

Partnering with families on

QUALITY IMPROVEMENT

From 2017 until 2022, Family Voices of Alabama participated as a member of the Alabama team working on the Children with Medical Complexity Collaborative Innovation and Improvement Network (CoIIN) project .

Below are some "take-aways" from our experience as a part of the project. We hope these positive outcomes will encourage more families and consumers to join Quality Improvement (QI) projects and will lead our professional partners to see the value of QI efforts and make those opportunities available to families.



Family partners with lived experience (parents, family members, or self-advocates) bring a commitment to the work. They were consistently engaged and at the table because they knew the importance of the initiatives

 The family partners were able to share actual experiences that helped our Quality Improvement Team to develop, implement, and evaluate small tests of change using the Plan, Do, Study, Act (PDSA) model.



- The family partners were able to connect one-on-one with families with children with complex conditions, to share resources and identify unmet needs.
- Family leaders who had a deep understanding and commitment to the project could provide a safe space during the Family Focus Groups so that participants felt comfortable sharing their personal experiences.
- Many families who received care at the clinic were often surprised at the focus
 on Quality of Life and the Well Being of the Family, and when these were
 explained during the focus groups, it often caused them to reflect on these
 topics for the first time with their family, and then share their needs with the
 care team.
- Partnering with a family-led organization gave the project an increased capacity for providing training and resources to the families in the clinic.





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