

# CHILDREN WITH SPECIAL HEALTH CARE NEEDS: A SYSTEMS PERSPECTIVE

## CHS M420 Course Syllabus

*Fall Quarter, 2007*

*Thursday, 1:00 – 4:00*

### **Instructors:**

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### **Course Description:**

Infants, children and adolescents with special health care needs and their families constitute a population with exceptional and often long-term health, educational, developmental and social service needs, which are extensive and expensive to deliver. The purpose of this course is to examine and evaluate the principles, policies, programs and practices (the systems) which have evolved to identify, assess and meet the special needs of these children and families, from both historical and current perspectives.

### **Course Objectives:**

At the completion of this course the student will be able to discuss:

1. The epidemiology of developmental disabilities and chronic illness.
2. Primary, secondary and tertiary prevention.
3. Developmental transitions and lifespan issues.
4. The critical issues in organizing and delivering health, education, developmental and social services to children with special needs and their families, including historic and current philosophies and principles, federal and state legislation and policies, strengths and barriers within the systems.
5. The influence of environmental factors, including culture, poverty, foster care, etc., on children with special needs and their families.
6. The role of the family, including parent/professional partnerships and parent-to-parent support.
7. Advocacy for children with special needs and their families and ethical issues facing this population and their care providers.
8. Values, beliefs and assumptions about individuals with disabilities or chronic illness.

\* Denotes required reading

**Session 1**  
**Sept 27**

**Introduction/Definitions/Epidemiology**

**History of Public Policy/Programs**

**Perspectives of Families of Children with Chronic Illness**

Key concepts

Introduction of instructors and class members  
Overview of course; sign-up for class discussion topics  
Defining the population  
Incidence and prevalence rates  
Beliefs and values regarding disabilities  
Practice of family-centered care  
Professional/family collaboration  
A family's view of the child with special needs and systems of care

Guest presenter:

Lisa Schoyer, Chief of Family Support, Children's Medical Services, Los Angeles County Department of Public Health

**Handouts:** Sample Outline for Final Paper

Words with Dignity & Disability Etiquette. Paraquad Organization. Available at:  
<http://www.paraquad.org/Issue/WordsDignity.html>

Readings

- \* Kessel W, Jaros K, and Harker PT. (2003). The Social Security Act and Maternal and Child Health Services: securing a bright future. In Wallace et al.: Health and Welfare for Families in the 21<sup>st</sup> Century, 2<sup>nd</sup> Edition. Jones & Bartlett Publishers, Sudbury, Massachusetts, pp. 164-170.
- \* McPherson M, Arango P, Fox H, Laurer C, McManus M, Newacheck PW, Perris JM, Shonkoff JP, Strickland B. (1998). A new definition of children with special health care needs. Pediatrics, 102:137-139.  
<http://pediatrics.aappublications.org/cgi/content/full/102/1/137>
- \* Farel A. (2005). Children with special health care needs. In Maternal and Child Health: Programs, Problems, and Policy in Public Health, (Ed) Jonathan B. Kotch. Jones and Bartlett: Boston, MA, pp. 385-415.
- \* van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. (2004). Prevalence and Characteristics of Children with Special Health Care Needs. Arch Pediatr Adolesc Med, 158:884-890.  
<http://archpedi.ama-assn.org/cgi/content/full/158/9/884>

**Session 2            Systems of Health Care for Children with Special Health Care Needs, Part I**  
**October 4            (Chronic Care Model, Medical Home)**

Key concepts

Evolution of public policy and programs for children with special health care needs  
Chronic care model  
Medical home

**Handout:**        L.A. Medical Home Project. Resources for Children with Special Health Care Needs,  
September 2007.  
Forthcoming at: <http://mchneighborhood.ichp.ufl.edu/medicalhomela>

Readings

- \*        Reiss J, Wallace HM, McPherson M. (2003). The Supplemental Security Income Program for Children. In Wallace et al.: Health and Welfare for Families in the 21<sup>st</sup> Century, 2<sup>nd</sup> Edition. Jones & Bartlett Publishers, Sudbury, Massachusetts: pp. 269-280.
- \*        Beckman P. (2002). Providing family centered services. In Children with Disabilities. Mark L. Batshaw, ed. In Brookes Publishing Company. Baltimore. 683-91.

**Session 3            Systems of Health Care for Children with Special Health Care Needs, Part II**  
**October 11            (Financing and Incentives)**

Key Concepts

Public funding sources for CSHCN  
Title V, SSI, Medicaid, SCHIP  
Issues of risk adjustment and financing  
Health care reform/managed care

**WEB RESOURCES**

The Guide to Medi-Cal Programs, 2001. MediCal Policy Institute.

Understanding Medi-Cal: The Basics, 2001. The MediCal Policy Institute.

Refer to *MediCal Policy Institute* website

Readings

- \*        Davidoff AJ. (2004). Insurance Coverage for Children with Special Health Care Needs: Patterns of Coverage and Burden on Families to Provide Adequate Insurance. Pediatrics, 114(2):394-403.  
<http://pediatrics.aappublications.org/cgi/content/full/114/2/394>
- \*        Understanding Title V. Maternal & Child Health Bureau. Available at:  
<ftp://ftp.hrsa.gov/mchb/titlevtoday/UnderstandingTitleV.pdf>

- \* Committee on Child Health Financing. Medicaid Policy Statement. (2005). Pediatrics, 116(1):274-280.
- \* Honberg L, McPherson M, Strickland B, Gage JC, Newacheck PW. (2005). Assuring adequate health insurance: results of the National Survey of Children with Special Health Care Needs. Pediatrics. 115(5):1233-9.
- \* Committee on Children with Disabilities. (1998). Managed care and children with special health care needs: A subject review. Pediatrics, 102(3):657-660.

**Session 4**                      **Developmental Services System**  
**October 18**                      **Special Education System**

Key concepts

Individuals with Disabilities Education Act (IDEA)  
 Part C, Part H  
 Service planning  
 IFSPs, IEPs, IPPs

Guest presenter:

Barbara Wheeler  
 Associate Director, USC UCEDD  
 Director, Center for Disability Studies and Community Inclusion  
 Associate Professor of Clinical Pediatrics, USC Keck School of Medicine

Readings

- \* <http://www.acf.hhs.gov/programs/add/Factsheet.html>
- \* Stahmer AC, Mandell DS. State infant/toddler program policies for eligibility and services provision for young children with autism. Adm Policy Ment Health. 2007 Jan;34(1):29-37.  
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=16758329>

**Session 5**                      **Adolescents with Chronic Conditions**  
**October 25**

Key concepts

Adolescents with special needs  
 Issues of care for adolescents with special needs  
 Vocational planning  
 Transition issues

## Readings

- \* Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics*. 2005 Jan;115(1):112-20.  
<http://pediatrics.aappublications.org/cgi/reprint/115/1/112>
- \* Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. *Pediatrics*. 2005 Jun;115(6):1562-8.  
<http://pediatrics.aappublications.org/cgi/reprint/115/6/1562>
- \* Betz CL. Facilitating the transition of adolescents with developmental disabilities: nursing practice issues and care. *J Pediatr Nurs*. 2007 Apr;22(2):103-15. Review.  
[http://linkinghub.elsevier.com/retrieve/pii/S0882-5963\(06\)00326-5](http://linkinghub.elsevier.com/retrieve/pii/S0882-5963(06)00326-5)

## **Session 6**                      **Mental Health System** **November 1**                      **Advocacy**

### Key concepts

Mental health services in the public and private sectors  
Advocacy

### Guest presenters

Marian Williams, PhD – USC UCEDD  
Lynn Kersey, MA, MPH – MCH Access

### Readings

- \* Satcher D, et al. (2000). Chapter 3: Children & Mental Health. In *Mental Health: A Report of the Surgeon General*. Report prepared by the Department of Health and Human Services under the direction of the Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, in partnership with the National Institute of Mental Health, National Institutes of Health. Available at:  
<http://www.surgeongeneral.gov/library/mentalhealth/pdfs/c3.pdf> .

## **Session 7**                      **Cultural Competency** **November 8**                      **Racial/Ethnic Disparities**

### Key Concepts

Culturally competent care for children with special health care needs  
Racial disparities in health care access and quality

### Presenters

Marjorie Kagawa-Singer, RN, MN, PhD – UCLA SPH

## Readings

- \* Kotelchuck M. (2003). Building on a life-course perspective in maternal and child health *Matern Child Health J*, 7(1):5-11.
  
- Ngui EM, Flores G. Satisfaction with care and ease of using health care services among parents of children with special health care needs: the roles of race/ethnicity, insurance, language, and adequacy of family-centered care. *Pediatrics*. 2006 Apr;117(4):1184-96.

## **Session 8                      Early Developmental Services and Prevention** **November 15                    Oral Health**

### Key Concepts

Early developmental services  
Early Head Start, Head Start  
Family supports  
Dental services for children with special needs

### Readings

- \* Cohn Donnelly A, Green F. (2003). The Head Start Program: Past, Present, and Future. In Wallace et al.: Health and Welfare for Families in the 21<sup>st</sup> Century, 2<sup>nd</sup> Edition. Jones & Bartlett Publishers, Sudbury, Massachusetts, pp. 206-214.
  
- Anderson LM, Scrimshaw S, Fullilove MT, Fielding JE, Normand J. (2003). Task Force on Community Preventive Services. Culturally competent healthcare systems. *Am J Prev Med*, 24(3S):68-79.
  
- \* Casamassimo PS. (2003). Oral Health in Maternal and Child Health. In Wallace et al.: Health and Welfare for Families in the 21<sup>st</sup> Century, 2<sup>nd</sup> Edition. Jones & Bartlett Publishers, Sudbury, Massachusetts: pp. 372-384.
  
- Waldman HB, Perlman SP. (1997). Children with disabilities are aging out of dental care. Journal of Dentistry for Children, pp. 385-390.

## **Session 9                      Measuring Quality** **November 29                    Quality Improvement**

### Key Concepts

Issues related to assuring quality care  
Challenges of managed care for CSHCN  
Improving quality of care  
Improving community systems of care for CSHCN

## Readings

- \* Perrin JM, Kuhlthau K, Klein Walker D, Stein REK, Newacheck PW, Gortmaker SL. (1997). Monitoring health care for children with chronic conditions in a managed care environment. *MCHJ*, 1:15-23.
- \* Gawande A. What happens when patients find out how good their doctors really are? *The New Yorker*. 2004. December 6.

Finkelstein JA, Lozano P, Farber HJ, Miroshnik I, Lieu TA. Underuse of controller medications among Medicaid-insured children with asthma. *Arch Pediatr Adolesc Med*. 2002 Jun;156(6):562-7.

## **Session 10 December 6**

### **Building an “Ideal” System of Care for Children With Special Needs**

#### Format

The last session will be devoted to designing a system of health care to meet the needs of children with chronic illness/disabilities and their families based on concepts presented during the previous sessions and knowledge of the strengths existing system as well as the barriers to service delivery. Each student will choose to represent one of the public or private agencies, which currently serve this population, or are otherwise "stakeholders" in the system. We will also invite representatives of selected community agencies and some of the family members to join us.

#### Readings

- \* Morris NM. (2003). Steps for the Future. In Wallace et al.: Health and Welfare for Families in the 21<sup>st</sup> Century, 2<sup>nd</sup> Edition. Jones & Bartlett Publishers, Sudbury, Massachusetts, pp. 540-554.

**Requirements:**

This is a seminar-type course. The most important requirements are completion of all assigned readings before each session, regular attendance and active participation in discussions.

**Weekly student-led discussion**

To encourage discussion of current issues for children with special health care needs, each week several students will present a specific program or policy-related news item related to children with special health care needs. In addition, each week two students will lead a discussion of the readings for the first 20 minutes of class.

**Final paper**

There will be a final paper, due the next to last class session (November 29) in preparation for the discussion of the ideal service system. For the paper, each student will select a specific chronic illness or developmental disability and become familiar with that condition and the services/resources in place (as well as gaps in services/resources) to meet the needs of a child and family who are living with that condition. This will be accomplished through readings, interviews with community agencies mandated to provide services and other available resources, as well as several interactions with an actual child and his or her family. While preparing this paper, each student will choose a particular agency involved in these services and will represent that agency in the last class session.

**Grading:**

Grades will be determined on the following basis: weekly response to reflection/discussion question 35%, leadership of discussion on assigned day 5%, general class participation (including sharing current news) 10%, final paper 50%.

**Additional  
References:**

Wallace HM, Green G, Jaros KJ: Health and Welfare for Families in the 21<sup>st</sup> Century. 2<sup>nd</sup> Edition. Jones & Bartlett Publishers, Sudbury, Massachusetts, 2003.

Lynch EW, Hanson MJ: Developing Cross-Cultural Competence: A Guide for Working with Children and Their Families. Paul H. Brookes Publishing Co.: Baltimore, MD. 2004.

**Useful Web Sites:**

Agency for Healthcare Research & Quality (AHRQ): <http://www.ahrq.gov>  
American Academy of Pediatric Dentistry (AAPD): <http://www.aapd.org>  
American Dietetic Association (ADA): <http://www.eatright.org>  
Association of Maternal & Child Health Programs (AMCHP): <http://www.amchp.org>  
American Academy of Pediatrics (AAP): <http://www.aap.org/advocacy>  
Association of University Centers on Disabilities (AUCD): <http://www.aucd.org>  
CA Department of Developmental Services: <http://www.dds.cahwnet.gov>  
CA Family Voices: [www.supportforfamilies.org](http://www.supportforfamilies.org)  
CA Healthcare Foundation: <http://www.chcf.org>  
CA Healthline: <http://www.californiahealthline.org/formslogin.asp>  
CA Legislature/Assembly Bills: [www.leginfo.ca.gov](http://www.leginfo.ca.gov)  
CA Protection & Advocacy: <http://www.pai-ca.org>  
CA State Councils on DD: <http://www.scdd.ca.gov>  
CA State Government website: [www.ca.gov](http://www.ca.gov)  
Centers for Disease Control (CDC), National Center on Health Statistics: <http://www.cdc.gov/nchs/slait.htm>  
CSHCN L-Digest (subscription page): <http://mchenet.ichp.edu/scripts/lyris.pl?enter=cshcn-l>  
Exceptional Parent Magazine: <http://www.eparent.com>  
Family Village: <http://www.familyvillage.wisc.edu>  
Family Voices: <http://www.familyvoices.org>  
Federation of Families for Children's Mental Health: [www.ffcmh.org](http://www.ffcmh.org)  
HRSA: <http://www.hrsa.gov>  
Institute for Family-Centered Care: <http://www.familycenteredcare.org>  
ICHP CSHCN: <http://www.ichp.edu>  
Managed Risk Medical Insurance Board: <http://www.mrmib.ca.gov>  
Maternal & Child Health Bureau (MCHB): <http://www.hrsa.gov>  
MCH Policy Research Center: <http://www.mchpolicy.org>  
MediCal Policy Institute: <http://www.medi-cal.org>  
National Association of Social Workers (NASW): <http://www.naswdc.org>  
National Center on Birth Defects & Developmental Disabilities (NCBDDD): <http://www.cdc.gov/ncbddd>  
National Center for Cultural Competence: <http://www.gucdc.georgetown.edu/nccc>  
National Information Center for Children & Youth w/Disabilities: <http://www.nichcy.org>  
National MCH Clearinghouse (NMCHC): <http://www.nmchc.org>  
National Mental Health Association (NMA): <http://www.nmha.org>  
Special Child: <http://www.specialchild.com>

Special Kids LA: <http://www.specialkidsla.com>  
Special Olympics: <http://www.sosc.org>  
Title V (MCHB) access & data: <http://www.MCHData.net>  
Urban Institute: <http://www.urban.org/>  
U.S. Dept. of Education: <http://www.ed.gov>  
U.S. Dept. of Health & Human Services: <http://www.dhhs.gov>  
U.S. Government Information (Federal Register, Congressional bills, GAO reports,  
public laws): [www.gpo.ucop.edu](http://www.gpo.ucop.edu); <http://thomas.loc.gov>