

# Conclusion

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The best place for children is at home and in their community. We hope this booklet has shown you that implementing a medical home in your office for children with special health care needs is attainable and helps make community living possible. With a few modifications and some advance planning, you can greatly enhance your ability to care for children with complex illnesses in your office and maximize opportunities for appropriate reimbursement.

**Key concepts include:**

- Identifying children in your practice
- Determining personnel needs and resources
- Developing individual health plans and other clinical documents to assist on-call partners
- Adapting office visits
- Improving communication among providers
- Utilizing parents as resources and family support
- Implementing reimbursement strategies

Staff of the PACC project and the Division of General Pediatrics at Children's Hospital, Boston wish you all the best in your endeavor to serve this special population.

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“PACC provides me with a kind of roadmap to the maze of caring for a child with special needs. There are paths marked by families that have been here before, clear road signs from my care providers and always pit stops for support.”

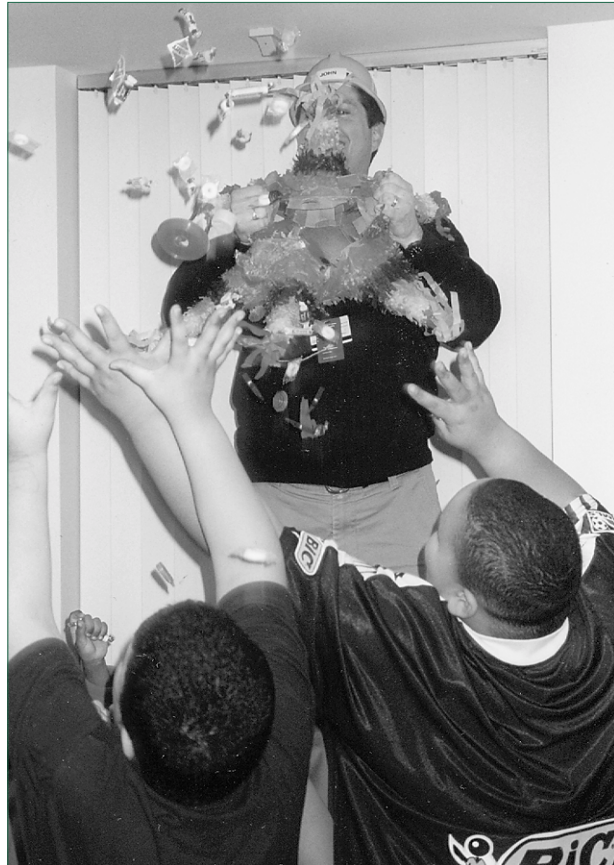
—Parent at Longwood Pediatrics



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“It probably would have taken 10 phone calls to get the same personal relationship that I was able to make in one home visit.”

—Pediatric Nurse Practitioner at Hyde Park Pediatrics

# APPENDIX A

# Contributors

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## APPENDIX B

### Other Innovative Programs for Children with Special Health Care Needs

#### Arizona

Phoenix Pediatrics is an urban, eight-physician practice serving 17,000 patients, of whom approximately 2,500 (15%) are children with special health care needs. The practice specializes in treating CSHCN, and since 1987 has developed successful strategies to enhance patient care under the medical home model and maximize insurance reimbursement. Central program features include proper documentation of encounters and data collection (e.g., tracking referrals, authorizations and care coordination). Dr. David Hirsch has also developed criteria for “medical/behavioral/psychosocial complexity levels” to better define the overall needs of CSHCN for clinical purposes as well as contract negotiations with payers. For this practice, which serves large numbers of CSHCN, Dr. Hirsch reports that the per member per month capitation rate (PMPM) is approximately \$85 to \$95. The average capitation PMPM for their typical patients is approximately \$12, which is the average for all ages for all the other capitated plans.

For additional information, contact Dr. David Hirsch of Phoenix Pediatrics, 6702 N. 19th Ave., Phoenix, AZ 85015, (602) 242-5121 x128, or e-mail CSHCNDOC@aol.com

#### Florida

Children’s Medical Services (CMS) is a Division of the State of Florida, Department of Health. CMS provides CSHCN a family-centered, comprehensive and coordinated statewide managed system of care, via two basic models—traditional fee-for-service and managed care, depending on eligibility. The agency has 22 offices in the state. Those offices offer clinical services that include all pediatric health specialties and primary care services in coordination with local providers, teaching hospitals that are university affiliated, and private home health care agencies. The case and care coordination is provided by registered nurses, social workers and resource parents who help to identify and meet the needs of CSHCN. The agency receives its funding from the Title V state initiatives, Maternal and Child Health Block Grants, and general revenue funding, as well as federal funding for Part C Early Intervention Funding and Florida Kidcare Title XXI funding.

Children’s Medical Services is forming contract alliances with the providers in the community. A capitated rate agreement for the provision of health care for the medically complex population is the projected method.

For additional information, contact Eric Handler, M.D., M.P.H., Deputy Secretary, State of Florida, Department of Health, Children’s Medical Services 2020 Capital Circle, SE, Tallahassee, Florida 32399-1700, (850) 487-2690 or e-mail eric\_handler@doh.state.fl.us



## Michigan

Kids Care of Michigan is a managed care program for children in Michigan's Children with Special Health Care Needs program. This voluntary initiative provides resources for a local care coordinator and principal coordinating doctor to work with the family and child to create an individualized health care plan for the child. The local care coordinator and principal coordinating doctor are chosen by the family with assistance from a plan-level care coordinator. The ability of the family to define this aspect of the medical home has proven crucial to the early success of this program. The individualized health care plan serves as an authorization template for services and no further approval of services or equipment is required, although amendments can be made as needed. Kids Care is developing a statewide network and is approaching 1,000 members. It is anticipated that when a threshold membership is reached, Kids Care will be able to provide administrative and care coordination for 15% of the monthly per member per month's capitation that it receives for medical care.

For additional information, contact either of the Kids Care co-Medical Directors: Craig Hillemeier, M.D. at (734) 763-9326 or Jose Cara, M.D. at (313) 874-4660.

## Northern New England

Rural Medical Home Improvement Project (RMHIP) assists pediatric practices in New Hampshire, Vermont and Maine to build quality medical homes. RMHIP supports core teams at each practice (two or more Parent Partners, a pediatrician and an enhanced care coordinator) to regularly and incrementally improve their provision of care. Educational retreats, team facilitation and consultation, chronic condition management tools and data analysis methods support teams in their efforts. Project outcomes include partnerships with parents, enhanced primary care coordination, linkages to community resources, continuous improvement processes for quality changes and improved office systems for the identification of children and for monitoring, tracking and evaluating outcomes.

Payment paradigms for care/care coordination include partnerships with Title V, shared funding with the area hospital, identification of the population with careful documentation of medical home encounters, and proactive and thorough use of care plans in anticipation of potential reimbursement (e.g., Vermont primary care case management effort reimburses PCPs \$40 per member per year for Medicaid enrollees who have a documented care plan). Lessons from this effort inform the RMHIP's development and validation of The Medical Home Index, a tool designed to measure the organization and delivery of true medical homes.

For additional information, contact W. Carl Cooley, M.D., Director or Jeanne McAllister, R.N., M.S., M.H.A., Manager and Practice Consultant; The Hood Center for Children and Families, (603)-650-6067 or e-mail [Jeanne.W. McAllister@Hitchcock.org](mailto:Jeanne.W.McAllister@Hitchcock.org)

## Washington, D.C.

Health Services for Children with Special Needs, Inc. (HSCSN) is a managed care program created exclusively to serve the District of Columbia's Medicaid and SSI children under age 22. HSCSN is based on a care coordination model that employs health plan-based "medical homes." Every enrollee is assigned to a care manager and a primary care provider who jointly serve as the medical home for the child. HSCSN originally had a shared risk contract with DC's Commission on Health Care Finance to manage this special needs population. The contract was for a per member per month capitation that included medical costs and care coordination costs with the anticipation that the care coordination costs would equal about 20% of the total capitation. Today, HSCSN does not share risk with the District but still provides care coordination services and helps ensure that all members have medical homes for a set fee.

For additional information, contact Kenneth F. Johnson, Vice President of Finance and Managed Care at (202) 467-2749.



# APPENDIX C

## Resources on the World Wide Web

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### [www.guideline.gov/index.asp](http://www.guideline.gov/index.asp)

The National Guideline Clearinghouse™ (NGC) is a public resource for evidence-based clinical practice guidelines. Click on “Disease/Condition” under the “Browse NGC” category to find 61 guidelines for mental disorders such as bipolar disorder and 533 guidelines for diseases such as nutritional and metabolic diseases and respiratory diseases. Click on “Treatment/Intervention” under the same category to access the following types of treatments: chemicals and drugs; analytical, diagnostic, and therapeutic techniques and devices; behavioral disciplines and activities. This Web site also contains a feature that sets up a comparison between two or more selected guidelines.

### [www.nichcy.org](http://www.nichcy.org)

The National Information Center for Children and Youth with Disabilities (NICHCY) is a referral center for disabilities and related issues, with a focus on birth to age 22. Click on “Publications” on the home page. Then click on “Fact Sheets and Briefing Papers” for information on disabilities such as spina bifida, speech and language impairments, epilepsy, etc.

### [www.ds-health.com](http://www.ds-health.com)

This Web site contains personal essays, articles and links to other medical sites, as well as Down Syndrome guidelines. Click on a category under the “Health Care Guidelines” section of the Web site to find medical flow sheets specifically for Down Syndrome patients. Information on clinical practice guidelines for Down Syndrome patients of various ages is also available.

### [www.nih.gov](http://www.nih.gov)

The goal of the National Institute of Health (NIH) research is to acquire new knowledge to help prevent, detect, diagnose, and treat all diseases and disabilities. To get facts about a specific condition, click on “Health Information.” Then click on “The 1999 NIH Health Information Index” to learn more about hundreds of health conditions.

### [www.modimes.org](http://www.modimes.org)

The March of Dimes is an organization that works to improve the health of babies by preventing birth defects and infant mortality. First click on the “Resource Center” option and then on “Fact Sheets” to choose from a list of conditions such as oral/facial clefts and PKU under the “Birth Defects and Genetics” category.

### [www.nichd.nih.gov](http://www.nichd.nih.gov)

The National Institute of Child Health and Human Development is part of the National Institutes of Health, U.S. Department of Health and Human Services. First click on “Publications/Clearinghouse” and then on “Fact Sheets” or “Reports” to gain information on conditions such as Williams Syndrome and Autism.

### [www.ncbi.nlm.nih.gov/Omim](http://www.ncbi.nlm.nih.gov/Omim)

OMIM™ stands for Online Mendelian Inheritance in Man. The Web site database is a catalog of human genes and genetic disorders. Click “Search the OMIM database.” Then type in the specific genetic disorder of interest. If the disorder is in the database, a list of accessible research articles appears.

### [www.ninds.nih.gov](http://www.ninds.nih.gov)

The NINDS is a component of the National Institutes of Health and the U.S. Public Health Service and is the leading supporter of biomedical research on disorders of the brain and nervous system. First click on “Patients,” then on “Health Publications” to find an alphabetical directory for specific conditions affecting the brain and nervous system.

### [www.ucp.org](http://www.ucp.org)

The United Cerebral Palsy’s mission is to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities. First click on “Health and Wellness” and then on “Children’s Issues” or on “Resources” under the “Health and Wellness” category to get to a list of links for further information on topics such as “children with disabilities”, “brain injury”, and “assistive technology.”

### [www.lungusa.org](http://www.lungusa.org)

The American Lung Association today fights lung disease with special emphasis on asthma, tobacco control and environmental health. Click on “Diseases A to Z” to get an alphabetical listing of lung diseases. Click on a specific lung condition for more information.

### [www.rarediseases.org](http://www.rarediseases.org)

NORD is a federation of health organizations serving people with rare disorders and disabilities. Click on “Rare Disease Database - alphabetical listing” to look up a disease such as sleep apnea, cystic fibrosis, and many others. There is information about specific conditions as well as links to other useful resources.

### [www.aap.org](http://www.aap.org)

The mission of the American Academy of Pediatrics is to attain optimal physical, mental and social health and well-being for infants, children, adolescents and young adults. From the homepage, click on the “Membership” option. Then click on the “Pediatric Internet” selection. This page provides links to many other internet resources about childhood conditions. Back on the home page, click on “Advocacy” and scroll to find the “National Center for Medical Home Initiatives for CSN”. It contains Medical Home Policy Statements, a checklist to include in healthcare plans, fact sheets, a Medical Home Training Program for Pediatricians, and how to obtain information on CPT coding and more.

### [www.pedinet.com/news/illness/disease/disease.htm](http://www.pedinet.com/news/illness/disease/disease.htm)

Dr. Al Gandy, MD, PhD, FRCP(c), designed this database to provide information on over 500 pediatric disorders. Simply scroll through the alphabetical list of disorders and diseases and select one to learn its definition, epidemiology, pathogenesis, clinical features, investigations, management, and prognosis.

### [www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

Family Village integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities. Click on “Library” and then on “Specific Diagnoses” in order to look up specific conditions such as epilepsy, chromosome disorders, AIDS and others.

# APPENDIX D

## American Academy of Pediatrics Policy Statement

Volume 90, Number 5

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The Medical Home (RE9262)

### Ad Hoc Task Force on Definition of the Medical Home

The American Academy of Pediatrics believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, and compassionate. It should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a relationship of mutual responsibility and trust with them. These characteristics define the "medical home" and describe the care that has traditionally been provided by pediatricians in an office setting. In contrast, care provided through emergency departments, walk-in clinics, and other urgent-care facilities is often less effective and more costly.

We should strive to attain a "medical home" for all of our children. Although geographic barriers, personnel constraints, practice patterns, and economic and social forces make the ideal "medical home" unobtainable for many children, we believe that comprehensive health care of infants, children, and adolescents, wherever delivered, should encompass the following services:

1. Provision of preventive care including, but not restricted to, immunizations, growth and development assessments, appropriate screening, health care supervision, and patient and parental counseling about health and psychosocial issues.
2. Assurance of ambulatory and inpatient care for acute illnesses, 24 hours a day, 7 days a week; during the working day, after hours, on weekends, 52 weeks of the year.
3. Provision of care over an extended period of time to enhance continuity.
4. Identification of the need for subspecialty consultation and referrals and knowing from whom and where these can be obtained. Provision of medical information about the patient to the consultant. Evaluation of the consultant's recommendations, implementation of recommendations that are indicated and appropriate, and interpretation of these to the family.
5. Interaction with school and community agencies to be certain that special health needs of the individual child are addressed.
6. Maintenance of a central record and data base containing all pertinent medical information about the child, including information about hospitalizations. This record should be accessible, but confidentiality must be assured.

Medical care of infants, children, and adolescents must sometimes be provided in locations other than physician's offices. However, unless these locations provide all of the services listed above, they do not meet the definition of a medical home. Other venues for children's care include hospital outpatient clinics, school-based and school-linked clinics, community health centers, health department clinics, and others. However, wherever given, medical care coverage must be constantly available. It should be supervised by physicians well-trained in primary pediatric medicine, preferably pediatricians. Whenever possible, the physician should be physically present where the care is provided; but it may be necessary for the physician to direct other health care providers such as nurses, nurse practitioners, and physician assistants off site. Whether physically present or not, the physician must act as the child's advocate and assume control and ultimate responsibility for the care that is provided.

#### AD HOC TASK FORCE ON DEFINITION OF THE MEDICAL HOME

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