

Consumer Representative Recommendations 4-12-18

Application Excerpts

Quality Council Recommendation:

Susan Kelley

4. What would you bring to healthcare reform discussions and how would your participation contribute to the overall process of improving healthcare?

My biggest contribution is bringing expertise both at the policy level (with special focus on behavioral health policy and issues concerning children and families), as well as the consumer perspective on healthcare. Focus on behavioral health is critical to ensure that reforms work across the full spectrum of healthcare and that behavioral health, with its emphasis on person centered and social determinates of care, is not dominated by the medical model as the two systems are integrated. The consumer voice is essential to the healthcare process. Consumers are often the most knowledgeable about healthcare because they've "lived" through what works and doesn't work about their healthcare, and consumers/families need to be a part of every step of healthcare reform design and development. Having both perspectives allows me to understand the why's and underlying principles of proposed reforms while also being able to step back, and say, wait-a-second---how will this potentially impact those people with boots on the ground who are the ultimate stakeholders in their care, and how might these concerns be addressed?

6. Who do you work for and in what capacity? (if applicable)

I am director of children's policy for NAMI Connecticut, and am the director of the Alliance for Children's Mental Health (ACMH). ACMH is a collective statewide advocacy group comprised of a wide spectrum of stakeholders in children's mental health. ACMH's goal is to develop smart policies to help improve outcomes for all children in the state. NAMI CT is a member participant of ACMH and currently acts as its fiduciary.

Consumer Advisory Board Young Adult Recommendations:

Kelly Ray

Q4 Why are you interested in healthcare?

I was treated at CCMC from 2012-2013 for bone cancer. Since then, I have spent time trying to give back to the hospital. I founded and manage a charity to supply and maintain slushy machines in the hospital to help put smiles on the faces of the patients. I also have helped Administration at the hospital by lobbying for the ACE Kids Act in Washington, DC in 2016 and testifying on behalf of the hospital on February 16, 2017 at the Connecticut State Appropriations Committee Meeting.

Q5 Describe an experience in which you advocated for yourself, a family member, or a community member to help them.

Part of my cancer treatment included the amputation of my left leg. I sat in on an Insurance and Real Estate Committee meeting on March 20, 2018 regarding the passage of SB376 JF to the floor for a vote. Our goal with SB 376 is to ensure coverage parity between private insurers and Medicare when it comes to prosthetic devices. Such parity would help the other 20,000 amputees across the state of Connecticut get more affordable access to these incredibly life-improving necessities.

Q6 Is healthcare accessible to young people? Why or why not?

Accessibility to health care is a very complicated issue. Of course there is the question of financial accessibility, but there is also a range of barriers to proper treatment that may include level education (and the ability to recognize a medical condition that requires attention) to access to transportation to and from medical appointments. In my case, healthcare was extremely accessible, but, during my cancer treatment, I learned that this was not the case for everyone in our state.

Q7 How would your participation in SIM CAB contribute to the overall process of improving healthcare?

I believe my participation in SIM CAB would contribute a unique perspective to the overall process. I have been a patient and "consumer" of healthcare in Connecticut who has had the opportunity to work collaboratively with administrators at Connecticut Children's Medical Center both in our home state and in Washington, DC. I am not afraid to express my thoughts and/or opinions and I can relate to other patients and provide insight into the patient/consumer experience.

Jason Prignoli

1. Why are you interested in healthcare? (50-150 words)

What inspires me about healthcare is that driving change in policy can save lives. From college to my short professional career, I have participated in biomedical design competitions where I have made theoretical healthcare solutions for early detection of foot ulcers to prevent leg amputations in type 2 diabetics. As an engineer, I marveled at the possibility of designing not only devices but also policies that enhance the quality of life. I have attended multiple digital healthcare events in Hartford in order to learn more about how technology can significantly benefit consumer healthcare and also be leveraged for healthcare providers. In addition, I attended the February SIM Quality Council meeting where I had the opportunity to meet Dr. Mark Schaefer, the SIM director, and discuss healthcare challenges and opportunities within the City of Milford, where I live. I am extremely passionate about healthcare and the policy that drives it, especially giving fair and equal healthcare to all.

2. Describe an experience in which you advocated for yourself, a family member, or a community member to help them. (50-150 words)

I am a literacy tutor for the Literacy Volunteers of Southern Connecticut and my student was unemployed and wanted to learn conversational skills in order to become more employable and find a job. In the beginning, my student lacked the confidence in him to reach his goal. With significant efforts, he was able to drastically improve his public speaking and softened his accent in order to speak clearly and effectively. After many months of hard work, my student obtained a job he enjoys and thanks me frequently for being the only one to not give up on him.

3. Is healthcare accessible to young people? Why or why not? (50-150 words)

Not all and not equal; that previous line is how I would classify the state of healthcare for the youth. Healthcare disparity has significant negative impacts not only on the patients but the state as well. The younger generation, for the most part, is uninformed about healthcare and health insurance as it is not as simple as knocking on the doctor's front door. Also, the providers are sometimes reluctant to accept healthcare coverages across the spectrum. Quality and accessibility are two extremely important aspects of health care for all ages and ethnicities. There are significant repercussions for the youth if care is not fair and accessible. For ailments both mental and physical, if not properly treated, can not only lead to eventual chronic conditions but a life not lived to its fullest potential.

4. How would your participation in SIM CAB contribute to the overall process of improving healthcare? (50-150 words)

If given the opportunity to serve on the SIM CAB I plan to bring a fresh and unique perspective to help drive innovation in policy that can lead to both health equity and lifestyle changes. Empowering healthy lifestyle changes will enable a prevention approach to healthcare as opposed to the traditional reactive healthcare system. I plan to bring a significant level of passion and energy to the board to advocate for much needed change to the current healthcare system. I serve on the Energy Advisory Board for the City of Milford and through this experience I have had to be creative in both outreach and education to drive change in the community. I plan to utilize a similar approach to empower the youth of the many Connecticut communities and provide a voice to those typically seen not heard.