

Family Voices Summary Report

Information about the Applicant

Family Voices of Wisconsin (FVW) is a community-based non-profit serving CYSHCN (Children and Youth with Special Health Care Needs), their families, and the professionals who support them. FVW is staffed by family members who have lived experience with CYSHCN and have helped other families for over 26 years. FVW has provided hundreds of learning sessions, regularly interacting with families from diverse communities and providing environments for mutual support, learning, and leadership. FVW believes families are often the best sources of information and support to each other in managing life with a child with special health care needs.

FVW has successfully demonstrated its ability to manage public and private grants and contracts. Since 2006, FVW has served as Wisconsin's Title V CYSHCN Family Engagement Hub of Expertise. FVW fulfills this role by developing and maintaining a family health policy and leadership network, implementing learning opportunities for families and professionals, and providing ongoing surveillance of families' needs in the state.

Additionally, for the past 18 years, FVW has served as the home of Wisconsin's Family to Family Health Information Center (F2F), first funded by the Centers for Medicare and Medicaid Services (CMS) and then through the Maternal and Child Health Bureau (MCHB) since the inception of that funding program. FVW was recently awarded a five-year grant to continue as the F2F for Wisconsin. FVW is the Family Voices Affiliate Organization (FVAO) for Wisconsin, designated by the national Family Voices organization to improve healthcare services and policies for CYSHCN. As the FVAO, FVW is part of a national learning community with other statewide Family Voices organizations around the nation.

The target audience of FVW is families of CYSHCN, including those with developmental disabilities and the professionals who support and serve them. The children, youth, and young adults with these conditions, and their families, are who Wispact also serves.

Statement of Need

FVW believes that a family voice at the table with health systems and state or local programs improves access and delivery of support and services. Focused on supporting families in their relationships with healthcare and community support providers who serve their children, FVW empowers families to have a voice in healthcare and long-term care systems. Families of CYSHCN have communicated to FVW a desire to bring their voices to the decision-making spaces in their communities.

FVW is committed to supporting the voices of families of CYSHCN at all levels of decision-making. Evidence indicates that family engagement, partnership, and improved care coordination with health professionals are essential for improving patient outcomes, including CYSHCN.¹

FVW believes families desire to engage with decision-makers, but many lack confidence in their advocacy skills which is an obstacle to these efforts. This is particularly true for members of culturally diverse communities.

FVW will work with community partners as cultural liaisons to promote opportunities and recruit families to participate in leadership training and ongoing development. These efforts will build not only the confidence of families but also their skills and knowledge.

Project Goals and Expected Benefits

FVW is committed to identifying and supporting increased numbers of family members, including those from diverse and underrepresented populations, to develop and utilize leadership skills to improve support and services at the local and state levels. FVW will work with family members to boost meaningful advocacy for all CYSHCN. FVW will provide skill-based training on shared decision-making and support family members to become leaders in their communities by becoming part of the Title V local, county, regional, and statewide committees, councils, and boards that serve CYSHCN. FVW will empower participants to tell their family stories and provide suggestions for improving systems or care. As a result, policymakers will understand better families' barriers and challenges in navigating public and private health care services and support systems.

To develop confidence in leadership engagement, FVW would like to offer two learning opportunities to address this need identified by a diverse group of CYSHCN families. These opportunities include the "Wisconsin Family Leadership Institute" (WiFLI), an evidence-based workshop series. As the next step from existing leadership training programs, this series focuses on the study and practice of service-based leadership models, development of public speaking skills, working with various ideas and inputs, practicing an action strategy, and culminates with individual community leadership projects. The other opportunity for which funding is sought includes "Advocacy for Change," an annual advocacy skill-building session for family members to learn about current policy issues addressing the systems and programs serving CYSHCN, develop the family stories of their experiences with these systems and programs, and meet with state legislators to discuss their concerns and suggestions.

The project goal is CYSHCN and their families, including those experiencing disparities or from underserved communities, and health professionals who support them will advance a well-functioning system of services in which families and health professionals partner in shared decision-making.

Associate objectives include:

- Identify community-based organizations to partner in engaging diverse families to participate in AFC and WiFLI
- Support 20 family members, including those from underrepresented populations, to participate in the March 2023 AFC
- Support 15 family members, including those from underrepresented populations, to participate in the 2023 WiFLI
- Provide ongoing support for leadership engagement to participating family members after AFC and WiFLI events are completed

Project Implementation Plan

FVW learning activities are coordinated and facilitated by FVW staff. FVW Co-Director Barbara Katz is the principal trainer, and Danielle Tolzmann, the Policy and Family Network Coordinator, will also facilitate WiFLI and AFC. These staff members are experienced in public speaking, teaching, and facilitation. Lynn Renner, FVW Information and Outreach Manager, organizes and promotes these events and is instrumental in coordinating all the details. Brigit Frank, Media, and Education Manager, designs accessible visuals and supports the technology needs of these events.

FVW will identify community-based organizations representing diverse populations to recommend and support individuals for leadership training. This may include personal encouragement to participate, transportation and childcare stipends, matching with other families to attend, and regular contact

during training. FVW recognizes community organizations know their families best and works to build on this philosophy to create effective leadership opportunities.

This work is planned to occur in 2023. FVW is tentatively holding a date in March for Advocacy for Change and is preparing for WiFLI to occur during October and early November.

The supporting written and video materials developed for AFC and WiFLI will be housed on the FVW website and will be freely available to families and professionals throughout Wisconsin, in addition to participants. The materials will be distributed widely to FVW membership of 5,000 through our newsletter, blog, and social media platforms. FVW will also encourage its network partners, including the CYSHCN Regional Centers, to inform families of these events and supporting materials.

Evaluation Plan

FVW seeks feedback from family participants in all activities. Each participant in an FVW educational event is asked to complete a paper or electronic evaluation to provide insights to inform improvements in programs and activities. These evaluations use a Likert scale, multiple-choice, and open-ended questions to get the best picture of the participants' feedback. The data gleaned from these evaluations and the input from community-based co-sponsors are compiled and reviewed with trainers. Feedback from evaluation and quality improvement activities enriches the depth of data used to analyze project activity, successes, barriers, and quality improvement.

FVW values input from participants, presenters, and volunteers in learning events and uses a variety of strategies to receive feedback on its work. Based on this feedback, revisions are made to curricula, materials, and outreach strategies. Recently, FVW used the Title V Community Engagement Assessment Tool to gain insight and recommendations from families and community partners. When asked how well FVW cared "about participant engagement," which means "feeling connected to and involved with the program," 83% of respondents said FVW was doing extremely well or very well.

Budget

Advocacy for Change (AFC): Meeting space, supplies, and materials, 20 people @\$100/each, family participant stipends for mileage/childcare, 20 people@\$100/each, 10@\$100/each lodging	5,000
Wisconsin Family Leadership Institute (WiFLI): Meeting space, supplies, and materials, 15 people@\$100 each; family participant stipends for mileage/childcare, 15 people@\$200 each	4,500

Staff Recommendation

The grant can be recommended for approval. The grant will directly benefit the disabled individuals through the programming provided by Family Voices. The grant will provide a scholarship making participation possible.