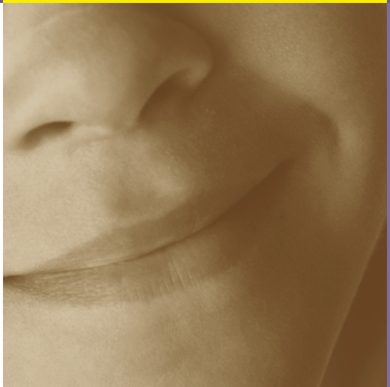
Identify

Collaborate

SHARED RESPONSIBILITIES

Tools for Improving Quality of Care for Children with Special Health Care Needs

Improve



New England
SERVE

About SHARED RESPONSIBILITIES

The Shared Responsibilities Toolkit is designed to assist health plans to improve systems of care for children with special health care needs. It is based on the belief that health plans share the responsibility for planning, payment and improvement of health services for this population with other partners, including families, providers, state agencies and community-based organizations. The Shared Responsibilities tools include a variety of strategies for identification as well as methods for building collaboration, all structured to support health plans to move forward to improve quality of care. The Shared Responsibilities toolkit includes:

- a framework for approaching quality improvement that emphasizes partnerships;
- tools and methods for identifying children with special health care needs;
- surveys for gathering information from families, providers and health plans;
- measures of organizational readiness to assess health plan capacity to focus on this population;
- best practice examples from other health plans.

About New England SERVE

New England SERVE is a health policy research and planning organization established in 1983 to promote quality systems of care for children with special health care needs and their families. New England SERVE is committed to assisting states, communities, health plans, hospitals and other health care organizations to enhance their capacity to provide family centered care and to build effective partnerships for quality improvement among consumers, providers and health policy makers.

Who are Children with Special Health Care Needs?

The phrase *children with special health care needs (CSHCN)* describes a large group of children with a vast array of diagnoses and conditions who share the need for a comprehensive system of care that allows them to live, be educated and build relationships in their community. Applying a definition developed under the leadership of the federal Maternal and Child Health Bureau[1], public health researchers now estimate that 15-18% of the nation's children have a *special health care need.*[2] This definition includes children with chronic medical conditions such as diabetes, sickle cell anemia and childhood cancers; children with developmental disabilities such as mental retardation, sensory impairments or spina bifida; as well as children with emotional or behavioral health needs including ADHD and mental health conditions.

CSHCN are recognized to be those between the ages of birth and 21 years who:

- have chronic physical, developmental, behavioral or emotional conditions expected to last twelve months or more, and
- require health and related services of a type or amount beyond that required by children generally,
- receive these services from a wide array of both public and private providers across health, education and social service systems of care,
- and, as a result of complex conditions and multiple providers may require specialized care coordination.

Adopting the new definition, which has been endorsed by the American Academy of Pediatrics and accepted by child health experts nationwide, shifts the focus of identifying CSHCN away from diagnosis to the consequences of an ongoing health condition, its impact on a child's functioning and need for health and related services.

Why identify children with special health care needs?

Health plans are currently spending significant health care resources for this population.

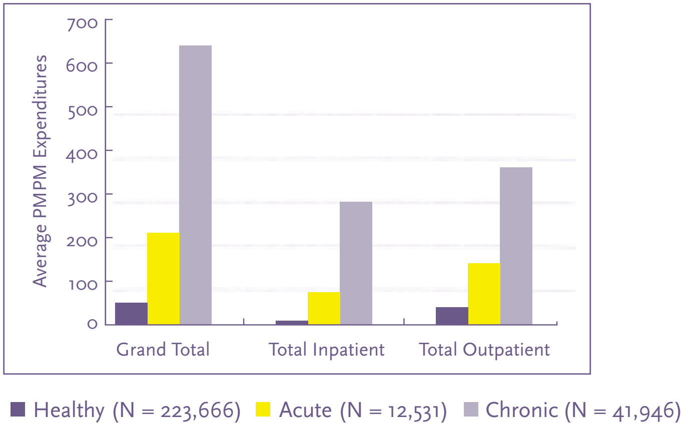
- Virtually all health plans, whether they enroll commercial members, Medicaid members, or both, are already serving many CSHCN. An estimated 90% of CSHCN have some form of health care coverage.
- CSHCN use physician services and inpatient hospital services three times as often as other children in the U.S.[3]
- Average per member per month expenditures for children with a wide range of chronic conditions are likely to be three times greater than the average expenditures for children with a significant acute condition and ten times greater than for healthy children. (see chart)[4]

Early identification of CSHCN can be a powerful predictor of future costs, allowing health plans to develop targeted interventions that can be cost saving and improve outcomes for children and families.

Service Use by CSHCN: One Plan's Experience

Neighborhood Health Plan, a Massachusetts managed care organization with more than 135,000 members serving primarily Medicaid enrollees, used the Shared Responsibilities model and found that 18% of its child members have special health care needs based on an analysis of administrative data. Survey findings from 542 families indicated that these children used many more health services than their healthy peers in the previous twelve months:

- One in four saw a primary care clinician more than eight times
- More than 60% used specialty medical services
- Nearly 40% were hospitalized
- Nearly half required some type of medical or adaptive equipment, nutritional products or supplies
- One in four required ongoing mental health services



This chart illustrates Average per Member per Month Health Plan Expenditures for CSHCN Compared to Expenditures for Healthy Children and Children with Acute Conditions in a sample of more than 275,000 children enrolled in three public health insurance programs in Florida in 2000-2001.

identify

Growing interest by purchasers, policymakers & providers

Health care policymakers, government agencies, providers, and purchasers are devoting new attention to CSHCN.

- Two federal initiatives, **Healthy People 2010**[5] and the **New Freedom Initiative**[6] include a commitment to building community-based service systems for CSHCN in every state.
- The **American Academy of Pediatrics** has endorsed the goal that every CSHCN will receive care within a medical home by 2010.[7]
- The **National Committee for Quality Assurance (NCQA)** adopted the Pediatric CAHPS® 2.0H Children with Special Health Care Needs Module for inclusion in the HEDIS performance measurement system beginning in 2002.[8]
- The federal **Centers for Medicare and Medicaid Services (CMS)** adopted safeguards for assessing the quality of care provided to CSHCN in mandated Medicaid managed care plans.[9]

Identifying children with special health care needs is central to all these initiatives.

Health plans will need to rely on multiple strategies to identify the full range of children who meet the CSHCN definition. These may include use of administrative and claims data, direct contacts with members at enrollment, screening at annual primary care visits, or discharge planning following hospitalization.

The IDENTIFY section of the Shared Responsibilities Toolkit contains sample tools developed by researchers that can be used by health plans to identify children with special health care needs.

Why invest in collaboration?

Health plans can make critical contributions to the quality of health services by building partnerships with families and providers as well as state and community-based agencies caring for CSHCN. Collaboration can help plans identify priority needs and low cost strategies for quality improvement.

> “Trying to provide quality care for children with special health care needs without family collaboration is like driving a car with a flat tire…you may get there, but the ride is rough and slow. We do not have the time or resources to waste, nor the tolerance for a bumpy ride.”
>
> *— Bev Crider • Children’s Choice of Michigan • Past President, Family Voices*

Families are experts – Parents of CSHCN are essential partners in improving health outcomes for their children and coordinating care. As frequent users of the health system, they may be the best source of information about what works well, what works poorly, and how to improve systems of care. To build partnerships with families health plans can:

- support meaningful roles for families to participate in quality improvement initiatives;
- establish Family Advisor positions to ensure ongoing consultation from consumers and facilitate connections with family organizations within the state;
- use existing family leadership groups and parent information centers to identify resources and parent-to-parent supports for member families caring for CSHCN.

Coordination of benefits – Health plans can assist CSHCN and their families to access and coordinate care by learning more about available public financing and community supports. Understanding the roles that other organizations play in financing or delivering care to CSHCN can lead to improved coordination of benefits.

> “Collaboration among physicians, families and health plans is essential to delivering cost effective quality care for CSHCN, and it is the only way to make the concept of Medical Home a reality.”
>
> *— Tom Tonniges, MD • American Academy of Pediatrics • Director of Community Pediatrics*

Providers are the best links to patients – Primary care physicians can play a critical role working with health plans to identify and support their members with special needs. To strengthen partnerships with providers health plans can:

- use targeted provider satisfaction surveys;
- establish provider advisory councils or focus groups;
- provide reports on individual clinician practice patterns and patient utilization;
- provide additional payment or support services to promote best practices such as care coordination and the creation of a **medical home** for CSHCN at the primary care level.

Tap state Title V resources – One-third of each state’s block grant through Title V of the Social Security Act must be spent on developing community-based systems of care for CSHCN. These state programs have clinical and programmatic expertise; many provide special financing programs, specialized case management services and information and referral resources.

Health Plans Provide Critical Utilization Data to Providers: One State’s Experience

Anthem Blue Cross Blue Shield and Cigna Health Care in New Hampshire have collaborated with the Hood Center at Children’s Hospital at Dartmouth to improve care for identified CSHCN. Using a diagnostic based algorithm for identifying CSHCN, these plans generate utilization reports on identified children within pilot pediatric practices. Practice groups receive special formatted reports on their patients to confirm CSHCN status, initiate outreach to families, and plan individualized care coordination efforts.

Sample tools and resources to assist health plans to build partnerships with families, providers and state Title V organizations are included in the COLLABORATE section of the Shared Responsibilities Toolkit.

How can health plans improve quality of care?

Once a health plan identifies members who are likely to be children with special health care needs and builds collaborating partnerships, the plan will be well situated to assess and improve care for these members. Many opportunities for improving care are uniquely within the control of the health plan's organization and resources.

> "Until we committed to full-fledged collaboration with parents, CSHCN (and their families) were faceless and voiceless. Today we know who these children are, what their families face on a daily basis, and what needs to change to use our financial resources more effectively."
>
> *— Robert Master, MD • Neighborhood Health Plan*

Examples of specific opportunities for quality improvement at the health plan level include:

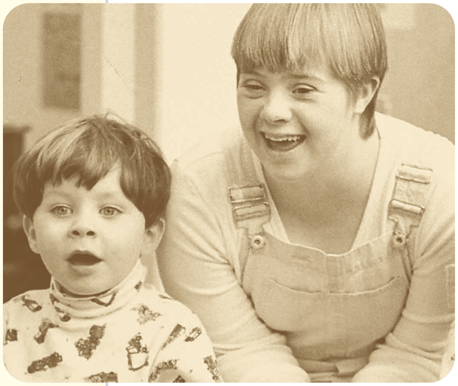
- **Provide families with information:** Families caring for CSHCN need information. Health plans can serve as a networking resource, linking families to information on their child's health condition as well as community-based services.
- **Simplify access to care:** Health plans can improve access to appropriate preventive and specialty services by identifying barriers and redesigning referral policies to simplify access for families caring for children with ongoing needs.
- **Enhance coordination:** Case management and disease management programs can be targeted to CSHCN or modified to meet the needs of children and their families. Health plans can build linkages to schools and improve coordination and information exchange between providers in health and educational settings.

- **Match resources to the needs of children and families:** Health plans have the incentive, and the financial flexibility, to pay for services that may not be specified in contracts but which are cost-effective for particular children.
- **Help families navigate the health care system:** As organized financing and care delivery systems, health plans can play an important role in reducing stress and out-of-pocket costs by helping families understand and use the health care system more effectively.
- **Link with other leaders in health care quality:** As more health plans develop new approaches and programs for improving care for CSHCN, they can join national efforts to improve quality of care for this population.

Additional examples of best practices at the health plan level, a checklist for health plans serving CSHCN, and a set of organizational readiness measures are included in the IMPROVE section of the Shared Responsibilities Toolkit.

What is the return on investment for health plans?

The experience of health plans that have undertaken significant efforts to enhance quality of care and care delivery systems for children with special health care needs suggests that there can be notable improvements in many important measures of health plan performance, including:



- Improved family and provider satisfaction;
- Enhanced quality of care, including improved linkages between children and appropriate primary care and specialty providers;
- Recognition for the health plan as a leader in quality improvement by purchasers, policymakers and other health plans;
- Lower costs for certain services, such as inpatient hospital care, and an improved developmental trajectory for many children, which may reduce health plan costs over the long-run;
- Improved services for **all plan members** as a result of enhanced plan-wide communications and connections between distinct service units;
- Transfer of lessons learned to other population groups.

Like many quality improvement efforts undertaken by health plans, it may be difficult to demonstrate a traditional financial return on activities designed to improve care for CSHCN, although such a return on investment clearly exists for certain interventions for children incurring very high costs.

While health plans may have limited resources to apply to quality improvement, a significant subset of the child population has needs worth examining. Identifying this population and building collaboration with key partners can lead to significant improvements in health plan operations and quality of care.

The SHARED RESPONSIBILITIES TOOLKIT was developed and tested in collaboration with several health plans to assist plans in improving systems of care for CSHCN. The tools and methods have been reviewed and revised based on the suggestions of many experts across the country.

The tools can be easily adapted for use by any health plan or by provider groups, purchasers, or state agencies working in partnership with health plans. The Shared Responsibilities tools can be obtained at no cost from the New England SERVE website: **www.neserve.org.**

Endnotes

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