

Family Voices of Wisconsin (FVofWI)

The Family Voices of Wisconsin (FVofWI) is the national Family Voices state affiliate organization in Wisconsin. It is a statewide network of families and children and youth with special health care needs (CYSHCN) and the providers who serve them. It is supported in part by the Health Resources and Services Administration (HRSA) of the United States (US) Department of Health and Human Services. The FVofWI work is directed through the following three areas:

- Education and information through training, newsletters and fact sheets
- Family leadership activities
- Public policy initiatives

To meet their objectives of providing education, training and advocacy for families, FVofWI developed an online training entitled “Coordinating Your Child’s Health Care.” This 40-minute online tutorial serves as an introduction to care coordination through real life examples from families, resources and how to use them, and much more. It is intended for families and available in English and Spanish. The online tutorial can be accessed [here](#).

As a starting point for developing their content, FVofWI used the [Pediatric Care Coordination Curriculum](#) (PCCC)—a 4-module curriculum available through the National Center for Care Coordination Technical Assistance (NCCCTA) at Boston Children’s Hospital. Funded by the US Maternal and Child Health Bureau, the PCCC aims to teach core competencies and key activities of care coordination. The NCCCTA team spoke with Brigit Frank, Education and Training Coordinator, FVofWI, about the development and implementation of their training to learn more about the process, lessons learned and future goals/continuation of the program.

What was the objective of this work?

To build and implement a training course that focused on care coordination for families. We found a lot of the available information was targeted toward professionals and providers, while we wanted our target audience to be families.

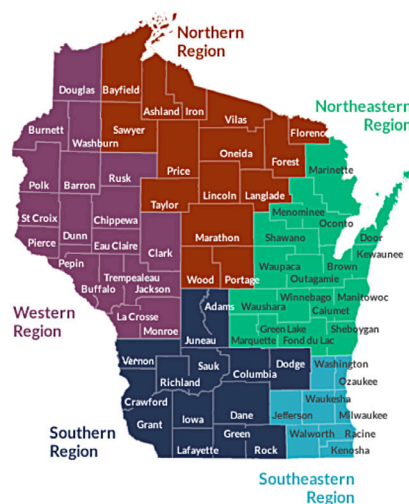
What was the catalyst for this work?

Response: At the time, Wisconsin did not have a statewide care coordination model as a developed program, so we were able to partner with the state’s Department of Health Services (DHS), Wisconsin’s Medical Home Initiative (WiSMHI), and the Waisman Center at the University of Wisconsin-Madison which serves as the southern regional center for the Wisconsin CYSHCN program, and work on this as a group. We took a step back to see what others were doing in their programs, because we needed advocacy to make this program happen. We had to develop it from

the ground up, incorporating basic education for families and use the tools we created—to encourage them to advocate for this type of health care program.

To share this content, we worked with our five Regional Centers for CYSHCN for the pilot pro-

gram, where I led training for each center. Additionally, the original training was posted on the FVofWI website, and invitations for feedback, using the online evaluation, were sent to partners for dissemination.



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Is FVofWI involved with any other local or state organizations, and in particular in any ongoing conversations regarding Medicaid and CYSHCN?

Yes, FVofWI is involved with the Survival Coalition, the Department of Health Services Long-Term Advocates Advisory Committee, and the Children's Long-Term Support Council. Personally, I am a member of the Wisconsin Birth Defects Prevention and Surveillance Council as well as the Family Voices, National Center for Birth Defects and Developmental Disabilities Family Liaisons (Cohort 2017).

The FVofWI has frequent conversations with Medicaid through the Children's Long-Term Support Council regarding Early and Periodic Screening, Diagnosis and Treatment (EPSDT) to create understanding and a path for families to access services and children's waivers. Also, fact sheets created by Family Voices are reviewed by Medicaid, when necessary.

What was your process for using PCCC as a starting point? What was useful and what would have been more useful in helping you build your own training content?

We found the first edition of the PCCC to be very helpful. We pulled information from the curriculum we thought would be important from the family perspective and created a basic outline of what we were trying to accomplish. We included family stories to encourage training participants to reflect on different scenarios and basic vocabulary for families to learn so that they felt more equipped to advocate for their children. It was really helpful to get input from the NCCCTA and other agencies to avoid reinventing the wheel.

The first version of the training was reviewed by the other agencies we worked with and once we received initial feedback, we incorporated it and set out to pilot it with families. Families reviewed it and did not find it approachable enough, so we changed it and incorporated their feedback into a revised version.

What were the goals for this training and how did you evaluate if they were being met?

The goal was to provide families with basic information about care coordination and helpful resources so that they would know what they should expect regarding services and be a part of the decision-making process. Feedback from families was given using a standard evaluation that we developed with DHS and the Waisman Center on the training materials from the pilot, which let us know what we needed to change for the second version.

Since launching, after receiving initial feedback, have you been able to collect any quantitative data on the use of the training?

For the online training, we were able to gather that there were 633 unique visitors in 2017.

What were some lessons learned from this process?

The biggest lesson learned from this process was to not be afraid to get feedback and seek it out from anybody—from families as well as professionals. The team process at the beginning—working with state agencies helped the initial shaping of the training. Finding partner agencies willing to give you a little time to sit down with you and say “well this doesn't work, or this is more important than that” was very helpful.

What are the next steps?

We are working on several different tracks at the moment.

We are trying to push online training to reach remote and rural areas of the state—where it can be difficult at times to even make it out there for face to face trainings—and building family groups using Facebook. We would also like to work with other agencies; for example, the Cooperative Educational Service Agency—to get this information into schools so school nurses can also provide guidance to families. Another next step is to get this training into all of the pediatric primary care clinics in Wisconsin.

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What other resources/materials were useful to your team that could be applicable to other groups?

- [Boston Children's Hospital Pediatric Care Coordination Curriculum](#)
- [Lucile Packard Foundation for Children's Health Care Planning Resources](#) development led by Jeannie McAlister
- Connecting with other [Family Voices](#) chapters

Works Cited:

1. Antonelli RC, Browning DM, Hackett-Hunter P, McAllister J, Risko W. [Pediatric Care Coordination Curriculum](#) 2014.

The Family Voices of Wisconsin Team



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