



**TASK FORCE ON PATIENT AND FAMILY ENGAGEMENT
FOCUS ON COMMUNITY LEVEL INTERVENTIONS**

**North Carolina Institute of Medicine
630 Davis Drive, Suite 100
Morrisville, NC 27560
10:00 – 3:00
August 14, 2014
Meeting Summary**

Attendees

Members: Kimly Blanton, Melanie Bush, Ashley Branham, Heather Burkhardt, Lucy Dorsey, Sharon Elliot-Bynum, Hannah Klaus, Nidu Menon, John Owen, Belinda Pettiford, Kathryn Pollak, Matthew Potter, Parrish Ravelli, Anita Schamback, Karla Siu, Melissa Thomason, R.W. “Chip” Watkins, Karen Woomer

Steering Committee and NCIOM Staff: Sue Collier, Michael Lancaster, Ruth Peterson, Andrea Phillips, Kimberly Alexander-Bratcher, Thalia Fuller, Kiah Gaskin, Adam Zolotor

Guests and Other Interested People: Brent Anthony, Robert Childs, Sarah Potter, Deborah Dokken, Amy Jones, Joanna Kaufman Maureen Mauer, Joanne Pierce

WELCOME, INTRODUCTIONS, & INPUT

Kimly Blanton, Patient Advocate, Vidant Health, *Co-chair*

Melanie Bush, MPAff, Assistant Director, Policy and Regulatory Affairs, Division of Medical Assistance, North Carolina Department of Health and Human Services, *Co-Chair*

Ms. Bush called the meeting to order and welcomed the Task Force members. The group went around the room so that each attendee could introduce themselves.

OVERVIEW OF DAY’S SESSION & TASK FORCE FEEDBACK

Kimberly Alexander-Bratcher, MPH, Project Director and Research Associate, North Carolina Institute of Medicine

Ms. Alexander-Bratcher reminded the Task Force about what we covered in prior meetings, gave a brief overview of the day’s meeting, and reminded the group what we will be covering in future meetings. Our plan for September is to have discussion around community outreach and partnerships. We will

also discuss policy, including the insurer perspective. In our October meeting we will begin refining our recommendations and discussing the report.

Ms. Alexander-Bratcher invited the group to engage in a brainstorming session around topics that we may need more discussion around. The Task Force suggested preventions, insurers, faith communities, community education in general (and particularly with populations with special needs), health provider education, training institutions, litigation barriers, disclosure and transparency of patient information, cultural competency of providers and health care staff, Accountable Care Organizations (ACOs), social determinants at both the internal and external level as they relate to a patient's ability to engage in their own health, state/Community Care of North Carolina/ACO Patient and Family Advisory Council (PFAC) requirements, and caregiver support. More suggested topics included implementation and sustainability, metrics, health literacy (for the general population as well as for adolescents), end of life decisions, affordability and being able to access cost information to make informed decisions about care, the "triple aim" (cost, quality, patient satisfaction), engaging the business sector in patient and family engagement, and patient rights in NC. Dr. Zolotor invited task force members to send any additional recommendations to Ms. Alexander-Bratcher.

COMMUNICATION AND FAMILY PRESENCE POLICY

Deborah L. Dokken, MPA, Family Advocate/Consultant, Institute for Patient- and Family-Centered Care

Joanna Kaufman, RN, MS, Program/Information Specialist, Institute for Patient- and Family-Centered Care

Ms. Alexander-Bratcher introduced the presenters Joanna Kaufman and Deborah Dokken. Ms. Kauffman gave an overview of the four principles of patient and family centered care. The overall idea is that patient and family centered care is working *with* rather than doing *to* or *for* them. Presence and participation enhances patient and family experience of care, improves management of chronic and acute illnesses, strengthens continuity, prevents readmissions, and provides cost savings. Task force members were given a document that highlights the "facts and figures," which can be found with the presentations and handouts on the NCIOM website.

Concerns amongst health professionals around moving to partnership with patients and families were discussed, including admission of error, insufficient time and resources, confidentiality and infection control. Moving to meaningful partnership means that patients define their "family" and how they will be involved. It was reiterated by Mr. Potter and others that patient engagement is often treated by providers as a "courtesy"; there is also a

culture in which patients are expected to be “grateful” for every form of engagement. This is the culture that needs to change. Ms. Thomason mentioned that an important part of Vidant’s culture change was addressing the barriers along the way. The Better Together toolkit includes strategies for addressing barriers.

The presenters discussed Better Together, a family presence campaign that provides a toolkit which includes strategies and resources for changing policies and educating staff and families. These toolkits can be downloaded on the website for free and can be modified to include organization logos.

LUNCH

OUTREACH TO VULNERABLE POPULATIONS PANEL

(Note: Our goal is health equity. By vulnerable populations, we mean those that have challenges and barriers to access health care. Vulnerable populations include those who do not understand how to access health systems. They often experience health disparities due to these barriers and challenges.)

Robert Childs, MPH, Executive Director, North Carolina Harm Reduction Coalition

Sharon Elliot-Bynum, PhD, MA, RN, BSN, Executive Director, CAARE, Inc.

Hannah Klaus, Youth Staff, Access to Care, Youth Empowered Solutions

The first panelist, Mr. Robert Childs, discussed his work at the North Carolina Harm Reduction Coalition (NCHRC). The NCHRC is the state’s only comprehensive harm reduction program. It engages in grassroots advocacy, resource development, coalition building and direct services for law enforcement and those made vulnerable by drug use, sex work, overdose, STIs, HIV and hepatitis. Mr. Childs explained the concept of harm reduction is taking an activity that could be inherently dangerous and making it safer for the individual and the community. Increasing harm reduction in communities decreases drug use, crime, and sexually transmitted infections including HIV. NCHRC has successfully advocated for legislation to improve the lives of vulnerable communities, including NC Senate Bill 20 which increases Naloxone access. Through the use of Naloxone, NCHRC has been able to reverse 116 drug overdoses.

NCHRC engages non-judgmental volunteers, typically former drug users and representatives of the community. Mr. Childs reiterated the importance of language in patient or consumer engagement. NCHRC does not use the term “drug abusers” as this dissolves trust. NCHRC makes itself visible through active communication. Naloxone access is given within 48 hours of request.

The dispensers are spread out over the state which makes response quicker and more effective.

Next, Dr. Sharon Elliot-Bynum presented her work with Healing with CAARE, Inc. Healing with CAARE, Inc. provides health support and wellness services to community members of Durham County and surrounding areas who experience health and socioeconomic disparities. The National Institutes of Health defines disparities as “the difference in the incidence, prevalence, mortality, and burden of disease and other adverse health conditions that exists among specific population groups in the United States.” Health disparities are influenced by lifestyle behaviors, socio-cultural factors, and system influences.

The key to systems change is integration, investment, and accountability. CAARE uses best practices such as providing a holistic approach to health services under one roof, which increases compliance. They also conduct outreach through free health fairs, community events, seminars, and family settings. Also, collaborations with other health providers to get participants the care that they need are essential. Diverse leadership is key. Clients are more willing to engage in activities if they trust the leadership.

Dr. Elliot-Bynum invited the task force to engage in discussion. Members wanted to know more about CAARE funding. The funding for CAARE comes from the Substance Abuse and Mental Health Services Administration, the Veterans’ Administration, the Office of Rural Health and Community Care, and other public and private entities. The clinic is structured by a community assessment that was conducted by Partnership for Healthier Durham. Dr. Elliot-Bynum also discussed CAARE’s prevention strategies, which include smoking cessation, a healthy eating program, exercise programs, and meditation.

Finally, Ms. Hannah Klauss gave a presentation about Youth Empowerment Solutions (YES). The mission of YES is to partner youth with adults for community change. Sixty percent of YES staff are youth. The YES model includes skill development, awareness, and opportunities. The focus is on policy system or environmental change. YES has influenced many organizations to incorporate youth involvement and leadership, including the North Carolina Division of Public Health which mandates a youth empowerment strategy in all its tobacco contracts with local health departments. YES is also working with the Montefiore Medical Center and school based health centers to incorporate youth advisory councils. Ms. Klauss emphasized that youth are a vulnerable population because they have not had the opportunity to navigate the health system on their own. Youth should be seen as a target for engagement because it is an opportunity to promote preventive measures. YES has developed training curriculums around incorporating health literacy in schools and the trainings use a peer to

peer model where youth teach other youth.

NEXT STEPS & FEEDBACK

Adam Zolotor, MD, DrPH, Vice President, North Carolina Institute of Medicine

Dr. Zolotor invited the task force to engage in discussion in response to these panelist presentations. It was suggested that the recommendations could be framed around a continuum including prevention and education. The presentations emphasized that programs need a shared language and goals, regardless of the populations who are partnering. Another theme shared by each presenter was the emphasis of consumer leadership in their organizations. Consumers are both volunteer leaders and hired staff, and always represent the community which the organization serves.

Dr. Elliot-Bynum emphasized the importance of a neutral entity that can bring a variety of sectors together to have conversations as essential to reducing silo work. It was also suggested that our recommendations should broaden “patient satisfaction while in the health facility” to include transitions and settings outside of health facilities. More community collaboration is needed to leverage resources and to be effective in this work. When asked how she mobilizes resources for CAARE, Dr. Elliot-Bynum mentioned being person centered, maintaining your own autonomy without being territorial, being inclusive, and using messages/messengers that communities can identify with.

The next Task Force meeting will be September 11.