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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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Organizing 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 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. The development and promulgation a few years ago of a formal definition of CYSHCN 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. 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.

See also pages 930, 937, and 1003
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 al12 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 centralize.

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.\(^1\,^{13}\)

**MEASUREMENT**

The concepts underlying the definition of a system of services include, potential additions or enhancement.

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**Table. Maternal and Child Health Bureau Core Constructs for CYSHCN\(^a\)**

| Families of CYSHCN are partners in decision making at all levels | MCHB receive coordinated, ongoing, comprehensive care within a medical home |
| 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.\(^a\)From Maternal and Child Health Bureau.\(^3\)

\(^a\)To Maternal and Child Health Bureau.\(^3\)

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measurement 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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