



# PROMISING STATE AND REGIONAL APPROACHES FOR EXTENDING ACCESS TO PEDIATRIC SUBSPECIALTY CARE AND COORDINATION WITH PRIMARY CARE

Prepared by the

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For the  
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Department of Health and Human Services

November 2006

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## INTRODUCTION

Gaining timely access to pediatric subspecialists is becoming increasingly difficult in the United States. Hospitals, primary care providers, families, and health plans are struggling with alternative ways to address this critical workforce shortage in pediatrics. One approach is to expand the reach of existing state and regional networks of pediatric subspecialty services and the other approach is to strengthen the capacity of primary care providers (PCPs) with more consultation support and coordination from pediatric subspecialists.

Efforts to improve access to specialty pediatric care must be centered on the medical home concept of care. The key attributes of the medical home are a personal physician who provides first contact, continuous, and comprehensive care; facilitates access to needed specialty and other related health services; and provides guidance and advocates for families. For most children, the primary care physician is the predominant source of care with specialists partnering in providing care. To the extent that primary care work in a coordinated way, following an integrated plan for ongoing care in partnership with families, the child's medical home is strengthened.

Expanding the role of state and regional networks of pediatric subspecialty care has the potential to improve access, health outcomes, satisfaction, and cost savings. Specifically, the use of scarce pediatric physician subspecialty personnel and tertiary care resources can be maximized, and access to rural and other underserved areas can be improved. The child's medical home can be strengthened, including better chronic care management, more efficient referrals and coordination of care, and better communication and access across primary and specialty systems. Health outcomes can be improved, including family and physician satisfaction, and safety and efficacy can be ensured. Information technology and data exchange can be enhanced, and training and research resources can be concentrated. Overall, cost savings can be achieved as a result of operational efficiencies and improved quality of care.

Unfortunately, there are several barriers that impede expanded pediatric subspecialty access and increased coordination between primary and specialty care. These barriers primarily pertain to the supply of pediatric subspecialists, communication and coordination between primary and specialty pediatric providers, and funding.

There are 30 pediatric medical and surgical specialties, and all but neonatology are in very short supply. These shortages have been exacerbated by dramatic increases in the prevalence and severity of many chronic conditions among children and by increasing referrals from families and PCPs. Communication and coordination difficulties between PCPs and pediatric subspecialists also represent significant roadblocks. Mechanisms for information exchange, consultation, and education are seldom well-defined and efficient.

Few, if any, financial resources are available to support planning, training, information systems, and quality improvement mechanisms necessary to achieve organized systems of pediatric specialty care linked with primary care. Public and, increasingly, private insurance fail to cover the time it often takes for physicians to communicate, coordinate, and manage chronic conditions. Moreover, insurers rarely reimburse allowable codes that enable physicians to communicate. Except for Title V, with its very limited financial resources, no other federal or state funding sources are available to directly support the necessary infrastructure.

Also limiting the organization of state and regional pediatric specialty systems coordinated with primary care is the fact that few purchasers, health plans, and foundations have invested in developing and expanding organized systems of pediatric care. Other factors impeding the organization of pediatric subspecialty care systems include dynamic market changes and competition, ever-increasing pressure to provide care in the least expensive facility, and licensure problems restricting cross-state practice arrangements.

Despite these major financial and non-financial barriers, many hospitals, primary care practices, and managed care plans have invested in developing innovative approaches for improving pediatric subspecialty care coordinated with the child's medical home. Thirteen examples of promising approaches are presented in this report. They consist of a mix of approaches and sponsoring agencies -- children's hospitals/academic medical centers, military medical centers, managed care programs, private foundations, and state and federal Title V programs. Importantly, North Carolina's IMPACC Program, has involved all of the state's academic medical centers, the state's pediatric managed care network and its 200+ primary care practices, Medicaid, and private foundations in its unique statewide initiative. Each of the promising practices was selected because of its exemplary

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efforts to extend the geographic reach of pediatric subspecialty care and to enhance the capacity of PCPs to identify and manage chronic conditions. However, they should not be construed as a formal endorsement by the Expert Work Group or the Maternal and Child Health Bureau.

This report is the second in a series of promising practice reports prepared by the Federal Expert Work Group on Pediatric Subspecialty Capacity. The Expert Work was established in 2005 to 1) assess the scope and impact of pediatric subspecialty workforce problems, 2) identify promising practices, and 3) develop a tactical plan to improve access to pediatric subspecialty care within the context of comprehensive, community-based medical homes. The first report, *Promising Approaches for Strengthen the Interface Between Primary and Specialty Pediatric Care*, identified 10 innovative approaches related to referral, consultation, and shared management (available at [mchpolicy.org](http://mchpolicy.org)).

This report is organized into 3 sections. The first section, the introduction, describes the rationale for strengthening state and regional networks of pediatric subspecialty care within the context of the medical home and the major barriers affecting the expansion of state and regional pediatric specialty systems linked with primary care. The second section contains descriptions of 13 promising state and regional pediatric delivery networks. The third section identifies promising features of state and regional pediatric subspecialty arrangements.

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## PROMISING STATE AND REGIONAL EXAMPLES

### 1. NORTH CAROLINA'S PLAN FOR IMPROVING ACCESS THROUGH COLLABORATIVE CARE (IMPACC)

North Carolina's IMPACC program is a new statewide coalition of all of the tertiary care pediatric centers, the majority of pediatric subspecialists in the state, and the state's Medicaid primary care case management network for children. It was formed to improve access to pediatric subspecialists within the context of the medical home using a combination of practice and financing improvements.

All 6 large medical centers with pediatric subspecialty services are involved --- Carolinas Medical Center (Charlotte), Duke Medical Center (Durham), East Carolina University Medical Center (Greenville), Memorial - St. Joseph's Medical Center (Asheville), University of North Carolina (Chapel Hill), and Wake Forest Medical Center (Winston Salem). In addition, North Carolina's Division of Medical Assistance and its managed care program, Community Care of North Carolina (CCNC), are also involved. Specifically, one of CCNC's plans, AccessCare, is taking a leadership role. Formed in 1998, AccessCare is a statewide pediatric managed care plan with more than 200 primary care practices of over 1,000 general pediatricians and other PCPs, who serve as the medical home for more than 180,000 low-income children. This unique pediatric organization employs local care managers to work closely with PCPs; supports web-based systems and system-wide education to enhance the network capacity and uses nurse triage systems to provide medical advice to families.

Three program strategies are being implemented: 1) comprehensive case management emphasizing communication and coordination of care between the medical center and the child's medical home; 2) a financial incentive pilot to encourage telephone consultation between primary care providers and pediatric subspecialties; and 3) 3 mini-surveys of referral practices and experiences among PCPs, consulting pediatric subspecialties, and families. Special case managers located at the 6 medical centers and financed by Medicaid will complement the case management already available through the primary care pediatric network. They will facilitate communication and care coordination between the medical center and the child's medical home. Each center will initially address diabetes care and, in

addition, each center will focus on one or more other chronic conditions. Guidelines for referral and protocols for care management of pediatric patients with diabetes will be developed through consensus meetings with pediatric endocrinologists and refined in partnership with PCPs. Other evidence-based care management protocols will be developed, as well. These educational tools will enhance the ability of the PCP to evaluate pre-referral and actively participate in post-referral care. The North Carolina Medicaid Program and the state's Area Health Education Center will spread this information through their ongoing educational programs. Also, web-based guidelines will be available at each medical center.

A financial incentive pilot is also being implemented to support pediatric subspecialty telephone consultations. In this demonstration, physician calls for advice and referrals will be reimbursed based on the time and complexity of the phone consult. Initially, in 5 of the 6 medical centers, infectious disease consultations will be tracked and, in one center, gastroenterology consultations. Subspecialists will complete a billing form that outlines the chief complaint, reason for consultation, recommendation, outcome of consultation, and some abbreviated demographics to allow tracking in the Medicaid payment system. Reimbursement will be paid to the subspecialty providers' department when referrals for care outside the medical home are avoided. Expected outcomes from the financial incentive are reduced spending for specialist referrals and fewer emergency room visits and hospital admissions.

An evaluation of referrals, using a 3-way examination of decision-making and satisfaction is being conducted. First, PCPs are being asked about reasons for referrals. Second, families are being asked about their understanding of the reason for the referral and satisfaction with the referral. Third, the pediatric subspecialist is evaluating the appropriateness of the referral.

The long-term outcome targets of IMPACC are improved access to necessary pediatric subspecialty care in a timely and efficient manner, development of statewide evidence-based management approaches for chronic childhood conditions, referral guidelines for streamlined consultation, improved quality of care, reduced costs of care, and development of a model for medical home/medical center collaboration for the care of children with special needs in other states.

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Funding partners for this initiative include North Carolina Medicaid, Duke Endowment, Foundation for Health Care Improvement, Centers for Education and Research in Therapeutics, Area Health Education Center, and departments of pediatrics at all of the medical centers.

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## **2. INTERMOUNTAIN HEALTHCARE'S MENTAL HEALTH INTEGRATION PROGRAM**

Intermountain Healthcare (IHC), a large non-profit health system based in Salt Lake City, has established a mental health integration program that is in 11 of their 68 primary care practices, with further expansion underway. The aim of this team-based program is to achieve improvements in: 1) detection of mental health problems in primary care settings; 2) treatment of mental health disorders based on best practice guidelines; 3) improvement of clinical outcomes in terms of symptoms, severity, and functional status; 4) satisfaction of patients, providers, and employers; and 5) cost controls for patients, families, and for IHC utilization and operations.

Mental health integration is not just about depression, but is applicable to helping care for patients with any mental health condition. IHC developed a set of standardized tools for several mental health disorders to assist the PCP in gathering patient information and in risk stratification of severity and complexity, diagnosis, and care planning. Specifically, for patients with mild severity or complexity, the level of care is defined as "routine care," and it is provided by the PCP with a mental health care coordinator, as needed. The mental health care coordinator follows up with patients and families to provide education and improve treatment adherence. For patients with moderate severity or complexity, the level of care is defined as "collaborative care," and it is provided by the PCP using a mental health team (psychiatrist and mental health care coordinator) to assist in clarifying the diagnosis, prioritizing treatment options, and developing follow-up care. For patients with the highest severity or complexity, the level of care is defined as "consultation with or referral to mental health specialist," and the PCP uses the psychiatrist and mental health team to stabilize the patient, guide care, and follow-up with the mental health

care coordinator. A standardized set of tools for the PCP and the patient/family are available on IHC's website.

IHCs internal and external data systems support this mental health integration program. The internal data system includes a longitudinal electronic medical record with assessment, communication tools, and follow-up alerts; the external data system includes medical and prescription claim records, satisfaction and productivity survey results, and more. A mental health registry has been created that extracts information from these various data systems for ready use by the PCP and the mental health team. The data system allows IHC to measure changes in the detection rate, use of standard tools, medication retention rates, referral rates, clinical outcomes, satisfaction, and costs.

To support this change in clinical practice, IHC has done extensive training. PCPs and mid-level staff have been trained in the use of evidence-based tools to diagnose and follow patients with mental health conditions and also in the role of mental health staff who can provide evaluation, diagnosis, and therapy. They have also been educated about what is available for patients and families to assist with self management and education, including the availability of community resources and an IHC Mental Health Online Center. All staff have received training on compliance, family engagement as well as on the mental health care management function and evaluation. Training in the mental health integration process varies based on the PCP's ability and interest and the severity of the patient's condition.

The level of implementation of mental health integration in a practice is determined by the resources available to the practice. It is done in careful coordination with IHC's clinical, administrative, and operational staff. Implementation of the mental health integration model involves assigning a PCP "champion." A plan for the care management function is developed with the PCP along with identification of tools for use in diagnosis and follow-up and how they will be entered into the medical record (web, scanning, paper chart). Also, a communication plan is prepared which describes how all team members relate and communicate. Local community resources are assessed to determine how to engage them in the process and determine their role at each site. In addition, a plan for mental health evaluation, diagnosis, and therapy is developed along with a plan for mental health prescriptive practice and consultation on difficult cases. Finally, a plan for

ongoing education, tracking of patients, and evaluation is prepared.

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### **3. PACIFIC ASYNCHRONOUS TELEHEALTH (PATH)**

The Pacific Asynchronous TeleHealth (PATH) is an internet-based store and forward teleconsultation system designed to link military treatment facilities in remote locations of the West Pacific to pediatric subspecialists and, most recently, to adult specialists. The Pacific Telehealth and Technology Hui, Tripler Army Medical Center, and the Department of Veterans Affairs Pacific Island System (in Honolulu) operate PATH. The forerunner of PATH was the Electronic Children's Hospital of the Pacific, designed in 1999. Its success resulted in the expansion to all providers at Tripler Army Medical Center and 13 Department of Defense military treatment facilities in the West Pacific.

Store and forward telemedicine strategies have been successful because they are simple, low cost, and require minimal infrastructure. The only hardware necessary at the primary care location is a standard web browser and peripherals to capture images (digital camera, scanner, or video camera). Compared to real-time teleconsultation, the store and forward telemedicine strategies are less disruptive to physicians and patient schedules and require less technical and bandwidth support. Patient information is secured through a Secure Sockets Layer connection, and each session is encrypted from client browser to web server.

PCPs can consult with pediatric subspecialists during or after office hours by entering free text clinical information, images, and brief digital motion images. Once a PCP request is submitted, the pediatrician consult manager is notified, and he/she emails the appropriate subspecialist(s). The website assigns a number to each case and each consult has a separate page on the website. Dialogue between the PCP and the pediatric subspecialist becomes an electronic medical record. Each time a new comment or image is uploaded, an automatic email message is sent to every physician involved in the case. Oftentimes the consult manager seeks the opinion of a range of specialists for the same question, giving the PCP unprecedented access to expert opinions. At

each of the remote PCP sites, either a pediatrician or family physician is trained via telephone teleconference in the use of the teleconsultation system. In turn, these physicians are responsible for training others at the site.

In 2003, PATH expended its reach as part of a congressionally supported, community-based pediatrics collaborative with Tripler Army Medical Center, the University of Hawaii Department of Pediatrics, John A. Burns School of Medicine, and the Hawaii Primary Care Association. In a no-fee software licensing agreement, the PATH software application has been extended to Kapiolani Medical Center for Women and Children. This has enabled a teleconsult network to be established among neighbor island community health centers with pediatric subspecialists on the mainland.

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### **4. SHRINERS HOSPITALS**

Shriners Hospitals provide medical care to children up to age 18 with orthopedic conditions, spinal cord injuries, cleft lip and palate, and burns. Throughout the US, Canada, and Mexico, their pediatric specialty hospital network includes 19 orthopedic hospitals, 4 burn hospitals, and 3 spinal cord injury hospitals providing acute and rehabilitation services, which together serve almost 125,000 children. These 22 hospitals are centrally administered from Shriners International Headquarters in Tampa, Florida. Eligibility for care is based solely on whether or not the child can benefit from Shriners specialty care, not on the basis of financial need. All care is provided at no charge to patients and families, and insurance is not billed. The absence of any financial barriers to care allows clinicians to create and implement a plan of care without involvement in insurance or managed care administrative processes.

The Shriners network of hospitals has several unique attributes that contribute to the delivery of their organized system of specialty pediatric surgical and rehabilitative services. The types of conditions treated and care provided at Shriners Hospitals are well-defined, allowing them to emphasize specific

areas of expertise. In the US, their orthopedic hospitals are located in 15 states, extending services to large, defined geographic areas. The Shriners spinal cord injury rehabilitation units are located in Chicago, Sacramento, and Philadelphia hospitals, and the Shriners burn hospitals are located in Galveston, Boston, Cincinnati, and Sacramento. Importantly, there are multiple access methods for physicians and families, including a national toll-free referral line. In addition, Shriners conducts screening clinics throughout the country at which Shriners physicians and staff regularly evaluate children to determine if they would benefit from Shriners-sponsored pediatric care.

Significant investments have been made by Shriners to ensure the provision of “world class medical care,” including basic and clinical research, medical education, and quality improvement studies. Shriners clinician/scientists conduct research in a wide range of conditions from metabolic bone diseases to molecular studies of burn injuries. Current basic and clinical research projects include studies on cultured skin for more effective burn treatment as well as best practices for maintaining physical and emotional wellness in children and young adults with spinal cord disorders. Shriners also has been actively involved in training pediatric residents and fellows in all of the specialty areas for which the system provides care. In addition, Shriners provides extensive support for interactive learning among clinical staff at each of its hospitals. This innovative online educational system is used to provide ongoing educational programs for all of the health professionals in the system. Corporate leadership has been very involved in quality improvement, including developing a common set of quality measures, having a performance improvement director at each hospital, funding outcomes research, and supporting longitudinal studies.

Communication and co-management with the child’s primary care provider is also a top priority. Specifically, Shriners is focusing on providing timely communication regarding their patients’ admission to the hospital, treatment plan, and follow-up, in addition to providing PCPs with educational materials on common pediatric orthopedic, burn, and spinal cord injuries as well as follow-up procedures. In Chicago, Shriners is piloting a co-management project where the specialists and PCPs come together to define their specific roles in patient care. This project, conducted in collaboration with the University of Massachusetts Medical School (Worcester) and the American Academy of Pediatrics, began with a series of telephone

interviews with Shriners’ staff and specialist consultants and PCPs to examine referral practices, coordination of care between referring PCPs and specialists, divisions of responsibility between providers, and ideas for improvement. Several system improvements are being tested, including telephone triage systems to facilitate communication from PCP to specialist and a directory of Shriners’ physicians, services, and application processes for PCPs; the identification and contact of the child’s PCP from the time a child is accepted for treatment; encouragement of information exchange with the child’s PCP from the time a child is accepted; sending of automatic letters to the PCP when the child is evaluated or discharged; and education of community PCPs about the conditions for which children are treated at Shriners. This pilot is being evaluated and will be disseminated to other Shriners hospitals as part of its quality improvement program with the aim of optimizing the effectiveness of the medical home for children and youth with special health care needs.

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## 5. SELECTED CHILDREN’S HOSPITALS

### A. CHILDREN’S HOSPITAL AT DARTMOUTH

The Children’s Hospital at Dartmouth (CHaD) is part of the Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire. In addition to CHaD’s broad array of specialized, multidisciplinary clinical services, it also offers several special programs to extend access to broader geographic areas and facilitate collaboration with community physicians.

One such program, the Regional Program for Women’s and Children’s Health, has a long history of working with physicians and nurses throughout New Hampshire and eastern Vermont. It offers 1) transport conferences, where CHaD subspecialists travel at least annually to all community hospitals and discuss maternal-fetal, neonatal, and pediatric case reviews of patients shared between the community hospitals and CHaD, emphasizing quality improvement and clinical collaboration; 2)

critical care conferences to ensure regional providers maintain their skills and learn about the latest technologies and therapies; 3) subspecialty clinical conferences where CHaD providers educate PCPs on various pediatric subspecialty topics to increase their comfort level with clinical assessment and management of the increasingly complex cases they see; and 4) regional leadership with Vermont's Prenatal Network and New Hampshire's state health department on task forces for newborn screening and maternal addictions. CHaD's Regional Program is also developing a birth condition registry for New Hampshire.

CHaD operates a Physician Connection Line, which provides physicians with a single point of entry not only to schedule appointments but also to consult directly with on-call physicians and obtain the status of patient care and clinical information. Communication guidelines are described online, defining the communication mode and time frame for each type of inpatient/outpatient service. For outpatients, specific communication methods are defined for an initial consultation visit, evaluation with immediate admission, follow-up visit, secondary referral to another Dartmouth physician, outpatient procedure, patient expresses dissatisfaction with PCP/referring physician, and emergency room visits (unstable). Outpatient referral forms are available online that elicit what management of care is needed, the child's presenting symptoms/diagnosis, and the urgency of the request.

A Steering Committee on Referral Relationships provides a more formal connection with referring physicians and their issues and ideas. The goals of the committee include discussing strategies for communication and practice standards, providing guidance for communication and practice standards, and recommending system solutions for referring physician problems.

A free Affiliate Information System (AIS) is available for physicians to access the electronic medical records of patients they refer to Dartmouth. Physicians are also provided with an e-mail account and access to on-line reference materials such as Ovid (access to Medline and other indices) and Clinical Pharmacology On-line. Individual or small group teaching is available and phone or e-mail help is available when problems are encountered.

Another special program is the Center for Shared Decision Making, which helps families make difficult health care decisions. The Center's services include one-on-one counseling for any medical

condition; a Decision Aid Library of helpful video and audio tapes, booklets, and websites; and a Healthcare Decision Guide worksheet to help families work through difficult decisions.

CHaD also operates the Boyle Community Pediatrics Program, which provides a range of services to families and professionals. Among these is the CHaD Family Advisory Board, where parents and CHaD leadership partner in policy, program development, and delivery of care.

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## **B. CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER**

Cincinnati Children's Hospital Medical Center (CCHMC) is a large and growing pediatric facility that serves children in Ohio and parts of Indiana and Kentucky. To extend the reach of pediatric subspecialty care, CCHMC has established affiliate relations with 2 regional hospitals in Ohio and one in Indiana and also with the Buffalo (NY) Women and Children's Hospital. More hospital affiliations are planned. Through joint on-site staffing, teleconferencing, and educational support, effective linkages are made with each hospital. Careful joint planning with the leadership of both institutions is necessary to define what transitional and permanent clinical and operational strategies make best sense, with the aim of strengthening the affiliate hospitals and ensuring that only those pediatric patients needing advanced treatment are referred to Cincinnati.

In addition to these affiliate arrangements, CCHMC has a network of pediatric outpatient service facilities to improve access to a wider variety of specialty services. It also operates The Diagnostic Clinic to assist PCPs with consultations or second opinions. The clinic also helps PCPs in managing complex problems or difficult to diagnose illnesses, including mental health or learning problems. Within 24 hours of the patient's visit, the referring physician will be called and within a week the PCP will receive a written report.

To facilitate timely pediatric subspecialty communication and consultation support to PCPs, CCHMC operates a Physician Priority Link (PPL). Via the PPL system, within 2 minutes, an on-call pediatric subspecialist is available to answer and

address PCP questions and needs. In addition, electronic clinical portals for patients, families and providers have been designed to improve the quality of patient care. Each portal is a secure website and includes accurate, up-to-date medical record information. There is also a "Question and Answer" section, which is a way for patients/families to ask non-urgent questions of doctors, nurses, and other team members. Portals are currently available for children with diabetes, cystic fibrosis, juvenile rheumatoid arthritis, and liver transplants.

CCHMC has recently established the Center for Health Care Quality, which provides education in quality improvement methods, research that integrates quality improvement with clinical and public health practice, and support to health care professionals in designing and testing innovative healthcare approaches. Among the quality projects underway is the Cincinnati Pediatric Research Group (CPRG), a regional practice-based research network of more than 40 child health professionals in more than 25 practices. The CPRG, part of a larger practice-based research network of Ohio-based pediatric practices, facilitates collaborative research and information sharing. ADD/ADHD, asthma, cystic fibrosis, otitis media, obesity, domestic violence, maternal depression and preparedness for influenza outbreak are among the areas that collaborative efforts are underway.

CCHMC was the only pediatric organization to receive the Robert Wood Johnson Foundation's Pursuing Perfection grant. As a result of this grant, which was designed to improve quality, safety, and efficiency of care, significant improvements were made related to youth and family-centered care, admission rates, appointment wait times, and discharge planning. Improvement teams are organized around strategic priorities which link to system level measures. These measures are reported to the board quarterly via an organizational scorecard. Strategic priorities include access to care, reducing delays across the system, patient safety, clinical excellence (evidence based care and chronic care), reducing hassles for care providers, team well being, and patient centered care. More than 50% of subspecialty programs have met CCHMC's target of 3<sup>rd</sup> next available new appointments within 10 calendar days as a result of redesign of ambulatory case scheduling practices.

To continuously improve outpatient care, each week 50 randomly selected families participate in a telephone survey about the care their children received. Questions are asked about appointment scheduling, wait times, physician listening skills,

respect and dignity of the child and caregiver, family involvement in decisions, understanding of answers to questions, and overall outpatient care rating. The results of these patient satisfaction ratings are reported for each quarter on the CCHMC website. Also posted on their website are other institution-specific quality measures. In addition to these hospital-based and multi-organizational collaborative improvement efforts, CCHMC Center for Health Care Quality is designing, with the American Board of Medical Subspecialist, a web-based safety education and quality improvement module for certified physicians in all pediatric specialties.

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### C. CHILDREN'S HOSPITAL, DENVER

The Children's Hospital (TCH), Denver, has a network of care that extends beyond the main hospital to children throughout Colorado, Montana, and Wyoming. Five regional clinics serve as remote sites for pediatric specialty care and 4 regional centers offer pediatric rehabilitation and therapies. Committed to working collaboratively on behalf of children with special needs, TCH has established partnerships with more than 10 other health care institutions. Most recently, an affiliation was established with a Colorado Springs hospital enabling their hiring of new pediatric subspecialists and increasing the number of specialty clinics. To identify additional opportunities for extending the geographic reach of pediatric subspecialists, a needs analysis is underway with community physicians.

For more than 10 years, TCH has provided short-term, temporary coverage to replace physicians in rural areas of Colorado and Wyoming who must be temporarily absent from their practices for reasons such as vacation, continuing education, or illness. The program, called Locum Tenens Service, has served about two-thirds of all pediatric practices in rural Colorado and Wyoming. It involves an orientation process that includes 1) verbal, onsite-orientation following written orientation guidelines, 2) a resource list filled out by the requesting pediatrician before the date of locum tenens coverage and used by the locum tenens pediatrician as a guide to important office and community resources; and 3) a list of complicated patients who are likely to be seen during the locum tenens period, with guidelines for their treatment. The hospital charges the requesting practice an amount equal to

the net income derived from the locum tenens coverage. This service has been shown to be cost effective for the private practitioners and the academic medical service and improves collaboration between community pediatricians and the academic institution.

TCH offers a mini-sabbatical program to community pediatricians. As a result of a new grant program, a week-long training opportunity is offered at TCH for 5 pediatricians per year from rural or small practices. At no cost, pediatricians in the Department of Pediatrics cover the community pediatric practice while the pediatrician obtains a self-directed learning experience with various specialties and programs.

The Physician Relations Program at TCH is responsible for many activities to facilitate communication and coordination with PCPs. One such initiative is the Lunch and Learn Program, a series of lunchtime presentations given by pediatric medical and surgical subspecialists. In addition, ongoing lectures and educational programs are also arranged throughout Colorado and Wyoming. Also available is a web-based Children's Link, which provides PCPs an opportunity to ask clinical questions and obtain answers from pediatric experts. PCPs can also access downloadable information, resources, and case-based training modules on all aspects of pediatric care. In addition, the hospital operates One Call for referring PCPs. Within 2 minutes, consultation will be provided for difficult diagnoses or plans for admitting a patient will be discussed; more than 4,000 calls are fielded each month. General inquiries are routed to the Diagnostic Dilemma Team, a rotating group of on-call general pediatricians.

Looking forward, TCH has a new effort underway at the hospital and its city clinics to facilitate communication using a fully integrated electronic medical record. The hospital plans to use Epic software to share electronic medical records between the hospital and community-based providers throughout the 3-state area.

In addition to partnerships between hospitals and community pediatric practices, TCH has established both a Family Advisory Council and a Youth Advisory Council to ensure families receive comprehensive, sensitive, and inclusive services. The Youth Advisory Council has joined with the Quality Performance Department to develop a patient satisfaction survey. It is also involved in providing feedback and suggestions on hospital programs and policies; advises on the programs for

children, teens, and siblings; prepares an annual report; assists in environmental design projects; and participates in hospital meetings and special events.

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## **6. SELECTED STATE TITLE V PROGRAMS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

### **A. FLORIDA CHILDREN'S MEDICAL SERVICES**

Florida's Title V Program, Children's Medical Services (CMS), operates a unique statewide managed system of care that links community-based primary care with multidisciplinary, regional, and tertiary care. The CMS managed care network serves a broad population of Medicaid and SCHIP-insured children with congenital, genetic, chronic, or catastrophic conditions, whose family incomes are below 200% of the federal poverty level -- almost 50,000 children. CMS offers the Medicaid benefit package and other medically necessary services, such as genetic testing, genetic and nutritional counseling, and parent support. CMS also operates a Primary Care Program for uninsured children with special needs, working closely with county public health units. Preventive and acute care in addition to subspecialty services and care coordination services are provided. More than 5,000 physicians are participating in the CMS network - almost half of whom are PCPs and the other half are pediatric subspecialists, as well as 94 hospitals.

Throughout the state, there are 22 local area offices each with a team of trained nursing, social work professionals, and support staff who coordinate primary and specialty care services with the family. For medically complex children receiving high-cost, long-term medical services, CMS has established 17 Children's Multidisciplinary Assessment Teams (CMAT). The CMAT was originally developed to make medical necessity recommendations to the Medicaid agency concerning certain high cost or complex services. CMAT develops treatment plans and recommendations for services on an ongoing basis. The treatment plans and recommendations help in minimizing patient wait times for specialty care and also the use of emergency systems in non-emergent situations. Each medically complex child who

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requires certain services (e.g., skilled nursing care) is assigned a CMAT team of professionals including a physician, registered nurse, and social worker, as well as appropriate representatives from CMS, Medicaid, the Family Safety Program, the Early Intervention Program, and the Developmental Disabilities Program. The team works collaboratively to establish an individualized care program encompassing a detailed nursing assessment and psychosocial assessment along with treatment recommendations. Family member and legal guardians form an integral part of each child's CMAT team, and teams are charged with making consensus-based decisions regarding children's particular services and levels of care.

Florida's Title V Program has several telehealth initiatives underway. One of them, called the Florida Initiative in Telehealth and Education (FITE) for children with diabetes. Families and children from the Daytona Beach area are able to receive real-time consultations with subspecialists in Gainesville, saving several hours of travel time. Between consultations, families may access web-based animated education that can answer questions about diabetes care. This service has been highly effective in reaching families in remote areas in earlier stages of diabetes and reducing the need for acute or emergency care.

Another telehealth effort is operated by the CMS Genetics Program, which provides genetic evaluation, diagnosis, and counseling for children with or at risk for developing genetic disorders. Using 2-way interactive video conferencing, the project enables pediatric geneticists at the University of Florida to diagnose infants born at hospitals in remote and underserved areas of northern Florida that lack access to genetic services. This project has succeeded in reducing wait times for genetic screening considerably, from an average of one year to an average of 2 months, as well as in providing continuity of care for patients in the Florida Panhandle. Other telehealth initiatives include dermatology, cardiology, and behavioral health.

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## **B. IOWA CHILD HEALTH SPECIALTY CLINICS**

Iowa's Title V Program, Child Health Specialty Clinics (CHSC), is headquartered at the University of Iowa's Department of Pediatrics. Benefits of CHSC's relationship with the University include access to information technology, public policy expertise, and research design and program evaluation consultation. Continuing education programming occurs on-site in Iowa City and at community locations via a statewide fiberoptic communication network and internet webcam connections. Health professionals and public health students participate in direct care specialty clinics and care coordination services.

CHSC annually serves about 5,600 children and adolescents with chronic physical, developmental, and behavioral conditions. Clinical evaluation, care coordination, and family support services are provided throughout the state at 13 regional centers, including CHSC's Iowa City office. Housed within each regional center are the Integrated Evaluation and Planning Clinic (IEPC) and the Birth to Five Program (B-5). These 2 programs provide evaluations and make recommendations for children with developmental, behavioral, and emotional problems, including children exposed to drugs during pregnancy or in their home environments, children who have been abused or neglected, and children in foster care.

As a major community-based resource, the IEPC assures family access to child psychiatry consultations (via telehealth communication) and intensive care coordination. IEPC multidisciplinary staffing includes some or all of the following: an advanced registered nurse practitioner or nurse clinician, a contracted medical consultant, an Area Education Agency psychologist and/or speech and hearing professional, a contracted or Department of Human Services social worker, and a parent consultant. The IEPC also provides ongoing support and consultation to PCPs caring for these special-needs children.

Each community-based B-5 program is staffed by an advanced registered nurse practitioner and is a component of Iowa's early childhood service system, especially through partnership with Iowa's IDEA Part C Program. The B-5 Program provides developmental screening and assessment for children with early drug exposure, a history of prematurity, or various medical syndromes. Enrollment in early intervention services, care coordination, and family support are the basic B-5

Program follow-up services. Nutrition consultation is arranged when indicated.

CHSC has a community-based Parent Consultant Network (PCN). Paid parent consultants provide problem-solving and peer support for other parents and families. A parent of a child with special health care needs serves as leader of the PCN and also spearheads data collection, training, and family advocacy efforts.

In partnership with the Children's Hospital of Iowa, CHSC developed the Continuity of Care Program for about 400 children with highly complex conditions. This is a care coordination service designed to improve efficiency, continuity, and discharge procedures for hospital-based inpatient and outpatient visits. An advanced registered nurse practitioner acts as the single point of contact for the family and the community-based PCP. The team orchestrates the child's hospital and discharge experience, resulting in reductions in lengths of stay and improved family and provider satisfaction.

With funding from Magellan Behavioral Healthcare of Iowa, CHSC uses telehealth communication technology to offer PCPs and patients remote access to psychiatric consultation, family counseling, and interpreter services. Telehealth is also being used for other pediatric specialty services, including genetic consultation and feeding evaluations.

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### **C. UTAH CHILDREN WITH SPECIAL HEALTH CARE NEEDS PROGRAM**

Utah's Title V Program, the Bureau of Children with Special Health Care Needs (CSHCN) has several programs underway to extend access to pediatric subspecialty care and to enhance the capacity of the medical home to better serve children with special needs. CSHCN provides a statewide system of rural community-based care for about 3,400 special-needs children. These traveling multi-specialty clinics and community-based satellite offices are based in 10 sites statewide, and most are provided in collaboration with local health departments. Local community health nurses play a pivotal role, working closely with PCPs and specialists to coordinate care in rural areas. CSHCN

also contracts with the Utah chapter of Family Voices to provide assistance with referrals for families.

Additional specialty clinics are available through CSHCN staff and supplemented by a contractual arrangement with Primary Children's Medical Center in Salt Lake City. Programs supported by Utah's Title V program are the Child Development Clinic, The ABLE Clinic, and the Neonatal Follow-up Clinic. The Child Development Clinic offers consultative and case management services for children up to 5 years of age; the ABLE Clinic also provides consultative and care management services for school-aged children; and the Neonatal Follow-up Clinic provides periodic screening of sensory, neurodevelopment, and general health to very low birthweight and prematurely born babies statewide. A summary report is shared with the child's primary physician, early intervention service, and respective newborn intensive care unit.

Care coordination is another service offered by the CSHCN program for 2 targeted populations. Through the Fostering Health Children Program, children in foster care receive nurse consultation in collaboration with Utah's Human Service staff. Through a contract with the Utah Medicaid Technology Dependent Care/Travis C. Waiver Program, nurse care coordination is provided for children who are at home and dependent on specific types of technology.

Utah's CSHCN Program directs the Collaborative Medical Home/Integrated Services Project with the University of Utah Department of Pediatrics, Utah State University, Medicaid, and Utah Family Voices. Working with medical home sites, the project has created the comprehensive web-based MedHome Portal, which includes information, tools, and resources to aid PCPs in caring for children with special needs. For each chronic condition reviewed, the module contents include a summary description, prevalence, and morbidity; clinical assessment information, including severity classifications and referral situations; treatment components, learning issues, and other related concerns; helpful articles; questions and answers; ICD-9 coding; practice guidelines; practice tools; patient education; pediatric subspecialty services and contact information; and community resources.

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## 7. EMERGENCY MEDICAL SERVICES FOR CHILDREN PROGRAM

The Emergency Medical Services for Children (EMSC) Program was established in 1984 to ensure that ill and injured children and adolescents receive state-of-the-art emergency care, including primary prevention, prehospital care, emergency care, acute care, and rehabilitation. The program is administered by the federal Maternal and Child Health Bureau in collaboration with the Department of Transportation's National Highway Traffic Safety Administration. The EMSC Program provides grants to states to improve existing systems of pediatric emergency care and to develop and evaluate improved procedures for treating children. Since the program's establishment, funding has supported: 1) state needs assessment; 2) implementation grants to initiate the development of a special pediatric focus within states' EMS systems; 3) state partnership grants to sustain system changes, including public education activities; and 4) targeted issue grants to help states develop and evaluate model products, programs, or strategies with regional or national significance.

The EMSC program funds 2 national resource centers and a national research network. The EMSC National Resource Center (NRC), based at Children's National Medical Center in Washington, DC, provides technical assistance, referral services, and networking for members of the EMSC community, and promotes public understanding of EMSC issues. NRC also provides leadership in strategic planning, coalition building, media relations, funding, injury prevention, public policy, quality improvement, and research. The National EMSC Data Analysis Resource Center (NEDARC), based at the University of Utah School of Medicine in Salt Lake City, provides technical assistance in data collection for EMS agencies and EMSC projects. NEDARC assists in the development of state and national EMS data systems, education and training of EMSC personnel in data collection, analysis, and related areas, and provides administrative and research-related support for federal EMSC program activities. The EMSC program, in collaboration with the Maternal and Child Health Research Program, also created the Pediatric Emergency Care Applied

Research Network (PECARN), which consists of a coordinating data center, 4 research node centers, and 20 hospital emergency department affiliates. PECARN promotes multi-center studies, supports research collaboration, and encourages the exchange of information.

Three core performance measures are used to continuously monitor the effectiveness of the EMSC Program State Partnership grants. These measures assess 1) the degree to which the state has ensured operational capacity to provide pediatric emergency care (including specific elements of operational capacity), 2) the adoption of requirements for pediatric emergency education for the recertification of paramedics, and (3) the degree to which the state has established permanence of EMSC in the state's EMS system.

A central goal of the EMSC program is the integration of EMSC into states' EMS systems. One state making significant efforts in this area is Maryland. Maryland's Emergency Medical System is a coordinated statewide network that includes volunteer and career EMS providers, medical and nursing personnel, communications, transportation systems, trauma and specialty care centers and emergency departments. Overseeing and coordinating the state's EMS system is the Maryland Institute for Emergency Medical Services Systems. Its responsibilities include operating a statewide communications system, designating trauma and specialty centers, licensing and regulating commercial ambulance services, and participating in EMS-related public education and prevention programs. Maryland also has established a regional infrastructure, dividing the state into 5 regions, each with its own advisory council. In 2 of the regions, providers work cooperatively with other states' EMS systems and military hospitals.

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Federal EMSC Program: [www.mchb.hrsa.gov/emsc](http://www.mchb.hrsa.gov/emsc);

Pediatric Emergency Care Applied Research Network: [www.pecarn.org](http://www.pecarn.org);

National EMSC Data Analysis Resource Center: [www.nedarc.org](http://www.nedarc.org);

Maryland Emergency Medical Services for Children: [www.miemss.umaryland.edu/EMSCwww/HomeEMSC.htm](http://www.miemss.umaryland.edu/EMSCwww/HomeEMSC.htm)

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## 8. REGIONAL NETWORKS OF COMPREHENSIVE HEMOPHILIA DIAGNOSTIC AND TREATMENT CENTERS

Developed as a model of best practices for the delivery of integrated, multi-disciplinary, comprehensive care for complex chronic conditions, the federal Maternal and Child Health Bureau (MCHB) established the National Hemophilia Program in 1975 to serve children and adults with hemophilia. Twelve regional grants currently support a network of about 130 hemophilia treatment centers (HTCs) throughout the U.S. and its territories. These centers also serve individuals with von Willebrand disease and other bleeding disorders.

Funds under this program are used to support regional planning, collaboration among HTCs within each region, comprehensive care teams, outreach to underserved individuals with bleeding disorders, and promotion of family-centered care. HTCs are typically located in academic medical settings and children's hospitals.

The regional networks of HTCs operate through a common set of program requirements. Specifically, each region has a designated program director and coordinator and each participating HTC must enter into a written agreement with its regional grantee. The regional grantee and each HTC are responsible for performing ongoing needs assessments, identifying the numbers and types of individuals needing HTC services as well as the special problems and barriers facing the target population. The grantee and each HTC are also responsible for performing outreach to identify underserved groups not being cared for by HTCs and for providing education to consumers, providers, and other organizations. Further, the regional grantee is responsible for coordinating referrals and linkages and offering training and technical assistance to affiliated centers. In addition, regional centers have responsibility for program monitoring and evaluation of the HTCs in their region. Among the reporting requirements, HTCs must report on the number of patients having a PCP and the number of patients whose PCP was sent a summary of the patient's HTC visit.

To facilitate these efforts, each regional grantee forms a regional executive committee comprised of multidisciplinary professionals from among the HTCs within the region plus consumers representing at least 20% of the group. The regional grantee also conducts an annual meeting attended by all of the HTCs within the region.

Each HTC adheres to a uniform set of standards and criteria for the care of children and adults with bleeding disorders, developed and periodically updated by the National Hemophilia Foundation. In addition, care is provided by a "core team," consisting of a physician, nurse, social worker, and physical therapist; other qualified professionals are made available as needed. The core team coordinates the patient's treatment with the patient's PCP, including ongoing consultation.

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## 9. REGIONAL GENETIC SERVICE AND NEWBORN SCREENING COLLABORATIVE GROUPS

A system of Regional Genetic Services and Newborn Screening Groups and a National Coordinating Center were established by the federal Maternal and Child Health Bureau in 2004 to address the shortage and maldistribution of genetic resources throughout the country. The main goal of the program is to bring services closer to local communities. The national center, based at the American College of Medical Genetics, supports 7 regional centers by providing the infrastructure, coordination, technical assistance, and resources necessary to avoid duplication of efforts and allow the regions to focus on their unique areas of need.

The national center is actively involved in the development of clinical genetics and newborn screening management guidelines for specialists and primary care providers. A series of newborn screening fact sheets and confirmatory algorithms have been prepared for PCPs that describe the short-term actions a health professional should follow in communicating with the family and in determining the appropriate steps in the follow-up of an infant that has screened positive. The algorithm details the basic steps involved in determining the final diagnosis in the infant. Corresponding links to experts and resource materials are also provided. In addition, each of the regional centers is being surveyed to determine the management guidelines most needed for the delivery of genetic services. These will be developed collaboratively with the American College of Medical Genetics and other key stakeholders. Other activities of the national center include efforts to improve the collection and analysis of screening and short- and long-term treatment and follow-up data; education and communication with

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consumer groups, professional organizations, and government agencies; technical assistance to regional centers in the areas of telemedicine, legal issues, and federal and state policies; and dissemination of best practices.

Each of the 7 collaborative groups serves as the center in their respective regions for genetic counseling, testing, information, education, and training. Among the important functions of these regional groups are assessing needs using epidemiologic methods, focus groups, and surveys; standardizing and expanding newborn screening programs; enhancing data sharing and integration; improving education and training to increase genetic literacy; developing partnerships with genetic and newborn screening specialty care providers, public health and Title V programs, pediatric and family practice providers, insurers, and family advocacy groups; and encouraging improvements in reimbursement of genetic services and support for regional infrastructure needs.

Developing clinical practice models is another activity of the regional groups. Several promising strategies have been identified for addressing gaps in genetic services and geographic maldistribution, including telemedicine and telephone genetic consultation in rural communities, interstate satellites, interstate licensing, and outstationed genetics clinics. Efforts are ongoing to assess outcomes, satisfaction, time, and costs associated with these different clinical practice models. Several educational efforts also are ongoing, including web-assisted training and conference calls, to connect PCPs with state-of-the-art condition-specific diagnostic and management information. The Western States Regional Genetics Collaborative, for example, contributed information for a Genetic Tools website which provides background information, teaching cases, and links to other resources to facilitate teaching about genetics in primary care settings.

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## KEY FEATURES

There are several key elements that were commonly found in the promising approaches featured in this report. These are organized according to the chronic care framework, which has been widely used to promote improvements in the care of children and adults with chronic conditions. Purchasers, policymakers, and health care executives are encouraged to consider these features in their efforts to improve timely access to pediatric subspecialty care and strengthen coordination between primary and specialty pediatric care.

### 1. Community

- Assessment of pediatric specialty shortages and referral and coordination difficulties
- Knowledge and involvement of pertinent community resources

### 2. Health Systems

- Commitment of senior leadership to clinical improvements and team-based approaches between pediatric specialists, PCPs, and other support staff, with agreement on aims and measures for tracking progress
- Centralization of responsibilities for planning, evaluation, and quality improvement
- Identification of pediatric specialists and PCP “champions” and support from local medical leadership
- Development of an economic model that adequately supports necessary infrastructure and rewards pediatric specialists for extending access and also rewards both pediatric specialists and PCPs for collaborative care
- Support from public and private purchasers, plans, public agencies, and foundations in adopting a new economic model

### 3. Delivery System Design

- Involvement of families in planning, implementation, and evaluation

- Specification of care processes for routine PCP care of chronic conditions, collaborative care, referral, and follow-up care
- Development of communication plan that defines how all team members communicate and relate
- Development of performance improvement plan that incorporates measures related to detection, treatment, clinical outcomes, satisfaction, and costs

### 4. Care Partnership Support

- Assignment of responsibilities for care management/care coordination functions at the primary and specialty care sites related to child/family education, communication, and follow-up
- Availability of child and family care management tools

### 5. Decision Support

- Integration of evidence-based guidelines into practice systems
- Availability of internal and external data systems to support practice improvements
- Training of all staff in the use of evidence-based tools, care processes, communication mechanisms, care coordination functions, respective roles of pediatric specialists and PCPs, community resources, and evaluation

### 6. Clinical Information Systems

- Development of fail-safe interactive methods for communication between pediatric specialists and PCPs, including telephone triage systems; automatic information exchange for evaluation, treatment planning, and follow-up; and e-medicine and telemedicine
- Availability of information system (eg, registry) that identifies, tracks, and evaluates patients’ progress