FAMILY-CENTERED CARE

SOME PRACTICAL ISSUES FOR BUILDING A SUCCESSFUL COLLABORATION

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April, 2013
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LEARNING OBJECTIVES

1. Understand the role of effective collaboration strategies in the context of family-centered care

2. Identify common barriers/impediments and facilitators for collaboration in the planning and implementation of family-centered care.
“My daughter has multiple complex problems and out previous hospitalizations have been nightmares; as a matter of fact the past experiences were so difficult that I did not want my child admitted. But with a medically fragile child, this was our only option…”

Adapted from: Kitchen (2005)
Fortunately with Family-Centered Care, things were different…

“…Our recent stay was the best we have experienced in years…The needless frustration and mistakes that the PNP saved for us was truly amazing. She familiarized herself with my daughter’s medical history and condition and stayed on top of everything that was happening. She reported to physicians and to us on a regular basis. The lack of continuity of care is the most frustrating and scary thing that occurs to parents/caregivers of complex children. I am still in awe of how much the PNP improved our experience.” Source: Kitchen (2005)
PRINCIPLES OF FAMILY-CENTERED CARE

- Educational and emotional support
- Peer-to-peer support
- Flexibility
- Collaboration
- Empowerment
- Dignity and Respect
- Recognize family strengths
- Choice
- Communication
- Information sharing

Institute for Family Centered Care, 2005.
IS THERE ANY DIFFERENCE BETWEEN PATIENT-CENTERED AND FAMILY-CENTERED?
SOCIAL ECOLOGY OF CHILD HEALTH
FAMILY CENTERED COMMUNITY-BASED SYSTEM OF SERVICES FOR CHILDREN
PATIENT- AND FAMILY-CENTERED CARE

Patient- and family-centered care is grounded in collaboration among patients, families, physicians, nurses, and other professionals in clinical care as well as for the planning, delivery, and evaluation of health care, and in the education of health care professionals and in research, as well.
COLLABORATION:

Patients, families, health care practitioners, and leaders collaborate in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.
PARTICIPATION:

Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
ROLE OF COLLABORATION WITH PATIENTS AND FAMILIES FOR IMPROVING CARE QUALITY

Transformative action at:
- The experience level
- The clinical microsystem
- The organizational level
- The environmental or societal level
AT THE EXPERIENCE LEVEL: HOW TO COLLABORATE

Providers:
- Must provide care in a manner that is respectful to the family culture and values
- Assure sharing of information in an ongoing manner
- Support and encourage the participation of patients and families

Family:
- Can contribute to the process of gathering information about patient and family perceptions of care
- Can contribute to the process of analyzing and responding to collected data
AT THE CLINICAL/SERVICE MICROSYSTEM:

**Providers:**
- Senior leaders and front line staff must be knowledgeable, skilled, and committed to collaborate with families in the design of the experience of care.
- Optimize access to that care, allow for participation, and support and stimulate activation and commitment to achieving their clinical goals.

**Family:**
- Patients and family advisors should participate as full members of quality improvement and redesign teams
- Participate from the beginning in planning, implementing, and evaluating change.
AT THE ORGANIZATIONAL LEVEL:

**Providers:**

- Mechanisms to integrate the perspectives and voices of patients and families into quality improvement, planning, and policy and programmatic development at the organizational level.

- Patient and family faculty programs should be an integral part of all schools and clinical programs preparing health professionals and administrative leaders.

**Family:**

- Patients and families should participate as full members of key committees such as patient safety, facility design, quality improvement, patient/family education, ethics, and research.

- Patient and family advisory councils should report to senior leadership, patient and family faculty programs should function in a way that assists academic institutions in achieving their academic mission.
AT THE SOCIETAL LEVEL: (THAT INCLUDE US)

Providers:
Local, state, federal, and international agencies, along with accrediting and licensing bodies, are in a position to set the expectation and develop reimbursement incentives that encourage and support the engagement of patients and families in health care decision-making at all levels.

Must support initiatives that build the collaborative skills of patients, families, and health care professionals, and agency personnel.

Family:
The perspectives of patients and families can inform policies developed and issued by these public and private agencies.
Programs in graduate and undergraduate schools for the health professions and health care administration.
Families mobilized through community-wide efforts to reach policy makers and other stakeholders.
WHY, IF FAMILY-CENTERED HAS RECOGNIZED VALIDITY, DO WE EXPERIENCE DIFFICULTY IMPLEMENTING IT?

COLLABORATION EFFORTS INSUFFICIENT OR INAPPROPRIATE
BARRIERS FOR COLLABORATION
ATTITUDINAL BARRIERS

- Fear that patients’ and families’ suggestions will be unreasonable.
- Fear that patients and families will compromise confidentiality.
- Belief that a customer service program is sufficient to ensure patient satisfaction and involvement.
MORE ATTITUDINAL BARRIERS

- Perception that there is a lack of evidence for patient- and family-centered practices.
- Belief that patient- and family-centered care is not necessary (“We are knowledgeable, caring professionals. We know what’s best for our patients. We are all patients.”)
MORE ATTITUDINAL BARRIERS

- Belief that patient- and family-centered care is time-consuming and costly resources.
- Belief that their patients are too poor, too violent, too uneducated, too humble to be engaged or to engage.
EDUCATIONAL BARRIERS

❖ Lack of understanding and skills for collaboration on the part of health care professionals and administrators as well as of patients and families.

❖ Leaders’ lack of understanding of patient- and family-centered and its benefits.

❖ Organizations unprepared to provide patient and family members with the training and support needed to participate effectively in collaborative endeavors.
ORGANIZATIONAL BARRIERS

- Lack of guiding vision.
- Tendency to implement either a top-down approach to initiating partnerships with insufficient effort put in to building staff commitment, or the tendency to implement a grass-roots effort that lacks leadership, commitment and support.
- Organizational culture.
- Scarce fiscal resources and competing priorities.
- Inadequate organizational leadership.
FACTORS THAT FACILITATE COLLABORATION
FACILITATORS FOR COLLABORATION

✓ Having senior leaders who are knowledgeable about and committed to collaboration with patients and families.

✓ Designating a staff member, with patient- and family-centered knowledge and skills to serve as a liaison for collaborative endeavors.

✓ Creating a variety of ways for patients and families to serve as advisors within an organization and ensuring that they can contribute meaningfully to decision-making—that their presence is not merely tokenism.
FACILITATORS FOR COLLABORATION

✅ Recruiting patients and families continually for various terms of service to support sustainability and ensuring that these individuals represent the diversity of the community served.

✅ Investing in orientation and training in patient- and family-centered care and in strategies for effective collaboration for patients, families, staff, and physicians.
FACILITATORS FOR COLLABORATION

- Investing in educational and planning activities for patients, families, physicians, and staff to engage in together in order to develop trusting relationships and understanding of shared and differing perspectives.

- Supporting the development of patient and family leaders.

- Providing staff and physicians with ongoing support and mentoring to address challenges related to collaborating with patients and families as they arise.
FACILITATORS FOR COLLABORATION

✓ Understanding that patient- and family-centered care is cost-effective—that initial investments in training are modest and will be quickly repaid in terms of increased family and patient satisfaction, improved staff satisfaction and retention rates, and greater market share.

✓ Ensuring that everyone involved realize that moving toward patient- and family-centered care is a process and that they trust this process and one another.

✓ Measuring outcomes.

✓ Celebrating accomplishments and rewarding efforts.
WHAT CAN WE DO TO INTEGRATE FAMILY-CENTERED IN OUR LOCAL PUBLIC HEALTH PROGRAMS AND SERVICES, INCLUDING HEALTHCARE?

Programs or health services in your community (non-clinical settings) where a family-centered approach is needed...
REFERENCES


Institute for Patient- and Family-centered Care. At http://www.ipfcc.org/


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