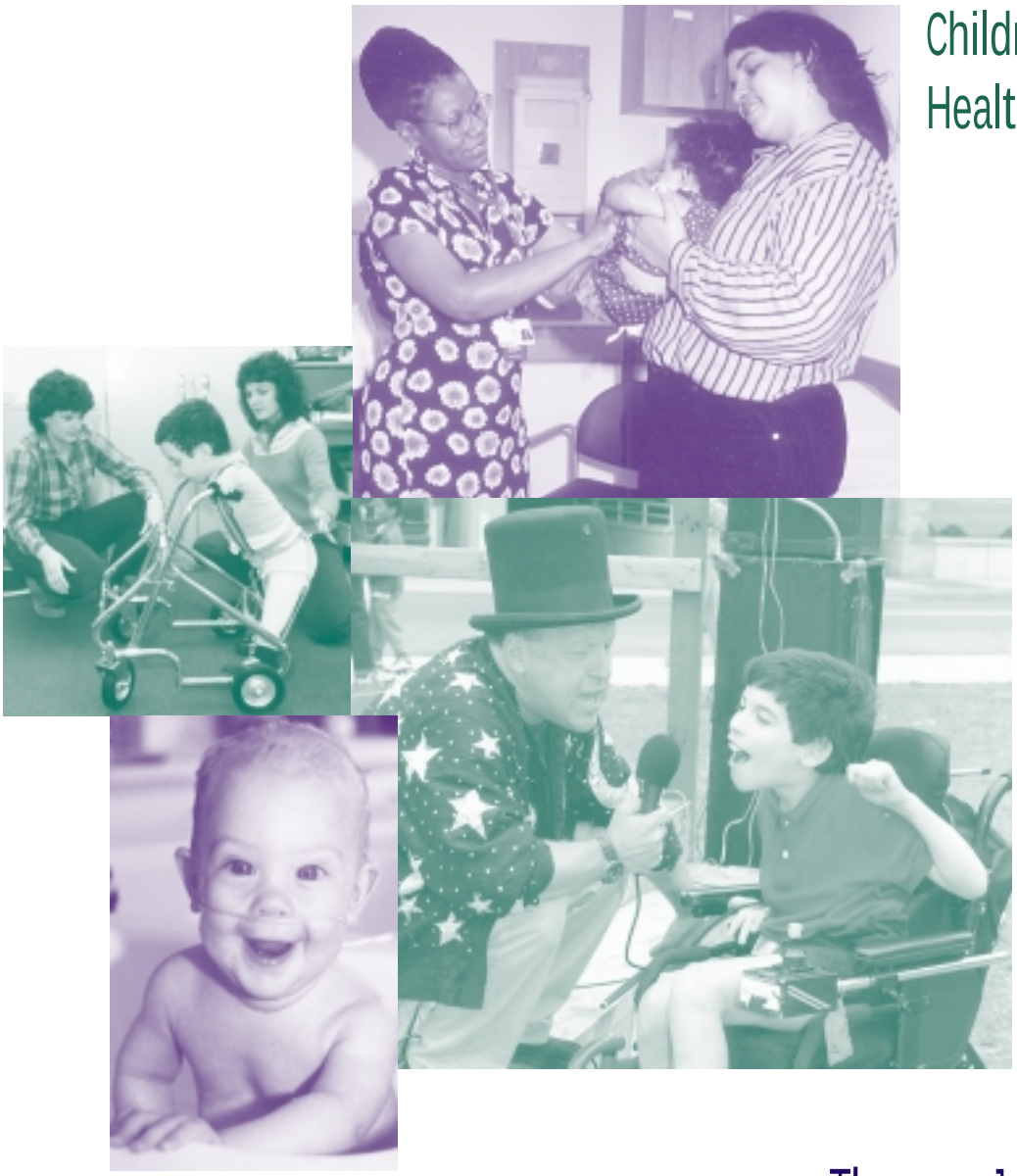
Practicing Comprehensive Care

A Physician's Operations Manual for Implementing a Medical Home for Children with Special Health Care Needs



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Children With Special Health Care Needs

"Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al., 1998)."

Table of Contents

“Peace of mind and a sense of belonging. That is what PACC has given me.”

—Mother of twins at East Boston Neighborhood Health Center

Introduction

Community-based physicians open their office doors to the children and families who live near them. As generalists, pediatricians are the first line of defense for all comers - children who are well, children who are acutely ill and children who have complex chronic conditions. In recent years, the challenges of providing excellent care to the latter group of children have increased. On the one hand, sophisticated technologies have been developed to address many biologic conditions. On the other hand, societal and economic factors have converged to make some common sense aspects of care exceedingly frustrating.

Over the past five years, a group of dedicated community-based physicians has been working together to find “can do” solutions to the problems presented by the current “non-system” of health care that threatens to confound our best efforts. This group of physicians, known as the Pediatric Alliance for Coordinated Care, has tried out a series of interventions that have helped each of its members organize their practices in a way that allows them to concentrate on the concerns parents bring to them. This booklet presents the ideas and the solutions they have devised. It is offered in the hopes that others will find the interventions helpful in our mission of caring for children and families.

photo courtesy of MO-PEDS project

Overview of the Medical Home Concept and the Pediatric Alliance for Coordinated Care

The medical home concept is a promising approach to meeting the challenges of service delivery through care that is "accessible, continuous, comprehensive, family-centered, coordinated, culturally competent and compassionate." (American Academy of Pediatrics, 1992). The concept recognizes that families and professionals working together create the best practices for improving children's care.

This booklet will:

- Describe the Pediatric Alliance for Coordinated Care program, a medical home initiative
- Outline the medical home concept and its relevance to physicians
- Describe how to organize and maintain a medical home
- Provide strategies for appropriate reimbursement

Caring for children with special health care needs (CSHCN) can be professionally and personally rewarding, but it requires spending more time with patients, providing more intensive services, counseling, and record keeping, and performing more evaluation and management (E/M) services. The medical home strategies in this booklet can help streamline the complexities of care for these children and offer ways to maximize reimbursement for services performed.

The Pediatric Alliance for Coordinated Care (PACC) program is a medical home demonstration project in Boston, Massachusetts. PACC was developed to better equip pediatric practices with the supports they need to care for this patient population in the community. PACC staff sought to:

1) Design a strategy
2) Pilot it for two years
3) Disseminate the concept and lessons learned to a broader audience

PACC is funded primarily by:

- The Robert Wood Johnson Foundation
- Health Resources and Services Administration's Maternal and Child Health Bureau
- Children's Hospital, Boston
- The Dyson Foundation

The late Marilynn Haynie, M.D., founded the project in 1995 while at Children's Hospital, in collaboration with a group of community physicians, to improve the care experience for families and CSHCN upon discharge from the hospital. Dr. Haynie and others saw first hand the frustrations and dilemmas families often face to ensure continuity of care, access to ancillary services such as home health care, and coordination of information among clinicians, families, and others involved in a child's ongoing care in the community.

The Pediatric Alliance for Coordinated Care Project is a consortium of providers, both primary care and specialists, who are working together to create an enhanced, integrated system of care for CSHCN. The Division of General Pediatrics at Children's Hospital, Boston provides coordination.

PACC's goals are:

- Improved care experience for families and practitioners
- Improved health outcomes
- Increased family satisfaction with care
- Reduced family caregiver stress
- Delineation of added expenses and/or savings attributed to the care of CSHCN

PACC Pediatric Sites

Each site has one lead physician primarily responsible for the PACC initiative.

- Children's Medical Office of North Andover, P.C.
- East Boston Neighborhood Health Center
- Hyde Park Pediatrics, P.C., Boston
- Longwood Pediatrics, LLP, Boston
- Martha Eliot Health Center, Boston
- Pediatric Associates Inc., of Brockton

PACC Patient Profile

- 154 children enrolled in six sites, averaging 25 per site
- Average age at enrollment: 6.2 years, ranging from one month to 26 years
- Most common primary diagnosis: prematurity
- Most common diagnostic categories: congenital anomalies and conditions originating in the perinatal period

Model Structure

PACC adds several features to routine primary care:

1) **The services of a designated pediatric nurse practitioner (PNP) employed by each site, specially trained by PACC in the care of CSHCN; key aspects include:**
   - Initial home visits to assess child's situation
   - Care coordination of medical and non-medical needs and resource assistance to families
   - Development of an individual health plan (IHP) for each child

2) **Family access to a trained parent volunteer who is familiar with the local community because of personal experiences caring for a CSHCN; this parent provides:**
   - Personal support to families
   - Resource guidance and tips to families and staff on helpful agencies, non-profits and other organizations
   - Special events and activities for children and parents

3) **Modifications of office routines to do a better job of incorporating the CSHCN population, including:**
   - Strategies for managing office visits for CSHCN within a busy practice
   - Office staff trainings and guidelines to serve families more compassionately and efficiently during a visit and on the telephone
   - Specialized on-call procedures to aid physician partners less familiar with the care of CSHCN

PACC physicians overwhelming report that the work of their nurse practitioners not only improves patient care but leads to significant increases in physician productivity. Nurse practitioners address and manage many issues for families so that the physician's time is most efficiently and cost-effectively used, not just for CSHCN but for typical patients as well.

"I have gained a lot of insight into what it means to care for a child with special needs at home . . . this important perspective helps the physician and me to set up doable action plans for each acute illness."

—Pediatric Nurse Practitioner at Longwood Pediatrics

SECTION 1

Getting Started In Your Practice

The following sections present concrete, tested suggestions for your medical home. There are many paths to pursue. Your needs, interests and resources will help determine which ones you follow. Remember that change does take time and that incremental steps can and will make a difference.

Assessing Your Personnel Needs

Some pediatric practices have sufficient staffing resources to implement a medical home, while others may need to consider hiring new staff. Begin by asking some key questions to help determine whether additional personnel are necessary.

1) Is more than 15% of your practice made up of CSHCN?
2) Are the tasks for these patients particularly time consuming (i.e., care coordination, non-patient contact time, letter writing and phone calls for durable medical equipment)?
3) Do typical appointments for CSHCN often take longer than ones for typical patients?
4) Does your current charting system make it difficult to find data and/or hinder the ability of your on-call partners to effectively serve these patients?
5) Is your schedule routinely set back on the days you see CSHCN?

Answering "yes" to any one of these questions may mean you need to hire additional staff, especially if your care coordination needs are great.

What Type of Care Coordinator Does Your Practice Need?

Think about the professional strengths your care coordinator requires.

Different types of professional staff offer different advantages. Do you want the person to focus on: 1) clinical interventions; and/or 2) care coordination; and/or 3) access to resources?

The advantages of employing a PNP include: billable office visits, ability to make home visits for urgent care, and prescription writing. RNs are a less costly choice but would have fewer clinical responsibilities. Social workers may be better

Where to Begin?

- Start by prioritizing the areas you feel are most important.
- Do you want to focus on enhancing your medical documentation?
- Do you need to set up a better safety net for your on-call partners?
- Would your office staff benefit now from a training on how to deal with the unique needs of CSHCN and their families?
- Are many families in serious need of enhanced care coordination?

Asking these types of questions can help you take the next steps.

Choosing a Care Coordinator

- Candidate should show strong interest in learning about and working with CSHCN
- Former staff in neonatal or pediatric intensive care units often have the interest and experience needed
- The care coordinator should be (or become) an integral part of your office staff (i.e., at least 3 days a week) to maximize opportunities to get to know families and familiarize themselves with local resources

equipped to manage the care coordination and resource and referral aspects for families but are unable to provide medical care. Some offices choose to staff with both a social worker and a nurse.

The PACC experience indicates that PNPs who dedicate one day a week to serving CSHCN can manage a total caseload of approximately 25 patients. Other staff members help with scheduling and triage issues for this population as part of their regular duties.

Identifying Children to Serve

There are different methods by which to identify children to serve.

1) **Decide what type of criteria to use to identify children; suggestions include:**
   - Criteria developed by PACC (see Figure 1)
   - Questionnaire for Identifying Children with Chronic Conditions (QuICCC) criteria, developed by Ruth Stein, M.D.
   - Criteria from the Hood Center for Children and Families that applies diagnostic codes to utilization data

2) **Develop an assessment form with the criteria to gather baseline diagnostic data**
   - Assign a clinician to review the medical records and fill out the form to determine who qualifies
   - Simultaneously organize demographic data such as parent names, telephone, and address to facilitate contact with families
   - Paper forms are workable, but a computerized template is highly preferred

3) **Devise a name for your group of patients and make it known - be creative!**
   - Name suggestions include: PACC, CATCH, Rainbow and Reach
   - Don't underestimate the importance of thinking of this patient population as a special, distinct group
   - With a group name, front office staff and clinicians will be able to identify the appropriate patients quickly when they call or come in
   - Distinguish the medical charts with a color code or special label with the group's name
   - Inform families that they are a member of your special group
     - Be sure to tell them the group's name and remind them often

- Be sure to choose one person to manage the care coordination and become very familiar with the caseload
- Families of CSHCN often have too many people superficially involved in their lives, none of whom have full awareness of the child's situation

Figure 1

PACC MEDICAL CRITERIA
For Identification of CSHCN

Check only if child has met criteria for the last 12 months or if criteria/condition is expected to last for more than 12 months.

Child must meet one or more criteria below:

1. Biologically-based health problems involving more than one body system *(developmental, psychiatric or psychological disorders also count as a single system)*

2. Severe single system disorders *(e.g., steroid dependent asthma, poorly controlled diabetes, mental retardation, severe developmental delay)*

3. Simultaneous involvement with more than one medical specialist *(M.D.-level)* with each referral expected to last for more than 12 months

4. More than three hospitalizations in the prior year or a hospitalization in the prior year that lasted for more than 15 days

5. Dependence on medical technology *(check all that apply)*
   - Gastrostomies
   - Tracheostomies
   - CPAP
   - Other
   - Ventilators
   - Oxygen
   - Mechanical Hospital Bed

   (nebulizers alone for asthma do not qualify)

6. Dependence on a wheelchair

7. Ongoing need for home or school-based health care services *(check all that apply)*
   - Home Health Aides
   - Visiting Nurses
   - Block Nursing Hours
   - Other
   - Physical Therapy
   - Speech Therapy
   - Occupational Therapy

8. For children under three years old, Early Intervention involvement for biologic risks and/or developmental impairment *(not psychosocial)*

9. Great difficulty in coordinating treatment and rehabilitation plans due to the complexity of the child's care *(e.g., coordination of home nursing, Durable Medical Equipment Companies, Department of Public Health case managers, physical/occupational therapies, Individual Health Plans, Medicaid reimbursements, etc.)*

Lead Physician Role

The "lead physician" is the physician in your office who has primary responsibility for coordinating your medical home activities. This role can involve a number of components, some administrative and some clinical, including:

- Establishing an office-based system for cohort identification
- Developing office record keeping systems that separate out the records of CSHCN so that they are readily accessible and contain all necessary material
- Creating linkages with hospitals
- Designing two-way communication with subspecialists
- Staying in touch with the care coordinator and parent consultant for your office
- Ensuring mechanisms of communication with obstetricians so that prenatal recognition of disabilities can be enhanced
- Interacting with geneticists to ensure that families have the full range of information about their child's condition and potential recurrence rates
- Providing age- and disability-appropriate preventive care
- Coordinating care when children are sick
- Anticipating the natural history of disorders and planning appropriate preventive interventions (often surgical, e.g., heel cord release)
- Devising transition strategies for older children

Pediatric Nurse Practitioner/Care Coordinator Role

The pediatric nurse practitioner or other person assigned to care coordination plays a critical role in assisting families with their medical and non-medical needs to live successfully in the community. Responsibilities can include:

- Triaging phone calls to determine need for office visit, home visit or emergency room
- Handling prescription refills, durable medical equipment orders, pre-authorization forms for services
- Managing and updating individual health plan (IHP), with attention to medications, problem list
- Creating an individualized emergency care plan for each patient (see Figure 2); disseminating to providers and family as well as to schools, Early Intervention Programs (EIP), home care nursing companies
- Serving as liaison for school teachers, school nurses, therapists
- Assisting with initial EIP referral and transition to HeadStart/preschool
- Conducting home visits to:
  - treat acute health care problems
  - follow up on acute health care problems
  - provide coordinated care
- Referring to family support services when needed (e.g., student mentor volunteer in the home)
- Assisting families in establishing family support network in the community
- Providing patient education regarding maintenance of health care issues (e.g., asthma management, tracheostomy care)
- Maintaining regular contact with your office's parent consultant

Physician/Care Coordinator Communication

Regular, ongoing communication between the physician and care coordinator is essential in implementing a medical home. Ways to achieve this include:

- Planned, weekly meetings (1/2 hour - hour) to review cases
- Easy access by care coordinator to lead physician (consider using a special beeper code)
- Periodic joint assessment of systems issues

Figure 2

EMERGENCY CARE PLAN

It is helpful to have an outline for each child's emergency care. It can cover issues such as presented below. An actual plan will have the level of detail indicated in Figure A.

COVERAGE INSTRUCTIONS FOR A PATIENT WITH CHRONIC PULMONARY DISEASE, GASTROSTOMY, SEIZURES AND VENTRICULOPERITONEAL SHUNT:

1. Indications for Emergency Transport to Hospital

2. Suggested History for Intercurrent Illness in a Child with a VP Shunt & Seizure

3. Potential Problems

   A. Seizures
   B. Headache/Fever, (VP shunt) *(see Figure 1 for further detail)*
   C. Increased Respiratory Rate, Cough
   D. Potential Complications of Gastrostomy

Figure A

B. Headache/Fever, (VP shunt)	1. Consider a shunt malfunction
Differential Dx:	(vomiting, lethargy may accompany headache)
a. *Shunt malfunction*;	2. If neuro exam warrants, or with high
Last shunt malfunction 2/11/00,	suspicion; transfer to ER for CT scan.
Most notable symptom:	with + malfunction, consult neurosurgeon.
Severe headache.	Call in expect to ER: 555-1212
b. S*inus infection*	Neurosurgeon on call, Dr. Occipito: 555-1212
c. V*iral illness*	3. If sent to ER consider sinus xray.
d. M*igraine*	Administer appropriate antibiotics if definitive diagnosis of sinusitis made.
	NOTE: MULTIPLE MED ALLERGIES.
	4. Note if baseline management of migraine not successful, send patient to hospital.

"Before making these changes in our practice, I thought that I did a good job taking care of children with complex special health care needs. Dedicating a staff person to this group of children has improved our ability to care for them so much, I am a little embarrassed about what we were doing before."

—Physician at East Boston Neighborhood Health Center