome areas by hosting two concept-mapping sessions with both families and F.A.C.T. staff. After analyzing the results and conducting key informant interviews with F.A.C.T. key leadership, F.A.C.T. was able to establish the concrete outcomes that were the focus of the Family Support Partner program for families with members with disabilities. Using this information UMKC developed a logic model to serve as the foundation for the evaluation process and recommendations moving forward. Table 1 summarizes the outcome areas.

Table 1. Long Term Goals and Expected Benefits		
Outcome	Family Outcomes	Person with DD Outcomes
All members of the family will be self-determined and will advocate for their needs.	Family gains knowledge and understanding of disability and accesses appropriate disability related supports. Family demonstrates confidence and adequate coping, problem solving, and advocacy skills for any challenges that may arise.	Person with a disability gains knowledge and skills for enhancing self-determination and self-advocacy for identifying and accessing supports.
Person with disability and their family will be accepted by, and have the same opportunities as, members of their communities.	Family learns skills for building relationships and memberships within their home, school/work, and play communities. The parent or family member has the skills or abilities to access community resources for enhancing safety, acceptance, and inclusion in a variety of environments for all family members.	Person with a disability is supported to build relationships and memberships within their home, school/work, play communities and he/she has the skills or ability to access resources for enhancing safety, acceptance, and inclusion in a variety of environments.
The physical and mental health needs of all family members will be met.	Family learns strategies to address his/her own physical and mental health needs as well as strategies for accessing health care for all family members.	Person with a disability is supported to learn healthy living strategies and access appropriate health/mental health care services.
Home life for all family members will be calm, safe, and stable.	Family learns and applies strategies for balancing family time, relationships, and the home environment of all family members.	Person with a disability is supported to maintain a calm, stable home environment.
Basic needs, such as food, stable income, and housing of all family members will be met.	Family secures income sufficient to meet basic needs and prioritizes the budget to address current and future family basic needs.	Person with a disability is supported to secure income sufficient to meet basic needs, works toward gaining employment skills, a job, or a

meaningful day, and can afford to address current and future basic needs.

Results-Based Evaluation

Utilizing the outcomes identified during the focus groups, F.A.C.T. leadership worked with UMKC to develop a survey to begin capturing initial data from families enrolled in the Family Support Program. The purpose of this survey was to capture initial data from those enrolled and to pilot the draft of the evaluation survey used to collect ongoing longitudinal data. The survey focused on three areas: a) Current Status of Outcomes of Families, b) Impact of Family Support Partner on Outcomes and c) Satisfaction with F.A.C.T. Family Support Program.

The first round of data collection targeted families enrolled in services for a minimum of 60 days to ensure full implementation of Family Support Partner services. Of the 374 individuals enrolled in the Family Support Partner program, 282 unduplicated families received the survey and 86 families did not meet the evaluation criteria (47 families are currently enrolled less than 60 days, 39 families were closed before reaching the 60 days).

Survey Respondents

Sixty-seven responses were received (23% response rate) between March 15, 2017 through April 30, 2017, using the online SurveyMonkey® version or mailed back paper copy. The respondents were then divided into two groups by whether they were still receiving services (Open) or if they had completed at least 60 days of supports (Closed); 51 respondents are currently receiving supports (Open), while 16 respondents received supports in the past (Closed).

Thirty-five respondents identified their connection to the person with the disability. In both the closed and open groups, the majority of respondents (82%) were mothers. Fathers (3), grandparents (1), and a foster parent also completed survey. The remaining 32 respondents did not provide their connection with disability. The majority of respondents were aged 22-40 years (47%), with ages ranging from under 21 to 64 years of age. Sixty-four percent of respondents identified as white, while 13% were African American and 2% were Asian and Biracial respectively. When compared to the overall data, the respondents reflect the overall demographics of those served by the program.

Respondents described diagnostic information on their family member with a disability. Several respondents listed multiple diagnoses; however, analysis only includes primary diagnosis. The highest diagnosis prevalence of those served was respondents was family members with Autism Spectrum Disorder (76% percent) and the remaining diagnoses divided between Intellectual Disabilities, physical disabilities, developmental delays, and others. The families represented life stages from early childhood to young adulthood, with 43% of respondents having School Aged (6-13 years) children followed by 30% with Transition aged (14-21 years) children. This information is representative of the overall demographics of those served in the program.

Finally, respondents (57) provided information about their highest level of education and annual income. Thirty-nine percent of families have a Bachelor's degree, 28% have some college without a degree, and 18% have a graduate degree. Annual household income ranged from less than \$20,000 a year to \$200,000 a year, with 25% of respondents indicating an annual income of \$50,000 to \$74,999 a year.

Survey Results

The survey focused on family outcomes and the impact of the Family Support Partner, in addition to demographic and satisfaction questions. Families were asked questions about their current beliefs about themselves and their family and then asked to indicate the impact that the Family Support Partner had on both. Respondents also provided open-ended feedback about the program.

Parent and Family Outcomes

Outcomes in the Parents Life. An area that is identified as major area of need when raising a child with a disability is the ability to advocate for their child, family or self, 95% families responding to the survey felt they had the ability to do this. They also felt that they able to problem solve day-to-day situations and they have access to someone they trust, who listens and talks when needed (93% respectively)¹. Eight-five percent of respondents indicated that they have a stable income or a job to meet their family's needs and 83% have the resources needed to support their child with a disability now and in the future

In comparison of families who are still being served to those who are closed or are no longer being served in the program, the highest level of agreement remained with the ability to advocate, problem solve, and access to someone respondents trust. For the closed group, stable income increased to 92% agreement, which could indicate that families had overcome whatever crisis was happening that required their need for the program. Access to needed resources decreased for the closed group (70%) and increased for the open group (87%), which indicates that those receiving the supports are continuing to have access to resources when needed.

Outcomes for the Family's Life. When asked about family life, families felt that they had a safe and stable home life (97%) with the ability to spend time together as a family (91%). Families generally felt that they met their physical and mental health needs (88%) as well as their basic needs (87%); however, this indicates the areas can improve. Three quarters of the families felt that they had people they could spend time with and that their family participated in community activities (religious, sporting, school, social, etc.) with others. Families ranked the lowest (65%) having someone on whom they can rely for help when needed which reflects the isolation and lack of relationship-based supports that often occur when raising a child with physical, cognitive and behavioral needs.

¹ Throughout this report, all items were voluntary; percentages may not total to 100% due to rounding.

In comparison of families actively served to those no longer receiving support, the strongest levels of agreement remained in the areas of having a safe and stable home life and spending time together as a family. Closed families experienced slightly higher agreement related to meeting their physical and mental health needs (92%) and when analyzed separately a higher percentage of families indicated an ability to meet their basic needs, 92% closed and 91% open respectively. Agreement around community participation and access to someone on whom to rely for help when needed remain lower for both groups.

Impact of Support Partner on Outcomes of Families.

Respondents shared how the Family Support Program affected their life in the same areas as above. Overall, the results found that respondents rated Parent Support Partners as helpful or very helpful in almost all areas assessed.

“They are able to relate to what you need and what you live because they are living it or have been through it themselves. My support partner is very knowledgeable about ways to help my children and myself to cope with day-to-day life, and planning for our future. She's there for me emotionally and that's a huge, huge help.”
~Mother

Impact of Family Support Partners on the Parent.

Respondents identified how the program made an impact on their own individual lives. Families highest ranking was the information the Family Support Partner helped them get to help their child or their family (86% agreed). Families equally (79% provided this response) found the Family Support Partner helpful in advocating for their child, family and self with helping family identify someone they could talk to that they trust, who listens when they needed. Only slightly less, 77% of the families felt that they were now able to problem solve and plan for day-to-day situations better because of being a part of the program. This is consistent with the national research, which indicates that parents that participate in family support programs evidenced greater increases in self-esteem, parenting self-efficacy, and increased knowledge and communication skills (Cavalaeri et al., 2011).

Impact of Family Support Partners on the Family. Families also shared how the program influenced their family overall. Families felt that by participating in the program that they could do more in the community (84%), they could spend time with friends and other community members (82%), their physical and mental health needs were being met (81%) and that they could do more things as a family (80%). The Family Support Partner assisted over 70% of the families in providing skills and knowledge for making the families' life safer and more stable, and connecting them to supports to meet basic needs, such as food, income, and housing.

In comparison of families still being served to those who are not, both groups indicated equally that their Family Support Partner was helpful in encouraging them to spend time with friends and other community members (82%). Both agreed that their Support Partner was helpful; however, statistically the mean for those currently receiving supports consistently ranked the level of helpfulness slightly higher (3.15) than those rating support received in the past (3.05).

During this initial survey, respondents identified their current employment status and any changes that may have occurred after Family Support Partner services started. More than half of respondents indicating being employed, 21% indicated they were homemakers and the remaining 10% were not employed (retirement, disability, or other reasons). Four respondents indicated that there was a change in employment for the better due to support received from F.A.C.T. with 2 increasing the hours they worked, 1 beginning to work, and 1 leaving employment to be able to provide supports for their child. For future data collection, it will become a mandatory question to identify employment status during intake, follow-up and post surveys.

Although employment services is not what Parent Support Partner provides directly, the increased resilience, decreased demands from school suspensions or issues that require a parent to leave work and the increased ability to coordinate supports can ultimately allow a parent to be successfully employed in the workforce. By collecting more rigorous data in the future, F.A.C.T. hopes to highlight the economic impact of its supports not only in regards to the financial impact on families through employment status but also the impact of child missing less school days, decrease in crisis situations involving police or emergency room, and the need for less out of home placements because families are able to balance the needs of the child's with their careers.

Respondents' Experience with F.A.C.T.

Satisfaction of supports received is often an indicator of the overall success of a program. Eighty-four percent of respondents are satisfied with the support provided by F.A.C.T. and 87% would recommend F.A.C.T. to others. All respondents indicated that staff treated them with respect and 96% indicate that staff responded to their needs in a reasonable amount of time, which indicates the strong commitment and dedication of the staff and organization. The following provides a summary of how

“F.A.C.T. means the world to me. Without this agency, I don't know where I would be. They have been very supportive to my family and needs. I have learned so much, and [am] thankful for everyone I worked with.” ~ Respondent

families described the impact of F.A.C.T. Family Support Partners in their own lives and their families. 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.

When asked if it was important that their Family Support Partner was a professional staff who was also a parent of a child with a disability, 95% indicated it was important. Respondents provided specific feedback to explain why this was important. The following summarizes some of the responses from families:

- This method of support is **unique** because Family Support Partners bring experience, understanding, and empathy to their interactions with families. This allows them to provide relatable, practical support to families in the program.
- This type of support is **valuable** because Family Support Partners understand the experience of families and help them *not to feel so different and alone*.
- They are also **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.

Conclusion

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.

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