



Resources for Teaching Family-Centered and Family-Directed Practices

The MCHB Family-Centered and Family-Directed Practices Training Priorities Workgroup has compiled a series of resources.* The information included is a selection rather than a comprehensive listing of all available resources. The purpose of this resource list is to provide educators and trainers with guidance about high quality, accessible resources that foster the practice of family-centered and family-directed care. As newly identified resources emerge, we hope training programs will update this document for their specific purposes. The resource materials were selected based on the following criteria:

- Up to date or developed within the past 10 years
- Offered in a variety of formats such as print, video, and articles
- Addressed different audiences and disciplines
- Addressed multiple skill levels from beginners to highly skilled practitioners

- Accessible and/or reasonably priced
- Relevant and had ease of application in the practice setting
- High quality

Family-centered care and cultural and linguistic competence are integrally linked, and are viewed by many as essential approaches to address the health care needs and preferences of families, children and youth. However, the literature to advance family-centered care and cultural and linguistic competence has often evolved along parallel tracks. A review of the literature conducted in 2005 found little mention of cultural competence in family-centered care resources (Arango & McPherson¹). Acknowledging this limitation in the extant literature and materials, the resources in this guide were reviewed to determine the extent to which culture and language and cultural and linguistic competence were addressed.

* The following workgroup members compiled the resources: Susan Horkey, Barbara Levitz, Tawara Goode, Angela Miney, and Mark Smith.

¹ Arango, P. & McPherson, M. (2005). National review of family-centered care. Paper presented at the meeting of the Maternal and Child Health Bureau, Division of Services for Children with Special Health Care Needs, "Family-Centered Care and Cultural Competence", Washington, DC.

Web-based Resources

The American Academy of Pediatrics Medical Home Initiative

Web Address: <http://www.medicalhomeinfo.org/training/programs.html>

Type of Information: Training tools

Last Updated: March 2006

Intended Audience/Skill Level: Residents and providers

Evaluation/Reviewer Comments: These are powerpoint presentations about CYSHCN and the “medical home.” They include strategies for culturally effective care and honoring the diversity of families.

Linguistic competence is not discussed in any depth, but the site does mention the importance of interpreters and translators and materials in the primary languages spoken by clients.



The Institute for Family Centered Care

Web Address: <http://www.familycenteredcare.org/advance/clinician-links.html>

Type of Information: Comprehensive set of resources including profiles of change, events, advancing the practice, articles of interest

Intended Audience/Skill Level: Health providers/New to advanced

Evaluation/Reviewer Comments: This site provides a long list of links to the home pages of other organizations. It may be helpful to someone looking for how organizations construct their policies regarding family and patient centered care. Some sites do not address cultural or linguistic competence at all; some do in depth (e.g., the NCCC); and some (e.g. the DOCS curriculum) discuss cultural competence (including the importance of interpreters) as a separate session, not integrated into the full curriculum.

US Department for Health and Human Services, Health Resources and Services Administration, Cultural Competence Resources for Health Care Providers

Web Address: <http://www.hrsa.gov/culturalcompetence/>

Type of Information: Comprehensive set of resources including assessment tools, web based courses, health topics (HIV/AIDS, breast cancer detection), culture/language specific issues, health professions education, technical assistance and training curricula

Last Updated: June 2006

Intended Audience/Skill Level: Health providers, educators/New to advanced

Evaluation/Reviewer Comments: This is a list of resources focused on cultural competence. Many are about specific culture groups or special populations. A number of items address linguistic competence. Many are also disease-specific, with particular emphasis on HIV, but there is also general cultural competence information, and assessment tools. This website only addresses the practice of family-centered care within the specific context of cultural competence.

Web-based Resources

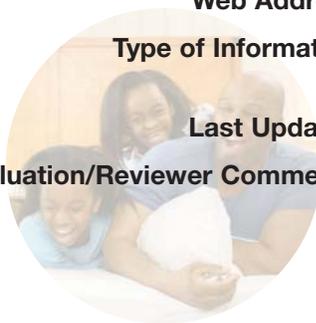
Practice Guideline from the Montana Disability and Health Program

Web Address: <http://rtc.ruralinstitute.umn.edu/advocacy/Advisory.htm>

Type of Information: Involving People with Disabilities as Members of Advisory Groups: Rural Practice Guidelines

Last Updated: July 2004

Evaluation/Reviewer Comments: This site addresses how to include people with disabilities (primarily developmental disabilities) in an advisory group. It does not explicitly address culture, but does have suggestions for how to be mindful of barriers to participation. Many of these suggestions could be relevant when including non-disabled patients and families, particularly those with lower English proficiency or literacy skills.



Beach Center on Families and Disability at the University of Kansas

Web Address: <http://www.beachcenter.org/>

Type of Information: Extensive website with numerous tools and resources on family-centered and family-directed practices as related to children with disabilities and their families

Evaluation/Reviewer Comments: The best way to link to family-centered resources at this site is to go to: http://www.beachcenter.org/resource_library/default.aspx, and then click the "Topic" button, and then "Family & Professional Partnership" there is a nice list of resources that include family involvement and cultural and linguistic competence. Some links go directly to the information (often lists of tips), some provide a link to an article, and some only provide a short description of a publication.

National Center for Cultural Competence, Georgetown University Center for Child and Human Development

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

Type of Information: Comprehensive array of resources on cultural and linguistic competence including curricula enhancement module series, policy briefs, guides, checklists, self-assessment instruments, consultant pool, annotated resource database, promising practices, Spanish language portal, and special features including one designed for families and youth

Last Updated: monthly

Intended Audience/Skill Level: 1-4th year students, residents, providers, university faculty, practicing health and mental health professionals (The web site has broad appeal to varied audiences including families, providers, researchers, university faculty, policy makers, administrators)

Evaluation/Reviewer Comments: This website has many resources on cultural and linguistic competence. Family-centered care is integrated into these resources and family-centered concepts and practices are apparent throughout. A search of the resource database yields several articles explicitly related to both cultural competence and family-centered care including a Family Support Policy Brief; A Guide to Advancing Care that is Family-Centered and Culturally and Linguistically Competent; The Story of Buda (written by the mother of a child with special health care needs) and several transitions articles and frameworks.

Web-based Resources

The Family Village Project

Web Address: <http://www.familyvillage.wisc.edu/new.html>



Type of Information: This is a web site for children and adults with disabilities, their families, and their friends and allies. Family Village brings together thousands of online resources in an organized, easy-to-use directory. The centerpiece of Family Village is the library, where visitors can find information on over 300 diagnoses. Visitors can also learn about assistive technology, legal rights and legislation, special education, leisure activities and much more.

Evaluation/Reviewer Comments: This is a very user friendly, family friendly site with many resources. It is designed to allow families to obtain information on their own. The site provides a good picture of resources and the needs and interests of families. Cultural and linguistic issues are only alluded to peripherally.

NICHCY

Web Address: www.nichcy.org

Type of Information: NICHCY is the National Dissemination Center for Children with Disabilities. It serves the nation as a central source for a wealth of information on disabilities:

- disabilities in infants, toddlers, children, and youth,
- IDEA, which is the law authorizing special education,
- No Child Left Behind (as it relates to children with disabilities), and
- research-based information on effective educational practices.

Offers publications and communication in English or Spanish

Evaluation/Reviewer Comments: This site provides numerous resources for families. There is no didactic information about cultural or linguistic competence, but materials are offered in Spanish.

New Health Partnerships: Improving Care by Engaging Patients

Web Address: <http://newhealthpartnerships.org/default.aspx>

Evaluation/Reviewer Comments: This site has a number of wonderful links, tools and videos for families and providers. While some links and tools encourage understanding the family's values and viewpoint, an initial survey of the site does not yield specific information on cultural or linguistic competence.

Pediatric Pulmonary Centers

Web Address: http://ppc.mchtraining.net/index.php?option=com_frontpage&Itemid=1

Type of Information: Family Involvement Pediatric Pulmonary Centers

Evaluation/Reviewer Comments: Although not a full curriculum, this document provides a tool for trainees that highlights the different aspects of family involvement and what each PPC does in this area. Available by clicking on Resources, then Documents.

Video Resources

“Worlds Apart: A Four-Part Series in Cross Cultural Healthcare” by Grainer-Monson, M and Haslett, J. Boston, Mass: Fanlight Productions, 2004.



Web Address: www.fanlight.com

Type of Information: A teaching tool funded by The Greenwall Foundation; The Commonwealth Foundation; The Arthur Vining Davis Foundation; and TheCalifornia Endowment.

Includes a series of four videos designed to help health care providers learn about working with families from other cultures. Discussion guide is included.

Evaluation/Reviewer Comments: This series is specifically designed to address differences in cultural beliefs and how best to partner with families with different cultural beliefs and/or who speak diverse languages. Family-centered care is not explicitly addressed, but is implied.

Institute for Child Health Policy

Web Address: <http://video.ichp.ufl.edu/>

Type of Information: Provides a series of videos about CSHCN and their families during transition to adult health care, Social Security programs, Family Voices

Evaluation/Reviewer Comments: Cultural and linguistic competence is rarely explicitly addressed, although working with and respect for families of all style and backgrounds is emphasized.

Fanlight Production

Web Address: <http://www.fanlight.com/catalog/subjects/maternal.php>

Type of Information: Provides extensive listing of videos on maternal and child health

Evaluation/Reviewer Comments: One subsection of the database is on “Cross cultural” videos all sub-sections contain videos that discuss a variety of cultures. As it is not possible to review the videos, the degree to which linguistic competence is addressed is difficult to assess. Videos cost varying amounts.

Remaking American Medicine, PBS video

Web Address: <http://www.pbs.org/remakingamericanmedicine/care.html>

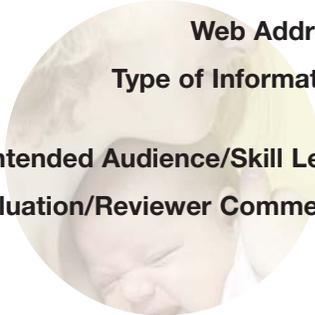
Type of Information: Addresses family-centered care topics through documentary

Evaluation/Reviewer Comments: Cost: \$29.99

The website does not address cultural or linguistic competence. It is not clear whether or not the documentary addresses these.

Family-centered Courses/Curriculum

Teaching Family-Centered Care to Medical Students and Pediatric Residents at the University of Vermont—A Partnership with Families



Web Address: <http://www.partoparvt.org/ffi.html>

Type of Information: Parent to Parent staff introduces the concept of family-centered care to medical students during their orientation to pediatrics in this 3-part session.

Intended Audience/Skill Level: Medical students

Evaluation/Reviewer Comments: This site provides extensive information about Family-Centered Care and the teaching of this topic. Cultural competence is addressed in one session; it is not clear from the instructor's manual whether or not linguistic competence is addressed. Respect for families with different challenges and beliefs and respect for differences are emphasized throughout the curriculum.

Pediatric Pulmonary Centers, Cross Cultural Health Care Case Studies

Web Address: http://support.mchtraining.net/national_ccce/

Type of Information: An interactive self-study program consists of a series of five tutorials in cultural competence, aimed at familiarizing health care providers with common issues that arise while working with people of diverse cultures.

Evaluation/Reviewer Comments: These case stories are designed to help health professionals communicate in a culturally competent manner. Linguistic competence is addressed and is the primary focus of one of the case stories.

Iwaishi L, Taba S, Howard-Jones A, Brockman D, Yamashita L, Ambrose A. Training on Family Centered Interprofessional Collaboration. Health and Education Collaboration Project, Hawaii Medical Association, 1998.

Intended Audience/Skill Level: Health care professionals, residents, and other health care trainees.

Evaluation/Reviewer Comments: Well designed 10 week curriculum, complete with learning activities, that teaches interdisciplinary, family-centered care. There is a specific section on "Respecting Diversity" with several exercises related to cultural competence. Linguistic competence is not specifically addressed, although the need to communicate in ways that are respectful of families and that families will understand is identified. Although cultural competence is not explicitly integrated into the rest of the curriculum, the need to listen to, learn about, partner with and respect families with different needs and beliefs is emphasized.

Workshops/Trainings

Federation of Families for Children's Mental Health training curriculum CD

Web Address: www.ffcmh.org

Type of Information: Provides conferences, publications, training, evaluation for families

Last Updated: 2007

Intended Audience/Skill Level: Families

Evaluation/Reviewer Comments: Has a number of resources designed to help families link with other families, negotiate systems, and advocate. While it is not possible to read all materials on this site, a brief perusal does not yield much specific information about cultural or linguistic issues. However, materials are written clearly at about a 3rd grade level and resources are included for underserved populations (e.g., Native Americans)



"Talk to Your Doc"

Web Address: <http://www.health-disciplines.ubc.ca/DHCC/student/student.htm>

Type of Information: A Workshop on Youth for Communicating with Physicians. Division of Health Care Communication, University of British Columbia College of Health Disciplines.

Last Updated: December 2005

Intended Audience/Skill Level: Medical students, youth

Evaluation/Reviewer Comments: This site also provides a teachers manual entitled, "Cross-Cultural Communication in Health Care Education": A Course Manual for Students and Teachers. This addresses both cultural and linguistic competence at length. Found under "educational resources" on this site.

Florida Development Disabilities Council

Web Address: <http://hctransitions.ichp.ufl.edu/ddcouncil/>

Type of Information: Provides transition training

Intended Audience/Skill Level: Families and health care providers

Evaluation/Reviewer Comments: Cultural and linguistic competence is rarely explicitly addressed, although working with and respect for families of all style and backgrounds is emphasized.

"A Historical Overview of Interdisciplinary Family Health: A Community-Based Interprofessional Health Professions Course" by Richard A. Davidson, MD, MPH, and Rhondda Waddell, MSW, LCSW

Web Address: <http://families.health.ufl.edu/IFH.pdf>

Intended Audience/Skill Level: Educators, students

Evaluation/Reviewer Comments: This article talks about a course designed by a group at UF to teach family-centeredness <http://families.health.ufl.edu/IFH.pdf>. This course addresses cross cultural communication, but is less specific about issues of linguistic competence and interpretation/translation.

Family-centered Articles/Abstracts

“Developing and Sustaining a Patient and Family Advisory Council” by Patty Devine Webster and Beverley H. Johnson.



Web Address: <http://www.familycenteredcare.org/resources/pinwheel/famcouncil.html>

Type of Information: This resource profiles a variety of consumer advisory councils, their structures, and activities. Guidance on establishing a new council and sustaining the momentum of an existing council is included. Descriptions include council responsibilities and the potential impact a council can have on an organization. Sample materials and forms from established councils across North America and an annotated bibliography are also included

Evaluation/Reviewer Comments: I received it from the Institute for Family Centered Care
7900 Wisconsin Ave., Suite 405 Bethesda, Maryland 20814

Wells, C and Reiss, J. “Making it Work: When Families That Represent a Service Population Become Employees. September, 2002.

Type of Information: This document is written for leaders in organizations that recognize the importance of hiring family representatives and for family members who would like to work in an organization as a family representative. It is designed to identify the most significant issues, describe reasonable approaches for addressing these issues, and identify promising approaches.

Web Address: cshcnleaders.ichp.edu/PDFFiles/CEPRManual_v1.pdf

LEND Family Discipline Competencies

Web Address: <http://www.aucd.org>

Association of University Centers on Disabilities (AUCD)

(Can be down-loaded on line as a web-based document or ordered as a print document)

Last Updated: October 2006

Intended Audience/Skill Level: Trainees

Evaluation/Reviewer Comments: Includes a brief article about best practices in Family-Centered Care training and a comprehensive list (in table format) of competencies trainees are expected to achieve and activities that might be used to achieve these. These include numerous objectives and activities related to cultural and linguistic competence.

Family-centered Articles/Abstracts

Promising Practices in Family Mentorship: A Guidebook for MCHB-LEND Training Programs. October 2006



Web Address: http://www.aucd.org/template/news.cfm?news_id=115

Association of University Centers on Disabilities (AUCD)

(Can be down-loaded on line as a web-based document or ordered as a print document)

Type of Information: This is a step-by-step guide for establishing or enhancing Family Mentorship programs as one way to incorporate the life experiences and expertise of families into professional training programs.

Developed around experiences of UCEDDs but also applicable to establishing family advisory groups for other training programs

Intended Audience: Program Directors, Training Coordinators and Family Faculty

Evaluation/Reviewer Comments: This includes discussion and consideration of both cultural and linguistic issues.

Consumer Advisory Committees: Recommendations for Meaningful Participation of Individuals with Disabilities and Families

Web Address http://www.aucd.org/template/news.cfm?news_id=390

Association of University Centers on Disabilities (AUCD)

(Can be down-loaded on line as a web-based document or ordered as a print document)

Evaluation/Reviewer Comments: This includes discussion and consideration of both cultural and linguistic issues.

Oklahoma Family Support Partnership Project, "Individual and family support principles to practice indicators. Oklahoma City, Oklahoma: Center for Learning and Leadership/UCEDD-College of Medicine, OUHSC and Oklahoma Family Support Partnership.

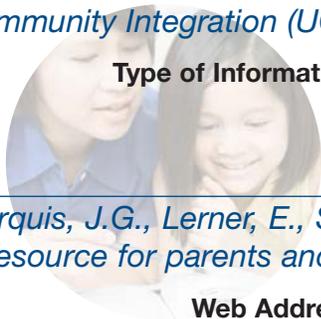
Web Address: <http://w3.ouhsc.edu/thecenter/familysupport.htm>

Type of Information: This document in booklet form, developed by members of the Oklahoma Family Support Council, identifies ways of interacting, providing services, and developing policies that reflect the principles of family support.

Intended Audience: This is highly relevant for family-centered and family-directed practices. It identifies "indicators" (actions and attitudes) and questions to guide self-assessment. Targets three groups: individual and family, provider and system.

Family-centered Articles/Abstracts

Impact: feature issue on enhancing quality and coordination of health care for persons with chronic illness and/or disabilities, Vol.18-No.1. Winter 2005 Minneapolis, MN: Institute on Community Integration (UCEDD).



Type of Information: A compilation of articles by families and professionals related to promoting family-centered and family-directed practices. Good addition to a recommended reading list for training program.

Marquis, J.G., Lerner, E., Santelli, B. & Turnbull, A.P. 1997. Parent to Parent Programs: A resource for parents and professionals. Journal of Early Intervention 21(1); 73-83

Web Address: www.beachcenter.org

Evaluation/Reviewer Comments: This article, while very useful, does not specifically address cultural or linguistic issues

Turnbull AP, Turbiville V & Turnbull HR (2000). Evolution of family-professional partnership models: Collective empowerment as the model for the early 21st century. In SJ Meisels & JP Shonkoff (Eds). Handbook of early intervention (pp. 630-650). New York, NW: Cambridge University Press.

Web Address: www.beachcenter.org

Evaluation/Reviewer Comments: This article, while very useful, does not specifically address cultural or linguistic issues

Wilson-Stonks, A, Galvez, Erica Exploring Cultural and Linguistic Services in the National's Hospitals: A Report of Findings

Web Address: <http://www.jointcommission.org/PatientSafety/HLC/>

Type of Information: *Hospitals, Language, and Culture: A Snapshot of the Nation* is a three year cross-sectional qualitative study funded by The California Endowment designed to explore how 60 hospitals across the country provide health care to culturally and linguistically diverse patient populations. The premise of the article is that the delivery of health care services in a manner that is respectful and appropriate to an individual's language and culture is more than simply a patient's right, but is, in fact, a key factor in the safety and quality of patient care (Schyve, 2002).

Evaluation/Reviewer Comments: This article focuses on the many valuable aspects of cultural and linguistic competence.

Family Advocacy Groups

Family Voices



Web Address: <http://www.familyvoices.org/>

Background: Family Voices is a national grassroots network of families and friends which advocates for health care services and provides information for families with children and youth with special health care needs.

Evaluation/Reviewer Comments: Family Voices has a strong, stated commitment to Cultural Competence and both cultural and linguistic competence are addressed in their “Diversity Statement”

Parent to Parent-USA (P2P-USA)

Web Address: www.p2pusa.org

Background: This a national non-profit organization committed to assuring access and quality in Parent to Parent support across the country. This site highlights statewide organizations that have parent to parent support as a core program. Parent to Parent programs provide emotional and informational support to families of children who have special needs most notably by matching parents seeking support with an experienced, trained ‘Support Parent’

Evaluation/Reviewer Comments: Cultural/linguistic issues are not specifically addressed on the website.

PACER Center

Web Address: www.pacer.org

Background: The mission of PACER Center is to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents.

Through its ALLIANCE and other national projects, PACER, a national center, responds to thousands of parents and professionals each year nationwide.

This nationally funded center offers assistance to individual families, provides workshops, materials for parents and professionals, and leadership in securing a free and appropriate public education for all children.

Evaluation/Reviewer Comments: Cultural/linguistic issues are not specifically addressed on the website.

Family Advocacy Groups

Family to Family Health Information Centers



Web Address: <http://www.familyvoices.org/info/ncfpp/f2fhic.php>
See also: <http://www.medicalhomeinfo.org/tools/F2F.html>

Background: Family to Family Health Information Centers (F2F HICs) are federally funded family-run centers established to assist families of children with special health care needs (CSHCN) to make informed choices about health care in order to promote good treatment decisions, cost effectiveness, and improved health outcomes. In addition, F2F HICs are charged with: identifying successful delivery models, providing information on the health care needs and resources available, encouraging collaboration between families of such children and health care professionals, and providing training and guidance on their care.

F2F HICs are funded through support from the federal Maternal and Child Health Bureau's Division of Services for CSHCN, as well as the Center for Medicaid/Medicare Services at the federal Department of Health and Human Services

Evaluation/Reviewer Comments: While the description does not specifically reference family-centered care, it is consistent with the mandates of the Family Opportunity Act, which is the legal basis for funding these centers, and also consistent with principles of family-centered care.

The Grass Roots Consortium on Disabilities

Web Address: <http://www.gcod.org/>

Background: The Grassroots Consortium on Disabilities is a national coalition of community-based, parent directed, family support and information organizations serving culturally and linguistically diverse families who have children with disabilities and are living in traditionally underserved communities. The services provided are individualized, flexible, and comprehensive, often including assistance with meeting basic life needs related to poverty along with the disability-related needs.

Evaluation/Reviewer Comments: The Grassroots Consortium is specifically described as a grassroots coalition of organizations of culturally and linguistically diverse, traditionally underserved families of children with disabilities.

Family-centered Books

Hanson, Marci J. and Lynch, E. (2007 third printing). Understanding families: approaches to diversity, disability, and risk. Baltimore: Paul H. Brookes.

Evaluation/Reviewer Comments: Addresses cultural and linguistic competence in relation to understanding diverse families and disability.

