

The Vanderbilt Kennedy Center's Community Advisory Council: Building Community and Leading Change

Evon Batey Lee, Ph.D., Laurie Fleming, Tina Prochaska, and Elise McMillan, J.D.

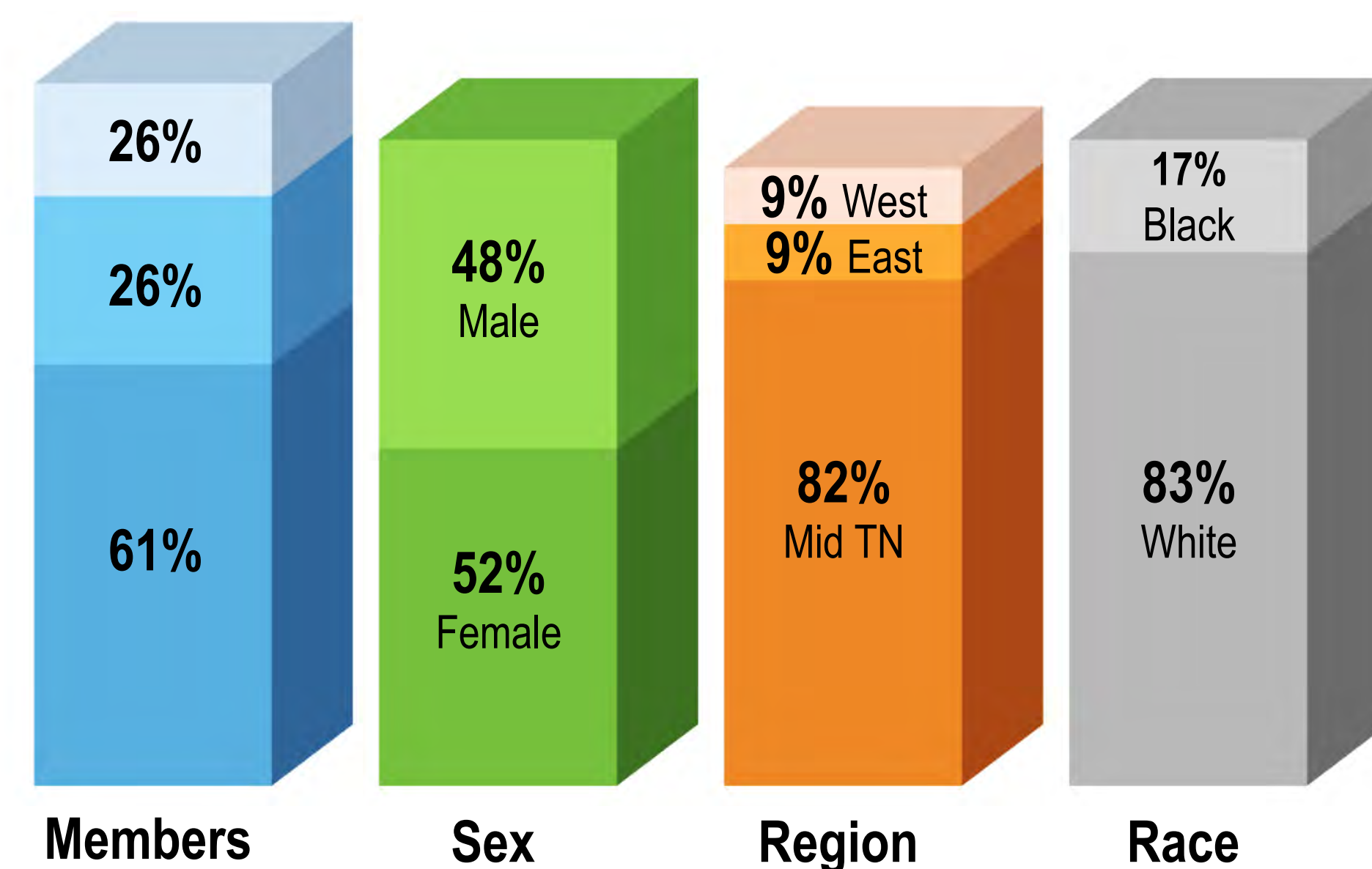
Abstract

Community Advisory Councils (CAC) are mandated by the DD Act, guide the leadership of UCEDDs, and partner in the planning, implementation and evaluation of activities designed to enhance the lives of individuals with intellectual and developmental disabilities (IDD) and their families. This poster describes features of the Vanderbilt Kennedy Center's (VKC) CAC that promote creativity, community, and collaboration.

CAC Member Composition

23 Members (some members appear in more than one category)

- People with disabilities [26%]
- DD Network partners (i.e., Disability Rights TN, TN Council on DD, and Boling Center for DD at the University of Tennessee LEND/UCEDD) and representatives from organizations, such as Empower TN, Support and Training for Exceptional Parents (STEP), People First, The Arc TN, and Centers for Independent Living (CILs) [26%]
- Family members of individuals with IDD [65%]



Members represent diverse backgrounds and come from all three main regions of Tennessee

CAC Meeting Organization

- The VKC's CAC meets quarterly in Nashville
- Most members attend in person, but members can attend by Zoom/distance technology
- The CAC chair or co-chair presides over each meeting
- UCEDD director and program coordinator provide updates and facilitate discussion
- Several Vanderbilt University Medical Center (VUMC) and Vanderbilt University (VU) faculty, staff and UCEDD trainees engage in focused and casual conversations with CAC members



Sample Meeting Agenda:

- Welcome and overview of the day
- Presentation by VUMC or VU faculty or others on topics often selected by CAC members
- Workgroups on the VKC UCEDD's areas of emphasis (Education and Early Intervention, Employment, Health and Mental Health, and Quality of Life) or projects
- Reports by disability community partners on their current activities and legislative & policy updates.

Ongoing CAC activities

- Since the VKC became a UCEDD in 2005, the CAC has played a crucially important role in guiding the center's activities
- CAC members review and provide input on the annual UCEDD report
- Review the attainment of goals and objectives
- Send one or more members to the annual AUCD meeting or Disability Policy Seminar
- Participate in 5-year planning retreats in preparation for the UCEDD application
- Play pivotal roles in the identification of service gaps in the community and the recruitment and retention of new CAC members
- Aid in the dissemination of information and products

Examples of VKC initiatives that have benefitted from the CAC's guidance

Volunteer Advocacy Project (VAP)	Trains interested individuals to become special education advocates so they can provide instrumental and affective support to families of children with disabilities in Tennessee. Since its inception in fall of 2008, the VAP has trained more than 300 advocates across the state.
Next Steps at Vanderbilt	A 4-year inclusive higher education program committed to providing students with intellectual disability an inclusive, transformational postsecondary education in academics, social and career development, and independent living, while honoring equality, compassion, and excellence in all endeavors.
Tennessee Disability Pathfinder	Provides free information, resources, support, and referrals to Tennesseans with disabilities and their families.
VKC TRIAD Community Engagement Program	An innovative partnership with community cultural and civic organizations that works to promote full inclusion of all children and adults. These organizations are prominent arts, education, athletic, and community organizations across Nashville, who readily took initiative in learning how to be a stronger and more reliable community for everyone.
Kindred Stories of Disability	The VKC and The Arc Tennessee collaborate annually to produce a collection of stories that highlight the challenges individuals with disabilities and their families face as they navigate service systems and supports. Booklets are shared with TN legislators and policymakers during TN Disability Day on the Hill and at the Disability Policy Seminar to educate them and share stories from their districts.
TennesseeWorks	A statewide collaboration of public and private agencies and organizations that work together to expand the employment opportunities for people with disabilities. TennesseeWorks offers resources to equip and encourage employers, educators, professionals, families, individuals with disabilities, and communities to elevate employment outcomes.
Tennessee Adult Brothers & Sisters	A support and networking group for adult siblings of individuals with disabilities.
Transition Tennessee	Offers online and in-person resources to prepare transition-age youth with disabilities for life after high school.



Conclusion

These endeavors are enhanced by the obvious sense of community that characterizes the relationships between CAC members who enjoy the experience of getting together, sharing meals, and conversing with each other. This impression is supported by the long distances many members travel to attend in person. Between meetings members stay connected through weekly emails (Monday Morning Message) and social media (Facebook group). In addition to working together on policies and programs, there are additional benefits, such as watching self-advocates who are CAC members develop greater self-confidence and leadership skills and seeing former LEND/UCEDD trainees graduate and transition to leadership positions as teachers and researchers -- and even CAC members themselves. In summary, an effective CAC can be rewarding to participants and have wide-ranging benefits for UCEDDs and the larger community.