

May 29, 2001

*Achieving Success for All
Children and Youth
with Special Health Care Needs*

A 10-Year Action Plan to Accompany Healthy People 2010

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Goal #3: All children will be screened early and continuously for special health care needs.

In public health, screening often refers to a population-based procedure to detect a particular condition or disease. However, as used in the context of this goal, screening is much more comprehensive and includes ongoing monitoring and assessment of children and youth to promote health and well-being. Seen this way, screening has two major goals. First, it is critical to identify children in the general population who have special health care needs as early as possible so that they and their families can be given appropriate services to address those needs. Some needs may be identified in infancy, or during the perinatal period, while others may emerge in later childhood and adolescence. Second, and equally important, children and youth with special health care needs must have ongoing assessments to identify newly emerging issues for them, including psychosocial issues, and to prevent secondary conditions that may interfere with their development and well-being. Ongoing assessment should also focus on identifying the unique strengths of each child and family.

When screening achieves these goals, it is clear that it results not only in improvements in the quality of life for children and families, but also in cost savings for the health and educational system. The undeniable benefits that have accrued to children and their families in certain types of screening programs, such as newborn heelstick screening, newborn hearing screening, and lead screening, point to the desirability of expanding our efforts in the screening arena.

Making effective screening available to all children and youth will require addressing several critical challenges. For example, currently screening is done according to different standards. A variety of screening guidelines are promoted by professional organizations, such as the American Academy of Pediatrics, State or Federal government agencies, and by private groups, such as the Health Employer Data and Information Set (HEDIS) of the National Committee for Quality. Reimbursement policies of third-party payers, such as Medicaid, health maintenance organizations, or private insurance companies, also influence what screening is done.

Screening of children and youth is also done in many different places: health care professionals' offices; hospitals; early intervention and Head Start programs, daycare centers, schools, and WIC clinics. Because children spend time in so many different places

DRAFT

and interact with so many different systems, it is probably unavoidable that there will be some overlap and duplication of screening services. However, it is critical to eliminate unnecessary duplication and to put effective coordinating mechanisms in place for linking screening programs to each other and to the end user—the family. The best place for the coordination to happen is the child’s medical home. Medical homes should ensure that children and families receive screening results, in an expeditious and helpful manner, appropriate, ongoing follow-up and services by health care professionals, and referrals to the other community services that may be needed. This will require building systems, at the community and State level, that enhance the capacity of medical homes to coordinate screening activities and assist medical homes, community and hospital screening programs to work more effectively with each other.

Screening is also paid for by a wide variety of different sources ranging from the WIC program for supplemental nutrition for women and children, to Early Intervention, Head Start, the Individuals with Disabilities Education Act (IDEA), Medicaid, State Title V CSHCN programs, among others. In some cases, parents must pay for these services themselves. In other cases, health insurance programs cover it. Some States have established specific funding programs for screening, while others have not. By making the medical home the coordination center for all screening data, we will be able to better focus on the way in which screening is financed in both the public and private sectors.

Inadequate reimbursement is a significant reason why Early and Periodic Screening, Diagnostic and Treatment (EPSDT) activities are not being adequately implemented. Assuring full implementation of EPSDT to provide any service that is “medically necessary” as defined by Title XIX is more critical than ever to ensure that improved screening ultimately leads to improved care for all children with special health care needs. The involvement and cooperation of many different stakeholders, including health care professionals, government agencies at the Federal and State level, families, advocates, professional organizations, businesses, and private insurers, is needed to make it possible for all children to receive early and continuous screening, follow-up, and all needed services.

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Action Step 1:

Improve access to and availability of screening services.

Strategies:

- Through Title V, expand and strengthen newborn screening systems and promote their linkage to medical homes, early intervention, and family-to-family support programs
- Incorporate EPSDT into medical homes through collaborative work among HCFA, State Title V, and State Medicaid programs. Work with HCFA and State Medicaid programs to increase compensation rates for EPSDT.
- Revise Bright Futures to be fully inclusive of children with special health care needs and to serve as the national standard for health supervision for all children.
- Ensure that the revised Bright Futures Guidelines are responsive to the needs of culturally ethnically diverse populations.
- Integrate Bright Futures/EPSDT screening standards into private insurance coverage.
- Develop, describe, and disseminate models for medical homes and the existing network of specialty/subspecialty providers (including University-Affiliated and tertiary care centers) to provide an adequate system of follow-up, referral, and management.
- Expand pre-service and in-service education and training initiatives for physicians, nurses, daycare providers, schoolteachers, social workers, and public health professionals, as well as opportunities for meaningful collaboration among them around the issue of screening. These initiatives should focus on: the importance of prevention; the translation of new technological and scientific knowledge into services; the accepted tools and procedures for various screening activities; and the benefits of screening in the context of the medical home.
- Fund projects to use telemedicine tools and techniques to provide screening, follow-up, and care coordination to children and families in rural and/or remote areas.

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Action Step 2

Support data capacity for integration of screening results.

Strategies

- Support States in coordinating activities among different screening programs and integrating child-related public health agency data (e.g. newborn heelstick screening, newborn hearing screening, lead screening, immunization, etc.) to allow tracking, assessment, and evaluation with a goal of creating more effective systems of care.
- Create a standardized report form for parents to keep track of results of screenings, immunizations, etc. until an electronic system is established. This report form might be a small booklet distributed by hospitals to parents of all newborns, or might take the form of a Health Diary.
- Develop an informatic system to make screening and follow-up data information easily available to the end user, while addressing privacy and confidentiality concerns.

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Action Step 3

Improve screening guidelines and standards.

Strategies:

- At the Federal level, convene a working group of the Federal Interagency Coordinating Council to oversee the coordination of various Federal programs related to early and continuous screening using the Bright Futures standards.
- At the State level, establish a working group with broad responsibility (e.g., prenatal to age 21, newborn heelstick screening to abuse/neglect) to specify appropriate screening tools and procedures (e.g., Pregnancy Risk Assessment and Monitoring Systems), standardize protocols, and achieve consensus as to who can do screening. This group would function under the authority of the State Department of Health.
- Develop and distribute better screening protocols for children with complex health conditions, such as cerebral palsy, spina bifida, autism, sensory impairment.
- Ensure that all professional training programs emphasize the importance of screening programs and include information on appropriate screening tools and best practices.

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Action Step 4

Promote awareness of the need for and benefits of early and continuous screening.

Strategies:

- In conjunction with families, advocacy and professional groups, and foundations, convey the importance of early and continuous screening as part of a national campaign to promote 2010 goals.
- Through family-professional collaboration, provide consistent and culturally appropriate health promotion information, anticipatory guidance, and prevention information via State Title V CSHCN programs, Head Start, IDEA Part C, and other Federally funded programs.
- Create a collaborative network for the development and dissemination of culturally appropriate information focusing, in particular, on new and emerging genetic information that will assist individuals in making informed choices about screening.
- Require applicants for grants funded by the Maternal and Child Health Bureau to document how they will incorporate Bright Futures Guidelines into their projects wherever appropriate, just as they are now required to discuss how they will provide and/or promote coordinated, culturally-competent, community-based family-centered care for all children with special health care needs.