



Expert Consultants and Bibliography by Topic Area

OVERALL SYSTEM OF CARE FOR CYSHCN

Experts Consulted

Holly Grason, Women's and Children's Health Policy Center, Johns Hopkins University

Charles Homer, National Initiative for Children's Healthcare Quality

Lynda Honberg, Maternal and Child Health Bureau

John Hurley, Minnesota Department of Health

Chris Kus, New York State Department of Health

Cassie Lauver, Maternal and Child Health Bureau

Maria Nardella, Washington State Department of Health

Chuck Onufer, Division of Specialized Care for Children, University of Illinois (Retired)

Phyllis Sloyer, Florida Department of Health

Websites and Written Resources

National Initiative for Children's Healthcare Quality: www.nichq.org

- Title V Index with Change Concepts and Change Ideas
- Title V/CYSHCN Program: Index
- Taylor, J., "Supporting Widespread Adoption of the Medical Home"

New Orleans, LA: NGA Best Practices Conference, January 2009

Perrin, J., Romm, D., Bloom, S., Homer, C., Kuhlthau, K., Cooley, C., Duncan, P., Roberts, R., Sloyer, P., Wells, N., Newachek, P. "A Family-Centered, Community-Based System of Services for Children and Youth With Special Health Care Needs." *Arch Pediatric Adolescent Medicine* 2007;161(10):933-936

Hill, I., Westphal, Lutzky, A., Schwalberg, R., Are We Responding to Their Needs? States' Early Experiences Serving Children with Special Health Care Needs Under SCHIP. (Washington, DC: Urban Institute. May 2001) <http://www.urban.org/url.cfm?ID=310286>

INTEGRATED SERVICES

Experts Consulted

Diane Behl, Champions for Inclusive Communities

Richard Roberts, Champions for Inclusive Communities

Websites and Written Resources

Champions for Inclusive Communities: [www. Championsinc.org](http://www.Championsinc.org)

Roberts, R. Behl, D., Akers, A., "Building a System of Care for Children with Special Health Care Needs," *Infants and Young Children* (2004), Vol. 17, no. 3, pp. 213-222.

MEDICAL HOME

Experts Consulted

Gerri Clark, Division of Specialized Care for Children, University of Illinois

Michelle Esquivel, American Academy of Pediatrics

Eileen Forlenza, CSHCN, Colorado Department of Public Health and Environment

Charles Humble, North Carolina AccessCare

Marie Mann, Maternal and Child Health Bureau

Danielle Matula, North Carolina Department of Human Resources

Chuck Onufer, Division of Specialized Care for Children, University of Illinois (Retired)

Fan Tait, American Academy of Pediatrics

Mary Takach, National Academy for State Health Policy

Renee Turchi, St. Christopher's Hospital for Children

Kathy Watters, Colorado Department of Public Health and Environment

Websites and Written Resources

National Center of Medical Home Initiatives for Children with Special Needs: www.medicalhomeinfo.org

Center for Medical Home Improvement: <http://www.medicalhomeimprovement.org>

Pennsylvania Medical Home website: www.pamedicalhome.org

Colorado Children's Healthcare Access Program: www.cchap.org

Community Care of North Carolina website: <http://www.communitycareNC.com>

Buntin, John. "Health Care Comes Home," March 1, 2009 *Governing Magazine*.
www.Governing.com/node/633

Kaye, N., Takach, M., Building Medical Homes in State Medicaid and CHIP Programs. National Academy for State Health Policy. Copyright 2009. www.nashp.org

Kaye, N., Takach, M., Beesla, R., "Strategies States Can Use to Support the Infrastructure of a Medical Home," *State Health Policy Briefing*, Vol. 2, No. 9 (Portland, ME: National Academy for State Health Policy) May 2008. http://www.nashp.org/sites/default/files/shpbriefing_pcmhsupport.pdf

CARE COORDINATION

Experts Consulted

Jim Bryant, Ohio Department of Health

Gerri Clark, Division of Specialized Care for Children, University of Illinois

Elizabeth Collins, New Hampshire Department of Health and Human Services

Deborah Garneau, Rhode Island Department of Health

Marilyn Hartzell, Oregon Center for Children and Youth with Special Health Care Needs

Lynda Honberg, Maternal and Child Health Bureau

Phyllis Sloyer, Florida Department of Health

Jennifer Warfel, Ohio Department of Health

Website and Written Resources

Oregon CaCoon Program: <http://www.ohsu.edu/cdrc/oscsn/community/nursing1.php>

Illinois Care Coordination: http://internet.dscc.uic.edu/dsccroot/core_prog.asp

New Hampshire Partners in Health: <http://nhpih.dartmouth.edu> and
<http://www.health.ri.gov/family/specialneeds/ppep.php>

Antonelli, R., McAllister, J., Popp, J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework Commonwealth Fund Report. Vol. 10;21, May 2009

Pediatrics 2005;116: 1238-1244; Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs.

Kay Johnson and Jill Rosenthal. Improving Care Coordination, Case Management, and Linkages to Services for Young Children: Opportunities for States. Commonwealth Fund. April 22, 2009, Volume 107

CULTURAL COMPETENCY

Experts Consulted

Sophie Arao-Nguyen, Family Voices

Juno Duenas, Family Voices, California

Wendy Jones, National Center for Cultural Competence

Websites and Written Resources

National Center for Cultural Competence: <http://www11.georgetown.edu/research/gucchd/nccc>

Goode, T. D., Jones, W., Dunne, C., & Bronheim, S. (2007). And the journey continues...Achieving cultural and linguistic competence in systems serving children and youth with special health care needs and their families. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development. Retrieved August 11, 2009. <http://www.gucchdgeorgetown.net/NCCC/journey/>

FAMILY CENTERED CARE

Experts Consulted

Betsy Anderson, Family Voices

Sophie Arao-Nguyen, Family Voices

Bev Crider, Children's Hospital Michigan

Eileen Forlenza, Colorado Title V CYSHCN Program

Bev Johnson, Institute for Family Centered Care

Leolinda Parlin, Hilopa's Family to Family Health Information Center, Hawaii

Nora Wells, Family Voices

Websites and Written Resources

Family Centered Care Self Assessment Tools: http://www.familyvoices.org/pub/projects/fcca_FamilyTool.pdf
and http://www.familyvoices.org/pub/projects/fcca_ProviderTool.pdf

Institute for Family-Centered Care: www.familycenteredcare.org

Association of Maternal and Child Health Programs, "State Profiles in Family Involvement" (2009). In process.

TRANSITION

Experts Consulted

Patti Hackett, Healthy and Ready to Work National Resource Center

Margaret McManus, National Alliance to Advance Adolescent Health

Patience White, George Washington University School of Medicine and Health Sciences.

Jeri Dickinson, Oregon Youth Transition Program

Ed O'Leary, Transition Outcome Projects

Barbara Gilpin, Missouri Department of Elementary and Secondary Education

Websites and Written Resources

Transition for Youth with Disabilities: A Look at State Programs, Progress and Promising Practices. American Public Human Services Association, Center for Workers with Disabilities. July 2006.
http://cwd.aphsa.org/center_initiatives/youth_in_transition.asp

Transition Outreach Training for Adult Living (TOTAL) Project. Illinois State Board of Education. The US Department of Education funded these multi-media training modules that are designed to inform students, families, educators and providers about issues regarding CYSHCN transition.
http://isbe.net/spec-ed/html/transition_video.htm

The Rehabilitation Act: Outcomes for Transition-Aged Youth, National Council on Disability. October 2008.
<http://www.ytporegon.org/content/news-ovrs#attachments>

Transition timeline created by University of Illinois–Chicago: <http://internet.dsc.uic.edu/forms/psu/4200.pdf>

Kids as Self Advocates (KASA): <http://www.fvkasa.org/>

"Improving Transition for Adolescents with Special Health Care Needs from Pediatric to Adult-Centered Health Care." American Academy of Pediatrics, December 2002, Vol. 110, #6

Margaret McManus, Harriette Fox, et al., Pediatric Perspectives and Practices on Transitioning Adolescents with Special Needs to Adult Health Care. The National Alliance to Advance Adolescent Health. October 2008.
<http://www.incenterstrategies.org/jan07/factsheet6.pdf>

PALLIATIVE AND RESPITE CARE

Experts Consulted

Ross Hays, Seattle Children's Hospital
Jill Kagan, National Respite Coalition
May Martin, Oregon Lifespan Respite Program

Websites and Written Resources

National Palliative Care Research Center: Center to Advance Palliative Care. A State by State Report Card on Access to Palliative Care in Our Nation's Hospitals. September 2008. <http://www.capc.org/reportcard>
Complete report: <http://www.capc.org/reportcard/state-by-state-report-card.pdf>
Chapel Hill Training Outreach Project. ARCH National Respite Network. This website provides respite resources including a state by state directory of respite programs. <http://chtop.org/ARCH.html>
State profile data and background related to caregivers as well as publicly funded support programs. Family Caregiver Alliance. http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1789
Partners in Care: Together For Kids 2007-2008 report.
http://ahca.myflorida.com/Medicaid/quality_management/mrp/contracts/med052/annual_report_2007-08.PDF

FINANCING

Experts Consulted

Gerri Clark, Division of Specialized Services for Children, Illinois
Margaret Comeau, Catalyst Center
Cathy Hess, National Academy for State Health Policy
Lynda Honberg, Maternal and Child Health Bureau
Henry Ireys, Mathematic Policy Research
Kathy Stiffler, CYSHCN, Michigan
Mary Takach, National Academy for State Health Policy

Websites and Written Resources

Catalyst Center for Improving Financing of Care for Children with Special Health Care Needs:
<http://www.catalystctr.org>
Relief Funds: A Safety Net for Children and Youth with Special Health Care Needs, The Catalyst Center:
<http://www.hdwg.org/catalyst/toolkit> (August 2007)
State-at-a-Glance Chartbook on Coverage and Financing for Children and Youth with Special Health Care Needs: <http://www.catalystctr.org> (January 2007)
"Breaking the Link Between Special Health Care Needs and Financial Hardship": <http://www.catalystctr.org> (February 2009)

HEALTH INFORMATION TECHNOLOGY

Experts Consulted

Carl Cooley, Center for Medical Home Improvement
Michelle Esquivel, American Academy of Pediatrics
Marie Mann, Maternal and Child Health Bureau
Jeanne McCallister, Center for Medical Home Improvement
Fan Tait, American Academy of Pediatrics