

# The Importance of the Family Voice in Quality Measure Development for Children's Health Care



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IN 1985, WHEN our youngest son was born with complex medical needs, my husband and I found ourselves learning how to advocate for our son and our family in the health care system. We soon recognized that we could use our experiences to improve how care was provided for others. In the 1980s, families were not routinely allowed to be involved in their child's care in the hospital, or even allowed to stay with their child during hospital physician rounds and many clinical procedures. Families were usually excluded from participation in the development of the care plan for their child. We were one of several families invited to form the first hospital family advisory committee (FAC) in our state—one of only a few of such committees in the country at that time. We saw the power of families sharing their experiences, expertise, and creative ideas, leading to many improvements in the physical environment for children and families, as well as improvements in the philosophy of how care was delivered and the role of families on the health care team.

In the 1980s, then–Surgeon General C. Everett Koop inspired and supported a movement among families and health care providers to collaborate in defining and implementing the concept of family-centered care for children with special health care needs and disabilities. Over the past 40 years, many families have worked to improve our nation's health care system. Families now routinely provide significant medical care in their homes and lead the team of professionals caring for their children. Beyond individual patient care, families play an important role in the development, implementation, and evaluation of health care programs and policies. In addition to the long-standing hospital- and public school-based FACs, families serve on clinic quality improvement teams, sit on hospital ethics committees, and partner with state and federal policy makers. In some cases, parents have become the leaders and drivers in these efforts. Although progress has been made, there are still many gaps in fully embracing

the unique experience and expertise families bring to improving the health care system, especially in research.<sup>1</sup> Too often, families sit far removed from the research and activities undertaken for the family's benefit.

The Center of Excellence on Quality of Care Measures for Children With Complex Needs (COE4CCN) provides a unique example of breaking this traditional barrier. Family Voices of Minnesota is one of many partners in this research project expanding the CHIPRA-related quality measures.

The COE4CCN includes work groups focused on developing quality measures on care coordination and mental health; transitioning between sites of care; and identifying children with social complexity. The role of Family Voices of Minnesota in the COE4CCN is multifaceted and dynamic. Families participate in the work groups and in a FAC that includes geographically and ethnically diverse families with children of different ages and diagnoses, well as, for this project, their use of the Medicaid system. When looking for families to participate in the FAC, we considered the evolution that often occurs over time: families move from a focus on the needs of their own children to looking at the needs of others, often wanting to improve the system of care for all children. For the FAC, we sought out parents whom we knew had been involved in other health care quality initiatives or committees. We also interviewed parents in advance to ascertain their level of advocacy in the community and their interest in research and health care quality.

As families joined the FAC, we oriented them to the goals of the center and provided an overview of the concepts of quality measurement so that they could optimally provide input into the measure development process. The FAC meets monthly, and parents receive a stipend for participation. In the early stage of each measure-development sequence, FAC members read and rated literature review summaries developed by the center work groups. Later, the group reviewed and commented on draft indicators and survey items, often leading to substantial changes. Family members participated in all the Delphi panels that reviewed and endorsed proposed quality indicators. In addition, Family

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Voices of Minnesota helped convene diverse family focus groups and cognitive interviews to help develop and validate survey items intended for families. These steps helped assure that draft items were meaningful, understandable, and acceptable to families.

Our success is partly the result of our including families from the very beginning in developing the research agenda and writing proposals. Other steps critical to success include having a defined but flexible role for family partners; preparing other members of the research team to engage with families; and building the project work processes and timelines to include family participation.<sup>2</sup> Ultimately through the COE4CCN project, if the proposed indicators are adopted, families may have meaningful report-card data to help them make decisions about where to obtain care.

The benefits and rewards of meaningful involvement of families of children and youth with special health care needs in improvement and measurement are limitless. Professionals often report that family engagement fuels, energizes, and reignites a passion for their work. Having families present during the work positively changed the tone of discussions: families were able to wonder out loud about why things were going in one direction or another. Researchers often have their usual modes of thinking, and by listening to families, they were able to see that something unimportant to the researcher may be critical to a family or patient. Researchers may sometimes want to get the family's perspective, but without a designated group of families to turn to, they would not have the contacts or resources to connect with the necessary speed. Several times the Family Voices advisory committee was able to bridge an essential gap between formal focus groups and researchers. One researcher involved in

the center said, "I can't count the number of times I (or others) have wished we could just bounce some ideas off a 'real' parent. This is the only project I've ever participated in where we could actually do that." Families were able to explain how services could be implemented differently from clinic to clinic and how important measuring the quality of services from the families' perspective is in knowing whether that service is helpful. Having families involved in various center work groups ensured a family-centered focus in all aspects of the work group's activities, including the conceptual model, literature review, survey development, and development of proposed quality measures. Families offer their perspective and expertise because they know how systems really work, not how they were designed to work. Families offer creative ideas for improvement because they are not constrained by the culture, history, or structural reporting relationships of systems.

Utilizing and valuing the unique expertise and experience families bring to this work implements the long-evolving concept of family-centered care. Including family expertise from the beginning—before programs, policies, and measures are implemented—assures that policies, programs, and quality measurement reflect the important values of families and what they, along with their provider colleagues, view as true quality in health care.

## REFERENCES

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