

Performance Measures

Introduction

In 1988, in his role as Surgeon General, Dr. C. Everett Koop, introduced a National Agenda for Children with Special Health Care Needs. This agenda, which has been endorsed by over 70 professional and voluntary organizations calls for the development of systems of services for CSHCN and their families that are family-centered, community-based, coordinated, and culturally competent. In 1989, this agenda was translated into legislation through Title V of the Social Security Act, which requires state CSHCN Program to:

to provide and promote family-centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families (OBRA 89).

Since the passage of this legislation, many in the broader child health community have partnered with state Title V Programs in support of CSHCN systems development initiatives. Families, providers, agency leaders and policy makers agree that much progress has been made, through these efforts, in developing community systems of service that are comprehensive and coordinated around the needs of children and families. However, documentation and measurement of these changes, in terms of meaningful indicators, has been challenging.

The broad definition of Children with Special Health Care Needs as ***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 that required by children generally,

The long-term outcome of systems development is that all families are able to access health and related services along the continuum of care in a manner that is both affordable and meets their needs; policies and programs are in place to guarantee that children have access to quality health care; providers are adequately trained; financing issues are equitably addressed; and families play a pivotal role in how services are provided to their children. This long-term national goal has been articulated in Healthy People 2000: National Health Promotion and Disease Prevention Objective (as well as the 2010 edition) as follows:

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.

Through our ongoing work to measure success, we can now identifying early indicators of emerging systems. Five critical indicators of progress toward this goal of systems development for children with special health care needs are:

Screening. Infant and children with high risk health conditions must be identified early in order to help assure that they receive the care and assistance that will help prevent future morbidity and promote optimal development; and that their families connect with the services and supports they need. Advances in brain research, the Human Genome Project, and increased effectiveness of early intervention have

expanded our capacity to identify children with special health care needs and offer an opportunity for early intervention.

Medical Home. Once identified, children with special health care needs require a medical home. Although they often receive excellent specialty care, they frequently lack a source of ongoing routine health care in their community. The medical home assists in the early identification of special health needs; provides ongoing primary care, and provides appropriate arrangements for and coordination with the broad range of other specialty, ancillary, and related services needed.

Insurance coverage. Not only must a continuum of primary and specialty services be available, but families must have a way to pay for them. While new initiatives such as the Children's Health Insurance Program (CHIP) have begun to address the issues of children who are uninsured, the problem of under insurance is a major concern for CSHCN and their families. In addition to coverage for medical costs, the range of wrap-around services needed by families requires linkages to public programs for services covered through other funding streams. Thus, availability of private and/or public health insurance that covers a full range of needed services and care is a key indicator of systems development.

Organization of services. Although there may be a wide range of services in a community, they may not be coordinated in a way that allows for families to access them. In order for services to be of value to CSHCN and their families, the system has to be organized in such a way that needs can be identified, that services are provided in accessible and appropriate contexts, and that there is a family-friendly mechanism to

pay for them. Thus, organization of services in ways that are appropriate, affordable, accessible, and effective is a key indicator of systems development.

Families' roles. Families are the constants in the child's life and are pivotal in making any system work. Systems of care can only be responsive to families if family members have a meaningful, enduring, and leading role in the development of such efforts at all levels of policy, programs, and practice. Families' voices must be heard and families should be at each table that decision making occurs. Thus, the involvement of families in policy making, systems development, and other leadership and decision making roles is a key indicator of systems development.

Critical Indicators for Measuring Progress in Achieving the National Agenda

In the new environment in which health care is being provided, this revised National Agenda for Children with Special Health Care Needs builds on past experiences and success to assure that policies and programs are in place to guarantee that:

- children have access to quality health care
- services are coordinated
- providers are adequately trained
- financing issues are equitably addressed
- families play a pivotal role in how services are provided to their children.

These changes must occur in ways that will provide optimal outcomes for children with special health care, need and their families. As the next step in the implementation of

this agenda, five national outcomes have been selected as critical to guide efforts within the Division of Services for Children with Special Health Care Needs.

Core Outcomes to be Achieved

1. All children will be screened early and continuously for special health care needs.
2. All children with special health care needs will receive regular ongoing medical care within a medical home.
3. All children with special health care needs will have adequate private and/or public insurance options to pay the services they need.
4. Services for children with special health care needs and their families will be organized in ways that families can use them easily.
5. Families of children with special health care needs will participate in decision making at all levels and will be satisfied with services they receive.

A Call For Action

We are once again asking all of our partners to join us in a common effort to develop and improve community-based systems of care for children with special health care needs and their families. As we work towards achieving these outcomes, each partner in this collaborative effort can contribute uniquely to this agenda by helping to document and measure success in the following ways.

Families: We call upon families to be knowledgeable and effective users of health and related services. Families as the constants in their children's lives are critical informants with respect to whether a system of systems is appropriate, accessible, ,

affordable, acceptable, and effective in meeting their needs. As such, families must be able to participate in all aspects and at all levels of measuring the success of this agenda. Effective family coalitions across the country have provided a much needed focus in providing basic information through a family survey of systems of care.

Communities: We call upon communities to assist states in documenting the degree to which all children with special health care needs have access to a medical home, including early and continuous screening; the degree to which services are organized in ways that are appropriate, accessible, affordable, acceptable, and effective; and the degree to which families participate in all levels of decision making.

Community coalitions have been formed to address issues within the national agenda and they have been instrumental in helping to develop measures and models of service systems that work collaboratively with families. Communities now must help us by participating in collaborative efforts to collect data on the five key indicators in ways that allow common measurement across communities and enhance the ability of the state to report progress on a statewide basis.

States: We call upon states to continue to carry out their legislative responsibilities to develop community systems of services, to provide or arrange for uncovered services, and to measure progress in systems development. Through block grant reporting, states can begin to document the progress using the indicators listed here. By partnering with families, communities, policy councils, providers, and others, states will ensure that systems are truly responsive to family priorities.

Service providers: We call upon service provider networks to assist in efforts to document and evaluate the spectrum of existing systems of identification and referral to help ensure that the data systems are linked and coordinated in ways that create more effective, technologically appropriate, and modern methods identifying children. Data systems need to be responsive to the complex issues of confidentiality and privacy while preserving ways to share data. As important partners in the service system, all providers, including those in education, child care, and health, can provide important information and data to document the range and the coordination of services for families with children with special health care needs.

Managed care: Managed care entities are an important source of information with respect to the insurance coverage and costs, as well as the utilization and types of services provided to families of children with special health care needs. As with all service providers, linkages with other data systems, confidentiality issues, early identification of children with special health care needs within managed care settings, and provision of appropriate primary care within a medical home need to be documented within these settings.

Federal and state partners: In concert with families, federal and state partners must collect and report on these five indicators, aggregating information from communities and states across the country to help inform us of our progress as a nation. The ongoing process of measuring progress in implementing the National Agenda for

CSHCN, by measuring our success in achieving intermediate outcomes, and narrowing the gap between the vision and the reality, must be coordinated at the national level.

Through collaborative action, we will be better able to monitor our progress, communicate the value of our efforts, and focus our limited resources on those activities that will best ensure enduring systems of care for CSHCN and their families within the ever changing health care environment.