

Insights

QI Skills Help Families Find Their Voice

For families with children who have special healthcare needs (CYSHCN), finding an optimal care system can sometimes be a challenge. While quality improvement (QI) is used a great deal in healthcare, a handful of parents participating in a NICHQ-led QI training are finding it can also help parents achieve their individual goals for improving as caregivers and their children's quality of life.

Shu-Chiung Chou recently participated in our ABC's of QI course, offered to members of Family Voices, a national nonprofit organization working to achieve family-centered care for CYSHCN. Chou was eager to join to learn how to better manage her daughter's care. Chou's daughter has continuous complex care needs and autism spectrum disorder (ASD), requiring highly specialized treatments and extensive care coordination. While Chou was formerly a nurse with a social worker degree, and has a master's degree in nursing and a doctorate in public health focused on quality of care, she wanted to improve as a caregiver and coordinator for her daughter's healthcare needs.

Chou recently spoke with us about why she participated in the course, what she learned from it and why she thinks families should embrace QI.

Why did you join this course?

After my daughter was born, I became her full-time caregiver. The complexity of her healthcare needs requires my full attention and care. It has been extremely challenging to find appropriate support for her and coordinate her care between multiple service providers. She is a typical 'falling through the cracks' complex care child, and I am constantly dealing with care fragmentation and service disconnection. It seems nothing works for her. I feel that we are sinking and suffocating in the system. I began to lose my confidence, feel helpless and sometime hopeless, as a frustrated and an isolated long-term caregiver. So, I wanted to improve my situation and learn how to help other parents whose children have similar complex medical needs. And because my career was so focused on quality of care, I thought this course would be a good opportunity to hone some skills for both of those goals.

Through the course, I focused on improving my quality of life through enhancing care coordination for my daughter by creating a care map for her. Over time I was able to visualize her care to see how complex it is and learn what was working and where the inefficiencies were.

What are some of the key lessons you learned?

Sometimes I would have an idea, and I would get stuck there. This course and QI helped me turn my ideas into action. I needed to see my challenges clearly, so I could go deal with them and develop ways to resolve them.

Developing a care map and driver diagram were extremely beneficial. [*Editor's note: Driver diagrams are diagrams that show the intended outcome, primary drivers that contribute to achieving that outcome and smaller, secondary drivers that feed into larger elements.*] Due to the complexity and severity of my daughter's care needs, I was overwhelmed all the time.

Being able to visualize my problems and challenges was always difficult for me. With the diagram, I can break things down into smaller components that I can focus on individually, like exercising to improve my resiliency as a caregiver and networking to find professional opportunities. This started to make my problems more manageable. Even though I would really only focus on one component at a time, I could still see how they were related. So while becoming a more resilient caregiver for my daughter became my main driver, it was still clear how that tied into my ultimate goal of improving my quality of life.

Why do you think the driver diagrams are beneficial?

The diagram gives a clear direction towards achieving a goal. Otherwise, a lot of ideas can get lost because it isn't obvious how you should go about putting into action. But with the driver diagram you have a direction to go in and can focus on certain components. Plan-Do-Act-Study (PDSA) cycles [*Editor's note: PDSA cycles are rapid cycles to test QI ideas and refine them.*] can be used to test ideas for improvements related to each driver. In my case, I started out focusing on finding additional support by creating ads for a personal care assistant and then refining it to improving care coordination by creating a care map.

How did the care map help you?

The care map is a great tool that allow me to visualize my daughter's care components in home, health care, school and community settings. It is beneficial for improving care integration. In some cases, specialists deal with one problem and don't communicate with each other. For instance, some providers don't see my daughter as a whole; they just address one specific problem. Very often, they fixed one problem but created disturbance in other components.

When we don't get the outcome we need, we search for other providers for second opinions and better outcomes. We need better coordinated and integrated care. Hospitals should start to think about helping families create their own care maps to get a better idea of all the resources needed to support a child with complex medical, communication and behavioral issues and their family. It also allows the care team to appreciate how each of these care components relates to each other's.

What advice would you give to other families navigating the healthcare system with a CYSHCN?

Set a goal, create a drive diagram and focus on one small component at a time. For example, creating a care map is the best thing to come out of this course for me; it's such a wonderful tool because it shows redundancies and inefficiencies between care components. Before I created my daughter's care map, I just feel overwhelmed and exhausted all the time and didn't know how

to improve my situation. Now I know what is missing and what services to focus on. After evaluating her care map, it becomes clear that she does not have any community-based program or activity. I need to work on community inclusion for her and building up her social capital.

This course and QI could be used by many families. Parents with children who have complex medical needs and behavioral issues imperatively need help improving care coordination and achieving better care integration. Such training program would be beneficial for those families and help them by identifying desired outcome, creating driver diagrams and improving their caregiving process through PDSA cycles. With better coordinated and integrated care, both children and their families could simplify how they manage their lives and experience better quality of life.