

Insights

Family Partners Help Create Sustainable Change



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Parents of children with special health needs become experts on their children's condition in a way that doctors and administrators cannot. Their countless hours on the front line, navigating the healthcare system and other community resources, gives them invaluable insight into how these systems work (and do not work) for them. That is why NICHQ emphasizes the value of utilizing the parent/family perspectives in change efforts.

“We make it a point to have at least one family representative, usually a parent, on each of our project teams,” says NICHQ Director of Programs Meghan Johnson, MSc. “Their perspectives, opinions and ideas help ensure that the team creates improvements that will work ‘in the real world’. Too often patients and families have ideas on how to improve the health system, but there is nowhere to share or implement them.”

Heather Joy Magdelano is a parent partner on NICHQ's [Improving Children's Vision](#) project. She has two deaf and blind children and is a leader in advocating for families with deaf and/or blind children. Both of Magdelano's children have a rare genetic syndrome diagnosed at birth, yet the oldest was not diagnosed with a vision problem until he was five months old.

"Most pediatricians do not check for vision problems at such a young age," says Magdelano. "If you are concerned, you may have to push to get vision checked, but you should because early intervention is critical."

Magdelano received news of her son's vision problem by a call from the Foundation for Blind Children.

"I was more than surprised to receive this call out of the blue. No one from my pediatrician's office had talked to me about vision problems," she recalls, as well as feeling validated, as she knew something was not quite right but did not know what it was.

Magdelano's son has cortical vision impairment where the brain does not process what the eyes see. It often goes undiagnosed. After needing to advocate for her own children, Magdelano says she did not want others to go through what she had experienced.

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Magdelano is a perfect example of what NICHQ looks for when recruiting parent partners. According to Johnson, it's best to look for family members who are passionate about the subject matter and ready to share their experience and advocate for others.

"A family partner is not just a token or a nice to have," says Johnson. "They are equal members of the team. Their lived experience is just as important as that of the medical, quality and administrative experts."

Family partners often change the trajectory of a proposed improvement idea, making it more successful. For example, Johnson recounted an instance when a NICHQ team was working on a tool for families to communicate outcomes on a daily basis. An online daily survey was proposed. However, the two family partners pointed out that it was difficult or impossible to get online daily to do this. Some didn't have a smart phone or a computer, others didn't have the time to log on and fill out the survey. One family partner suggested that families text their answers to the team. To try out the idea, the improvement team bought inexpensive phones for those who needed texting capability. It worked! More people communicated outcomes, which of course informed the project and made it more successful.

In another example, Magdelano's team was attempting to create a letter that pediatricians could give to families, recommending that they see an optometrist. The two parent partners had very different views on the letter's language. This reinforces the importance of remembering that one or two parent partners do not necessarily represent the views of all parents. These parent partners decided to run the language by their friends who had children with the same condition, but were not part of the team. In the end, family members on and off the team were instrumental

in designing the letter. In turn, the letter will help more families obtain vision testing which is often overlooked.

There are some barriers to engaging family partners on quality improvement teams. Attendance is at the top of the list and is influenced by lack of time, funds, transportation, childcare and scheduling.

“We need to do everything we can to avail ourselves of family members’ perspectives so that we can make real, sustainable change,” says Johnson. “This means scheduling meetings around family partners’ schedules, providing childcare, using technology to hold virtual meetings when necessary, and even paying family partners.”

Magdelano suggests that teams help keep family partners engaged by sending them notes from the meeting and having the team leader call to catch up. “Calls are important,” says Magdelano. “There is so much more communicated through talking to someone versus reading notes.”

Magdelano reports myriad benefits for her and the community just by being a part of the NICHQ team.

“I have never been in a quality improvement process and it is interesting to see the issues from this perspective,” she says. “It got me to step out of my box and think in a different way. It also helped me see where a quality perspective could be beneficial in other community organizations.”