Ensuring Access

Family-Centered Health Care Financing Systems for Children with Special Health Needs

New England SERVE

Dedicated to all families,
health care providers,
policy makers and advocates
who are contributing their time,
energy and expertise
to the challenge of
reforming the system for financing and
delivering health care in our nation.

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Introduction

Proposals for reforming the financing and delivery of health care in the United States are being discussed in many forums at the national as well as the state level. Numerous articles in professional journals and the popular press have documented that spending on health care in the United States has risen dramatically while the number of uninsured Americans has also risen and become more visible. A significant policy debate has begun on how to reform health care financing so that rising costs can be contained and health care coverage provided to the over 30 million Americans currently without health insurance.

This debate is occurring in Congress, in state legislatures, in health care settings, in corporate boardrooms, in state public health agencies, and in living rooms across the country. It is a critical issue in the business community and for labor organizations. Largely framed in terms of increasing coverage for the uninsured, concern for the costs of long term care for the elderly, and the cost-shifting currently required by uncompensated care, the debate has led to many different proposals to expand access to health insurance. Such proposals assume that extending the current health insurance system, both public and private, will address the main barriers to health care that currently exist.

Children with special health needs are a vulnerable group in this debate. This group of children and youth (from birth through twenty-one years of age) have chronic illnesses or disabling conditions that require specialized health and related services and/or interfere significantly with normal functioning and development.

Characterized by health care needs that are broader (more comprehensive) and deeper (longer in duration) than the population as a whole, these children require health care financing that can cover a wide range of benefits and services, as well as a health care financing system that can support planning, coordination and quality assurance efforts. Although the percentage of children with special health needs is relatively small in the population, the amount spent on health and related services for these children is significantly larger by comparison, ranging from 25-50% of all child health care expenses. In addition to placing demands on schools, community programs, and health care institutions, this group of children and their families are often required to forego basic health services and/or make sizable out-of-pocket payments. Because of pre-existing conditions, children with special health needs may be excluded from existing family insurance coverage and as a result are more likely to be dependent upon public programs for their care.

In April 1990, New England SERVE, a regional network of parents, health care providers and state Title V agencies (within Departments of Public Health) established a Regional Task Force on Health Care Financing. This working group consists of 35 parents and professionals who are concerned about improving health care financing for children with special health care needs. The Task Force includes public health professionals, physicians, state legislators, insurance industry representatives, parents, and staff from state insurance commissions and state Medicaid programs.

In order to assess both the adequacy of existing health financing systems (public and private) as well as new proposals for reform from the perspective of children with special health needs, the New England SERVE Regional Task Force on Health Care Financing has developed a set of specialized criteria.

This document, entitled *Ensuring Access: Family-Centered Health Care Financing Systems for Children with Special Health Needs*, presents 14 separate criteria for consideration. The criteria evolved from a year-long study by the Task Force of characteristics of our current health financing system that create barriers for children and youth with special health needs and their families. The criteria are organized into 5 main headings: Access, Benefits, Quality, Family Participation, and Cost Containment. Within each heading, individual criteria are briefly defined and then followed by a list of indicators, in question format in order to facilitate their application.

Under each defined criteria, indicators are presented on two levels. "Individual Child and Family Indicators" include measures that relate to how individuals may experience the health care delivery system. "System-level Indicators" address how the health financing system facilitates or supports the design and delivery of appropriate personal health services to children and families. Indicators on both levels can contribute to an assessment of how well the health care financing system meets a given criteria. Some indicators are repeated in parallel fashion to emphasize their importance at both the individual and system levels.

"Individual Child and Family Indicators" provide a framework for measuring the degree to which an existing or proposed health financing system reflects the values of family-centered care. They suggest strategies for improving the health financing system in ways that contribute directly to the family's ability to access appropriate care for children with special needs.

The "System-level Indicators" are designed to assure that population-based health promotion and prevention services are available to all. Resources to support critical system-level functions such as injury prevention, newborn screening, and disability prevention, while invisible at the level of an individual child or family's experience, are critical components to build into a quality health care financing system for children with special health needs.

Ensuring Access is intended to be used to: 1) assess financing proposals at the state or federal level for their appropriateness for children with special health needs and their families, 2) educate parents, providers, policy-makers, and the public about the components of a family-centered financing system, and 3) evaluate current health financing systems at the local, state, or federal level. The format includes additional space for users to add new questions that can indicate progress toward meeting each criteria.

The criteria included in *Ensuring Access* reflect what is needed if a family-centered, community-based, coordinated, and comprehensive health care system is to be implemented in local communities. *Ensuring Access*, which defines criteria for health financing systems, can be used as a companion to another New England SERVE publication, *Enhancing Quality: Standards and Indicators of Quality Care for Children with Special Health Care Needs*. *Enhancing Quality* provides criteria for assessing the quality of health services.

The New England SERVE Regional Task Force on Health Care Financing will be refining and improving these criteria. We welcome all comments and feedback from users.

ACCESS

1. Universal Coverage

Universal coverage is achieved when every family has access to affordable adequate health care, including both primary and specialty care as needed.

Access to health care is maintained regardless of changes in child's age, health status, family income, employment status, geographic location, or change in health insurance. Universal coverage is essential in order to eliminate barriers to care such as: discrimination in service delivery, pre-existing condition exclusions, waiting periods, or financial hardships.

Individual child and family indicators:

- Is insurance available and affordable to all families through private coverage, Medicaid, or other public programs?
- Do children with special health needs have access to appropriate and necessary primary and specialty care as defined by the child, family, and health care provider?
- Are families able to change health plans, employment, or geographic location without losing coverage for their child?
- Can children maintain access to services if they lose eligibility for public programs due to changes in age, income, severity of condition, or changes in availability of public services?
- Can children continue to access services once they reach annual or lifetime caps through private or public insurance programs?
- Can young adults extend previous coverage beyond age 18?
- Are out-of-pocket expenses for families for covered health services limited by an annual cap that is scaled to income?
- Is information accessible to families regardless of linguistic or educational background?
- _____

System-level indicators:

- Is there a system to identify children who fall into the cracks between private and public insurance programs and provide them with affordable coverage?
- Are there state mandates or other public strategies that assure access for children to appropriate and necessary primary and specialty care?
- Are there regulations or legislation that allow families to change health plans, employment, or geographic location without losing coverage for their child?
- Do eligibility criteria for public programs assure that children with special health needs qualify for existing services based on service needs rather than diagnosis, age, income, or severity of condition?
- Are eligibility workers for public programs located in service delivery sites?
- Are programs and services that finance health care publicized in order to be known to families and providers?
- Are enrollment procedures for health insurance plans simple and clearly communicated?
- _____

2. Provider and Service Availability

Provider and service availability is achieved when children with special health needs have timely and affordable access to appropriate specialists.

The health care financing system creates incentives and provisions for supporting services in medically underserved areas. Families with children with special health needs are especially vulnerable when they live in geographically isolated or urban areas that are medically underserved.

Individual child and family indicators:

- Do children with special health needs in medically underserved areas have access to licensed providers within their community?
- Do families with children with special health needs in isolated geographic areas receive financial assistance to access care elsewhere if it is not available in their area?
- _____

System-level indicators:

- Are there mandates or incentives to assure that licensed providers accept public reimbursement as well as all other third party payments?
- Is reimbursement to providers adequate to ensure access to care?
- Are public financing mechanisms comparable to private insurance programs in level of compensation, timely reimbursement, and administrative requirements?
- Are there incentives to support equitable distribution of provider or health resources?
- Are there incentives to encourage the provision of services in isolated geographic or medically underserved areas?
- Are there programs that provide financial assistance to families who live in medically underserved areas to access care outside their community?
- _____

3. Consumer Choice

Consumer choice is achieved when family preference is supported in determining primary and specialty care providers, health care facilities, and benefits for children with chronic health conditions who are in need of specialized services.

The ability to choose providers is especially critical because children with special health needs may require specialized services with pediatric expertise. As managed care options expand, such skilled providers may not be available in all settings and this may be of increasing concern. The maintenance of long-term relationships with providers contributes positively to continuity of care.

Individual child and family indicators:

- Do children with special health needs have access to appropriate providers and facilities?
- Do children with special health needs and their families have a choice of providers and facilities?
- Do children and their families have timely access to specialists with pediatric expertise?
- Do children and their families have timely access to second opinions?
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System-level indicators:

- Are there requirements that health care plans provide access to appropriate providers and specialists with pediatric expertise?
- Are there mechanisms to assure early and timely access to specialists?
- Are there mechanisms to assure early and timely access to second opinions?
- Are there mechanisms to assure that families have a choice in health plans?
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4. Family Coverage

Family coverage is achieved when children with special health needs are not excluded from their own family's insurance plan because of pre-existing conditions clauses or because they have exceeded annual or lifetime benefit caps.

The financing system should facilitate access to coverage and financing for the family as a unit. Parents should not be forced to use extraordinary measures in order to access health coverage for their child.

Individual child and family indicators:

- Are all children within a family, including newborns, included in family coverage regardless of pre-existing conditions or health care needs at birth?
- Can children with special health care needs access public programs regardless of family structure?
- Can both routine and specialized health needs be met through the same health coverage?
- _____

System-level indicators:

- Does the financing system ensure that all children with special health needs, including newborns, are included in family coverage regardless of pre-existing conditions?
- Does the financing system foster the continuation of the family as a unit and not contribute to its dissolution in order to access services for the child?
- _____

BENEFITS

5. Prevention

An appropriate range of effective prevention services, including screening and family and child education, is supported by the financing system.

Children with special health needs require the usual range of primary prevention services needed by all children. In addition, they may be at particular risk for secondary disabilities or injuries due to a lack of timely or appropriate medical interventions aimed at improving health status and/or long-term outcomes.

Individual child and family indicators:

- Do all children access financial coverage for both primary and secondary prevention services?
- Do families access appropriate prenatal prevention services such as maternal serum alphafetoprotein, ultrasound, amniocentesis, genetic counseling, carrier testing, and nutritional services?
- Do newborn children receive appropriate tests for PKU, hyperthyroidism, and other newborn screenings?
- Are preventive services during childhood such as immunization, lead screening, de-leading, dental screening and prophylaxis, developmental screening, and early intervention services available to and financed for all children with special health needs?
- Do families have access to health promotion services, such as smoking cessation, stress reduction, exercise, parenting skills and education, etc., through the health care financing system?
- Do families have access to injury prevention services, such as automobile restraints, smoke detectors, safety locks, etc., through the health care financing system?
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System-level indicators:

- Does the financing system ensure coverage for injury prevention and health promotion services, both prenatally and throughout early childhood?
- Are there financial incentives to providers to deliver primary prevention services including health education?
- Can families obtain services prior to pregnancy that include family life education, parenting skills, education regarding substance use and abuse during pregnancy, and AIDS?
- Does the financing system promote strategies for community-based prevention programs?
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6. Comprehensive Benefits

Comprehensive benefits are achieved when the financing system covers the full range of health and health-related services required by children with special health needs for as long as necessary.

Children with chronic illness or disability have broader and deeper needs for health services than the overall population of children. These needs are often of extended duration and may continue for their entire lives.

Individual child and family indicators:

- Do children with special health needs have access to a comprehensive benefits package including the following:
  - adequate primary and specialty medical and surgical services (both in-patient and out-patient),
  - specialized nursing and support services,
  - mental health services,
  - assistive technologies,
  - nutritional counseling and services,
  - specialized dietary products,
  - home health care,
  - hospice,
  - care coordination,
  - long-term occupational and physical therapy,
  - long-term speech, language, and hearing services,
  - adaptive equipment, and
  - medications?
- Can families access family support services through the health care financing system, such as family counseling, respite care, and other services, that increase the family's capabilities to participate in the child's care?
- Can families access specialized services through the health care financing system, such as housing adaptation, that support the integration of the child and family into the community?
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System-level indicators:

- Does the financing system ensure coverage for a full range of comprehensive benefits through a combination of public and private programs?
- Does the financing system include payment for family supports as health or health-related benefits?
- Does the financing system assure access to care on a long-term basis regardless of annual limits or lifetime caps on private insurance benefits?
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7. Community-Based Care

Community-based care is achieved when the financing system facilitates integration of health care services with other aspects of community living by allowing for the provision of services as close to home as possible and in community-based settings.

Family-centered care for children with special health needs includes the goal of community integration. This is greatly enhanced when health services are financed when delivered in community settings.

Individual child and family indicators:

- Is financing available for children to receive health services, such as nursing, occupational therapy, physical therapy and speech therapy, in their home or other community settings such as clinics, schools, and out-patient facilities?
- Is financing available for services when delivered by alternative health care providers if the usual provider of the service is not available in that community?
- _____

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System-level indicators:

- Does the financing system facilitate the delivery of health services in the child's home and in other community settings such as clinics, schools, and out-patient facilities?
- Are there incentives to encourage community-based providers to obtain necessary skills and/or training to serve children with special health needs?
- Does the financing system support needs assessment and planning at the community level?
- Are approved services that are paid for when delivered in hospital settings also covered in home or certified community settings?
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8. Care Coordination

Coordination of care for children with special health needs occurs when cooperative planning and communication is financed across multiple, specialized providers and between health care and education systems.

Children with chronic health conditions frequently receive services from multiple providers and the task of coordinating these services most often falls to family members. It may be necessary to access services from both public and private sources as well as across agencies such as health, education, and social services. Effective coordination of services requires a comprehensive knowledge of available resources as well as a mandate for ongoing communication among diverse providers.

Individual child and family indicators:

- Is financing available to support care coordination across multiple providers at the community level?
- Is financial support available for communication between the child's health care providers and school or other community-based service providers?
- Is financing available to support ongoing communication between the child's primary health care provider and all other specialists who care for the child?
- _____

System-level indicators:

- Does the financing system provide reimbursement for care coordination at the community level?
- Does a uniform definition of care coordination services exist to guide reimbursement?
- Do major providers of services for children with special health needs have the designated function and resources to coordinate care?
- Does the financing system support coordination/communication among all providers (primary care, specialty care, education) and parents?
- _____

QUALITY

9. Quality Assurance

Quality assurance is supported when the financing system builds in mechanisms that can eliminate underutilization, unnecessary utilization, and maximize best practices.

Children with special health needs are especially vulnerable due to their high demand for health services. Because of their extensive experience in using the health care system on behalf of their children, families can offer an important perspective to be included in any assessment of quality.

Individual child and family indicators:

- Do children with special health needs receive services that meet standards of care specifically designed for children?
- Are families involved in the design and implementation of quality assurance systems?
- Do families have access to information regarding the effectiveness and appropriateness of specific health services for their children?
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System-level indicators:

- Do public or private third party payors use a quality assurance system that includes standards of care specifically designed for children with special health needs?
- Are there mechanisms available to monitor inappropriate use of adult services for children with special health needs?
- Are there mechanisms for monitoring providers and service delivery in order to enhance the quality of care?

System-level indicators: *(Continued)*

- Are there mechanisms for financing education and training for a broad range of providers to serve children with special health needs?
- Does the financing system regularly update criteria used to define quality care?
- Are there mechanisms to assure that unnecessary, inappropriate, or ineffective services are not provided?
- Is there a system that identifies and disseminates information about the appropriateness and effectiveness of specific treatments or procedures?
- Does the definition of quality include indicators of family satisfaction, provider satisfaction, and health status outcomes?
- Does the financing system support and encourage a uniform data collection system and the dissemination of information on best practices?
- Does the financing system support the development of billing and information systems that can facilitate assessments of service quality?
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FAMILY PARTICIPATION

10. Family Role in Decision-Making

The roles of families as primary decision-makers and caregivers are acknowledged and supported when the health financing system pays for services that support these roles.

When decisions are of a technical or complicated nature and involve the relative efficacy of different medical procedures, the health system provides support and education to families to allow them to exercise their roles as primary decision-makers more effectively.

Individual child and family indicators:

- Is funding available for families to receive education and training in order to support them in decision-making and care-giving roles?
- Are families allowed to determine their own priorities for health care financing resources within each category of benefits?
- _____

System-level indicators:

- Are there mechanisms for providing families with necessary education and training to enhance their decision-making and care-giving roles?
- Are families involved in the design and implementation of public and private health care programs and services?
- _____

11. Family Role in Resource Allocation

Family participation in the allocation of health resources is achieved when the parent is recognized as the primary decision-maker in the development of individual plans of care.

Families should be involved in decision-making regarding the utilization and deployment of all health care benefits to which their child is entitled. Parents and advocates must also be included in the planning, authorization, and development of programs that finance care.

Individual child and family indicators:

- Do families receive cost estimates for services included in their child's care plan?
- Are families involved in decision-making regarding allocation of resources and health benefits for services for their child?
- Do families have opportunities to participate in public policy development and the allocation of public and private resources?
- _____

System-level indicators:

- Is there a mechanism that ensures that families are given cost estimates and participate in auditing payments for services?
- Are there mechanisms that guarantee consumer involvement in public policy development and the allocation of public and private resources?
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COST CONTAINMENT

12. Flexible Benefits

Flexible benefits allow the financing system to pay for the most efficient and effective services that meet a child's needs and contain the costs of care.

Medical requirements for children with special health needs often do not match standard insurance benefit packages. It is incumbent upon the system to provide efficacious and flexible solutions to assure that a child's health needs will be met. Because of heavy reliance on medical services, children with special health needs are best served by a system that can reassess the effectiveness of treatment services on a regular basis to take advantage of emerging technology.

Individual child and family indicators:

- Can individual families negotiate changes in their benefit package?
- Can families access family support services, such as adaptive housing, respite care, and camperships, through the health care financing system?
- Can family members be reimbursed for providing direct services to their child?
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System-level indicators:

- Is there a mechanism for negotiating changes in benefits that is responsive to changing health needs, technology, and the development of new therapies?
- Is there a mechanism for negotiating changes in benefits that is accessible to families in a timely manner?
- Are there systems for providing needed family supports such as adaptive housing, respite care, and camperships?
- Are there mechanisms for providing public subsidies or tax credits to families of children who have substantial ongoing health care needs that are not covered by health insurance?
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13. Coordination of Benefits

Coordination of benefits is achieved when a child who is entitled to health care financing from multiple sources receives maximum access to services and resources are used efficiently.

Children with special health needs often are eligible for multiple programs and services. Some services may be covered by private health insurance, others may be provided through public funding. Duplication of effort can be avoided and resources efficiently applied when such benefits are coordinated.

Individual child and family indicators:

- Do families receive ongoing and up-to-date information concerning entitlements and available resources?
- Do families understand the implications of the decision to use different payors for services, such as using private insurance benefits to cover services provided in schools?
- Is assistance available to families to coordinate benefits?
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System-level indicators:

- Are there requirements or effective incentives that encourage coordination among service providers and third party payors regarding payment for services?
- Are there mechanisms for ensuring that families have continued access to information regarding current available resources and entitlements?
- Does the financing system reimburse providers or facilities for coordinating benefits on behalf of children and families?
- Are there mechanisms to prevent duplication of payment for a service from more than one source?
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14. Administrative Efficiency

Administrative efficiency is enhanced when the financing system includes incentives for and places a high priority on avoiding duplication and unnecessary services.

Because the needs of children with chronic illness and disability are both costly and extensive, it is especially important that their care be delivered in the most efficacious and cost effective manner and that the financing system does not create additional administrative burdens for the family in accessing care.

Individual child and family indicators:

- Do families have access to easily understood descriptions of benefits for both public and private systems of financing?
- Do families receive information that is simple and clearly communicated regarding enrollment procedures?
- Do families receive timely and efficient services in the management of claims and other administrative functions?
- _____

System-level indicators:

- Are descriptions of benefits designed to be easily accessible and understood by families?
- Are there well-publicized and non-biased appeals processes for claims rejection in both the public and private systems?
- Does the financing system provide adequate data to facilitate assessments of service quality and cost?
- Is reimbursement to health care providers done in a timely manner?
- Are there mechanisms for standardizing definitions of benefits and services among third party payors?
- Are there mechanisms that encourage use of common forms, maintenance of quality MIS systems, and sharing of aggregate data?
- Are there mechanisms for streamlining claims processing and payments?
- Does the financing system place a limit on the percentage of total cost that can be attributed to administration?
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NOTES