North Carolina Institute of Medicine
shaping policy for a healthier state

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
September 11, 2014
Meeting Summary

ATTENDEES
Members: Ashley Branham, Heather Burkhardt, Lucy Dorsey, Lin Hollowell, Hannah Klaus, Helen Marie Mack, Nidu Menon, Jo Morgan, John Owen, Kathryn Pollack, Matthew Potter, Parrish Ravelli, Anita Schambach, Karla Siu, Bill Smith, Margaret Toman, R.W. Watkins, Karen Woomer, and Joan Wynn

Steering Committee and NCIOM Staff: Kimberly Alexander-Bratcher, Liz Chen, Sue Collier, Thalia Fuller, Kiah Gaskin, Andrea Phillips, Michelle Ries, William Schwartz, and Adam Zolotor

Guest and Other Interested People: Valencia Anderson, Brent Anthony, Alison Cooper, Pamela Dardess, Gayle Harris, Maureen Mauer, and Dawn Porter

WELCOME, INTRODUCTIONS, & INPUT

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

Warren Newton, MD, MPH, Director, North Carolina AHEC Program, William B. Aycock Professor and Chair, Department of Family Medicine, University of North Carolina School of Medicine, Co-chair

Dr. Warren Newton opened the meeting and started the round of introductions. Dr. Adam Zolotor, interim president of the NCIOM, honored September 11th with a moment of silence.

OVERVIEW OF DAY'S SESSION

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

Ms. Alexander-Bratcher reminded the task force of what was discussed in the August meeting and framed the discussion topics for the day.

COMMUNITY OUTREACH

Gayle B. Harris, BSN, MPH, RN, Public Health Director, Durham County Department of Public Health

Ms. Harris gave a presentation about her experience with outreach and engagement within the Durham County Department of Public Health (DC DPH). She began by outlining the mission and vision of the Department, Durham County's strategic plan, and DC DPH's strategic plan. The largest share of revenue sources for Durham DPH comes from local dollars. Durham DPH has many unique collaborations, including Lincoln Community Health Center, Partnership for a Healthier Durham, NCCU, UNC Hospital, and Duke Medicine. The Department utilizes the Health Impact Pyramid and DPH uses a County Health Rankings Model to determine how to address the needs of the community. Ms. Harris discussed how structure can support engagement and empowerment. There is an emphasis on engaging participants in planning and processes (see Arnstein's ladder of citizen participation slide). The community health assessment process involves collecting data using community informed questions that will render valid and reliable data. This data is then used to set health priorities for the community. The full community assessment can be found at www.healthydurham.org. The Department engages the community in assessment and asking questions to inform action plans, fund requests, etc. through the Healthy North Carolinians Initiative.

ROADMAP FOR PRACTICE AND RESEARCH IN PATIENT AND FAMILY ENGAGEMENT

Pam Dardess, Principal Researcher, American Institutes of Research

Maureen Maurer, Principal Researcher, American Institutes of Research

After lunch, Ms. Dardess and Ms. Mauer presented the new roadmap for practice and research in patient and family engagement. The roadmap, found at www.patientfamilyengagement.org, includes eight strategies with practical actions for different stakeholders. The strategies were developed using evidence-based and promising practices. The eight strategies include: patient and family preparation; clinician and leadership preparation; care and system redesign; organizational partnership; measurement and research; transparency and accountability; legislation and regulation; and partnership in public policy. In addition, the roadmap lists five actions for different stakeholder groups such as health care professionals, organizations, leaders, insurers, employers, and researchers to start today. Ms. Dardess and Ms. Mauer concluded their presentation by encouraging task force members to send them any relevant resources as they are still collecting them.

After the presentation, there was discussion about a need for more information about the use of technology and its role in patient and family engagement. There was a lot of support for the roadmap since it provides a useful framework that is not "one size fits all". Practitioners and researchers can start at different places and tackle different issues within the roadmap, but still compare results using common tools and measures. Others brought up the concern that this roadmap emphasizes a lot of process measures and wonder if process measures can truly improve care (and change outcome measures). The health care system cannot just ask for providers to "check-off boxes"; they must develop a system that ensures better care. It is also offensive to assume that individuals working in these systems have never tried to engage patients and their families. Thus, we need to support ongoing efforts and continue to tap into an existing resource: patients and families. In order to do this, we need to employ an asset-based mindset (instead of a deficit-based one). Those in attendance expressed that they wanted the task force report to be an invitation to patients and families for increased engagement, using the presented road map as a framework for future engagement efforts.

NEXT STEPS & FEEDBACK

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

Dr. Zolotor facilitated the last discussion of the day and started by asking task force members where patient and family engagement needs to take place. In response, members listed workplaces, faith communities, areas with large aging populations (e.g. senior centers, nursing homes, and program sites like Meals on Wheels), schools, online communities, and rural communities. Then, the discussion transitioned as task force members pondered the following question, "Are we trying to engage communities? Or are we trying to engage patients and families through communities?" The consensus from the task force was to do both. It is also important to broaden the definition of "patient" in our discussion because "patients" may include people who do not see a provider. Therefore, we want to be sure that we try to reach them as well. Lastly, members engaged in a final discussion about patient and family engagement in hospice and long-term care. There is a different level of engagement required for families in these situations. In prior sessions, we have assumed that patients can be activated, but this may not be the case when working with the aging population. Thus, we must learn more about patient and family engagement for hospice and long-term care situations.