

Success Story: Consumer Advisory Board Strengthens the Kansas Disability and Health Program



Disability and Health Program
kansans with disabilities can be healthy

Summary

For the five-year cycle ending in 2021, the Kansas Disability and Health Program (DHP) engaged a Consumer Advisory Board (CAB) comprising Kansans with mobility disabilities and intellectual disabilities (ID) plus two advocates to guide program activities. These CAB members, including many seasoned advocates who represent disability organizations across Kansas, provided critical feedback on the work of the DHP and ensured that the health concerns of Kansans with disabilities were represented. The DHP created an environment where CAB members were encouraged to draw on both their personal experience with disability and their representation of others with disabilities to shape a program aimed at reducing health disparities for all Kansans with disabilities.

Challenge

Identifying and retaining engaged board members is a challenge for many organizations. Because Kansas is a large, rural state, sustaining the interest and participation of advisory board members willing to travel for in-person meetings can be difficult (although participating virtually was always an option for the CAB). Additionally, managing personal health issues and interacting with health care systems that too often present accessibility challenges can limit the availability of time and energy of people with disabilities for board service. Still, the DHP staff believed that the input of an advisory board representing a variety of disability experiences was crucial to the success of the program.

Solution

The DHP recruited 13 CAB members from across Kansas with strong interest in the program, with several of them staying on board for the entire five-year term. Members represented a variety of disability organizations, including: the Self-Advocate Coalition of Kansas (SACK); four centers for

independent living; and the Kansas Disability Caucus, a cross-disability organization that holds bi-yearly meetings to provide opportunities for Kansans with disabilities to learn, share, and provide solutions to disability-related issues. CAB members experience a variety of disabilities, including autism, amputation, ID, post-polio syndrome, spinal cord injury, and spina bifida; and include representation of the Native American and Hispanic communities.

Meetings were held three to four times yearly, with each meeting including three activities:

1. A question posed to all CAB and staff members to facilitate team building (e.g., what is the best health advice you have received, what is your health goal for the year).
2. An opportunity for each board member to share a brief personal update of their lives.
3. Presentation of DHP plans, activities, and products with time for CAB members to ask questions and provide feedback.



The Consumer Advisory Board (CAB), a diverse group of consumer advocates, ensured the DHP's work was guided by people who live with disabilities and advocate for others with disabilities.



Kathy Lobb, CAB member and disability advocate

Results

The guidance and input of the CAB members strengthened the DHP by broadening understanding of how to address health disparities experienced by Kansans with disabilities and by increasing participation in program interventions. The impact of this guidance and input is evident in many ways including:

- Revision of a resource titled “Take Charge of Your Own Health” to encourage healthy habits in the context of self-determination, resulting in the addition of information about nutrition, exercise, oral health, and smoking cessation programs.
- Participation of CAB members in several presentations to health care providers on the topic of accessible health environments, and on self-advocacy in health care situations for people with ID.
- Creation of a resource titled, “CHANGING IT UP: How to modify your brushing routine when your body just won’t cooperate” to facilitate oral health for people with limited use of their upper limbs.
- Suggestions of numerous accessible recreation sites in Kansas based on personal experience to be added to the online “Kansas Accessible Recreation Opportunities” resource.
- Recruitment of participants for the Feeling Good About Your Smile, Stoplight Health Living, WOWii, and NCHPAD’s 14 Weeks to a Healthier You interventions.
- Assistance with recruitment of participants for listening sessions and distribution of public service announcements videos for adults with ID managing diabetes.
- Review of materials to ensure that they used plain language.

Sustaining Success

At the close of the funding cycle, CAB members were invited to share highlights of their service to the DHP. They mentioned appreciating the opportunity to use their expertise to guide the program; the chance to meet and exchange ideas with other advocates; and the camaraderie of the meetings, both in-person and virtual.

Some of the specific activities they liked included:

- Interacting with health care providers and teaching them about accessibility and also the fact that people with disabilities have “regular” health care needs not related to their disabilities
- Learning about healthy eating and other issues related to health
- Editing documents and making them more user-friendly
- Opportunities to share information about policies and practices across Kansas affecting the disability community

Overall, the involvement of the CAB ensured that members of the targeted populations, people with mobility and intellectual disabilities, were able to use their expertise to strengthen work of the DHP. This practice adheres to the slogan of the disability rights movement, “nothing about us without us,” and ensured relevance of the program.

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