

# A Family-Centered, Community-Based System of Services for Children and Youth With Special Health Care Needs

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**Objective:** To present a conceptual definition of a family-centered system of services for children and youth with special health care needs (CYSHCN). Previous work by the Maternal and Child Health Bureau to define CYSHCN has had widespread program effects. This article similarly seeks to provide a definition of a system of services.

**Design:** Comprehensive literature review of systems of services and consensus panel organized to review and refine the definition.

**Setting:** Policy research group and advisors at multiple sites.

**Participants:** Policy researchers, content experts on CYSHCN, family representatives, and state program directors.

**Outcome:** Definition of a system of services for CYSHCN.

**Results:** This article defines a system of services for CYSHCN as a family-centered network of community-based services designed to promote the healthy development and well-being of these children and their families. The definition can guide discussion among policy makers, practitioners, state programs, researchers, and families for implementing the “community-based systems of services” contained in Title V of the Social Security Act. Critical characteristics of a system include coordination of child and family services, effective communication among providers and the family, family partnership in care provision, and flexibility.

**Conclusions:** This definition provides a conceptual model that can help measurement development and assessment of how well systems work and achieve their goals. Currently available performance objectives for the provision of care for CYSHCN and national surveys of child health could be modified to assess systems of services in general.

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**O**RGANIZING HEALTH AND other community services in ways that enhance access and coordination may substantially benefit children and families. Much work in the past decade has described aspects of community services for children and youth with special health care needs (CYSHCN), but the principles arising from that work also apply to

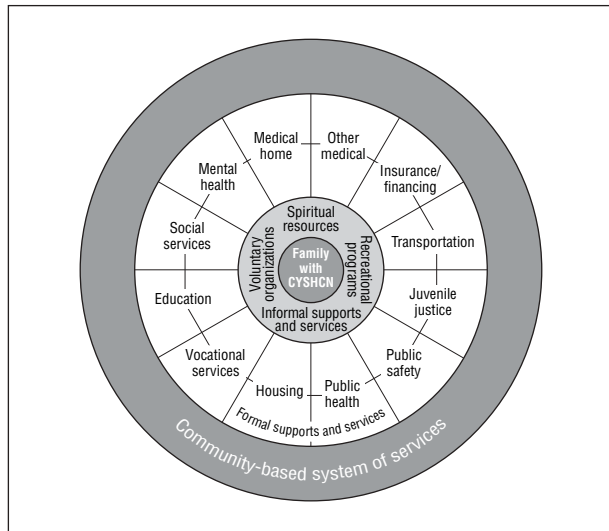
*See also pages 930, 937, and 1003*

all children and families. The past decade has seen tremendous growth in knowledge regarding CYSHCN. Increasing numbers of children and adolescents have chronic health conditions that affect their daily lives and often require complex and long-term health services from various agencies.<sup>1</sup>

The development and promulgation a few years ago of a formal definition of

CYSHCN<sup>2</sup> greatly improved public and private understanding of this population and enhanced planning efforts to meet their needs. This effort defined children with special health care needs as 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 for children generally. Approximately 13% to 18% of children ranging from birth to 18 years of age meet this definition.<sup>3,4</sup> An operational definition of the community-based system of services may similarly help with ensuring the breadth, comprehensiveness, and organization of services that will benefit CYSHCN and their families. Although efforts have been made to address the needs of CYSHCN and their families, implementation of a well-integrated and comprehensive community-based system of services fully responsive to the needs of CYSHCN has not yet been fully realized.

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**Figure.** Family-centered community-based system of services for children and youth with special health care needs (CYSHCN).

This document provides an overview of a definition of a community-based system of services for CYSHCN and their families, including its underlying principles, some issues in its implementation, and notions relating to measuring or assessing the system of services. We focus on systems issues for CYSHCN, but the lessons and principles apply broadly to all children and youth and their families. Numerous demonstrations have examined the feasibility, financing, and effects of various ways of organizing services for CYSHCN.<sup>5-8</sup> Although these efforts have strengthened the knowledge base regarding the organization of services, they have not led to a systematic effort to put into place a universal, equitable, and sustainable system that adequately meets the needs of CYSHCN. We hope that this effort to develop consensus on defining a system of services will help progress toward this goal.

## METHODS

We carried out an extensive and systematic review of literature concerning systems of services for children with chronic health and mental health conditions, based on MEDLINE searches, review of the past 10 years of key journals in child health, maternal and child health, child mental health, and education. Based on this review of earlier work (mainly definitions and program descriptions in the mental health field), we developed a draft definition.<sup>9,10</sup> We then convened a consensus conference involving representatives from parent groups, health economists, state and federal program managers, public health experts, and pediatric clinicians who reviewed the background information leading to the definition and reviewed and revised the definition itself.

## DEFINITION

A system of services for CYSHCN is a family-centered coordinated network of community-based services designed to promote the healthy development and well-being of children and their families. Families can gain entry to the system through any service. Once in the system, the child and family would have expedited access to the broader system of services. This access is particularly important to families with CYSHCN, who often need a

range of services (eg, specialized therapies, counseling, home health care, school-based services, family education) and may enter the system through the use of any of several services or organizations. These services, even when available, are often poorly coordinated.<sup>11</sup> A well-functioning system of services will coordinate and integrate the full range of needed child and family services, including health care, education, and social services, with the goal of optimizing outcomes for the children and families it serves. Seamless communication among the providers of services and with the family is a critical component of a system of services. Because families typically provide most of the supportive care needed by their children and know their children best, families must be involved in decision making at all levels; family partnership is an integral aspect of the system of services for families of CYSHCN. From the family's perspective, a responsive system of services should provide a seamless and transparent spectrum of community-based services that are accessible, flexible, responsive, and targeted to address their child's mental, physical, emotional, and social needs (**Figure**).

Although the term *community* is often defined as a geographic construct, we use the term in a broader sense insofar as some families select services based on criteria other than proximity to their homes. For example, services used by only a small proportion of children, such as subspecialty care, may not be available in all local communities. Therefore, community refers here to the available services, supports, and resources with which a family interacts given their child's needs, the family's economic resources, and their cultural background. Each component of the system shown in the Figure makes a unique contribution to the system of services for children and families, especially those with special health care needs. We anticipate that some families will use services in addition to those represented in the Figure and that also belong in the model.

## PRINCIPLES OF THE SYSTEM OF SERVICES

The primary goal of an operational system of services is to promote the healthy development and well-being of the child and family. Efforts to meet this goal must be sustainable, equitable, and universal. Roberts et al<sup>12</sup> delineated 6 central principles or values for a system of services for CYSHCN: (1) responsive to family challenges, priorities, and strengths; (2) developed in partnership with constituents; (3) reflective and respectful of the cultural norms and practices of the families participating; (4) accessible to everyone; (5) affordable to those who need assistance; and (6) organized and coordinated through collaboration so that resources are equitably distributed in an efficient and effective manner. In addition, services should recognize and address the specific developmental needs of infants, children, and adolescents, and important developmental transitions (eg, making a transition from preschool to school, to adolescence, or from school to work). Achieving these developmental milestones is important for all children but may provide particular challenges for CYSHCN. The service system should also be organized to promote the cost-effective provision of services. Achieving this principle necessitates the development of an evidence base for the services that comprise the system and for the system as a whole. Overall, these system principles and values apply to achieving optimal well-being for all children, but they particularly affect CYSHCN and their families, who often have extensive needs.

## IMPLEMENTATION OF A SYSTEM OF SERVICES FOR CYSHCN

Implementing a community-based system of services requires changes at both the macro and micro levels of society. Some

structural changes pertain to governance, organization, or infrastructure; process changes focus on the critical functions of the services delivered.

### Macro Level

The macro level includes agency-level (federal, state, and local) constituents. The main responsibilities of this level relate to organizing and financing services through coordinating eligibility determination, enabling flexible funding streams, and providing clear programmatic responsibility and accountability for service provision. Entities involved at this level, in addition to the Social Security Administration and the Maternal and Child Health Bureau (MCHB), include (but are not limited to) federal and state Medicaid agencies, private health insurers, public and private mental health and substance abuse providers, the Supplemental Security Income program, public education (including early intervention and special education through the Individuals with Disabilities Education Act), juvenile justice, and the social service system.

Developing a system of services at the macro level requires (1) standardized eligibility protocols developed jointly by the federal and state agencies contributing funds to the system; (2) legal and accounting mechanisms or vessels for blending (flexible use) funding streams; (3) development of cost-sharing mechanisms to allocate costs fairly among families, private insurers, government, and other payers; (4) measures to eliminate duplication of effort based on resource allocation procedures developed through intergovernmental agreements; and (5) a flexible point of entry such that a family need only apply once, with this application appropriate for all needed services. The methods to accomplish these goals include interagency agreements at the federal, state, and local levels; waivers of program rules or legislative changes; institutional flexibility to enhance the ability of organizations to meet family needs; and overall federal support.

### Micro Level

This level includes community-level service systems. Families, physicians, other health care providers, local schools, public transportation, and social service providers are among the entities involved at this level. Although families will receive most services close to home, some specialized or rarely accessed services may be more centralized.

The goals at the micro level include the creation of operational interagency collaborative relationships such that families access services when they need them. The creation of community grants or other incentives to encourage coordination across delivery agencies and providers, including the medical home, could facilitate these arrangements. A local governing or organizing structure could also help achieve this goal. The governing structures could be tailored to local customs and needs, but operate under broad state and federal guidelines to ensure accountability and universality of access to system resources.

Families should view the services they receive as available and affordable and as comprehensive, seamless, and without barriers to coordination and access. Service providers should see reduced duplication and overlap, greater communication among key players and stakeholders, streamlined eligibility processes, and greater flexibility in the use of program resources. Characteristics of services should also include high quality (including safety and timeliness), cost-effectiveness, and equity in access.<sup>13,14</sup>

## MEASUREMENT

The concepts underlying the definition of a system of services allow measurement, including potential additions or enhance-

**Table. Maternal and Child Health Bureau Core Constructs for CYSHCN<sup>a</sup>**

Families of CYSHCN are partners in decision making at all levels
CYSHCN receive coordinated, ongoing, comprehensive care within a medical home
Families of CYSHCN have adequate private and/or public insurance
Children are screened early and continuously for special health care needs
Services for CYSHCN are organized so families can use them easily and are satisfied with the services they receive
Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence

Abbreviation: CYSHCN, Children and youth with special health care needs.

<sup>a</sup>From Maternal and Child Health Bureau.<sup>16</sup>

ments to measures currently available for assessment of the health component. As indicated before, the goals of well-functioning systems of services are high levels of child, family, and community health and well-being—all measurable domains. Other system characteristics for measurement include broad notions of equity and universality, with questions such as, “Are service access and provision equitable?” “Are they universally available to families with CYSHCN?” and “Are outreach efforts adequate to ensure enrollment and retention of eligible children?” Assessment can also be framed developmentally: “Are services organized so as to meet the developmental needs of children and do they take into account the long-term needs of CYSHCN, including the complex transition to adulthood?” Other measurement domains could include the comprehensiveness and seamlessness of services from the view of families—their cultural or value-based responsiveness, quality, efficiency, and cost-effectiveness.

Specific items that might inform some of these structural and process domains include implementation of standardized eligibility protocols and applications across system components, ability to access all services regardless of the point of entry, methods to blend funding from several sources, measures to eliminate duplication of effort, interagency agreements, and waivers of program and financing rules to enhance seamlessness.

In some cases, measures of system effectiveness can be adapted from other systems (eg, the health care quality measurement systems developed by the National Committee on Quality Assurance). In other cases, new measures will need to be developed. A thoughtful evaluation design will reap many benefits. For example, a formal economic evaluation of the costs and benefits of the system should provide important information for fine tuning eligibility and service provision. A well-executed evaluation design will provide a much-needed evidence base that may ultimately contribute to ensuring continued funding of the system.

The Social Security Act requires the MCHB to “facilitate the development of community-based systems of services for CYSHCN and their families,” and, partly in response to the Supreme Court *Olmstead* Decision,<sup>15</sup> the federal New Freedom Initiative also requires MCHB to develop and implement a plan to achieve community-based systems for CYSHCN and their families. To help facilitate systems development, MCHB has defined 6 core constructs that help to describe a system of services<sup>16</sup> (**Table**).

The National Survey of Children with Special Health Care Needs<sup>17</sup> has operationalized these criteria to provide state and national estimates of the status of children and families regarding each construct. With respect to the overall system of services, the definition put forth here delineates the characteristics of an operational system for CYSHCN, thus providing opportunities for the development of new and expanded mea-

surement strategies that will lead to the creation of evidence-based research initiatives.

## CHALLENGES

The development and implementation of a system of services for children and youth that fully includes CYSHCN provides several challenges. These include the following: (1) organizational and boundary-related concerns among service providers, government agencies, and nongovernmental organizations; (2) legal, policy, and regulatory impediments at state and federal levels; (3) ensuring the availability of adequate funding for individual services as well as the system infrastructure; (4) obtaining the necessary program and financing waivers to blend funding sources to best fit children's needs; (5) developing an evidence base for informing the design of a cost-effective service delivery system; and (6) balancing families' rights to privacy with agency and service providers' needs for information. Meeting these challenges will require a concerted effort on the part of all the constituencies in the service system. Success will require finding creative ways to work within those impediments or garner sufficient evidence and advocacy to alter the codes that create the impediments.

## CONCLUSIONS

A comprehensive community-based system of services for CYSHCN has not yet been implemented. Moreover, to our knowledge, there has been no consensus to date on what constitutes a system of services. The absence of a broadly accepted definition has hindered progress in implementation of a systematic approach to delivering services. The definition of a system of service presented here is intended to provide a basis for discussion among policy makers, practitioners, state programs, researchers, and families as they move toward operationalizing a definition of the "community-based systems of services" contained in Title V of the Social Security Act. A core aspect of the definition is the central role of the family in decision making. The approach taken is intended to be an inclusive one that encompasses the broad range of services that CYSHCN may require at different points in their development. It recognizes the importance of the individual components but stresses the need for coordination to achieve optimal health and well-being of children. Building on the efforts of MCHB to develop measures of elements of services needed by CYSHCN, this new definition of a system of services provides opportunities to broaden measurement and accountability across the system of services.

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