

Target Population Estimations

A Guide for Assessing Quality Care for Children with Special Health Care Needs

Colleen A. Monahan, DC, MPH
Director, Center for Advancement of Distance Education
Director, Information Technology
University of Illinois at Chicago
School of Public Health

Henry T. Ireys, PhD
National Policy Center for Children with Special Health Care Needs
Johns Hopkins University
School of Public Hygiene and Health

This project was funded by a grant from the federal
Maternal and Child Health Bureau
(DHHS/PHS/HRSA MCJ 17R018-01-0)



© Copyright 2000

Coordinator, Digital Graphics Wendi Lam Thourson, MFA

Coordinator, Marketing and Publications Margaret M. Maloney, MA

For more information on Quality Community Managed Care project or to
download an Adobe .PDF version of this Guide, visit the Web site

http://www.uic.edu/sph/cade/mch_managed_care/publications.htm

Copies of this Guide may be obtained from:

National Maternal and Child Health Clearinghouse (NMCHC)

2070 Chain Bridge Road, Suite 450

Vienna, VA 22182-2536

703-821-8955 (phone)

703-821-2098 (fax)

<http://www.nmchc.org>

Contents

List of Tables	v
Preface	xi
About this Project	xi
Acknowledgements	xii
Chapter 1 The National Health Interview Survey and Children with Special Health Care Needs	1
Henry T. Ireys, PhD	
Introduction	1
Definitional Issues	2
Estimating Prevalence Rates	3
Identifying Service Needs	4
Identifying Unmet Needs	5
Assessing Quality of Care	6
References	7
Chapter 2 Creating State and Local Estimates of the Population of Children with Special Health Care Needs	9
Colleen Monahan, DC, MPH	
Using National Survey Data to Develop Synthetic Estimates	9
Developing a State Estimate for CSHCN	10
References	14
Appendix A Tables	15
Appendix B Glossary of Variables	69

Tables

- Table 1:** Number of children with special health care need(s) (CSHCN) age under 18 by poverty by race by age. (NHIS-D 1994, 1995)
- Table 2a:** Number of children under 18 by activity limitation status by race and age. (NHIS-D 1994, 1995)
- Table 2b:** Number of children under 18 by activity limitation status by age and by sex by age. (NHIS-D 1994, 1995)
- Table 2c:** Number of children under 18 by activity limitation by race and race by ethnicity. (NHIS-D 1994, 1995)
- Table 2d:** Number of children under 18 by activity limitation status by family structure, size of family, health status, NHIS Poverty Index, income, region, and MSA. (NHIS-D 1994, 1995)
- Table 3:** Number of children under 18 by presence of a learning disability by poverty by race by age. (NHIS-D 1994, 1995)
- Table 4a:** Number of children under 18 by presence of a learning disability by age and sex by age. (NHIS-D 1994, 1995)
- Table 4b:** Number of children under 18 by presence of a learning disability by race, race by ethnicity, and race by age. (NHIS-D 1994, 1995)
- Table 4c:** Number of children under 18 by presence of a learning disability by family structure, size of family, health status, NHIS poverty index, income, region, and MSA. (NHIS-D 1994, 1995)
- Table 5:** Number of children ages 5-17 with personal care limitations by poverty by race by age. (NHIS-D 1994, 1995)
- Table 6a:** Number of children ages 5-17 with personal care limitation by age and sex by age. (NHIS-D 1994, 1995)
- Table 6b:** Number of children ages 5-17 with personal care limitation by race, race by ethnicity, and race by age. (NHIS-D 1994, 1995)
- Table 6c:** Number of children ages 5-17 with personal care limitation by family structure, size of family, health status, NHIS poverty index, income, region, and MSA. (NHIS-D 1994, 1995)
- Table 7:** Unweighted sample frequencies for all children, under 18, children with special health care need(s) (CSHCN), children with activity limitation status, children with presence

of a learning disability with personal care limitation ages 5-17 by poverty by race by age. (NHIS-D 1994, 1995)

Table 8a: Unweighted sample frequencies for all children under 18, children with activity limitation status with presence of a learning disability with personal care limitation ages 5-17 by poverty by race by age. (NHIS-D 1994, 1995)

Table 8b: Unweighted sample frequencies for all children under 18, children with activity limitation, children with presence of a learning disability and children with personal care limitation ages 5-17 by race, race by ethnicity, and race by age. (NHIS-D 1994, 1995)

Table 8c: Unweighted sample frequencies for all children under 18, children with special health care need(s) (CSHCN), children with activity limitation, children with presence of a learning disability, and children with a personal care limitation ages 5-17 by family structure, size of family, health status, NHIS Poverty Index, family income, region, and MSA. (NHIS-D 1994, 1995)

Table 9a: Number of children under 18 years with legal blindness or serious difficulty seeing by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)

Table 9b: Number of children with special health care needs (CSHCN) under 18 years by sensory (vision) limitations according to selected characteristics. (NHIS-D 1994, 1995)

Table 10a: Children under 18 years, with hearing limitations by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)

Table 10b: Children under 18 years, with hearing limitations by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)

Table 11: Children ages 5-17 years with communication and learning limitations by race, NHIS Poverty Index and age. (NHIS-D 1994, 1995)

Table 12a: Children under 18 years, by mobility aid use by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)

Table 12b: Children under 18 years, by mobility aid use by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)

Table 12c: Children under 18 years, by mobility aid use by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)

Table 12d: Children under 18 years, by mobility aid use by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)

Table 13a: Children ages 5-17 and need for another person to help perform ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)

- [Table 13b](#): Children ages 5-17 years and need for another person to help perform specific ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 13c](#): Children ages 5-17 and need for another person to help perform specific ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 14a](#): Children ages 5-17 years, by requirement of reminder/someone near to perform selected ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 14b](#): Children ages 5-17 years, by requirement of reminder/someone near to perform selected ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 14c](#): Children ages 5-17 years, by requirement of reminder/someone near to perform selected ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 15a](#): Children ages 5-17 years, by use of special equipment for selected ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 15b](#): Children ages 5-17 years, by use of special equipment for selected ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 15c](#): Children ages 5-17 years, by use of special equipment for selected ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 16a](#): Children ages 5-17 years, by difficulties with selected ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 16b](#): Children ages 5-17 years by difficulties with selected ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 16c](#): Children ages 5-17 years by difficulties with selected ADLs by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 17a](#): Children ages 5-17 years, by ADL problems lasting at least 12 months by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 17b](#): Children ages 5-17 years, by ADL problems lasting at least 12 months by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 17c](#): Children ages 5-17 years, by ADL problems lasting at least 12 months by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- [Table 18a](#): Children under 18 years, by problem/delay in development by race, NHIS Poverty Index, age. (NHIS-D 1994, 1995)
- [Table 18b](#): Children under 18 years, by problem/delay in development by race, NHIS Poverty Index, age. (NHIS-D 1994, 1995)

- Table 19a:** Children under 18 years, by conditions requiring physician visits or prescription medication by race, NHIS Poverty Index, age. (NHIS-D 1994, 1995) . (NHIS-D 1994, 1995)
- Table 19b:** Children under 18 years, by conditions requiring physician visits or prescription medication by race, NHIS Poverty Index, age. (NHIS-D 1994, 1995). (NHIS-D 1994, 1995)
- Table 20a:** Children under 18 years, by conditions requiring special breathing equipment, counseling, or physical therapy by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- Table 20b:** Children under 18 years, by conditions requiring special breathing equipment, counseling, or physical therapy by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- Table 20c:** Children under 18 years, by conditions requiring occupational therapy or other procedures by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- Table 21a:** Children under 18 years, by conditions causing difficulty in strenuous exercise or in getting along with others by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- Table 21b:** Children under 18 years, by conditions causing difficulty in chewing, swallowing, or digesting, or in toileting or eating by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- Table 22a:** Children ages 3-17 years, with learning limitations in school by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- Table 22b:** Children ages 3-17 years, with learning limitations in school by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- Table 23a:** Children ages 3-17 years, with special education services by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- Table 23b:** Children in selected age groups with special education services by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- Table 24:** Children under 18 years with respondent perceived disability by race, NHIS Poverty Index, and age. (NHIS-D 1994, 1995)
- Table 25:** Unweighted sample frequencies for children under 18 years by sensory (vision) limitations according to selected characteristics. (NHIS-D 1994, 1995)
- Table 26:** Unweighted sample frequencies for children under 18 years by sensory (auditory) limitations according to selected characteristics. (NHIS-D 1994, 1995)
- Table 27:** Unweighted sample frequencies for children ages 5-17 years by communication and learning limitations according to selected characteristics. (NHIS-D 1994, 1995)

- Table 28a:** Unweighted sample frequencies for CSHCN under 18 years by mobility aid use according to selected characteristics. (NHIS-D 1994, 1995)
- Table 28b:** Unweighted sample frequencies for CSHCN under 18 years by mobility aid use according to selected characteristics. (NHIS-D 1994, 1995)
- Table 29a:** Unweighted sample frequencies for children ages 5-17 years by requirement of another person to help perform specific ADLs according to selected characteristics. (NHIS-D 1994, 1995)
- Table 29b:** Unweighted sample frequencies for children ages 5-17 years by requirement of another person to help perform specific ADLs according to selected characteristics. (NHIS-D 1994, 1995)
- Table 30a:** Unweighted sample frequencies for children ages 5-17 years by requirement of reminder/someone near to perform selected ADLs according to selected characteristics. (NHIS-D 1994, 1995)
- Table 30b:** Unweighted sample frequencies for children ages 5-17 years by requirement of reminder/someone near to perform selected ADLs according to selected characteristics. (NHIS-D 1994, 1995)
- Table 31a:** Unweighted sample frequencies for children 5-17 years by use of special equipment for selected ADLs according to selected characteristics. (NHIS-D 1994, 1995)
- Table 31b:** Unweighted sample frequencies for children 5-17 years by use of special equipment for selected ADLs according to selected characteristics. (NHIS-D 1994, 1995)
- Table 32a:** Unweighted sample frequencies for children ages 5-17 years by difficulties with selected ADLs according to selected characteristics. (NHIS-D 1994, 1995)
- Table 32b:** Unweighted sample frequencies for children ages 5-17 years by difficulties with selected ADLs according to selected characteristics. (NHIS-D 1994, 1995)
- Table 33a:** Unweighted sample frequencies for children ages 5-17 years by ADL problems lasting at least 12 months according to selected characteristics. (NHIS-D 1994, 1995)
- Table 33b:** Unweighted sample frequencies for children ages 5-17 years by ADL problems lasting at least 12 months according to selected characteristics. (NHIS-D 1994, 1995)
- Table 34:** Unweighted sample frequencies for children under 18 years by problem/delay in development according to selected characteristics. (NHIS-D 1994, 1995)
- Table 35:** Unweighted sample frequencies for children under 18 years by conditions requiring physician visits, prescription medication, hospital stay, or special diet according to according to selected characteristics. (NHIS-D 1994, 1995)

- Table 36a:** Unweighted sample frequencies for children under 18 years by conditions requiring special breathing equipment, counseling, or physical therapy according to selected characteristics. (NHIS-D 1994, 1995)
- Table 36b:** Unweighted sample frequencies for children under 18 years by conditions requiring occupational therapy, or other procedures according to selected characteristics. (NHIS-D 1994, 1995)
- Table 37:** Unweighted sample frequencies for children under 18 years by conditions causing difficulty in strenuous exercise, getting along with others, chewing, swallowing, or digesting, or in toileting or eating according to selected characteristics. (NHIS-D 1994, 1995)
- Table 38a:** Unweighted sample frequencies for CSHCN ages 3-17 years by child learning limitations in school according to selected characteristics. (NHIS-D 1994, 1995)
- Table 38b:** Unweighted sample frequencies for CSHCN ages under 3-17 years by child limitations in school according to selected characteristics. (NHIS-D 1994, 1995)
- Table 39a:** Unweighted sample frequencies for children ages under 3-17 years by education services according to selected characteristics. (NHIS-D 1994, 1995)
- Table 39b:** Unweighted sample frequencies for children ages under 18 years by education services according to selected characteristics. (NHIS-D 1994, 1995)
- Table 40:** Unweighted sample frequencies for CSHCN age under 18 years by perceived disability according to selected characteristics. (NHIS-D 1994, 1995)

Preface

Maternal and child (MCH) programs target a wide variety of population groups for services. One targeted group is children with special health care needs (CSHCN). Estimating the size of this population is crucial for state CSHCN programs, which are in transition from providing direct services to promoting and monitoring comprehensive systems of care. Recent changes in health care financing have led to an increase in the number of CSHCN entering managed care plans, placing them at risk if treatment is not appropriate, or if specialty care is not provided. Estimating the size of this population is difficult as there are a number of approaches that have been used to classify and characterize CSHCN. In addition to the lack of consensus on a definition for CSHCN, there is no single data source from which a direct measurement of the size of the CSHCN population can be estimated. To address this problem, the federal Maternal and Child Health Bureau's (MCHB) Division of Services for Children with Special Health Care Needs developed a definition of CSHCN (defined in Chapter One of this manual).

Using the MCHB definition of CSHCN, Dr. Paul Newcheck and others worked with a large nationally representative survey—the National Health Interview Survey Disability Supplement (NHIS-DS)—to determine the number of CSHCN in the United States. In the July 1998 edition of *Pediatrics*, the group reported that “...between 15% and 20% of U.S. children have a significant, ongoing health care need related to a chronic health condition. Additional children are at-risk of developing an ongoing health care need, but no estimates of their number are available at present.”

Building upon this work, this guide contains tables that calculate the number of CSHCN based on 80 different variables. This manual will also help MCH and CSHCN professionals to use data from the National Health Interview Survey Disability Supplement to create estimates of the number of CSHCN or the number of CSHCN with specific characteristics in their states or regions. These estimations will enhance the ability to plan, monitor, and assess programs affecting the health of CSHCN.

About This Project

Quality Community Managed Care (QCMC) was a project funded by a grant from the Maternal and Child Health Bureau (MCHB) from October 1, 1994 through September 30, 1998 to address the need for effective, ongoing mechanisms for quality assurance to monitor how managed care systems reach, appropriately serve, and improve the health of CSHCN. The goal of this project was to develop and field test a model for systematic evaluation of service delivery and outcomes at the community and family levels for CSHCN, including children eligible for publicly funded programs under managed care. A model method to collect and assess selected indicator data, a process for evaluating cost effectiveness and efficiency of the model, and the modification and retesting of model elements were addressed by QCMC project staff. Information about this project, as well as Adobe PDF versions of the several publications produced by the QCMC project staff may be accessed at http://www.uic.edu/sph.cade/mch_managed_care/publications.htm

Quality Community Managed Care: A Guide to Quality Assurance Measures for Children with

Special Health Care Needs provides a set of performance measures that can be used to monitor CSHCN in managed care plans, or to monitor services funded through state CSHCN programs. Each measure pertinent to the CSHCN population is described, along with necessary data items, and sources(s) for collecting the data. *Developing and Monitoring a Quality Assurance System for Connecticut's Children with Special Health Care Needs Program* details the experience of testing the QCMC model in Connecticut's CSHCN program. The guide, *Developing and Analyzing Performance Measures: A Guide for Assessing Quality Care for CSHCN* details a ten-step analysis plan for the ongoing and dynamic process of generating all required indicators of quality, a method of interpreting the indicators, and the subsequent review process that includes the state program and local contracted managed care agency staff. This guide is intended to assist these stakeholders in developing goals and objectives, including correctives measures, to improve effectiveness, efficiency, accessibility, provider competence, and program management.

Acknowledgements

The authors of this manual would like to thank the following individuals for their valuable contributions. Paul Newacheck, DrPH, of the Maternal and Child Health Policy Research Center provided the algorithm that was used to generate the tables in this guide. This algorithm was developed by the Maternal and Child Health Policy Research Center under a grant from the federal Maternal and Child Health Bureau.

Sylvia Furner, PhD, MPH, of the University of Illinois at Chicago, School of Public Health and Deborah Rosenberg, PhD, of the University of Illinois at Chicago, School of Public Health generated the standard error (SE) used in the tables this guide.

Antoinette S. Hernandez, MPH, spent countless hours generating the data and creating the tables used in this manual.