

ERRATUM

Disability and Maternal and Child Health

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D.J. Lollar and E.M. Andresen (eds.), *Public Health Perspectives on Disability: Epidemiology to Ethics and Beyond*, DOI 10.1007/978-1-4419-7341-2, pp. 151–161,
© Springer Science+Business Media, LLC 2011

DOI 10.1007/978-1-4419-7341-2_12

The publisher regrets that the author or chapter 7 is mistakenly listed as Debbie Allen, and should be Deborah Allen. In addition, chapter 7 is missing the two tables and four figures that should have been included in the chapter. The tables and figures are given on the following pages.

MCH and Disability

Table 1 (p. 153)

Table 1 The Federal Legislative Framework for Services to Children with Special Health Care Needs

Legislation	Year Passed	Original Elements	Key Changes Since Passage
Title V (of the Social Security Act)	1935	Formula funds to states for “crippled children’s services”	<ul style="list-style-type: none"> • Training component added • Program incorporated into MCH block grant • Stigmatizing language dropped; “children with special health care needs”
Medicaid (Title XIX of the Social Security Act)	1965	Provides insurance coverage and access to specialized as well as primary and preventive health care for eligible children	<ul style="list-style-type: none"> • Income eligibility broader for children with special health care needs; at highest level of medical need almost all children are eligible
Section 504 (of the Rehabilitation Act)	1973	Establishes right to physical access to federally funded facilities, including schools	
Individuals with Disabilities Education Act (IDEA)	1975	Right to “free and appropriate public education” established for all children 3-22	<ul style="list-style-type: none"> • Part C extends services to children 0-3 • Original name of law changed omitting the word “handicapped”
Supplemental Security Income (SSI) Disabled Children’s Program	1976	Provides income support to individuals lacking social security work history due to disability	<ul style="list-style-type: none"> • Eligibility extended to parents of children with special health care needs • Children’s eligibility loosened and then tightened over time • Confers Medicaid eligibility in 32 states and the District of Columbia
Americans with Disability Act	1990	Establishes right to physical and programmatic access to public facilities, including child care and recreation programs	

Table 2 (p. 154)

Table 2 Disability-Related Class Offerings in Maternal and Child Public Health Programs

School	Dept Name	MCH Funded	Disability		Topics	Focus
			Focused Classes	Topics		
1.	Community Health & Prevention	N	0			
2.	Community Health Sciences	Y	2		Children with Special Health Care Needs (including Mental Health needs); Disability and the Family	
3.	Population & Family Health	N	0			
4.	NA	NA	NA			
5.	Community Health Education	N	0			
6.	Community Health Sciences	Y	1		Children with Special Health Care needs	Policy and programs
7.	Prevention & Community Health	N	2		Children and Youth with Special Needs; High Risk and Special Populations	Policy and Programs
8.	Health Promotion Disease Prevention	N	0			
9.	Society, Human Development & Health	Y	3		Developmental Disabilities (2); Services for Children with Disabilities;	Policy and programs
10.	NA	NA				
11.	MCH	N	1		High Risk Infants & Children	Policy and programs
12.	Health Behavior & Promotion	N	0			
13.	Population, Family & Reproductive Health	Y	2		Attitudes, Programs, & Policies for Children with Special Health Care Needs; HIV Infection in Women, Children and Adolescents	Policy and programs Biological/clinical

(continued)

Table 2 (continued)

School	Dept Name	MCH Funded	Disability Focused Classes	Topics	Focus
14.	NA	NA			
15.	NA	NA			
16.	Community Health Sciences	Y	0		
17.	Community Health Sciences	Y	0		
18.	NA	NA	NA		
19.	Family & Child Health	Y	0		
20.	MCH	Y	0		
21.	Healthy Policy & Management	N	1	Children with Special Health Care Needs	Policy and Programs
22.	Health Care Organization & Policy	Y	0		
23.	NA	NA			
24.	Health Policy, Management & Behavior	N	1	Social and Behavioral Aspects of Chronic Illness	Policy and Programs
25.	Community & Behavioral Health	N	1	Prevention and Early Intervention of Mental Health Disorders	Clinical
26.	NA	NA			
27.	NA	NA			
28.	Behavioral and Community Health Sci	N	0		
29.	Social & Behavioral Health Sciences	N	0		
30.	Epidemiology & Community Health	Y	1	Children and Youth With Special Health Care Needs	
31.	Health Promotion Sciences	N	0		
32.	NA	NA			

33.	Social & Behavioral Sciences	N	0		
34.	MCH	Y	1	Special Child Population	Growth & Development; Programs
35.	Health Promotion & Behavioral Sciences	N	0		
36.	Human Development	N	0		
37.	Health Behavior	N	0		
38.	Health Promotion, Education & Behavior	N	0		
39.	Social & Behavioral Health Sciences	N	0		
40.	Community & Family Health	N	0		
41.	Health Behavior & Health Education	Y	1	Chronic Illness Interventions: Infancy to Young Adulthood	Programs and Policies
42.	MCH Leadership Interdisciplinary Training Program	Y	0		
42 certified schools	35 have a department that covers MCH	13	17		

Figure 1 (p. 157)*Definition of Family-centered care*

Family-Centered Care assures the health and well being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.

Principles of family-centered care

The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following principles:

- *Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.*
- *Everyone respects the skills and expertise brought to the relationship.*
- *Trust is acknowledged as fundamental.*
- *Communication and information sharing are open and objective.*
- *Participants make decisions together.*
- *There is a willingness to negotiate.*

Based on this partnership, family-centered care:

1. *Acknowledges the family as the constant in a child's life.*
2. *Builds on family strengths.*
3. *Supports the child in learning about and participating in his/her Care and decision-making.*
4. *Honors cultural diversity and family traditions.*
5. *Recognizes the importance of community-based services.*
6. *Promotes an individual and developmental approach.*
7. *Encourages family-to-family and peer support.*
8. *Supports youth as they transition to adulthood.*
9. *Develops policies, practices, and systems that are family-friendly and family-centered in all settings.*
10. *Celebrates successes.*

Fig. 1 MCH Definition of Family-Centered Care

Figure 2 (p. 157)

Differences	
<u>MCH</u>	<u>Disability</u>
Focus on family	Focus on individual
Focus on services	Focus on rights
Concerned with quality of medical and related services	Resistant to medicalization of disability
Interested in maximizing child's development	Interesting in maximizing individual's self-determination

Commonallities	
<u>MCH</u>	<u>Disability</u>
Family living	Community living
Full social inclusion	Full social inclusion
Primacy of family	Autonomy of individual
Focus on child and family strengths	Accomodations to build on strengths of individual

Fig. 2 Comparison of MCH and Disability Persepectives

Figure 3 (p. 159)

In classes on reproductive health, teach students about:

- Strategies and resources for sex education, and family planning guidance for adolescent and adult women with disabilities, including women with cognitive impairments
- Anticipatory guidance and linkages to appropriate pediatric care and supports for parents who receive positive prenatal test results for congenital conditions
- Accommodations, including adaptive equipment and involvement of specialists as needed, in prenatal care for women with disabilities.

In classes on child health and development teach students about:

- Resources for early identification and intervention of special needs
- Medical home and care coordination as a core service within the medical home for families of children with special health care needs
- Community, parent, and diagnosis-specific organizations as resources for families of children with special health care needs
- Parent organizations as sources for education of providers about family needs
- Issues of parent-professional communication and collaboration in care of children with special health care needs
- Anticipatory guidance for children and especially for adolescent with disabilities
- Age appropriate education of all children, including children with disabilities, to understand and take on management of their own health care
- The unique challenges, including material and psychosocial challenges facing parents raising children with special health care needs
- Policy at federal, state and local levels relevant to services for children with special health care needs and their families.

In classes on MCH methods:

- The rationale for and strategies to promote family involvement in MCH program and policy planning, implementation and evaluation
- Participatory Action Research methods
- Strategies for gaining input from and evaluating satisfaction among individuals with communication or cognitive impairments

Fig. 3 Including Disability in Current MCH Classes

Figure 4 (p. 160)

Reproductive needs of women with disabilities

<http://www.bcm.edu/crowd/>

<http://www.bhawd.org/sitefiles/index2.html>

http://www.acog.org/departments/dept_web.cfm?recno=38

Parents with disabilities

<http://www.disabledparents.net/>

<http://lookingglass.org/index.php>

Disability in child health

http://www.medicalhomeinfo.org/about/def_cshcn.html

<http://www.medicalhomeinfo.org/>

<http://www.medicalhomeinfo.org/about/CSOCWDreports.html>

<http://www.cshcndata.org>

<http://www.familyvoices.org>

<http://www.familyvillage.wisc.edu/>

Fig. 4 Resources for Filling Disability Gaps in MCH Courses