

Special Children, Special Care



This Viewer Guide is designed to stand alone or accompany **Special Children, Special Care**, a documentary exploring the challenges and opportunities that South Carolina families face in caring for their children with special health care needs.

The Definition of Special Health Care Needs

Children with special health care needs have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and require health and related services of a type or amount beyond that required by children generally. Special needs conditions can include everything from asthma and sickle cell anemia to developmental delays and disabilities and mental health problems, to spina bifida and muscular dystrophy.



More than one-third of a million children in South Carolina have special health care needs.

Caring for children with special health care needs is often a complicated, round the clock job for parents stretched thin with challenges most people can't even imagine. Parents juggle multiple hospitalizations . . . midnight trips to the emergency room . . . the financial pressure that a serious illness or chronic condition brings . . . social isolation . . . the complicated search for services and care . . . and more.

The number of children with special needs is growing. National data shows that roughly 15% of all children fall into this category and that they account for 80% of pediatric health care expenditures. A stalled economy, changes in insurance and health delivery systems, and funding reductions in many programs are threatening comprehensive care for children with special needs.

Parents struggle to find and coordinate a sometimes bewildering array of services and physicians. Sometimes it is difficult to access primary care. Sometimes accessing sub-specialty care is wrought with transportation, communication and coordination problems.

The Medical Home Concept

Linking all children with special health care needs to a comprehensive medical home has become a priority of the Healthy People 2010 objectives and the American Academy of Pediatrics.

Traditional pediatric care is designed to provide well child preventive services and acute illness management to children who do not have special health care needs. The challenge is to build upon this traditional approach to improve care for the children who use the health care system most often.

A medical home is not a building, house or hospital. It is an approach to providing health care services to children with special health care needs in a high-quality and cost-effective manner. Children and their families in a medical home, receive the care they need from a pediatrician or family physician. Physicians, families, and allied health professionals are partners in a medical home. This team identifies and accesses medical and non-medical services to help children achieve their maximum potential. This approach builds upon and expands the traditional medical home concept. By focusing on prevention, early intervention and improved care coordination, the medical home approach will reduce the incidence of high cost emergency room visits and higher cost hospitalizations.

The Importance of Family-Centered Care



One of the most important aspects of the comprehensive medical home is family-centered care. Parents know their children better than anyone else and are also the child's most

important advocate. Parents deserve to be respected, fully included members of their child's medical home team.

The family-centered care concept:

- Recognizes** that the family is essential to the child's care;
- Helps** families and professionals work together better;
- Considers** all needs of the child and family including medical, emotional, educational and more;
- Finds** new ways to meet the child and family needs in the doctor's office and the community including schools;
- Promotes** family support, parent-to-parent connections and networking with other families.

Along with family-centered care, parents of children with special needs can benefit greatly from parent-to-parent support activities.

The Face of Medicaid in South Carolina

Darlynn Thomas: *I don't think many people realize how important Medicaid is to South Carolinians. We have almost a half a million children who are Medicaid beneficiaries. These children may come from very poor families or they may come from middle-income families where Medicaid saves them from crushing medical expenses for their child with disabilities.*

Medicaid has become a primary, perhaps in some cases, the only insurance source these families have. Medicaid is no longer tied to the welfare system but has become insurance for the poor, uninsured and the underinsured in our state. The Medicaid agency supports the medical home concept because it encourages and delivers family centered, comprehensive, compassionate, coordinated, culturally competent and continuous medical care. No longer is the family left frustrated navigating the health care system but has a point of access from which to build a medical plan of care. Prevention and early intervention in medical homes will allow Medicaid to be responsible and accountable to the SC taxpayer who partners with the Federal government to pay for Medicaid service.

Our SC families, especially those who have children with special health care needs, deserve a doctor who knows their name. A doctor who can help the family meet their medical and special needs to achieve the best optimal healthcare outcome. The SC Medicaid program is a proud participant in the medical home for special needs children project and will continue to encourage the concept for all beneficiaries throughout the state.



Darlynn Thomas
Bureau Chief
S.C. Dept of Health and
Human Services

About Medicaid

The Department of Health and Human Services is South Carolina's agency designated for the administration of Medicaid, defined by the federal government as providing health insurance for low-income families, and the aged, blind and disabled.



Quick Facts on the Broadcast

Special Children, Special Care

SCETV worked closely with the State Medical Home Team to produce this one-hour documentary that explores the challenges facing families of children with special health care needs and examines solutions to these problems with a focus on the medical home concept. The broadcast, **Special Children, Special Care**, was funded by **Sound Partners for Community Health**, a program of the Benton Foundation supported by a grant

from The Robert Wood Johnson Foundation. The S. C. Department of Health and Human Services also provided support.

SCETV President and CEO Maurice “Moss” Bresnahan said, “This is an excellent example of the way SCETV can work with professional groups, community organizations, and government agencies on a critical issue.”

Special Children, Special Care was broadcast statewide on April 3, 2003 and April 6, 2003.

This one-hour program is now being used for a variety of training and education efforts targeted to a broad array of health care providers, to families of children with special needs, and to community decision makers. If you’d like to purchase this program for your own library, visit SCETVStore.org and click on “New Releases”, or enter “special care” in the search box or send your request to SCETV Marketing Department, P. O. Box 11000, Columbia, SC 29211.

Discussion Questions

- (1) What challenges do the parents of children with special needs face in accessing comprehensive medical care for their children? How can providers, agencies, and nonprofits work to help parents and children solve these problems?
- (2) What is family-centered care? What benefits does it provide for children and families?
- (3) More than a third of a million South Carolina children have special health care needs. What can be done to improve the health of these children while reducing costs to the health care system?
- (4) How does a comprehensive medical home improve care for children with special health care needs?
- (5) What can be done to increase the focus on improving access to care? Is there enough emphasis on prevention and early intervention services?

The History of the Medical Home Project in South Carolina

South Carolina's State Medical Home Team was established in 2001 as a partnership between the state chapter of the American Academy of Pediatrics, Children's Rehabilitative Services at the S. C. Dept. of Health and Environmental Control, the state chapter of the American Academy of Family Physicians, Family Connection of S. C., Inc., and the S. C. Dept. of Health and Human Services. CATCH funding from the AAP supported the team's development activities that included setting the following goals for children with special health care needs:

- ❑ All CSHCN will have an identified medical home where care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, culturally competent and cost-effective by 2010.
- ❑ These medical homes will result in improved child health status, function and quality of life for CSHCN and their families.
- ❑ Medical home teams will promote early identification and screening of CSHCN.
- ❑ There will be a plan for transition of care at the end of childhood to adult-oriented resources.
- ❑ All children will have health care insurance that covers health care costs.

In April 2002, The CRS Division of DHEC (Title V) received a three-year grant from the Maternal and Child Health Bureau of HRSA to build upon the initial goals of the State Medical Home Team. Grant priorities include a broad-based education campaign on medical homes, mentor medical home sites to develop and share strategies to improve care, strategies to strengthen the linkages between primary care providers and specialists, and between physicians and community organizations. Speakers, trainers and educational materials are available upon request.



Information for Providers

Under the leadership of President Rob Walker, MD, The State Chapter of the American Academy of Pediatrics is promoting the medical home concept through a variety of educational activities and by taking a major role in the State Medical Home Team. This collaborative is promoting the medical home concept as a way to more efficiently and effectively deliver care, to save health care dollars over the long-run, and to improve the health outcomes of children with special health care needs.

What does this model emphasize?

- Improved access to care at all levels
- Family-centered care that results in true partnerships with families
- Primary care-based care coordination
- Continuous improvement process
- Improved office systems that:
 - Identify CSHCN
 - Track and monitor progress
 - Evaluate health and systems outcomes

What are the benefits of this approach?

- Increased provider, patient and family satisfaction
- Improved coordination of care
- Improved linkages to sub-specialists and community organizations
- Establishment of a forum and system for problem solving
- Efficient use of limited resources
- Increased wellness resulting from comprehensive care



Getting Started

The State Medical Home Team can provide curricula for training, trainers and speakers, and basic brochures targeted to the family and to the health care provider. For more information contact Linda Price at Children's Rehabilitative Services at DHEC at (803) 898-0789 or Project Coordinator Betsy Wolff at (803) 782-0238 or at betsywolff@aol.com.

Agencies and Organizations Who Can Help

Health, Medical, Developmental

BabyNet Early intervention program offering special services to children up to age three who have a disability or are slow to develop. Not income based. Website: www.scdhec.net
1-800-868-0404

Children's Rehabilitative Services (CRS) Medical evaluation and treatment to children with special health care needs. Covered conditions include: endocrine disorders, bone and joint diseases, cleft palate, congenital heart conditions, spina bifida, epilepsy, cerebral palsy, cystic fibrosis, hemophilia, sickle cell disorders, kidney diseases, and developmental delays. Family size/income based. Website: www.scdhec.net (803) 898-0784

The SC Department of Disabilities and Special Needs (DDSN) Serves persons with mental retardation, autism, head and spinal cord injuries, and related conditions. Provides early intervention services to age 6 for those eligible for BabyNet. Not income based. Website: www.state.sc.us/ddsn/
1-888-376-4636

SC Children's AIDS Care System (Ryan White) Assures access to comprehensive care, including case management, social, and support services for families with HIV-exposed or HIV-infected children/adolescents. Not income based.
(803) 898-0291

Shriner's Hospital in Greenville is a 60-bed pediatric orthopaedic hospital providing comprehensive care to children at no charge. Website: www.shinershq.org
(864) 271-3444

SC Department of Mental Health (DMH) provides a full range of community and inpatient services to persons of all ages who are emotionally disturbed or psychiatrically disabled. (803) 898-8581

The Continuum of Care for Emotionally Disturbed Children Provides intensive case management to assist child, family, and agency providers to develop individualized service plans for children eligible through a formal evaluation. Not income based.
(803) 253-6272

NAMI (National Alliance for the Mentally Ill) 17 local groups in South Carolina provide support, education, and advocacy for families/friends of people with mental illness and for persons with mental illness. Not income based. 1-800-788-5131 Email: NAMIoFSC@logicSouth.com website: www.namisc.org

The Federation of Families of South Carolina Serves families of children/ youth who have or are at risk of emotional, behavioral, or mental disorders. Services include support groups, parent-to-parent support, referrals, and educational materials. Not income based. Website: www.midnet.sc.edu/ffsc (803) 779-0402

CHADD (Children and Adults with Attention Deficit Disorders) Serves people affected by attention deficit disorders and similar disabilities through family support and advocacy, public and professional education. Website: www.chadd.org
1-800-233-4050

Educational

SC Department of Education Office for Exceptional Children Kids Hot Line 1-800-763-5437 or (803) 734-8224 or your Local School District Office of Special Services

Headstart A comprehensive child development program for children birth to 5 Increases school readiness of preschoolers in low-income families. Programs allocate at least 10 percent of enrollment to children with disabilities and special needs. (803) 898-2861

PRO-Parents (Parents Reaching Out to Parents) Provides information and training about special education law to families of children with disabilities and special needs. Not income based. (803) 772-5688 or 1-800-759-4776 Email: PRO-Parents@aol.com

Protection and Advocacy for People with Disabilities (P&A) Provides support and protection of legal and civil rights of persons with disabilities. Advocates for children on rights to services under the Individuals with Disabilities Act. Not income based. 1-800-800-6997, website: www.protectionandadvocacy-sc.org

Other

South Carolina Services Information System (SCSIS) Statewide database of disability and aging services on the website: www.scsis.org

Office of the Governor South Carolina Developmental Disabilities Council Develops policy and advocates for people with disabilities while monitoring programs and service delivery. 803-734-0465 website: mySCgov.com

Family Connection of South Carolina Support network for families who have children with developmental delays, disabilities or chronic illnesses. As the statewide parent-to-parent organization with offices in several cities, Family Connection helps thousands of children in South Carolina reach their potential by providing parent-to-parent connections, linking families to community resources, and sponsoring educational and support programs. Programs are free. 1-800-578-8750 www.familyconnectionsc.org

Log on to www.scetv.org/medicalhome or www.familyconnectionsc.org for further information.

This list was adapted from a resource brochure compiled by Family Connection of S. C. Copies of the complete brochure are available from this organization.



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Front photo: Susan Aude hosted Special Children, Special Care. Pictured with Susan are Patrick Fernald and Tiffanie Hayes.

South Carolina Educational Television
PO Box 11000
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Place
postage
here

Special Children, Special Care, a SCETV documentary, provides critical information about children with special health care needs and how the medical home approach can improve care.

For more information, log on to www.scetv.org/medicalhome (brochures, viewer guides, and streaming video) or call 888-761-8132. Video copies of the documentary will be available at your public library in June.

For more information about securing speakers and trainings on the medical home concept call 803-782-0238 or e-mail to betsywolff@aol.com.