

Member Spotlight

Q & A with Meg Comeau

Meg Comeau, MHA, has a deep and abiding commitment to improving the system of care for children and youth with special health care needs (CYSHCN). She's worked in the field for 17 years. Recently she shared her experiences working in child health policy and raising a medically complex child to adulthood.

Why are you involved in CYSHCNet?

I've seen so many opportunities for change and progress that have resulted from the nexus of research, quality improvement, technical assistance, training, and policy all coming together. And I've had some experience in each of those areas, so being part of the network means that I can bring that perspective to the work of folks who are dedicated in their individual areas.

For example, to make better policy, you have to have better data to inform the policy. This comes from the research world. To assess how the policy is working and make improvements to the policy, you have to do quality improvement work, which involves assessing and measuring change over time and outcomes for individual populations. And then to make all of that work, you have to do technical assistance and training that supports the workforce. The network understands how these areas are interconnected, and I just find it fascinating when I can make a contribution by helping to connect these various things.



What are the challenges of bringing all of those spaces together?

There's a song I love where the singer says she wants "pens that don't run out of ink, and cool quiet and time to think." These are the resources we have the least of in the work we do. The work can be up close and personal and intense. In the moment, it's hard to take a step back and think about the system from a broader, more universal perspective. So when we have the space to make those connections and get a chance to articulate them, a little light bulb goes off. And you think, yes, of course. But it's not easy to do, unless you have the opportunity. The network offers an opportunity to take that step back, and think with other passionate, interdisciplinary content experts about the issues and challenges facing kids, families and providers.

What have you learned about creating meaningful change on behalf of CYSHCN?

One of the things families have told us—in the literature, among my friends, and from my own experience as having a kid with complex conditions and special health care needs—is it goes beyond “better” health. It in and of itself is not the ultimate goal. Because in the context of having a disability, it's an ableist construct that only health is important.

Of course people want to maximize their kids' health to the fullest extent possible. But it's also about being able to have a quality of life that's meaningful. That means if your kiddo is school-aged, they get to be in school with their friends learning ... that they can stay out of the hospital as much as possible ... that families have an opportunity to be together and to live at home. It also can mean having strong interpersonal relationships with one another, as well as the support of their communities.

Another meaningful thing is being able to spend your time and your energy and your effort and your money on things that are important to you and your family rather than on things that are important to the healthcare system. A lot of families would rather spend their money on their kid's soccer league fees, as opposed to co-pays and deductibles. They'd rather spend their time in the backyard playing than sitting on the telephone arguing with the insurance company. Many families raising CYSHCN don't have a choice currently.

It's those kinds of resource allocation questions that families articulate to us that have been really meaningful to me to hear. It's validating from a personal perspective. But it also means that there are all kinds of opportunities in the area of research where we could better understand the experience of families so that we can then better understand what the actual real-world research questions are, and the need for data around them. So that we can then inform quality improvement and training and technical assistance and policy to make life better for kids and families in direct relationship to what they've identified as the challenges and issues in their lives.

What have you learned from being part of CYSHCNet?

It has been an incredible honor to be part of this group, to have the opportunity to learn from and with such incredibly distinguished professionals. It's been an enormously rewarding experience for me to be part of that group and to be able to learn from everyone. To feel like I've been even a small part of the work that they're all doing is great, because we all share a very strong commitment and passion around improving the system of care for kids with special healthcare needs and their families. It has meant a lot to me to be part of the work.

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