

Consumer Consensus - Strengthening Consumer Voice is Key to System Change

by Sarah Potter and Laurie Coker

The Consumer Caucus at i2i's Visionary Voices conference in Pinehurst was a lively meeting, with most of its participants being actively vocal. We thank the i2i Center for hosting this annual consumer-led discussion. This has been a yearly gathering held at the conference for well over 15 years. It is one of the rare spaces that consumers and family members can speak about shared hopes and concerns in an open forum. About 25 consumers and family members from across the state, many of whom represented local or state level Consumer and Family Advisory Committees (CFACs), came together to discuss changes under Medicaid Transformation.

There was no pre-set agenda, but Laurie Coker of NC CANSO - North Carolina Consumer Advocacy, Networking, and Support Organization graciously volunteered to lead the discussion, beginning by sharing some history of consumer engagement in our public mental health system. She has been a strong advocate for fifteen years and has witnessed system changes.

The key theme that emerged was the need to ensure a vibrant role for the voices of consumers and families in ensuring higher quality services and supports during this time of Medicaid Transformation in our state. The following are some highlights from the discussion:

- 1) The role of CFACs is unclear and even uncertain in the future of Medicaid funded service delivery and administration.
 - We need new language in State statute 122C to reflect today's operational environment and to ensure that there is meaningful and integrated advisory input from system users, families, and those who have recovered health and understand how best to serve people through the system.
 - To better identify gaps in service, CFACs should work to be better connected to their communities, possibly through hosting regular listening sessions so they can hear the needs from those who most experience them or who have ideas to contribute toward improvement.
 - Local CFACs should work more closely and collaboratively with State CFAC. Development of unifying principles that promote this collaboration will help.
- 2) Consumer inclusion should be a defining characteristic of our Transformation process with consumers being engaged at every table to provide input and guidance *and not just as tokens*.
 - Their roles, through CFACs and otherwise, should be supported by policy and contractual language that puts teeth in their efforts so that advisory input is seriously considered and

integrated into local or state system change. CFACs must not simply be a presence to offer opinions.

- With the Standard Plan being currently rolled out, a statewide MH/SUD Advisory should be formed and guaranteed an active part in developing and overseeing changes to healthcare delivery in NC. The concern is that in these dimensions of the system, there is too little engagement of consumers and families, which is illogical and does not even make good business sense if we want a sustainable system with good outcomes.

Current Actions Planned

- The group agreed to focus on educating especially new legislative members through personal stories and introducing ourselves to new members on the Legislative Oversight Committee. Martha Brock is working on another **Legislative Advocacy Day** for the spring through SCFAC. (Addendum: Ms. Brock has since clarified that SCFAC Subcommittee on Legislation is being engaged to help with planning).
- There is a Legislative Breakfast scheduled for February 2 at the Friday Center in Chapel Hill. SCFAC will have a table there, and everyone was encouraged to attend.
- A statewide CFAC meeting is in the planning for the spring as well. It was agreed that we need to do a better job of informing families and consumers about what's going on, more clearly define the role of CFAC members, and be active in soliciting input from our community members about what they need and want.

Wrapping up the discussion, one family member participant who has worked in health care bureaucracies challenged the group and the state staff who were in participation. As a current member of an MCO board of directors, she stated that boards and officials needed to hear *what we want and not just what has already been decided by administrations then passively approved by consumers and families!* She states, with many agreeing, that CFAC members should be far better informed by those they are to advise so that they can do their work effectively! She stated that her experience has been that too often people working in bureaucracies give lip service to consumer involvement and we must see this change in our state if Medicaid Transformation is to work.

This meeting was a great opportunity to see old friends, meet new advocates, and to voice what needs to be done going forward. There is a lot of work to be done, and we will need to strengthen our collective voice to ensure future success!

Sarah Potter is a Parent Advocate and Triad CFAC member. Laurie Coker is the Executive Director for NC-CANSO. <https://nccanso.org/> and runs GreenTree Peer Center in Winston-Salem www.greentreepeercenter.weebly.com/

i2i Note - to assist in furthering these recommendations from advocates, CFACs and family members, i2i has shared this document with key leader at the Department of Health and Human Services, including Dave Richard, Director of Medicaid, Deputy Secretary for Behavioral Health and I-DD, Kody Kinsley, Debra Farrington, Chief of Staff for the Division of Health Benefits and chair the Medicaid Beneficiary Engagement Committee of the MCAC?, Walt Caison,

Section Chief, Community Mental Health, Division of MH/DD/SAS and Ken Schuesselin,
Associate Director of Consumer Policy, NC Division of MH/DD/SAS