



TASK FORCE ON PATIENT AND FAMILY ENGAGEMENT

North Carolina Institute of Medicine

630 Davis Drive, Suite 100

Morrisville, NC 27560

May 22, 2014

10:00 – 3:00

Meeting Summary

Attendees

Members: Val Atkinson, Kimly Blanton, Ashley Branham, Eliane Brown, Janet Bull, Heather Burkhardt, Melanie Bush, Brian Caveny, Betty Currier, Teresa Cutts, Lucy Dorsey, Sharon Elliot-Bynum, Nancy Henley, Lin Hollowell, Peter Lichstein, Helen Marie Mack, Jill McArdle, Jo Morgan, Belinda Pettiford, Melanie Phelps, Matthew Potter, Parrish Ravelli, Sarelli Rossi, Anita Schambach, Bill Smith, Melissa Thomason, Margaret Toman, Karen Woomer, Joan Wynn

Steering Committee and NCIOM Staff: Sue Collier, Andrea Phillips, William Schwartz, Kimberly Alexander-Bratcher, Thalia Fuller, Michelle Ries, Elena Rivera, Pam Silberman, Adam Zolotor

Guests and Other Interested People: Julie Barnes, James Bundy, Anthony Caprio, Earl Craig, Darren DeWalt, Ed Fisher, Michelle Hayes, Erin Isenberg, Hannah Klaus, Maureen Mauer, Melissa Mayer, Ben Moulton, Tamara Norris, Anna Norton, Sara Potter, Stacey Sheridan, Karla Siu, Patrick Tang, Jessica Waters

WELCOME, INTRODUCTIONS, & INPUT

Kimly Blanton

Patient Advocate

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

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

Melanie Bush, Assistant Director, Policy and Regulatory Affairs at the Division of Medical Assistance in the North Carolina Department of Health and Human Services, welcomed the group and asked participants to introduce themselves.

OVERVIEW OF PAST AND UPCOMING MEETINGS

Adam Zolotor, MD, DrPH

Vice President

North Carolina Institute of Medicine

Adam Zolotor, Vice President of the North Carolina Institute of Medicine, presented an overview of the previous meetings, reviewed the day's agenda, and reminded the group what we will be covering in future meetings.

HEALTH LITERACY

Darren DeWalt, MD, MPH

Associate Professor of Medicine

Division of General Medicine

University of North Carolina at Chapel Hill

Ms. Bush introduced Dr. Darren DeWalt, who is an Associate Professor of Medicine at UNC Chapel Hill. Dr. DeWalt began by defining health literacy and explaining the current status of health literacy in the US. According to the National Assessment of Adult Literacy, 43% of Americans have basic or below basic literacy. He discussed how health literacy relates to patient activation; they are different attributes, but may have some affect on each other. When patients struggle with understanding health information it impedes their engagement. Health literacy is a skillset and patient activation is a mindset, and both are important. He explained how improving understanding hinges upon increasing skills/ability and reducing demands/complexity. One key point is that "less is more"; clarity should be the goal, not simplicity. Providing information in an ordered and focused way increases understanding and improves decision-making. One technique for increasing ensuring understanding is the teach-back method. The Task Force was sensitive to the idea that teach-back method might be perceived as condescending, as though the provider is "testing" the patient. Dr. DeWalt and the task force discussed that the teach-back method can be used without condescension and can be a very supportive part of the information exchange. The Task Force also brought up the question of what patients need to know versus what they would like to know, pointing out that patients with varying levels of health literacy might need or want varying levels of information. There needs to be discussion about when additional information is helpful and when it is harmful.

SHARED DECISION MAKING PANEL

Stacey Sheridan, MD, MPH

Associate Professor of Medicine

Division of General Medicine

University of North Carolina at Chapel Hill

Anthony J. Caprio, MD

Department of Family Medicine

Carolinas Healthcare System

Benjamin Moulton, JD, MPH

Senior Health Policy & Legal Advisor
Foundation for Informed Medical Decision Making

Ms. Bush introduced Dr. Stacey Sheridan, an Associate Professor of Medicine at UNC Chapel Hill. Dr. Sheridan presenting on shared decision making (SDM). SDM supports the core ethical principle of autonomy and embodies the central quality criteria of patient-centeredness. It has been shown to improve patient outcomes, such as increased knowledge and reduced decisional conflict, and has cost saving potential. Dr. Sheridan discussed when and how to use SDM. One of the most important components of SDM is values clarification, in which providers elicit values from patients and then present options in the context of those values. Another key component is discussing harms (physical, psychological, financial, hassle, and opportunity). Dr. Sheridan concluded by discussing several tools for SDM, such as option grids and decision aids, which reduce barriers to implementation.

The next presenter was Dr. Anthony Caprio, a physician with Carolinas Healthcare System. He presented on the topic of SDM for end-of-life care. He introduced the Medical Orders for Scope of Treatment (MOST) form, which is a type of medical order that is more detailed and empowers patients to make decisions. The MOST form includes five sections: CPR, medical interventions (scope of treatment), antibiotics, medically administered fluids and nutrition, and physician and patient (or surrogate) signatures. It helps elicit and prioritize goals of care, discuss prognosis and uncertainty, discuss benefits and burdens of treatments, and offer recommendation based on goals. The three key partners are the patient, the surrogate, and the provider. Dr. Caprio brought up goals of care (function, longevity, and comfort), which should be discussed prior to decision-making in a process called goal-based advance care planning. Patients are able to prioritize their goals before decision-making, and providers use goals to provide context for their recommendations. North Carolina uses the MOST form in clinical practice.

The final presenter was Ben Moulton, Senior Health Policy & Legal Advisor for the Foundation for Informed Medical Decision Making. He presented on SDM, ethics, and health policy. Mr. Moulton began by discussing the ethical obligation of informed consent, which occurs less often than it should. SDM is a component of informed consent, and it involves information exchange between clinicians and patients. He presented a Cochrane Collaboration review of decision aids, which demonstrated the benefits of decision aids. Some benefits include increased knowledge, increased accuracy in risk perceptions, and increased congruency between patient values and their decisions. Mr. Moulton covered the example of Washington State's implementation of SDM and patient decision aids. Studies of Group Health, a Washington-based nonprofit health care system, found the use of decision aids to be linked to lower hip and knee surgery rates and costs. Mr. Moulton also highlighted the importance of physician leadership in culture change around SDM. The presentation concluded with a discussion of health policy reasons for large scale adoption of SDM, including the potential to bridge health disparities.

The panel of presenters concluded with questions and discussion from the Task Force. Some members brought up the real barriers to implementing SDM, including our fee for service health care system, lack of time, lack of belief in the benefits, provider perceptions of patients' knowledge and abilities, and patient willingness to engage in SDM. The Task Force also discussed the need to ask patients who else needs to be involved in SDM, such as family members and friends.

PEER SUPPORT NETWORKS

Edwin Fisher, PhD

Professor, Health Behavior
Gillings School of Global Public Health
University of North Carolina at Chapel Hill

Dr. Ed Fisher presented on peer support and the engagement of patients and families. He began by introducing the fundamental role of social connections and support. Lack of support is linked to poor health outcomes. Peers for Progress is an organization founded in 2010 that connects organizations worldwide doing peer support work. Key functions of peer support are: assistance and consultation in applying management plans in daily life, social and emotional support, linkage to clinical care, and ongoing support extended over time. Dr. Fisher explained that people look to doctors to tell them what is important, but look to others like them (peers) to find out if they can really do it. Peer support has been found to be especially effective at reaching the hardly reached, higher-risk, lower health literacy populations. This field should take examples of programs and scale them to populations. The Task Force discussed how important peer support is and expressed frustration that this model is not used; lack of utilization of peer support can be because it is seen as a less scientific, less medical approach. The Task Force hopes to recommend policies for giving community organizations (such as faith based organizations and local nonprofits) more opportunities and resources to implement peer support.

PANEL OF PEER SUPPORT COUNSELORS

James H. Bundy

Member of Peer Support Group
Alzheimer's North Carolina

Earl M. Craig, Jr.

State Certified Peer Support Specialist
Presenter, In Our Own Voice
National Alliance for the Mentally Ill (NAMI-North Carolina Chapter)

Tamara Norris, MSSW, MPA

Clinical Associate Professor
Associate Director, Family Support Program
School of Social Work, University of North Carolina at Chapel Hill

Anna Norton

Operations Manager
Diabetes Sisters

Dr. Zolotor introduced the panel and asked the panelists to introduce themselves and describe their experience with peer support. Jim Bundy has been a member of several peer support groups over the last 25 years. In his experience, knowledge is power and support groups provide a great deal of knowledge. Support groups also help individuals think about how they will deal with certain situations before they arise. Earl Craig introduced himself and described his mental illness diagnoses. He provides peer support to others over the phone through the National Alliance for the Mentally Ill (NAMI). Tamara Norris described her work with the

Family Support Program at UNC's School of Social Work, which provides parent to parent support for families with special needs children. Anna Norton oversees a national network of local support groups for women living with diabetes through Diabetes Sisters.

There were several common themes from panelists. Peer supporters provide wisdom from experience as well as empathetic listening. Peer support is a proven, cost-effective way to engage patients in their health and health care. Panelists also discussed ways to improve peer support. Education is vital, and we must find a way to raise awareness about the value of peer support by communicating the evidence that peer support works. There is a great need to decrease stigma and promote the model among providers. Building capacity for community based organizations that do a lot of peer support work is another area to work on.

There was Task Force discussion about whether peer supporters should have the same diagnosis as those they are supporting. Some think that they should, while others believe it is more helpful to match peers based upon what they want to get out of the relationship. The Task Force also discussed formal versus informal peer support networks. There is an added benefit of accountability that comes from more formal support relationships. In both cases, peer supports need to be informed and well-trained. It is important to be mindful of ways that peer support groups can be improved upon to support individuals with varying practical and emotional needs. The Task Force should make recommendations that bridge gaps between groups that need support rather than keeping them separate.

NEXT STEPS

Adam Zolotor, MD, DrPH

Vice President

North Carolina Institute of Medicine

Dr. Zolotor facilitated a discussion on next steps. He compiled preliminary recommendations from the Task Force and asked members to continue to think about how to refine recommendations. Moving forward the Task Force would like to continue to explore how to incentivize and reimburse SDM and peer support.