

Family Medicine's Role in Policy and Advocacy: Reflections From a Team's Advocacy for People With Disabilities

Kaitlyn Davis, MS, MPH; Allison Casola, PhD, MPH, MCHES; Mary M. Stephens, MD, MPH

AUTHOR AFFILIATION:

Department of Family and Community Medicine, Thomas Jefferson University, Philadelphia, PA

CORRESPONDING AUTHOR:

Kaitlyn Davis, Department of Family and Community Medicine, Thomas Jefferson University, Philadelphia, PA, kaitlyn.davis@jefferson.edu

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Medicine is a social science, and politics is nothing else but medicine on a large scale. . . . If medicine is to fulfill her great task, then she must enter the political and social life. . . . The physicians are the natural attorneys of the poor, and the social problems should largely be solved by them.

—Rudolf Virchow¹

According to the American Academy of Family Physicians, family medicine providers are “the only specialists qualified to treat most ailments and provide comprehensive health care for people of all ages.”² Research in the area of family medicine improves clinicians' ability to deliver this comprehensive care by advancing the knowledge base they rely on. Legislation, particularly at the state and federal levels, affects the work of clinicians and researchers, and the lives of their patients and participants, every day. Being aware of policies and how they will affect their day-to-day work is in their best interest.

With their clinical experience and study data, family medicine clinicians and researchers are in a prime position to get involved with advocacy efforts. Aristotle asserted the existence of three “means of persuasion”: ethos (credibility), logos (reason), and pathos (emotion).³ Clinicians and researchers have the ability to naturally meet all of these means. These providers are very often seen as trustworthy and respected by people in the community and in power. They bring with them the facts and knowledge of their training, experience, and data. They can give voice to their patients and participants in a way that makes the issue at hand personal.

This past year, the team from the Jefferson FAB Center for Complex Care (for Adolescents and Beyond), a primary care medical home for adolescents and adults with complex childhood-onset conditions, has been working with the National Down Syndrome Society (NDSS) to get involved with advocacy. In July 2023, one of the providers from the FAB Center was invited by NDSS to testify at a Congressional briefing in support of the Charlotte Woodward Organ Transplant Discrimination Prevention Act (“Charlotte's Bill”). Motivated by the importance of this bill, the FAB Center clinical and research teams worked together to cover this provider's clinical schedule, understand the details of the bill, and gather stories and data for the testimony.

Charlotte's Bill (HR 2706/S. 1183) was introduced into Congress in April 2023 for the purpose of establishing a law to prevent “covered entities” such as health care providers, hospitals, and various long-term care facilities, as well as any transplant hospital, from discriminating against individuals based solely on their diagnosis of a disability when being considered for an organ transplant.⁴ This bill was drafted in response to a 2019 report from the National Council on Disability that found that people with disabilities are often denied equal access to organ transplants based solely on their disability.⁵ This discrimination often is rooted in the assumption that people with disabilities have a poorer quality of life.

This ableism, whether explicit or implicit, is often the cause of discrimination within health care.⁶

In January 2023, the FAB Center received an education/research grant from the Pennsylvania Developmental Disabilities Council that allowed them to create a Community Advisory Board (CAB) of people with lived experience with disabilities, including people with disabilities and their family members or caregivers. At the time that NDSS reached out, the grant team had been gathering stories and photos from the FAB Center CAB and were able to include some of these in the testimony. In particular, the story of one of the CAB members who was born with Down syndrome was told. His parents were given a pretty grim outlook on what his life would look like. Fast forward more than 30 years and today he has completed a postsecondary program, has a job, and loves to ride his bike, play sports, and spend time with his family. He told the team himself, with a smile on his face, that he has a great life. Imagine though if there was a time that this young man had needed an organ transplant and doctors decided that he was not worthy of one just because he had Down syndrome and his quality of life was poor anyway.

The provider from the FAB Center who spoke at the briefing set the stage by explaining that she has been a family medicine provider for more than 25 years. She was able to share that, in her medical opinion and clinical experience, what was set forth in Charlotte’s Bill was important to improving the lives of people with disabilities. She shared the stories and pictures from our CAB to make it personal. The legislators and legislative aides in attendance were moved by these stories and grateful for this perspective.

The team members from the FAB Center hope that their experience will show you the power you have to influence change as a provider or researcher. You can get involved in advocacy activities in many ways:

- ▶ Start by identifying your legislators so that you are ready to contact them when bills related to your area of expertise need to be introduced or voted on. You can visit [Congress.gov](https://www.congress.gov) and type in your home address to find your US Representative and Senators. City and state websites have similar capabilities to find your legislators at that level.
- ▶ Federal, state, and local websites also typically have spaces where you can search bills currently under consideration by topic. For example, on [Congress.gov](https://www.congress.gov), you can search for things like “diabetes,” “prescriptions,” or, of course, “disability,” and all related bills will be listed.
- ▶ If you are not sure where to start, your professional organizations are great places to get some direction. For example, the American Academy of Family Physician’s website has an “Advocacy” tab that outlines current legislative priorities related to family medicine and groups examples by topic.
- ▶ Finally, when you do identify an area or specific bill you want to advocate for, organizations out there can help! These organizations typically have templates you can use to call or email your legislators—there’s no need for you to gather the data points all over again when someone else already has! You can add your personal perspective to what has been provided.

In discussions regarding the social determinants of health, a generally accepted benchmark is that up to as much as 80% of what contributes to a person’s overall health occurs outside of health care and the exam room.⁷ As Rudolf Virchow suggested, medicine needs to infiltrate politics to solve the social problems that affect the well-being of patients, research participants, and the community as a whole.

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