

Spotlight on Success

Serving Families through Missouri EHDI

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My daughter was identified with a hearing difference at 2 ½ years old. She also has a rare syndrome that had been diagnosed a year prior. We had so much support for the rare syndrome, but felt completely alone and lost with the hearing diagnosis. We struggled to find help for her, because with all of her other needs, the hearing seemed to be the smallest challenge. I became a Deaf/Hard of Hearing (D/HH) Family Partner to assist other families because I never wanted another family to feel the way we did on our journey.



In 2017, the State of Missouri Early Hearing Detection and Intervention (EHDI) program joined with the Bureau of Special Health Care Needs (SHCN) to add a Family Partner that had a child that was D/HH. In 2019, SHCN added another Family Partner for D/HH. In Missouri, the D/HH Family Based Organization (FBO) is a part of the FBO that works with families who have children with special health care needs, not specific to D/HH. That program is called the Family Partnership Initiative. The Family Partnership has six Family Partners, with two of the six serving specifically families who have children that are D/HH. Both of the Family Partners for D/HH have children who are D/HH, one of which has other disabilities (D/HH Plus).

Within this program, the D/HH Family Partners contact families that have children who have been identified with permanent hearing differences. Our program and the state EHDI program are housed under the umbrella of the Missouri Department of Health and Senior Services. We receive referrals from the state's EHDI program and are usually able to connect with families within a month of the referral to assist them with resources and information. In 2018, we added D/HH families to the annual Parent/Caregiver retreat hosted by the FBO for families that have children with special health care needs. In 2023, the D/HH Family Partners also began hosting monthly Parent Chat video calls. Some of the ways that we have achieved goals for the joint collaboration between EHDI and the FBO is that we are available to fully and attentively listen, answer questions and provide information or resources to our families. Families are able to connect with other families throughout the state by attending the annual retreat or through the monthly Parent Chat video calls that we host. It has been rewarding to build relationships with families and caregivers.

We know our program has been impactful due to the increase in our retreat registration for D/HH families. In 2018 – 20 registrants identified as D/HH compared to 44 registrants in 2023. We also hear from families that they appreciated being called early in the diagnosis. They like having another parent to talk to that understands what they are going through. No one should ever feel alone. Often, families just want to feel like their stories are being heard and that they matter. Our families benefit by being able to connect to other families, but also by having stress levels lowered by knowing our program is here to assist them. We like to tell families that we are here to do the research for them, so they can enjoy their children.

We have implemented a few Plan-Do-Study-Act (PDSAs) strategies through the years. In order to increase our general Family Partnership enrollment numbers (not specifically for the retreat), we have attempted to contact families at different times of the day and even on the weekends. Although this PDSA was unsuccessful, we are continuing to search for more ways to increase enrollment, such as adding texting as an option for contact. Our current PDSA is adding a personalized letter that will be

mailed to the family after a failed attempt to contact via telephone. We are hoping to have success with this PDSA to ensure all Missouri families have the resources and information needed.

Our best advice to other Family Based Organizations is to meet families where they are. Often, they are not ready for resources, but they are ready to be heard and encouraged. Building relationships is the start.