

Supporting Families of Children with Special Health Care Needs

Children with special health care needs can be among the most vulnerable of all children. Such children have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children generally.¹ While the term “children with special health care needs” is used to describe children and youth with a range of conditions, many have serious illnesses, chronic conditions, or disabilities that profoundly affect their lives and their families.

A new national survey, conducted by the National Center for Health Statistics, is yielding perspectives on the size and vulnerabilities of this population that can assist health grant-makers and public officials in responding more effectively to their needs. Preliminary data indicate that one in five American households has at least one child with special health care needs.² The data also suggest that many of these children are not getting all the health and related services they need.

The first National Survey of Children with Special Health Care Needs, slated to be completed by mid-2002, will provide the first accurate national *and* state-level estimates of the number of children with special health care needs. It will also provide valuable information on the services these children and their families require and use, the adequacy of their health coverage, and their satisfaction with services received.

By definition, children with special health care needs require more health care and related services than other children. In addition to preventive and acute care, these children may need specialty care, prescription medications, therapies, durable medical equipment, assistive technologies, psychological services, medical supplies, or home health care. A 1998 survey of families of children with special health care needs found that more than three-quarters of children had used specialty doctors and prescription medications in the preceding year, almost half had received ancillary therapies, and nearly a fifth had received mental health services.³ About 20 percent had seen their primary care doctor eight or more times in the preceding year; and 20 percent had seen an outpatient specialist at least as often.

Timely access to high quality health and related services is important for all children, but is imperative for children with

special health care needs. Many of these children have conditions that can worsen without prompt treatment, sometimes dramatically so. Children who don't get the care they need can end up in emergency rooms and hospital beds. Others can be left with lifelong impairments that impede their ability to learn and participate fully in family and community life. For all children with special health care needs, ready access to health care and related services plays a key role in preventing problems, maximizing health and development, and averting the need for more costly interventions.

Despite the importance of timely, effective services, health coverage and care coordination for children with special health care needs are often problematic. An estimated 89 percent of children with special health care needs have some form of health coverage, either private insurance or coverage through a public program like Medicaid or the State Children's Health Insurance Program.⁴ The trend toward managed health care, however, means that families must navigate an increasingly complex health care system that typically puts limits on the types of providers children can use or the services they can receive. Although some children and families can access information, assistance, and care coordination through state maternal and child health programs, early intervention services, and other systems, these programs are typically overburdened and underfunded.

THE ROLE OF FAMILY CAREGIVERS

Families of children with special health care needs play a central role in finding and coordinating care for their children. Even when children have access to care coordination services, family members – especially mothers – shoulder much of the responsibility for identifying providers, scheduling appointments, meeting with doctors and school officials, and working with insurers on coverage and payment issues. The 1998 survey of families of children with special health care needs found that about half of them spent some time each week coordinating their child's care, with more than a quarter of mothers reporting that they spent five or more hours per week coordinating care for their child.⁵

Caring for a child with special health care needs places other stresses on families as well. The 1998 survey found that, between care coordination and providing health care to

children at home, more than 80 percent of families reported an impact on employment status, family finances, or the time available to meet other family needs.

Information and support services can reduce family stress and help families fulfill their roles as caregivers and care coordinators. In particular, the development of family-centered systems of care can help families meet the challenges of providing for a child with special health care needs. Family-centered care is an approach that views services for individuals in the context of their families and communities, and that actively involves patients and families in the planning, implementation, and evaluation of health care. Family-centered care focuses on patient and family strengths, promotes communication and collaboration, facilitates peer support, and encourages empowerment.

OPPORTUNITIES FOR GRANTMAKERS

There are many opportunities for grantmakers to ensure that children with special health care needs get the services and support essential for their health and development. The following list illustrates some of the approaches available.

- **Community needs assessments** – Foundations can encourage collaborations among providers, families, and communities to conduct community needs assessments. Assessments can focus on such things as the availability of key services and supports, the ability of families to readily access the services their children need, and family satisfaction with services. Information from community needs assessments can be used to improve information and referral services for families and to target service development and systems advocacy on identified gaps.
- **Family-to-family information and support networks** – Most families of children with special health care needs rely heavily on other families for help in finding good providers, navigating service systems, and becoming effective advocates for their children. They also rely on other parents for the emotional and practical support that can help families weather the stresses of caring for a child with special health care needs. Family-to-family information and support networks can help families find relevant information and connect with other families. Among the foundations that have supported family-to-family information centers and support networks are the Dakota Medical Foundation, The Health Trust, The Healthcare Foundation of New Jersey, The Robert Wood Johnson Foundation, and The New York Community Trust.
- **Parent education and training** – To ensure that children receive the services they need to thrive, families must have information about their child's condition, know how to access the service systems in their community, and be confident enough to act as their child's advocate. Foundations can play a critical role in making parent education and training available. For example, the Rose Community Foundation provided funding to a national peer information and support organization to train parents of children with facial disfigurements on advocating for their child. A different approach was taken by The Robert Wood Johnson Foundation, which held a two-day workshop for 10 parents of children with special health care needs to train them on public and private health care financing mechanisms. These parents then trained others in their states and regions.
- **Provider education** – Health care providers frequently need education about children with special health care needs and about working with parents as partners. One foundation, the United Hospital Fund in New York City, met this need by funding a parent-created training program that involves parents in educating medical residents at city hospitals about the special health care needs of severely chronically ill children. Foundations can also support staff training in other children's service sectors to help them integrate children with special health care needs. An example is the Phoenixville Community Health Foundation, which funded training at a preschool day care center that wanted to enhance its ability to serve children with special health care needs.
- **Development of family-centered systems of care** – Grantmakers can encourage the adoption of family-centered principles among their grantees by explicitly including principles of family-centered care in grantmaking guidelines and requests for proposals. They can encourage grantees to include youth and families in all phases of project development and implementation; enhance the collaborative skills of grantees, youth, and families; and invest in opportunities for professionals, youth, and families to plan together. Grantmakers can also incorporate family-centered care principles into their own administrative practices and procedures by involving consumers and families as part of the proposal review process.

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