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BIBLIOGRAPHY AND OTHER RESOURCE MATERIALS FOR ADVANCING PATIENT- AND FAMILY-CENTERED CARE

This bibliography includes written and multimedia resources related to patient- and family-centered care for maternity care, newborn intensive care, pediatric care, adult health care, end-of-life care, patient safety, education of health professionals, facility design, and leadership and organizational change. A section on cultural competency is also included as it is integral to the practice of patient- and family-centered care. In advancing the implementation of patient- and family-centered care, it is helpful to read the literature beyond one's own specific discipline or field. A list of relevant websites is included at the end of this bibliography.

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Selected Web Sites

Institute for Family-Centered Care

www.familycenteredcare.org

The Institute extends its efforts to advance the practice of patient- and family-centered care through its website. The site includes a wealth of practical resources and stories from patients, families, providers, and institutions.

Action Pact, Inc

www.actionpact.com

Action Pact, Inc. is a firm that works with nursing homes and other elder organizations, assisting them in becoming more resident-directed.

Agency for Healthcare Research and Quality

www.ahrq.gov

AHRQ funds, conducts, and disseminates research to improve the quality, safety, efficiency, and effectiveness of health care. The information gathered from this work and made available on the web site assists all key stakeholders - patients, families, clinicians, leaders, purchasers, and policymakers - make informed decisions about health care.

American Association of Critical Care Nurses

www.aacn.org

AACN provides leadership and resources to their members to improve health care for critically ill patients and their families. Core concepts of patient- and family-centered are integrated throughout their practice guidelines.

American Hospital Association

www.aha.org

The AHA is the premier membership organization for U.S. hospitals and provides leadership and advocacy for member hospitals to improve care for patients and their families. IFCC collaborated with AHA to develop the toolkit, *Strategies for Leadership: Patient- and Family-Centered Care* and is available for download at, http://www.aha.org/aha/key_issues/patient_safety/resources/patientcenteredcare.html

Center for Health Design

www.healthdesign.org

The Center for Health Design is a nonprofit research-and-advocacy organization of health care and design professionals who are leading the effort to improve health quality through architecture and design.

Center for Medical Home Improvement

www.medicalhomeimprovement.org

A “medical home” is a model for providing comprehensive primary care to children with special health care needs. The site has practical assessments and resources for providers in community practices and families serving on improvement teams. The complete *Medical Home Improvement Kit* including measurements, strategies, and *A Guide for Parent and Practice “Partners” Working to Build Medical Homes for CSHCN* can be downloaded from the site.

Childbirth Connection

<http://www.childbirthconnection.org>

Formerly known as the Maternity Center Association, this organization is dedicated to improving maternity care quality and value. The executive summary of their second survey of women’s experiences of childbirth is available on the website.

Clinical Microsystems

www.clinicalmicrosystem.org

Funded through the Robert Wood Johnson Foundation, several centers within Dartmouth-Hitchcock Medical Center, in New Hampshire, have been collaborating on exploring health care improvement through the lens of the clinical microsystems model. The Web site offers information and resources and includes examples of how different organizations across the world are applying the model.

Collaborative Family Healthcare Association

www.cfha.net

The mission of the CFHA is to develop a better healthcare model through the collaboration among family medicine practitioners, family therapists, and patients and their families. Educational resources, including selected articles from their journal, *Families, Systems, and Health* are included.

The Eden Alternative

<http://www.edenalt.com>

The Eden Alternative™ is changing the experience of aging and disability. It seeks to eliminate loneliness, helplessness, and boredom by promoting dynamic and humanistic environments supportive of caring relationships.

Emergency Nurses Association

www.ena.org

The ENA has been actively promoting family-centered emergency care. Their position statement, *Family Presence at the Bedside During Invasive Procedures or Resuscitation* is available on the site.

Family Voices

www.familyvoices.org

Family Voices offers a variety of information and resources for families and providers caring for children with special health care needs. Family Voices activities embody the principles of patient- and family-centered care.

Foundation for Informed Medical Decision Making

www.fimdm.org

The mission of FIMDM is to strengthen the ability of patients in making decisions about their health care. The site offers evidence-based information about treatment options, interviews with patients, decision-aids to guide decision-making, and other tools on a variety of conditions.

Improving Chronic Illness Care

www.improvingchroniccare.org

As a national program of the Robert Wood Johnson Foundation, ICIC is dedicated to improving the experience of chronic illness care for patients and their families. This site provides resources about the Chronic Care Model, which views the patient as a partner with providers in decision-making, participation in care, and quality improvement.

Institute for Healthcare Communication

www.healthcarecomm.com

Formerly the Bayer Institute for Health Care Communication, this organization has been providing education and resources to promote partnerships between patients and providers in clinical practice. The site offers many resources for professional development including, an *Annotated Bibliography for Clinician Patient Communication to Enhance Health Outcomes* as well as case studies and training resources.

Institute for Healthcare Improvement

www.ihl.org

IHI has been a leader in advancing the improvement of health care. IHI's ever-expanding Web site has a wealth of information on patient and family involvement in quality improvement and research. This includes strategies to capture the patient and family experience of care as well as to involve patients and families on evaluation teams.

Institute of Medicine

www.iom.edu

The IOM is affiliated with the National Academies of Science and serves as a non-profit organization devoted to providing leadership on health care. IOM's major report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, serves as a landmark publication in examining the problems of the current U.S. health care system and offering strategies for change.

International Alliance of Patients' Organizations

www.patientsorganizations.org

The IAPO is an international alliance of patients' organizations that promotes patient-centered health care throughout the world. Core principles include respect for unique needs, preferences, and values; choice and empowerment; information sharing; and patient involvement in health policy.

Josie King Foundation

www.josieking.org

In 2001, Josie King, the 18 month old daughter of Tony and Sorrell King, died from medical errors. This organization is dedicated to preventing others from dying or being harmed by medical errors. Efforts to promote partnerships among patients, families, and health care providers are integral to the foundation's work.

MITSS Medically Induced Trauma Support Services

<http://www.mitss.org>

MITSS is a patient-led non-profit organization creating awareness about medically induced trauma, promoting open communication among patients, families, and health care professionals, and providing support to individuals who have been affected by medical error.

National Association of Emergency Medical Technicians

www.naemt.org

NAEMT is an international membership organization representing emergency technicians, paramedics, and others working in emergency care. In 2000, NAEMT in partnership with the Emergency Medical Services for Children, published a series of documents on family-centered emergency care which are available online.

National Center for Cultural Competency

<http://gucchd.georgetown.edu/nccc/>

This center's work is focused on increasing the capacity of health and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems. They offer numerous and valuable online resources including self-assessment tools and publications.

National Family Caregivers Association

www.nfcacares.org

NFCA serves as a clearinghouse of information and support for those caring for others who are aged, disabled, or chronically ill. There are a variety of stories and tools to empower family caregivers and promote advocacy.

National Patient Safety Foundation

www.npsf.org

With its mission to improve the safety and welfare of patients in the health care system, NPSF provides an indispensable amount of resources including a specific area devoted solely to resources for patients and families who wish to get involved in patient safety initiatives.

New Health Partnerships

<http://www.newhealthpartnerships.org>

New Health Partnerships is an online community for patients, their families, and health care providers dedicated to improving the health care and lives of people with chronic conditions. Profiles of individuals and organizations, information, tools and other resources promoting collaborative self-management support are offered.

Orelena Hawks Puckett Institute

www.puckett.org

The Puckett Institute develops and conducts research and evaluation, implements demonstration projects, and provides training and technical assistance on issues affecting infants, young children, and their families. The Directors of the Institute have over two decades of research experience and have focused efforts on eliminating the factors that interfere with the ability of research to lead to evidence-based practice.

Patient Decision Aids

<http://decisionaid.ohri.ca>

This site is part of the Ottawa Health Research Institute and was created to assist clinicians and patients make difficult health care decisions. The program is research-based and the site offers online tools, clinician training programs, and other resources.

Patients Accelerating Change (PAC)

www.pickereurope.org/page.php?id=13

Patients Accelerating Change (PAC) is a program in the United Kingdom bringing patients together with clinicians and managers in hospitals and primary care settings to transform health care services. A resource packet with case studies and lessons learned through this collaborative work is available from the Picker Institute Europe and the Clinical Governance Support Team.

Patient Safety and Quality Healthcare

www.psqh.com

This online journal offers numerous articles highlighting the role of patients and families in patient safety and identifying strategies and benefits.

People at the Centre of Care Initiative – World Health Organization

www.wpro.who.int/sites/pci/

This new initiative of the World Health Organization aims to promote policy and program development throughout the world to insure the provision of safe and high-quality people-centered health care.

Pioneer Network

www.pioneernetwork.net

The Pioneer Network is an organization bringing together elders, family members, administrators, nurses, physicians, other providers, advocates, and architects to promote culture change in all settings where elders live.

Planetree

www.planetree.org

Planetree is a non-profit membership organization based in Derby, Connecticut. It works with hospitals and healthcare organizations to develop and implement patient-centered care in healing environments.

Professionals with Personal Experience in Chronic Care

www.ppecc.org

This group of health care professionals established PPECC to advocate for improved systems of care after personal and family experiences with chronic illness and long-term care. Health care professionals are encouraged to share their personal experiences with the health care system in order to promote greatly needed change.

Remaking American Medicine

www.ramcampaign.org

In 2006, PBS will air the Remaking American Medicine series that will both present the current state of health care and strategies for improvement. This Web site was created to support the work of local communities across America to effectively improve the quality of health care.

Robert Wood Johnson Foundation

www.rwjf.org

RWJF has been working for over 30 years to improve U.S. health care through supporting research, advocacy, and policy work. RWJF has funded innovative programs that integrate patient- and family-centered care into their initiatives. A good example can be found in a current project, *Designing the 21st Century Hospital: Serving Patients and Staff* and is a great resource for leaders and managers undergoing a design project, <http://www.rwjf.org/files/publications/other/Design21CenturyHospital.pdf>.

The Kenneth B. Schwartz Center

www.theschwartzcenter.org

Shortly before his death from lung cancer in September of 1995, Kenneth B. Schwartz established a Center dedicated to strengthening the relationship between patients and caregivers in the changing health care system through professional education, public education, and support.

The Sorry Works! Coalition

www.sorryworks.net

This coalition composed of all stakeholder groups, including providers, lawyers, and patients, is promoting a transparent model of disclosure of medical errors titled, Sorry Works! Details about the model and related data are presented on the site.

United Hospital Fund

www.uhfny.org

Although this is a New York state organization, it has been at the forefront of shaping positive change in health care systems. A key focus has been on aging and chronic care and the site offers family-centered resources and information for supporting caregivers at www.uhfny.org/homepage3223/index.htm.

Voice for Patients

www.voice4patients.com

Voice4Patients is an organization devoted to empowering patients to be their own health care advocates in order to address patient safety concerns and medical errors. The organization advocates building partnerships between patients and providers and provides information and tools to strengthen consumer skills.

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