

Children and Youth With Disabilities and Public Health

A Model Syllabus for Health Professionals

Donna M. Noyes-Grosser, PhD

Programs and services traditionally included in the purview of public health—such as Medicaid and Title V of the Social Security Act—have an important role to play in services to people with disabilities. More recently, the educational system under the Individuals with Disabilities Education Act has emerged as the major service delivery system, including many healthcare services, for children and youth with disabilities. Public health professionals are often called upon by the special education system to support, evaluate, refer, or provide direct interventions for children and youth with disabilities as part of an early intervention or special education program. Yet many public health professionals have limited or no training in public policies related to children and youth with disabilities, service delivery models that have proven effective, or their role in support and providing family-centered, community-based care for children and youth with disabilities. This model syllabus is primarily designed as a survey course to provide students in schools of public health with a broad-based overview of public policies, service delivery systems, and family-centered approaches to care for children and youth with special healthcare needs. This model syllabus could also serve as a framework for a survey course for students in medical schools and schools of allied healthcare professionals, and other professional development programs for individuals in health, human service, and education professions—many of whom are also called upon to provide services to children and youth with special healthcare needs in conjunction with public systems. **Key words:** *children, disabilities, early intervention, health professionals, personnel preparation, special education, special healthcare needs*

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The syllabus described in this article was developed in partial fulfillment of requirements for completion of the Northeast Public Health Leadership Institute, School of Public Health, University at Albany, State University of New York. The Northeast Regional Public Health Leadership Institute (NEPHLI) brings together state and local health departments, academia, public health associations, and organizations committed to improving the skills of leaders in the field of public health. Collectively, this partnership strengthens leadership skills and promotes healthier communities. NEPHLI receives funding from its partners (the states of Main, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont, and the city of New York) and the Centers for Disease Control and Prevention.

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I'm personally proudest of the things I've done for children with handicaps. We've started a new system of family-centered, community-based, comprehensive care for kids with special needs. We've had workshops all over the county to adopt a new approach to understanding kids with handicaps, to learn how they should be cared for, and to include their families as part of the treatment.

—C. Everett Koop, MD, ScD, Surgeon General,
US Public Health Service,
The Washingtonian, April 1990.

THE Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities (NCBDDD) estimates that 17% of US children younger than 18 years have a special healthcare need, defined as “a diverse group of physical, cognitive, psychological, sensory, and speech impairments that begin any time during development up to 18 years of age.” In their

report on research to develop an epidemiologic profile of children with special health-care needs as defined by the federal Maternal and Child Health Bureau of the Human Resources Administration of the US Department of Health and Human Services (federal MCHB), Newacheck et al. (1998) estimated that 18% of children younger than 18 years in 1994, or 12.6 million children nationally, had a chronic physical, developmental, behavioral, or emotional condition, and required health and related services of a type or amount beyond that required by children generally. Newacheck et al. concluded that “A substantial minority of US children was identified as having an existing special health care need using national survey data. Children with existing special health care needs are disproportionately poor and socially disadvantaged. Moreover, many of these children face significant barriers to health care” (Newacheck et al., 1998).

More recently, the federal MCHB commissioned a study by the National Centers for Health Statistics (NCHS) of the Centers for Disease Control and Prevention on the size and characteristics of children with special health-care needs. The federal MCHB defines children with special healthcare needs as those children “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (U.S. Department of Health and Human Services, 2004b). To complete the study on children with special healthcare needs, the NCHS conducted a telephone survey with a total of 38 866 families nationally between October 2000 and April 2001. The results of this study provide detailed information about the self-reported prevalence, characteristics, and types of health and support services received by children with special healthcare needs nationwide and within each state (U.S. Department of Health and Human Services, 2004b).

Based on study results, the Health Resources and Services Administration estimates

that 12.8% of children in the United States, or 9.4 million children, have a special health-care need consistent with the Federal MCHB definition. Twenty percent of all households nationally were found to have children with special healthcare needs (U.S. Department of Health and Human Services, 2004b). Prevalence of special healthcare needs was found to increase with age and surprisingly, in contrast to earlier studies, was not found to vary substantially among income groups. The prevalence of special healthcare needs was found to vary by child race and ethnicity, with the highest prevalence among Native American/Alaskan Native children, multiracial, and non-Hispanic White children; and the lowest prevalence rates among Hispanic children and non-Hispanic Asian children (U.S. Department of Health and Human Services, 2004b).

As summarized by the NCBDDD, “disability status” is determined in a variety of ways, depending on the reasons why such a distinction is being made. Often, a determination of “disability status” is made relative to access for specific types of public benefits, including public-funded programs such as childhood early intervention programs, special education, and Medicaid or supplemental income (CDC-NCBDD, 2005). As used by the federal MCHB, and more generally within the context of public health, the term “children with special healthcare needs” is broadly defined to include children with developmental and other disabilities, *in addition* to children who have special medical needs who may *not* be considered to have a “disability” across different public service delivery systems. In this respect, children and youth with disabilities can be considered—and often are practically viewed—as a subset of the broader group of children with special healthcare needs. Public health professionals are more likely to be experienced and knowledgeable about children with chronic health conditions than about children with developmental disabilities; however, public health professionals are increasingly embracing the broader definition of children with special healthcare needs to include developmental, behavioral, and

emotional concerns in addition to chronic health conditions. Because the acronym "CSHCN" is widely used to refer to children with a broad spectrum of health and developmental concerns, the acronym will be used throughout this article for consistency.

Programs and services traditionally included in the purview of public health—such as Medicaid and Title V of the Social Security Act—have an important role to play in services to people with disabilities, including the CSHCN. In 1988, the Committee for the Study of the Future of Public Health, Division of Health Care Services, Institute of Medicine, defined the mission of public health as "fulfilling society's interest in assuring conditions in which people can be healthy. Its aim is to generate organized community efforts to address public interest in health by applying scientific and technical knowledge to prevent disease and promote health." The promotion of health among people with disabilities, including the healthy development of the CSHCN, is an area of increasing interest and concern for public health professionals.

More recently, the educational system under the Individuals with Disabilities Education Act (IDEA) has emerged as the major service delivery system, including many healthcare services, for the CSHCN aged birth through 21 years and their families. The enactment of mandated preschool special education and discretionary early intervention services under Parts B and C of IDEA in the 1980s has strengthened this trend. Although special education and related health services for children and youth aged 3 through 21 years are the responsibility of local education agencies, the Part C Early Intervention Program under IDEA allows states to designate a lead agency responsible for implementation and oversight of a statewide, coordinated, comprehensive, multidisciplinary system of early intervention services for infants and toddlers with disabilities and their families. Twenty-six of all state agencies administering the Part C early intervention program are public health or health and human service agencies, and many local

public health agencies have also assumed a primary role in administering early intervention services (Danaher & Armijo, 2004).

Public health professionals are also often called upon to support, evaluate, refer, or provide direct interventions for young children with disabilities as part of an early intervention "individualized family service plan" or an individualized education program (IEP) for pre-school- and school-aged children and youth with disabilities. Yet many public health professionals have limited or no training in public policies related to children and youth with disabilities, service delivery models that have proven effective, or their role in supporting and providing family-centered, community-based care for the CSHCN and their families.

This article presents a model syllabus that could be used to develop and offer a survey course to provide students in schools of public health with a broad-based overview of public policies, service delivery systems, and family-centered approaches to caring for the CSHCN. The syllabus could also be used as a framework for the development of a similar coursework for students in medical schools, schools of allied health professions, and other health professions. As a result of our growing national success in ensuring children and youth with disabilities have full access to their communities, all healthcare providers are becoming increasingly involved in services for the CSHCN and their families, and students of these professions could also benefit from the proposed course content. Finally, although the syllabus was developed with preservice institutions in mind, the syllabus could also be used to develop in-service training opportunities for practicing public health professionals.

COURSE OBJECTIVES

This course is designed to teach students in public health and health professions about the CSHCN and the role of health and public health professionals in serving this population. Specifically, the course is designed to

cover the following.

- How disabilities in children are defined, measured, and reported in the United States and the extent and nature of disability as related to demographic factors, including age and socioeconomic factors.
- The major federal and state programs and service delivery systems designed to address the needs of children and youth with special healthcare needs and their families, including Title V and IDEA.
- Financing of services for the CSHCN.
- National agendas for the care and education of the CSHCN.
- Principles of family-centered, community-based care for the CSHCN.
- Examples of evidence-based practices for assessing and intervening with young CSHCN.
- Early childhood development and young CSHCN.
- The role of public health in service delivery for the CSHCN.

COURSE CONTENT

The course is structured in 17 sessions that provide a broad-based overview of topics related to the CSHCN and public health. These sessions could be combined to accommodate teaching schedules within institutes of higher education, or for use in providing in-service education opportunities in a variety of venues. The syllabus also lends itself to the development of an interactive, Web-based instructional course (or courses). The following briefly describes the content for each session. Recommended readings and other resources are presented in Table 1.

The concepts of family-centered and community-based care have become fundamental to health and educational services for the CSHCN and their families. Public health professionals need to understand these concepts from a variety of perspectives to be successful in working with families and their children with special needs at both the systems and individual levels. This syllabus includes 3 sessions on family involve-

ment in services to their children offered at various points throughout the course. It is recommended that at a minimum these sessions—and potentially other sessions as well—include 1 or more parents (or family members) of the CSHCN as copresenters. Including parents of children of *differing ages* in these sessions as copresenters would be most valuable, since experiences and perspectives on the system evolve as parents and their children transition through life and service delivery systems.

Session 1: Introduction to children and youth with special healthcare needs and public health

Session 1 should introduce students to the purpose of the course and basic concepts related to children and youth with special healthcare needs and public health. The first session should present the arguments why public health professionals should be concerned about, and interested in, the interface of the public health system, children and youth with special healthcare needs, and the other service delivery systems that are used and have an impact on the CSHCN and their families. The session should introduce basic definitions of disability and special healthcare needs, and of public health and public health systems. Students should be introduced to the history and rationale related to the shift away from using a disabling condition as a health status measure, and focusing on health and functional status outside of the disabling condition (CDC-NCBDD, 2005). These concepts will be explored in more detail in session 4 (*Epidemiological and Social Policy Perspectives*).

Session 2: National agendas for the care and education of children and youth with disabilities—Where does public health fit in?

In the second session, national agendas for children and youth with disabilities developed by health, educational, and other public systems should be reviewed and discussed in the context of the overall role for public

Table 1. Recommended teaching resources

Session	Recommended readings
Introduction to Children with Disabilities and Public Health	<p>Laplante, M. P., & Carlson, D. (1996). <i>Disability in the United States: Prevalence and Causes, 1992</i> (Disability Statistics Reports 7). Washington, DC: U.S. Department of Education, National Institute on Disability and Rehabilitation Research.</p> <p>Institute of Medicine, Committee for the Study of the Future of Public Health, Division of Health Care Services. (1988). <i>The future of public health</i>. Washington, DC: National Academy Press.</p> <p>U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2004). <i>National agenda for children with special health care needs: Achieving the goals 2000</i>. Rockville, MD: Author.</p>
National Agendas for the Care and Education of Children with Disabilities: Where Does Public Health Fit in?	<p>U.S. Department of Health and Human Services. <i>National agenda for children with special health care needs</i>.</p> <p>The David and Lucille Packard Foundation. (2001, spring-summer). Caring for infants and toddlers. <i>Future of Children</i> 11(1).</p> <p>Future of Children—Packard Foundation Publication Series. Retrieved from http://www.futureofchildren.org</p>
Principles of Family-Centered, Community-Based Care for Children with Disabilities	<p>American Academy of Pediatrics. (2001). Role of the pediatrician in family-centered early intervention services. <i>Pediatrics</i>, 107(5), 1155-1157.</p> <p>Shelton, T., & Stepanek, J. (1994). <i>Family centered care for children needing specialized health and developmental services</i> (3rd ed.). Washington, DC: Association for the Care of Children's Health.</p>
Defining, Identifying, and Estimating Disability in Children: Epidemiological and Social Policy Perspectives	<p>Blumberg, S. J., Olson, L., Frankel, M., Becker, C. J., Srinath, K. P., & Giambo, P. (2003). <i>Design and operation of the National Survey of Children with Special Health Care Needs, 2001</i>. National Center for Health Statistics, Vital Health Statistics 1(41).</p> <p>Fujitara, G. T., & Yamaki, K. (2000). Trends in demography of childhood poverty and disability. <i>Exceptional Children</i>, 66(2), 187-199.</p> <p>Newacheck, P. W., Strickland, B., Shonkoff, J. P., Perrin, J. M., McPherson, M., McManus, M., et al. (1998). An epidemiologic profile of children with special health care needs. <i>Pediatrics</i>, 102, 117-123.</p> <p>Stein, R., et al. (1997). The Questionnaire for Identifying Children with Chronic Conditions: A measure based on a noncategorical approach. <i>Pediatrics</i>, 99(4), 513-521.</p> <p>Westbrook, L., et al. (1998). Implications for estimates of disability in children: A comparison of definitional components. <i>Pediatrics</i>, 101(6), 1025-1030.</p> <p>Overview: The epidemiology of neurodevelopmental disorders. <i>Mental Retardation and Developmental Disabilities Research Reviews</i>, 8, 133-166.</p> <p>Shackelford, J. (2002). State and jurisdictional eligibility definitions for infants and toddlers with disabilities under IDEA. NECTAC Notes No. 11, 14 pp.</p>

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Table 1. Recommended teaching resources (*Continued*)

Session	Recommended readings
Overview of Major Federal Policies and Programs to Assist Children with Disabilities	<p>CDC National Center on Birth Defects and Developmental Disabilities. Retrieved from http://www.cdc.gov/ncbddd/dd/default.htm</p> <p>U.S. Department of Education, Office of Special Education Programs. Retrieved from http://www.ed.gov</p> <p>HRSA Bureau of Maternal & Child Health. Retrieved from http://www.mchb.hrsa.gov/programs/blockgrant/overview.htm</p> <p>National Policy Center for Children with Special Health Care Needs. Retrieved from http://www.jhsph.edu/WCHPC_/Projects/cshcn.html</p> <p>National Information Center for Children and Youth with Disabilities. Retrieved from http://www.nichcy.org/index.html</p>
Title V—Children with Special Healthcare Needs	<p>U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2004). <i>Understanding Title V of the Social Security Act: A Guide to the Provisions of the Federal Maternal and Child Health Block Grant</i>. Rockville, MD: Author.</p> <p>AHQR User Liaison Program – CSHCNs: Developing Integrated Systems of Care. Retrieved from http://www.ahcpr.gov/news/ulp/ulpcshcn.htm#contents</p>
Individuals with Disabilities Education Act: Historic and Current Perspectives	<p>The David and Lucille Packard Foundation. (1996, spring–summer). Special education for students with disabilities. <i>Future of Children</i>, 6(1).</p> <p>Turnbull, H. R., & Turnbull, A. P. (2000). <i>Free appropriate public education: The law and children with disabilities</i> (6th ed.). Denver: Love Publishing Company.</p> <p>Danaher, J. (2001). Eligibility Policy and Practices for Young Children Under Part B of IDEA. NECTAC Notes No. 9, 17 pp.</p> <p>U.S. Department of Education, Office of Special Education Programs. Retrieved from http://www.ed.gov http://www.wrightslaw.com</p>
IDEA Part C Early Intervention Program: A Model Approach to Comprehensive, Integrated Care for Children with Disabilities	<p>Danaher, J., & Armijo, C. (Eds.) (2004). <i>Part C Updates: Sixth in a series of updates on selected aspects of the early intervention program for infants and toddlers with disabilities, (Part C) of IDEA</i>. Chapel Hill, NC: NECTAC.</p> <p>Striffler, N., Perry, D., & Kates, D. (1997). Planning and implementing a finance system for early intervention services. <i>Infants and Young Children</i>, 10(2), 57–65.</p> <p>Infant Toddler Coordinators Association. Retrieved from http://www.ideainfanttoddler.org/index.htm</p> <p>National Early Childhood Technical Assistance Center. Retrieved from www.nectac.org</p> <p>National Early Intervention Longitudinal Study. Retrieved from http://www.sri.com/neils/</p>

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Table 1. Recommended teaching resources (*Continued*)

Session	Recommended readings
Family Perspectives on the Service Delivery System	<p>Wells, N., Anderson, B., & Popper, B. (1992). <i>Families in program and policy: Report of the 1992 Survey of Family Participation in State Title V Programs for Children with Special Health Care Needs</i>. Boston, MA: CAPP National Parent Resource Center.</p> <p>Family Voices. Retrieved from http://www.familyvoices.org</p> <p>Research and Training Center on Early Childhood Development. http://www.researchtopractice.info</p> <p>Healthy and Ready to Work Web site. Retrieved from http://www.hrtw.org</p>
Issues in Public and Private Financing for Children with Disabilities: Part I - Medicaid and SSI	<p>Kates, D. (1998). Constructing interagency funding systems for early intervention services. <i>Infants and Young Children, 11</i>(2), 73-81.</p> <p>Rosenbach, M., & Gavin, N. (1998). Early periodic screening, diagnosis, and treatment and managed care. <i>Annual Review of Public Health, 19</i>, 507-525.</p> <p>Social Security Administration. (2001). <i>Benefits for children with disabilities</i>. SSA Publication No. 05-10026.</p>
Issues in Public and Private Financing for Children with Disabilities: Part 2 - State Child Health Insurance Programs, Commercial Insurance Coverage, and Parent Participation	<p>American Academy of Pediatrics. (1998). Principles of health care financing. <i>Pediatrics, 102</i>(4), 994-995.</p> <p>Wells, N. (1997, Fall). What parents need to know about managed care early childhood. <i>Bulletin, 8</i> pp.</p> <p>http://www.mchlibrary.info/knowledgePaths/kp_insurance.html</p>
Early Childhood Development and Young Children with Disabilities - Special Considerations and Opportunities for Public Health Involvement	<p>American Academy of Pediatrics. (1996). The role of the primary care pediatrician in the management of high-risk newborn infants. <i>Pediatrics, 98</i>(4), 786-788.</p> <p>American Academy of Pediatrics. (2000). Hearing assessment in infants and children: Recommendations beyond neonatal screening. <i>Pediatrics, 105</i>(2), 448-451.</p> <p>American Academy of Pediatrics. (1996). The role of the pediatrician in prescribing therapy services for children with motor disabilities (RE9629). <i>Pediatrics, 98</i>(2), 308-310.</p> <p>Carnegie Corporation of New York. (1994). <i>Starting points: Meeting the needs of our youngest children: The report of the carnegie task force on meeting the needs of young children</i>. New York: Author.</p> <p>McLearn, K., et al. (1998). Child development and pediatrics for the 21st century: The Healthy Steps Approach. <i>Journal of Urban Health: Bulletin of the New York Academy of Medicine, 75</i>(4), 702-723.</p> <p>Regalado, M., & Halfon, N. (2000). Primary care services promoting optimal child development from birth to age 3 years: Review of the literature. <i>Archives of Pediatric and Adolescent Medicine, 155</i>, 1311-1322.</p>

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Table 1. Recommended teaching resources (*Continued*)

Session	Recommended readings
The Role of Public Health Professionals in Screening, Identification, and Referral of Children with Disabilities	<p>U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics. (2002). <i>Summary statistics from the national survey of early childhood health, 2000</i> (Series 15, No. 3). Atlanta, GA: Author.</p> <p>American Academy of Pediatrics Policy Statements. Retrieved from www.aappolicy.aappublications.org/</p> <p>American Academy of Pediatrics, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2002). The medical home. <i>Pediatrics</i>, <i>110</i>(1), 184-186.</p> <p>American Academy of Pediatrics. (2001). Screening examination of premature infants for retinopathy of prematurity. <i>Pediatrics</i>, <i>8</i>(5), 809-811.</p> <p>American Academy of Pediatrics. (2000). Developmental surveillance and screening of infants and young children. <i>Pediatrics</i>, <i>108</i>(1), 192-196.</p> <p>American Academy of Pediatrics. (2007). Improving developmental screening: Combining parent and pediatrician opinions with standardized questionnaires. <i>Pediatrics</i>, <i>119</i>(3), 655a-656.</p> <p>American Academy of Pediatrics. (2006). Developmental surveillance and screening algorithm within a pediatric care visit. <i>Pediatrics</i>, <i>117</i>(1), 404-419.</p> <p>American Academy of Pediatrics. (2005). Pediatrician's reported practices regarding developmental screening: Do guidelines work? Do they help? <i>Pediatrics</i>, <i>116</i>(1), 174-179.</p> <p>Bethel, C., Peck, M., & Schor, E. (2001). Assessing health system provision of well child care: The promoting healthy development survey. <i>Pediatrics</i>, <i>107</i>(5), 1084-1093.</p> <p>Campbell, T., et al. (2003). Risk factors for speech delay of unknown origin in 3-year-old children. <i>Child Development</i>, <i>74</i>(2), 329-646.</p> <p>Baird, G., et al. (2001). Screening and surveillance for autism/pervasive developmental disorders. <i>Archives of Disease in Childhood</i>, <i>84</i>, 468-475.</p> <p>Grosse S., et al. (2000). Universal newborn hearing screening. <i>Pediatrics</i>, <i>106</i>, 617.</p> <p>Joint Committee on Infant Hearing Year 2000 Position Statement: Principles and guidelines for early hearing detection and intervention programs. http://www.medicalhomeinfo.org</p>
Interagency Collaboration in Service Delivery to Children with Disabilities: Federal, State, and Local Issues and Models of Success	<p>American Academy of Pediatrics, Committee on Children with Disabilities. (1999). Care coordination: Integrating health and related systems of care for children with special health care needs. <i>Pediatrics</i>, <i>104</i>(4), 978-981.</p> <p>Shackelford, J. (Ed.). (2004). <i>State ICC overview: Policies, programs, and practices of state interagency coordinating councils under idea</i>. Chapel Hill, NC: NECTAC.</p>

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Table 1. Recommended teaching resources (*Continued*)

Session	Recommended readings
Emerging Trends: Accountability and Science-Based Interventions for Children and Youth with Special Healthcare Needs	<p>Zimmerman, B., Schwalberg, R., Gallagher, J., Harkins, M., & Sines, E. (2000). <i>Title V roles in coordinating care for children with special health care needs</i>. Rockville, MD: U.S. Department of Health and Human Services. http://www.medhomeportal.org</p> <p>Division for Early Childhood, Council for Exceptional Children. Task Force on Recommended Practices. (1993). <i>DEC recommended practices: Indicators of quality programs for infants and young children with special needs and their families</i>.</p> <p>Institute of Medicine. Committee on Clinical Practice Guidelines. (1992). <i>Guidelines for clinical practice: From development to use</i>. Washington, DC: National Academy Press.</p> <p>National Council on Research. (2001). <i>Educating children with autism</i>. Committee on Educational Interventions for Children with Autism. Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.</p> <p>Noyes-Grosser, D. M., Holland, J. P., Lyons, D., Holland, C., Romanczyk, & Gillis, J. (2005, April-June). Rationale and methodology for developing guidelines for early intervention services for young children with disabilities. <i>Infants & Young Children, 18</i>, 2.</p> <p>Smith, B. J., Strain, P., Snyder, P., Sandall, S., McClean, M. E., Ramsey, A. B., et al. (2002). An analysis of the literature review that contributed to the DEC recommended practices: Nine years of EI/ECSE research. <i>Journal of Early Intervention, 25</i>, 108-119. http://www.evidencebasedpractices.org/ http://ies.ed.gov/ http://www.researchtopractice.info/ http://www.whatworks.ed.gov/</p>
Partnership with Families in Caring for Children: Parent Advocacy and Leadership Development	<p>Bishop, K. K., Woll, J., & Arango, P. (1993). <i>Family professional collaboration for children with special health care needs and their families</i>. Burlington: University of Vermont, Department of Social Work.</p> <p>Edelman, L., Greenland, B., & Mills, B. L. (1992). <i>Building parent/professional collaboration: Facilitator's guide</i>. St. Paul, MN: Pathfinder Resources, Inc.</p>

health in the delivery of services to children with disabilities and their families. The National Agenda for Children with Special Health Care Needs presented in Table 2 should be reviewed as a foundation for the course (U.S. Department of Health and Human Services, 2004a).

This session also should provide students with an opportunity to discuss the long-term

national goal, first articulated in *Healthy People 2000: National Health Promotion and Disease Prevention Objectives* (and included in the 2010 edition): "Increase the proportion of states and territories that have service systems for children with or at risk for chronic and disabling conditions as required by Public Law 101-239," and the role of public health professionals and public health practitioners

Table 2. Summary of the US Department of Health and Human Services, Maternal and Child Health Bureau National agenda for children with special healthcare needs

<p>National agenda</p> <ol style="list-style-type: none"> 1. Sustain the national consensus for building community-based and family-centered systems of care for children with special healthcare needs. 2. Stimulate professional preparation programs to provide new skills needed by providers in changing delivery systems. 3. Support the development of models that resolve cost and utilization issues for children with special healthcare needs. 4. Provide leadership in the establishment of quality assurance programs for children with special healthcare needs in managed care systems. 5. Identify and support the implementation of models of family participation in managed care settings. 6. Develop national strategies for improving data and evaluation activities to monitor the success of the National Agenda for Children with Special Health Care Needs. 7. Integrate managed care programs within the community system of services. <p>Six indicators of progress</p> <ol style="list-style-type: none"> 1. <i>Medical home.</i> Once identified, children with special healthcare needs require a medical home: a source of ongoing routine healthcare in their communities where providers and families work as partners to meet the needs of children and families. The medical home assists in early identification of children with special healthcare needs; provides ongoing primary care; and coordinates with a broad range of other specialty, ancillary, and related services. 2. <i>Insurance coverage.</i> Families must have a way to pay for services. The Children’s Health Insurance Program has begun to address the issues of children who are uninsured, but the problem of underinsurance remains a major concern for children with special healthcare needs and their families. In addition, the range of wrap-around services needed by families requires the availability of private and/or public health insurance that covers a full range of needed services. 3. <i>Screening.</i> Infants and children with high-risk health conditions must be identified early to help ensure that they and their families receive the care and assistance to prevent future morbidity and promote optimal development. Advances in brain research, the Human Genome Project, and increased effectiveness of early intervention have expanded our capacity to identify children with special healthcare needs and offer an opportunity for early intervention. 4. <i>Organization of services.</i> In order for services to be of value to children with special healthcare needs and their families, the system has to be organized in such a way that needs can be identified, and services provided in accessible and appropriate context, and that there is a family-friendly way to pay for them. Thus, effective organization of services is a key indicator of systems development. 5. <i>Families roles.</i> Families are the constant in the child’s life and are pivotal in making any system work. Family members, including those representative of the culturally diverse community served, must have a meaningful, enduring, and leading role in the development of systems at all levels of policy, programs, and practice. Family voices must be heard and families should be at each table in which decision making occurs. Thus, the involvement of families is a key indicator of systems development. 6. <i>Transition to adulthood.</i> Youth with special healthcare needs, as adults, must be able to expect good healthcare, employment with benefits, and independence. Appropriate healthcare options must be available in the community and provided within developmentally appropriate settings. Healthcare services must not only be delivered in a family-centered manner, but must prepare individuals to take care of their own healthcare and to lead a productive life as they choose. The broad definition of children with special healthcare needs includes those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions who require health and related services of a type or amount beyond required of children generally. <p style="text-align: right;"><i>(continues)</i></p>

Table 2. Summary of the US Department of Health and Human Services, Maternal and Child Health Bureau National agenda for children with special healthcare needs (*Continued*)

<p>Critical indicators for measuring success</p> <ol style="list-style-type: none"> 1. Children have access to quality healthcare services that are coordinated. 2. Providers are adequately trained. 3. Financing issues are adequately addressed. 4. Families play a pivotal role in how services are provided to their children. 5. Children grow up healthy and ready to work. <p>Critical outcomes to be achieved</p> <ol style="list-style-type: none"> 1. All children with special healthcare needs receive coordinated, ongoing comprehensive care within a medical home. 2. All families of children with special healthcare needs will have adequate private and/or public funding to pay for what they need. 3. All children will be screened early and continuously for special healthcare needs. 4. Services for children and families with special healthcare needs will be organized so they can use them easily. 5. Families of children with special healthcare needs will partner in decisions at all levels, and they will be satisfied with the services they receive. 6. All youth with special healthcare needs will receive the services necessary to make appropriate transitions to adult healthcare, work, and independence.
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in making this goal a reality. Students should have an opportunity to have an open discussion about whether and how this goal fits with the mission of public health, and the potential conflicts that can arise in times of diminishing resources. Indeed, many public health professionals continue to view the care of children (and adults) with disabilities as an ancillary, rather than central mission of public health. This session should focus the course in a way that allows students to understand the central and vital role of public health professionals (and health practitioners with whom they work) in services for the CSHCN and their families.

Session 3: Involving families: Principles of family-centered, community-based care for children and youth with special healthcare needs

We need to participate, not merely be involved. It is, after all, the parent who knew the child first and who knows the child best. Our relationship with our sons and daughters is personal and spans a lifetime. (Ripley & Kupper, 1997)

Family-centered care has been broadly defined as an approach to the planning, delivery, and evaluation of healthcare that involves active participation between families and professionals. A family-centered approach to care acknowledges families as the ultimate decision makers for their children's care and services (U.S. Department of Health and Human Services, 2004b). Family-centered care applies not only to individual, family-provider-level interactions; family-centered practices also translate into the active involvement of parents of the CSHCN in systems-level planning, policy-making, and operations. Family-centered care recognizes, respects, and values the rich diversity among families. Community-based care emphasizes the need to ensure that services are available and accessible to the CSHCN and their families to enable these children to successfully participate in their homes, schools, and larger communities.

Public health professionals and health practitioners need to understand the principles of family-centered, community-based care to be effective in providing services to the

CSHCN and their families. This session should focus on the evolution of family-centered, community-based care in the health and educational systems and assist students in learning and understanding principles of family-centered, community-based care. Efforts made at the Federal and state levels with respect to both Title V and the Part C Early Intervention Program should be described and discussed as having a key role in promoting these concepts.

Session 4: Defining, identifying, and estimating disability in children: Epidemiological and social policy perspectives

Public health professionals depend on, and use, data and expertise from areas such as epidemiology and biostatistics to identify and address the health needs of whole populations (Committee for the Study of the Future of Public Health, 1988). However, many public health professionals are unfamiliar with existing definitions of disability that are relevant to children and youth, methods to identify and estimate the incidence and prevalence of childhood disabilities, and existing data sources available on children and youth with disabilities. Session 4 should focus on historical and current definitions of childhood disabilities, including the Federal definition of children with special healthcare needs; the issues involved with identifying and estimating the CSHCN at the community level; and, how needs estimates influence decision making and resource allocation for services for these children and their families. Students should be introduced to the NCHS of the Centers for Disease Control and Prevention and the National Survey of Children with Special Health Care Needs as important resources.

An emerging and important trend in disability and health services research is the move away from using a disabling condition as a health status measure, and a shift toward focusing on health and functional status outside of the disabling condition (CDC-NCBDD, 2005). The International Classifica-

tion for Functioning, Well-being, and Health (World Health Organization, 2001) has provided impetus and an essential vehicle for these new directions and should also be discussed.

Session 5: Overview of major federal policies and programs to assist children and youth with special healthcare needs

Session 5 should present an historical overview and the current status of the major federal policies and programs available to assist the CSHCN and their families. Federal policies that affect individuals with disabilities of all ages should be reviewed, including the Rehabilitation Act of 1973 and amendments, the American with Disabilities Act, and the Developmental Disabilities Assistance Act, and Bill of Rights. Special emphasis should be placed on policies and programs that impact directly on children and youth, including the IDEA, Medicaid, including the Early Periodic Screening Diagnostic and Treatment (EPSDT) program; and the Social Security Act, including the Title V Maternal and Child Health Block Grant and Supplemental Security Income (SSI) for children with disabilities.

Section 504 of the Rehabilitation Act, the federal law that protects the rights of individuals with disabilities in programs and activities that receive federal funds, including public schools, should also receive special emphasis. Section 504 of the Rehabilitation Act assures that the CSHCN have full access to regular education programs, including public school buildings and classrooms, field trips, extracurricular activities—any and all activities and opportunities available to their peers without disabilities. To be protected under Section 504, a student must be determined to have a physical or mental impairment that substantially limits 1 or more major life activities. Children and youth who are eligible for protection and services under Section 504 are required to have an individual accommodation plan to enable them to access appropriate educational activities and opportunities in least restrictive environments.

Session 6: Maternal and Child Health Services Title V Block Grant

The Maternal and Child Health Services Title V Block Grant, established in 1935 when the Social Security Act was passed, is a Federal-State partnership to design and implement a range of maternal and child health programs that meet national and State needs (U.S. Department of Health and Human Services, 2004c). The Title V Block Grant provides states with resources to facilitate the development of comprehensive, family-centered, community-based, culturally competent, coordinated systems of care for children with special health needs. This session should present an overview of Title V and provide a more in-depth discussion of the programs associated with the Federal Maternal and Child Health Bureau, Division of Services for Children with Special Needs, including the following program areas: Medical Home; Financing/Managed Care; Family Professional Partnership/Cultural Competence; Health and Ready to Work; Community Integrated Services; and Universal Newborn Hearing Screening.

Session 7: IDEA: Part I—Historic and current perspectives

President Clinton described IDEA as “the driving force behind the simple idea that every American citizen is a person of dignity and worth, having a spirit and a soul, and having the right to develop his or her full capacities” (National Information Center for Children and Youth with Disabilities, 1997). Of all Federal Acts related to children and youth with disabilities, IDEA—enacted in 1975 as the Education for All Handicapped Children Act to provide all children and youth with disabilities a free, appropriate public education (FAPE)—has been the most far-reaching of Federal policies related to children with disabilities. Yet many, if not most, public health professionals are least familiar with IDEA among all Federal programs and policies that affect children and youth. This curriculum is designed to present IDEA in 2 sessions: the first session should present a historical overview of IDEA, discuss

its purpose and intent, and review the major provisions and requirements of IDEA.

This session should also discuss the relationship between Section 504 of the Rehabilitation Act of 1973, the federal law that protects the rights of individuals with disabilities in programs and activities that receive federal funds from the U.S. Department of Education, and requirements under IDEA to provide children and youth with disabilities with access to FAPE. In particular, the differences in eligibility for IDEA and eligibility for protection under Section 504, and differences between an individual education plan and individual accommodation plan, should be highlighted and discussed.

Session 8: IDEA—Part II: The Part C early intervention program: A model approach to comprehensive, integrated care for children with disabilities

The IDEA Part C Early Intervention Program was established in the 1986 reauthorization of the IDEA to provide states with funding to design and implement statewide, comprehensive, interdisciplinary, coordinated systems of early intervention services for infants and toddlers with disabilities and their families. The Part C Early Intervention Program is discretionary to states; all 50 states and 6 territories currently maintain statewide early intervention systems. An important tenant of Part C is to ensure that states maximize and coordinate all existing Federal, state, and local programs within state early intervention systems, to provide infants and young children with special needs and their families access to family-centered services to enhance child development and functioning. Part C of IDEA is arguably the most important and comprehensive national program for young children with special needs and their families. This session should provide students with an overview of the major provisions of Part C of IDEA, as well as the current status of national and state-level implementation of Part C. The session should also highlight the variation in the implementation of Part C of IDEA among the states and territories, including the variation in state lead agencies, eligibility requirements,

approaches to service delivery, and financing. The influence of state health agencies as lead agencies for early intervention program, including the challenges and benefits of health lead agencies for Part C programs, should be discussed.

Session 9: Family perspectives on service delivery systems

Public health professionals need to understand and learn from family perspectives on the health and educational service delivery systems for the CSHCN. During the past 3 decades, a number of organizations have emerged dedicated to understanding and communicating family perspectives on the health and educational systems. To convey this information in a meaningful way to students, the session should involve 1 or more family members of the CSHCN and a youth or adult with disabilities as guest speakers.

The content of this session should offer students the opportunity to learn about family perspectives using both quantitative and qualitative approaches. Students should become familiar with national advocacy organizations, including Family Voices, the Institute for Family-Centered Care, and the National Information Center for Children and Youth with Disabilities (NICHCY). Results on family-centered care from the National Survey of Children with Special Health Care Needs (U.S. Department of Health and Human Services, 2004b) should be presented and discussed, as well as the results of surveys conducted by Family Voices and other parent advocacy organizations. State-level efforts should also be described.

In addition to the perspective of family members, this session should also focus on the perspectives of youth and adults with disabilities on service delivery systems. One of the 6 critical indicators of progress for the CSHCN identified by the federal MCHB is ensuring a successful transition to adulthood, including the ability to expect and access good healthcare, employment with benefits, and achieve independence (“children grow up healthy and ready to work”).

Youth development and leadership opportunities should be discussed as important strategies in ensuring successful transition to adulthood.

Sessions 10 and 11: Issues in the public and private financing of services for children and youth with disabilities

For all children, including the CSHCN, access to healthcare depends on access to health insurance. Among the CSHCN nationally, two thirds have private or employment-based coverage, 22% have public coverage, 8% have both, and 5% had no insurance at all (U.S. Department of Health and Human Services, 2004b).

Health insurance coverage in the United States is complex, involving large Federal and state programs and private sector health plans, generally governed by a myriad of Federal and state laws and regulations. As permitted under the Employee Retirement Income Security Act of 1974, an increasing percentage of employers are purchasing their own plans for employees, leaving many children and families with insurance outside jurisdiction of state insurance commissions and state regulations. The emergence of managed care over recent decades as a growing force in efforts to contain the costs of healthcare has also created many challenges for the CSHCN and their families.

At the individual level for the CSHCN, access to healthcare services, including habilitative and rehabilitative services, is essential not only to their health status but to their educational achievements, functional abilities, and capacity to engage and participate in their families, schools, and communities. At the systems level, public agencies administering services for children and youth with disabilities (especially state agencies administering Part C of IDEA early intervention programs and Title V Children with Special Health Care Needs programs) rely on public *and* private sector insurance to fund healthcare services needed by their target populations.

Sessions 10 and 11 of this course focus on the major public health insurance programs, provide an overview of how private sector

insurance works, and introduce students to issues and concerns related to health insurance coverage for the CSHCN.

Part I: Medicaid and SSI

Medicaid and Social Security benefits ("SSI") are 2 of the most important funding streams available to support the provision of preventive health, diagnostic, and treatment (including rehabilitative) services to children and youth with disabilities and their families. The EPSDT program, established in 1989, is Medicaid's comprehensive, preventive health program for children and youth aged birth to 21 years. The EPSDT requires states to ensure a periodic assessment of children's physical and mental health development at intervals that meet reasonable medical standards, and follow-up screening, diagnostic, and treatment services necessary to ameliorate defects, and physical and mental illnesses and conditions discovered by the screening services. Under the Medicaid program, states can also apply and receive waivers to allow children with significant disabilities and healthcare need, whose families do not meet income eligibility requirements, to participate in the Medicaid program. Social security benefits ("SSI") are available to children and youth with disabilities in accordance with established Federal definitions ("a physical or mental condition [or a combination of conditions] that results in marked and severe functional limitations) (Social Security Administration, 2001). In most states, eligibility for SSI also qualifies children for Medicaid.

Session 10 should provide students with an overview of Medicaid and SSI, focusing on the impact of these important programs on health and developmental services for children and youth with disabilities. The session should also highlight the relationship between the role of the Federal and state governments in the administration of Medicaid in particular, and the variation across states in the administration of Medicaid and how this variation affects access to services for the CSHCN and their families.

Part II: Issues in the public and private financing of services for children and youth with special healthcare needs: State child health insurance programs, commercial insurance coverage, and parent participation

In addition to Medicaid and SSI, public health professionals need to be informed about other financing mechanisms for services for children and youth with special healthcare needs, including the State Children's Health Insurance Program (SCHIP), created as part of the Balanced Budget Act of 1997. SCHIP, like Medicaid, is a Federal and State partnership designed to expand health insurance to children whose families have incomes too high to qualify for Medicaid, but insufficient to purchase private insurance. States can use SCHIP funds to expand Medicaid eligibility to children who previously did not qualify for the program, implement a separate children's health insurance program entirely separate from Medicaid, or combine both the Medicaid and separate program options. Also, like Medicaid, states have significant flexibility in the administration of SCHIP.

A number of factors influence both public and private sector health insurance coverage for the CSHCN. In particular, managed care and the role of definitions of medical necessity used by managed care plans and other types of insurance have enormous implications on access to healthcare services needed by children with disabilities to maintain their functional as well as health status. This session should provide students with an overview of SCHIP and private insurance coverage, and the issues that influence healthcare coverage and access to healthcare services for the CSHCN.

Session 12: Early childhood development and young children with special healthcare needs—Special considerations and opportunities for public health involvement at the systems level

Public health professionals have a long-standing involvement and interest in perinatal

and early childhood health services. Programs traditionally under the purview of public health, including newborn home visiting programs, high-risk infant follow-up programs, early childhood immunization, the Women, Infants, and Children nutrition program (WIC), lead screening programs, and universal newborn hearing screening, are all important avenues for public health professionals to identify and refer the CSHCN to resources and programs that can offer valuable assistance. This session should familiarize students with Federal and state maternal and child health programs and assist students in understanding how these programs can and should play an important role in the identification and referral of the CSHCN to appropriate services.

This session should also address challenges encountered by public health professionals as they increasingly assume administration of early childhood programs (especially Part C early intervention programs under IDEA) that in the past have been external to public health. Discussion should address not only the benefits to public health officials in assuming these responsibilities (eg, increased resources, increased outreach and intervention capacity, etc) but also the potential barriers to coordination of care that must be addressed (eg, confidentiality requirements under the Federal Family Educational Rights and Privacy Act and the Health Insurance Portability and Accountability Act) and the conflicts posed by what may be viewed as a diversion of resources from traditional public health activities to services to children with disabilities.

Session 13: The role of health professionals in screening, identification, and referral of children with disabilities at the individual child level

Healthcare professionals, particularly primary healthcare providers, are uniquely positioned to conduct ongoing developmental surveillance—as part of healthcare surveillance—that can help identify developmental problems and disabilities as early

as possible. Once a problem (or potential problem) is identified, primary healthcare providers can and should continue to play a central role in ensuring that children are referred for appropriate evaluation and treatment services, including Part C early intervention services or Part B special education services under IDEA.

Public health professionals, particularly local and state officials administering Part C and Title V programs, have responsibility for ensuring or contributing to child find activities to identify children and youth with disabilities. These professionals can play a key role in educating primary healthcare providers on the importance of developmental surveillance, particularly in very young children, and when and how to refer children and their families to public programs. Public health professionals can also be a valuable resource in promoting the concept of the *medical home* for the CSHCN. As defined by the American Academy of Pediatrics (AAP, 2002), a medical home is...“primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.”The medical home is a model of care that promotes a partnership between the healthcare provider and the family/patient to ensure that all of the medical and nonmedical needs of the child are met. Medical home providers help the families and their children access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child/youth and family (AAP, National Center for Medical Home Initiatives for Children with Special Needs, 2003).

This session should focus on both the role of health professionals involved in direct healthcare services in early identification of developmental problems and the importance of collaboration and coordination with public health professionals (and other professionals) involved in the administration of public programs that offer services to children with disabilities and their families. Position papers issued by the AAP and other

professional associations should be used as teaching tools. The National Survey of Early Childhood Health (Department of Health and Human Services, Centers for Disease Control and Prevention, 2002) is also a valuable resource for this discussion.

Session 14: The role of public health professionals in coordinating and collaborating in supports and services for children and youth with special healthcare needs

Public health professionals are frequently involved in individual, client-level care as case managers for children in Part C early intervention programs and/or Title V children with special healthcare needs programs. A national study commissioned by the U.S. Department of Health and Human Resources on Title V roles in coordinating care for children with special healthcare needs found that 42 of 46 respondent states either directly provide or contract to provide care coordination services to children with special healthcare needs. The AAP defines *care coordination* as “a collaborative process that links children and families to services and resources in a coordinated manner to maximize the potential of children and provide them optimal health care” (AAP, 1999). Service coordination is a required component of Part C early intervention programs, and many state and local health agencies also directly provide or fund service coordination services to infants and toddlers with special needs and their families.

Protocols related to delivery of care coordination/service coordination services, different models/approaches to care coordination/service coordination, responsibilities of care coordinators/service coordinators, and financing of these services should be discussed. Some examples of what care coordination means in practical terms at the State and local levels should be presented. The benefits and challenges of public health involvement in care coordination/service coordination activities should also be presented.

Session 15: Interagency collaboration in service delivery to children and youth with special healthcare needs: Federal, state, and local issues and models of success

One activity to which Title V agencies are particularly suited, given their federal mandate to serve the entire maternal and child population, is convening the many agencies, programs, and systems that serve women and children, including CSHCN. These forums can serve to enhance programs' understanding of each other's roles and issues, and in turn, facilitate the coordinated development of policies and strategies for improving service delivery for CSHCN and their families. (Zimmerman et al., 2000)

State and local public health agencies responsible for Title V children with special healthcare needs programs and Part C early intervention programs have, as part of their core mission, the goal of coordinating and collaborating with other State and local agencies, organizations, community-based programs, and service systems that serve the entire child health population, including children with special healthcare needs/disabilities (Zimmerman et al., 2000). The role of public health agencies and professionals in 6 areas, as described in Zimmerman et al. (2000), facilitating interagency coordination, building structures to link children and families to needed services, establishing standards and mechanisms to facilitate appropriate receipt of services, monitoring of services, and coordinating the financing of services, should be presented and discussed.

The Part C Early Intervention Program under IDEA should also be discussed as an exemplary model of Federal, state, and local interagency collaboration for infants and toddlers with disabilities and their families. A fundamental tenant of Part C is that *all* systems, programs, and services targeting children aged birth to 3 years and their families should work together in a coordinated fashion, under the auspices of lead agencies responsible for administering a statewide, comprehensive, multidisciplinary, coordinated system of early

intervention services. The role of state interagency coordinating councils, child find activities, interagency agreements, and coordination of multiple funding sources to support early intervention services should be emphasized.

Session 16: Emerging trends: Accountability and science-based interventions for children and youth with special healthcare needs

The reliance and emphasis on science-based approaches to assessment and interventions, particularly through the development and use of evidence-based clinical practice guidelines, has been relatively well established in the healthcare arena. In the past decade, work on the development and compilation of evidence-based practice recommendations for evaluating and intervening with children and youth with disabilities has been increasing. National education policies, including “No Child Left Behind” and the IDEA, have embraced the quest for science-based practices. Indeed, the recently reauthorized IDEA includes new requirements on states, practitioners, and families to provide science-based interventions to the extent possible under the Early Intervention Program. In addition to the increasing emphasis on science-based practice, there has been a growing interest in the measurement and reporting of outcomes being achieved for children and families through participation in government service delivery systems, including both health and educational systems.

This session should familiarize students with the various approaches to the use of data to inform practices in evaluating, assessing, and intervening with children and youth with disabilities. Approaches developed by the Agency for Healthcare Research and Quality, National Institutes for Medicine, National Academies of Science, and Division of Early Childhood of the National Council for Exceptional Children should be described and discussed. In addition, initiatives undertaken by states and organizations to

develop and issue evidence-based guidelines should be discussed. Limitations and challenges, as well as the benefits of developing and using evidence-based guidelines, should be discussed. The relationship of science-based practices to national and state measurement systems to identify and report outcomes should be presented and discussed.

Session 17: Partnerships with families in caring for children: Parent advocacy and leadership development

Parent advocacy and leadership development efforts are essential to involving families of the CSHCN in federal, state, and local policy-making and systems-level change. Helping parents gain advocacy and leadership skills can also assist them in negotiating complicated service delivery systems and advocating effectively on behalf of their own children and families. Many exemplary parent advocacy and leadership programs for families of the CSHCN exist at the national, state, and local levels. The U.S. Department of Education sponsors parent training and information centers in all states and territories to provide training and information to parents of infants, toddlers, children, and youth with disabilities and to people who work with parents to enable them to participate more fully and effectively with professionals in meeting the educational needs of their children and youth with disabilities. The *Partners in Policymaking* leadership-training program, created in Minnesota by the Governor’s Council on Developmental Disabilities in 1987, is a program that teaches parents both best practices in disability and competencies needed to influence public officials. *Partners* has been implemented in 46 states and in some international locations. The New York State Early Intervention Program has adapted the “Partners in Policymaking” training program to meet the unique needs of parents engaged in the early intervention system.

The final session of this course should present students with an overview of the resources and approaches available related to parent advocacy and leadership training.

The session should emphasize the importance of these training opportunities to helping parents be successful participants in policy-making arenas, such as participating in state interagency coordinating councils for Part C early intervention programs and other venues for promoting high-quality, family-centered services for the CSHCN and their families.

DISCUSSION

Public health professionals have an essential role in ensuring the healthy development of children and youth with disabilities, yet many are unprepared to manage and provide services that meet the needs of these children and their families. This article outlines a survey course for students of public health on the CSHCN and their families. Universities with schools of public health are envisioned as a primary audience for this type of course. Although the primary target audience for this course is public health professionals, the course content proposed could also serve as a framework for the development of a course on this topic for medical schools and schools of allied health professions. To enhance the relevance of this type of course for medical and allied health professions students, course content could be expanded or revised to also emphasize the practice implications of delivering healthcare services to the CSHCN and their families. Finally, this type of course could also offer a valuable venue for cross-disciplinary training among public health and allied health students and students from other disciplines involved with children and youth with disabilities, including education, psychology, and social welfare. Although developed primarily with preservice training in mind, the syllabus could also be used to

develop in-service training opportunities for practicing professionals.

The proposed syllabus is designed to be delivered using an interdisciplinary, faculty-team approach. In addition, parents of children with disabilities, and *youth and adults* with disabilities, including parent and disability advocates, should be involved as part of the teaching team or, at a minimum, as guest lecturers. Parents offer students a unique perspective on the experience of families with the CSHCN and on the state of the service delivery system(s) for their children and themselves. Youth and adults with disabilities can convey, without equal, the experience and implications of how services are delivered for the quality of their lives.

State and local policymakers and administrators can also make valuable contributions to the teaching team as guest lecturers. Such individuals can articulate the challenges involved in developing and implementing policies that make sense for children and families, and the pressing resource issues involved in maintaining quality service delivery systems for children and youth with special healthcare needs and their families.

This course will be most effective when individualized with case examples of state and local implementation of Federal programs for the CSHCN and their families. Federal laws, regulations, and funding provide the foundation for service systems for the CSHCN, but state and local delivery systems function differently within this broad Federal framework. Students and professionals need to be informed about and understand the state and community policies where they reside to positively affect child and family experiences and outcomes achieved for children with disabilities/special healthcare needs and their families.

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