

COMMENTARIES

Opinions expressed in these commentaries are those of the authors and not necessarily those of the American Academy of Pediatrics or its Committees.

A New Definition of Children With Special Health Care Needs

ABBREVIATIONS. MCH, Maternal and Child Health (program); CSHCN, Children With Special Health Care Needs (program); DSCSHCN, (Maternal and Child Health Bureau's) Division of Services for Children With Special Health Care Needs.

Developing community systems of services for children with special health care needs represents a significant challenge for pediatricians, families, managed care organizations, and public and private agencies providing services to this population. At the state level, Maternal and Child Health (MCH) and Children With Special Health Care Needs (CSHCN) programs are vested with the responsibility for planning and developing systems of care for all children with special health care needs. Historically, these programs have been supported through Title V of the Social Security Act, with state-matching funds, to provide health services to selected groups of children with special needs, typically those with complex physical conditions. However, during the last half-century, service systems have become increasingly complex as a result of health, education, and social policy changes, as well as changes in the epidemiology of child health, including increases in the number and proportion of children with chronic conditions and disabilities and changes in their case-mix.¹⁻⁴ These changes have resulted in gaps in some service areas and duplication in other areas, as well as fragmentation in the way service systems are organized.⁵

Recognizing these difficulties, health policy leaders at the state and federal levels, with broad input from public and private agencies, providers, and families, effected legislative changes in the federal Omnibus Budget Reconciliation Act of 1989, which expanded the mission of CSHCN programs to facilitate the development of community-based systems of services for children with special health care needs and their families. Since then, the explosive growth of managed care has presented new challenges and opportunities as well as a heightened urgency for the development of systems of care that integrate health and related services for this population.^{6,7}

Developing systems to serve children with special

health care needs requires a clear definition of the population to be served. State CSHCN programs and others have struggled with defining this population. Should the population include only children with significant disabilities or be limited to those with specified types of physical conditions? Should need for services be a factor in defining the population? Should the definition encompass children with chronic physical, developmental, behavioral, or emotional conditions? Should children at risk of these chronic conditions also be included for planning purposes? A clear articulation of the concept of children with special health care needs requires that these questions be addressed. Substantial progress in this direction has occurred in recent years through the publication of two reports on the conceptual issues that must be addressed in defining children with special health care needs.^{8,9}

Building on these past efforts, a new definition of children with special health care needs is presented in this report. The purpose is to assist state Title V CSHCN programs and other interested parties in planning for the needs of this population. Although not developed as a definition to establish eligibility for CSHCN services, it may be used by states at their discretion for this purpose. Families, pediatricians, and public and private programs serving children may also find this definition useful for advocacy and other purposes. In the sections that follow we describe the process of developing the new definition, articulate that definition and its components, and conclude with some thoughts concerning the implications of the new definition for service planning. Elsewhere in this issue we present epidemiologic estimates of the number of children with special health care needs.¹⁰

THE PROCESS OF DEVELOPING THE NEW DEFINITION

To assist states in their systems development activities, the federal Maternal and Child Health Bureau's Division of Services for Children With Special Health Care Needs (DSCSHCN) established a work group to address the questions posed above and recommend a preferred definition. In selecting members of this work group, an effort was made to represent the expected constituencies for a new definition, including federal and state CSHCN program directors, parents, and health care professionals. In addition, epidemiologists and policy analysts familiar with the needs of the target population were included in the work group. More specifically, the authors of this report comprised the work group. The work group met a total of three times over the course of the fall and winter of 1994-1995.

Received for publication Jan 27, 1998; accepted Jan 27, 1998.

Address correspondence and reprint requests to: Merle McPherson, MD, Maternal and Child Health Bureau, Room 18A27, Parklawn Bldg, 5600 Fishers Ln, Rockville, MD 20857.

PEDIATRICS (ISSN 0031 4005). Copyright © 1998 by the American Academy of Pediatrics.

The work group began its deliberations by establishing a set of principles to help guide the development of a definition. To the extent possible, the definition should:

- be simple and easy to understand;
- have utility for major policy and program directions for the federal Title V Program for Children With Special Health Care Needs;
- have utility for the state Title V systems development mission, specifically the development of comprehensive community systems of family-centered services for children with special health care needs;
- recognize linkages among primary health services, specialty health services, and related services (eg, education, social services);
- be specific and measurable; and
- reflect current scientific knowledge.

Based on these principles, the work group assessed several alternative approaches to defining children with special health care needs. The approaches considered were identified through a review of the literature and federal and state eligibility criteria for programs serving various segments of the population of children with special health care needs. These included population definitions and eligibility criteria for existing state programs for children with special health care needs (Title V), special education and early intervention programs, and the Supplemental Security Income program eligibility criteria. This effort yielded three generic definitional approaches: 1) definitions based on the presence of a chronic condition; 2) definitions based on the presence of a functional impairment; and 3) definitions based on the presence of an elevated service need.

An approach based solely on condition or diagnostic lists was rejected because chronic conditions vary considerably in severity, degree of impairment, and service needs. Furthermore, any complete condition list would be unwieldy and include many children who do not require special services. A definition based solely on functional status was also considered inappropriate because such an approach leaves out many children who may function well but still need special services to maintain function. For example, a child with a seizure disorder who functions well may only do so with medication for control of seizures. Furthermore, there are substantial problems in the measurement of children's functioning, especially for infants and very young children.

Given the substantial problems with the condition list and functional status approaches, the work group gravitated toward an approach based on elevated service needs. Work group members viewed a definition based on elevated service needs as addressing many of the deficits of definitions based on the presence of a chronic condition or functional limitation. That is, a service-based approach does not require making individual judgments concerning the appropriateness of including each of a large number of childhood chronic conditions, as is required when using a condition-based approach to define children with special health care needs. Moreover, a service-based approach can be presented in succinct form, avoiding the potentially unwieldy nature of a condi-

tion list. A service-based approach also circumvents some of the major problems inherent in using functional status as a means for defining children with special health care needs. Specifically, a service-based approach does not leave out children who function well but need special services to maintain that level of functioning. Furthermore, problems in the measurement of children's functioning, especially among very young children, are largely obviated using a service-based approach.

A second significant decision, that being to include children at risk for a condition that results in a need for elevated services, was reached by the work group after much discussion. The decision to include at-risk children was made based on the premise that the definition of children with special health care needs was to serve as a planning aid for state and federal maternal and child health agencies. Planning for this population requires focusing on those at risk as well as those with existing special health care needs. Further discussion of the rationale for and the public policy implications of including children at increased risk for special health care needs is presented below.

THE NEW DEFINITION

After much deliberation, the following definition of children with special health care needs was developed by the work group:

Children with special health care needs are those 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.

Several of the terms and concepts used in this definition require further elaboration. These include the concepts of increased risk, require health and related services, and a type or amount beyond that required by children generally.

Children at Increased Risk

Included in this group are children exhibiting certain biological or environmental characteristics associated with a heightened probability of developing a chronic physical, developmental, behavioral, or emotional condition. Biological risks include pathologies and physiological abnormalities that have been shown to increase the likelihood of future onset of chronic conditions. Examples of biological risk include very low birth weight, the presence of certain metabolic deficiencies, and the existence of some chromosomal abnormalities.¹¹ Improvements in our understanding of the molecular basis of childhood disease has led to greatly expanded opportunities to define and determine biological risk. Examples include greatly improved testing for cystic fibrosis and other genetically determined conditions.

Environmental risks are those social and economic factors as well as other characteristics of the child's environment that have been demonstrated to place children at increased likelihood of developing chronic physical, developmental, behavioral, or emotional conditions. Examples of economic and social risk factors include extreme poverty,¹² absence of social support,¹³ and child abuse or neglect.¹⁴ Exam-

ples of risk factors related to the physical environment include air pollution, second-hand smoke, and infestations that can exacerbate conditions such as asthma.¹⁵

It should be recognized that not all children exposed to biological or environmental risks ultimately develop chronic conditions. Moreover, no single risk factor reliably predicts future onset of a chronic condition. The limited available research suggests, however, that the greater the number of risk factors, the greater the probability of a chronic condition.^{16,17}

Require Health and Related Services

The term require should be interpreted in the context of professionally accepted pediatric practice standards. We define health and related services broadly to include the continuum of services that may be required to maintain or improve the health and functioning of children. These services may include:

- specialized/enhanced medical and nursing services (eg, physician subspecialists, hospitals specializing in the care of children, and enhanced preventive and primary services);
- therapeutic services (eg, physical, speech, and occupational therapies, mental health services, and home health and home nursing services);
- family support services (eg, family counseling and education, comprehensive case management and care coordination, and respite care);
- equipment and supplies (eg, durable medical equipment and assistive devices); and
- related services (eg, early intervention, special education, transportation, and social services).

Services of a Type or Amount Beyond That Required by Children Generally

Services of a type or amount beyond that required by children generally may refer to one or more of the health and related services listed above, or to the use of routine health services at a level that exceeds the requirements of most children. For example, a child with regular visits to a primary care physician to monitor a chronic condition, such as asthma, would fall into the latter category.

Need Versus Use

The work group recognized that many children may need services even though they are not receiving them resulting from lack of knowledge, limited provider availability, or other financial and nonfinancial barriers to care.¹¹ This definition is intended to include those needing but not receiving health and related services of a type or amount beyond that required by children generally as well as those currently using such services. For example, all children with functional impairments resulting from a chronic physical, developmental, behavioral, or emotional condition would be included in this definition, independent of whether they were receiving an elevated level of services, because all such children need at least ongoing monitoring of their health and well-being.

DISCUSSION

The definition of children with special health care needs presented here is intentionally broad and inclusive. In particular, the inclusion of children at increased risk substantially expands the target population for program planning purposes. Indeed, we included this group precisely because of their importance in program planning and development. Child and adolescent health programs appropriately have long emphasized prevention. Including attention to children at risk of needing special health care services encourages a focus on the prevention of both primary and secondary disability. We recognize, however, that this definition, unlike a definition limited to children who currently have special health care needs, is particularly difficult to implement. No adequate quantifiable definition of at-risk status currently exists, and a dedicated research effort will be required to articulate the concept of increased risk in a manner that can be used by state programs in their planning efforts. Even though we are not presently able to delineate which children are at increased risk, other than in the general fashion described earlier in this commentary, there was a consensus among work group members as to the importance of including those at risk in the definition of children with special health care needs.

This decision by the work group to propose a definition that includes the at-risk population was guided by two considerations. First, and perhaps most important, the decision was informed by science. Child health and development are the result of a dynamic interplay among molecular biology, personal experience, and community context that results in a continuum of relative well-being rather than sharp distinctions among health, elevated risk, and frank disease or disability. Increasing data demonstrate the complex interaction of physical illness and disability with the social and physical environment.¹²⁻¹⁷ Environments that place the child at risk can negatively affect both physical and mental development. Our improved knowledge of these interactions demands efforts to identify populations at risk and ways of diminishing risk.

Second, recommendations to include the at-risk population have certain economic implications. A broader net that includes more children may imply greater public expenditures. However, the work group does not suggest that all children at risk receive a full array of services. Rather, the purpose is to help identify populations that should be targeted for careful and deliberate planning. Prevention aimed at populations at increased risk should diminish long-term needs for specialized health care. Yet, historically, there has been little public investment in prevention efforts for this population of children. We believe these historic shortcomings in programmatic and therapeutic capabilities to intervene effectively in the lives of children who are at risk for special health care needs should stand as a stimulus for greater commitment to the task, rather than a reason to retreat from the inclusion of at-risk populations. From an economic perspective, the development of

effective preventive strategies for children who are at risk should save considerable money in the long run.

CONCLUSION

The explosive growth of managed care and changing public responsibilities, especially in state programs for children with special health care needs, accentuates the importance of a clear definition of children with special health care needs. Working as a broad-based consensus panel, we considered several ways of defining children with special health care needs, including diagnostic listings and measures of functional status, but concurred on a definition based on increased service use or need. We also clarified the importance of including at-risk populations along with those already demonstrating special health care needs.

This new definition of children with special health care needs should help guide public programs and other organizations interested in program planning for this population. The definition is currently being used at the federal level for program development and interagency policy planning. State Title V programs are expected to use this definition in meeting federal legislative requirements for needs assessments and development of plans for community systems of services for children with special health care needs. Additional efforts are now underway to develop operational methods for identifying children with special health care needs within health plans for the purposes of monitoring, quality assurance, and risk adjustment.

MERLE MCPHERSON, MD
Division of Services for Children With Special Health
Care Needs
Maternal and Child Health Bureau

POLLY ARANGO
Family Voices

HARRIETTE FOX, MSS
Fox Health Policy Consultants

CASSIE LAUVER, ACSW
Bureau of Children, Youth and Families
State of Kansas

MARGARET McMANUS, MHS
McManus Health Policy, Inc

PAUL W. NEWACHECK, DRPH
University of California, San Francisco

JAMES M. PERRIN, MD
Ambulatory Care Programs
Massachusetts General Hospital

JACK P. SHONKOFF, MD
Florence Heller Graduate School
Brandeis University

BONNIE STRICKLAND, PhD
Integrated Services Branch
Maternal and Child Health Bureau

ACKNOWLEDGMENT

This work was supported by the Maternal and Child Health Bureau, US Department of Health and Human Services, (Cooperative Agreement MCU-06 MCP1).

REFERENCES

1. Nelson R. The legislative base of programs for children with special health care needs. In: Wallace HM, Nelson RP, Sweeney PJ, eds. *Maternal and Child Health Practices*. Oakland, CA: Third Party Publishing Company; 1994:681-686
2. Halfon N, Newacheck P. Trends in hospitalization for acute childhood asthma, 1970-84. *Am J Public Health*. 1986;76:1308-1311
3. Klerman LV, Perloff JD. Recent trends in the health of US children. In: Stein REK, ed. *Health Care for Children—What's Right, What's Wrong, What's Next*. New York, NY: United Hospital Fund; 1997:15-37
4. Kaye HS, LaPlante MP, Carlson D, et al. Trends in disability rates in the United States, 1970-1994. *Disability Statistics Abstract*. No. 17. Washington, DC: US Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR); 1996
5. Hobbs N, Perrin JM, Ireys HT. *Chronically Ill Children and Their Families*. San Francisco, CA: Jossey-Bass Inc, Publishers; 1985
6. Newacheck PW, Stein REK, Walker DK, et al. Monitoring and evaluating managed care for children with chronic illnesses and disabilities. *Pediatrics*. 1996;98:952-958
7. Neff JM, Anderson G. Protecting children with chronic illness in a competitive marketplace. *JAMA*. 1995;274:1866-1869
8. Stein REK, Bauman LJ, Westbrook LE, et al. Framework for identifying children who have chronic conditions: the case for a new definition. *J Pediatr*. 1993;122:342-347
9. Perrin EC, Newacheck PW, Pless IB, et al. Issues involved in the definition and classification of chronic health conditions. *Pediatrics*. 1993;91:787-793
10. Newacheck P, Strickland B, Shonkoff JP, et al. An epidemiologic profile of children with special needs. *Pediatrics*. 1998;102:117-123
11. Stanton WR, McGee R, Silva PA. Indices of perinatal complications, family background, child rearing, and health as predictors of early cognitive and motor development. *Pediatrics*. 1991;88:954-959
12. Newacheck P. Poverty and childhood chronic illness. *Arch Pediatr Adolesc Med*. 1994;148:1143-1149
13. Runyan DK, Hunter WM, Socolar RS, et al. Children who prosper in unfavorable environments: the relationship to social capital. *Pediatrics*. 1998;1:12-18
14. National Committee to Prevent Child Abuse. *Child Abuse and Neglect Data: Fact Sheet #1*. Englewood, CO: National Committee to Prevent Child Abuse; 1994
15. Rosenstreich DL, Eggleston P, Kattan M, et al. The role of cockroach allergy and exposure to cockroach antigen in causing morbidity among inner-city children with asthma. *N Engl J Med*. 1997;338:1356-1363
16. Bendersky M, Lewis M. Environmental risk, biological risk, and developmental outcome. *Dev Psychol*. 1994;30:484-494
17. Sameroff AJ. Environmental context of child development. *J Pediatr*. 1986;109:192-200

Physician's Duty to Warn Third Parties About the Risk of Genetic Diseases

Although the traditional legal rule states that a physician has a legal duty only to the patient, courts have expanded the duty to third parties other than the patient in situations involving the protection of public health or the community at large. Current examples of this expanded duty rule include: a physician's duty to warn a specific third party about potential harm threatened by a patient¹; a physician's duty to warn a third party who may be at foreseeable risk for contracting a sexually trans-

Received for publication Jul 28, 1997; accepted Feb 5, 1998.

Address correspondence to: Gary N. McAbee, DO, JD, FAAP, 40 E Laurel Dr, Suite 100, Stratford, NJ 08084.

PEDIATRICS (ISSN 0031 4005). Copyright © 1998 by the American Academy of Pediatrics.