Practicing Comprehensive Care

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

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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.

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> “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)
Differential Dx:
a. *Shunt malfunction*;
Last shunt malfunction 2/11/00,
Most notable symptom:
Severe headache.
b. S*inus infection*
c. V*iral illness*
d. M*igraine*

1. Consider a shunt malfunction
(vomiting, lethargy may accompany headache)
2. If neuro exam warrants, or with high
suspicion; transfer to ER for CT scan.
with + malfunction, consult neurosurgeon.
Call in expect to ER: 555-1212
Neurosurgeon on call, Dr. Occipito: 555-1212
3. If sent to ER consider sinus xray.
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

SECTION 2

Helpful Modifications to Primary Care Office Routines

Making some adjustments to basic primary care protocol can facilitate caring for CSHCN in your practice.

Enhancement to the Medical Record–Individual Health Plan (IHP)

Patients and providers benefit greatly when IHPs are added to the medical record of CSHCN. These are four-five page computerized summaries of patient care and most effective when broadly disseminated to other providers and the family. A Web-based application is ideal, but you can maintain the documents on personal computers. IHPs require an initial investment in time, but updates are quickly done and standard approaches to likely complications can be developed for your office. In a standard panel size of 1,200 to 1,500 patients, 30 - 40 may benefit from having an IHP (see Figure 3).

Key Components - first two pages

- Identifying and family contact data for the child
- Principal Diagnosis
- Active problem list; medications and allergies; consultants
- Active Agencies involved in child's care; equipment

Subsequent Components

- History
- Review of Systems
- List of predictable complications that may present
- Requirements for transport
- Team goals

Distribution

- Print and file initial document and subsequent updates in patient's office chart
- Make IHP available to covering physicians after hours
- Give copy to patients to bring to outside encounters
- Obtain parental consent to share IHP with other providers
- Fax/mail IHP to specialists along with consultations
- Send IHP to school

Benefits

- Concise, up-to-date snapshot of patient
- Enhances communication during referral process and emergency room visits
- Reduces family burden to continually repeat their child's situation to new providers
- Increases comfort of covering providers in managing complex cases

Figure 3

INDIVIDUAL HEALTH PLAN
Condensed Entries

CSHCN Program/Our Town Pediatrics
10 Harmony Ave., Our Town, MA
Office ### PNP # 555-1212

James Joyce **Last Revision 2/2/00**
(Children's Hosp. Med. Ctr [CHMC] ####)
Date of Birth
Address/Phone/Parent

Principal Diagnosis: Complications of Prematurity (26 weeks)

Problem List:
1. s/p Gr IV IVH Hydrocephalus, VP Shunt
2. seizure disorder
3. Gastrostomy
4. gross/fine motor impairment

Consultants/Hospital/Phone #/Last Seen:
1. Dr. Smith, Neurosurg CHMC 355-5555 4-8-99
2. Dr. Mason, CHMC 355-5555
3. Dr. Thomaso, CHMC 355-5555
4. Early Intervention: Harbor Area 569-5555

Admissions (12m):

3-1-99 HMC Heel chord lengthenings
3-23-99 pneumonia, treated at home

Medications:

Chronic
1. Phenobarbital (20mg/5cc) 80mg qhs
   (increased post admission 1/13/00)
   Detail on medication changes by date
2. VPA (250/5cc) Give 300mg TID
   (increased post admission 1/13/00)
   Detail on medication changes by date
3. Klonopin (100mcg/ml) 0.6mg susp TID
   PGT (refilled 12/1/99 X 3)
4. Zantac (15mg/ml) 30 mg TID PGT
   (refilled 10/4/99 X 5)
5. Bactrim 200/5 1 tsp Qd (began 8-26-98, pulm)
   4-14-99

PRN
1. Ventolin 0.5/2ccNS given up to q 4 hrs
2. Tylenol 240mg q 4hrs
   PRN temp > 101.5/pain

Allergies:
None known

Equipment:
Feeding pump, O2 stationary, O2 portable, suction stationary, suction portable, Mic-key gtube 18Fr. 2.0cm, portable LP10 vent, suction supplies, feeding tube supplies, O2 sat and Apnea monitor, snug seat, lap tray, carseat, bath chair, 3/5/10cc syringes. Wheelchair ordered/fitted: 2/19/98, Pediasure 4can/day., 4.5 TTS Bivona (has cuff)

INDIVIDUAL HEALTH PLAN (continued)

DME:	Home Care: Sarah Stuart, Phone #, Fax #, Supervisor name/#
Home Care:	VNA of Greater Boston, Case Manager – C. Sullivan, R.N., 555-5555
Department of Public Health:	Kathy Reyes, 888-8888
MA Commission for Blind:	Susan Carter, 555-5555
School:	Kennedy School, Nurse Harris, 444-4444
Pharmacy:	Hometown Pharmacy, 10 Main Street, Boston 02115 555-5555

History:
This 26 week premature infant twin, Gr IV- IVH in the NICU, Intub x 3 months, trach for subglottic stenosis. 10/9/95: admit continuous mild to moderate resp distress on 30% O2, vented. 4/10/97 D/C to home from Children's Hospital.

Review of Systems (ROS)

Nutrition/Swallowing: PEG placed 12/96. NPO as of 12/12/97. 840 kcal daily. Pediasure with Fiber **Vision:** Cortically blind **Hearing:** Moderate bilat. conductive loss **Communication:** No words, cries/smiles **Respiratory**: LP10 portable vent A/C mode. Tidal volume: 200. Peep 5. Back up rate 10. 4.5 pediatric shiley trach changed monthly. CPT and suctioning q 4 hrs. Vent 8 hours/night. Swedish nose x 4 hours/day Rest of day room air mist via trach collar. Abx prophylaxis per pulmonary.	**Dental:** Cleaning 3/99 **Cardiac, Renal, Endocrine**: No known problem **Orthopedic**: Hip/knee contractures. Grade IV IVH. **Neurologic:** Profound gross/fine motor impairment. Profound cognitive impairment. Multiple seizures per day of mixed types. Phenobarb + VPA levels q 4 weeks. **Skin Integrity**: Very sensitive skin. Aquaphor for dry spots.

Potential Problems for Coverage

Please see care plan/coverage book for information regarding:
1. Escalating seizures
2. VP shunt malfunction
3. Respiratory distress
4. Complications of tracheostomy use/mechanical ventilation
5. Complications of gastrostomy

Team Goals: Family Meeting 2/12/00
1. Attempt to wean from ventilator
2. Re-evaluate hearing status
3. Apply for respite care from Department of Mental Retardation
4. Camp placement for sister

Clinical Practice Guidelines

Finding appropriate clinical practice guidelines to address the complexity of care for CSHCN can be very challenging. Here are some useful established guidelines, some "informal" office-specific ones, and suggested ways to manage the subspecialist referral process.

Established Guidelines

- The Web offers some excellent guidelines that specialize in issues affecting CSHCN (see Appendix C)

Informal Guidelines

- Providers caring for CSHCN should know what complications they are comfortable treating and clearly communicate this to parents
- Standardize the approaches to common problems within a practice group and among all covering physicians. Following the same approach will avoid confusion and misunderstanding among patients. This may vary depending on geographic area or referral patterns.

Subspecialist Network

- Working closely with a tight web of consultants will allow you to understand these consultants' approach to problems likely to arise in this group of patients
- A review of your practice's evaluation and treatment patterns with local consultants can help ensure, at least, that your approach is not unusual or unsafe for your community
- Choice of referrals to specialists may depend on a number of factors: insurance coverage or lack thereof, patient preference, provider preference, or idiosyncrasies arising from department-level policies within hospitals

Tips to Facilitate the Referral Process

- Try to limit your practice's referrals to each hospital to one specialist per department. This will facilitate team-building and enhance communication between the primary care provider and specialists.
- Use a pre-referral fax coversheet for clinical information. This should be separate from the managed care organization (MCO) referral process as the MCO form may never reach the provider in question. Using information from the IHP, include:
  - ♦ patient's name
  - ♦ identifying information
  - ♦ problems and medications
  - ♦ reason for consultation
  - ♦ pertinent prior testing/treatments
  - ♦ call back information

  This "clinical fax sheet" should include your fax number, voicemail, and back-office phone number. Encourage the consultant to briefly respond with the same form prior to sending the full consultation report.

- Develop an office system to track whether patients have been seen and when consultation information has been received. Try to utilize consultants who make the effort to conscientiously respond to you.
- Follow-up with patients/families after their visits with consultants. Focus on whether they understood whatever information they received and whether they felt generally well cared-for.
- Under some MCO contracts, requesting an "out of panel" consultation may have a direct adverse financial impact on the primary care practice or provider. Address this issue when the practice group signs MCO contracts. As CSHCN are, by definition, likely to require more referral services than other children, practice managers should think twice about approving these types of MCO contracts if the practice wishes to service a substantial number of CSHCN.

After Hours Care

It can be particularly challenging to coordinate with covering physicians and to communicate key information about the CSHCN in your practice. The measures outlined below can enhance the effectiveness of the on-call staff less familiar with these patients. The following outlines steps applicable to an 11-physician group.

Among your practice partners, devise a plan to communicate information at the start and at the end of the nightly coverage period.

- After hours nurse screens calls, with "significant" calls and those from families of children dependent on technology forwarded to the covering physician
- Primary care physician informs covering physician at the end of the day if a patient has been admitted, if significant lab tests are pending or if there are patients who likely will need assistance after hours
- In the morning, the covering physician informs the primary care physician if any patients call with significant issues, are seen in the Emergency department or are admitted
- A coverage group "rule" never to send a child to the emergency department without speaking directly to the ER attending and relating summary sheet information reduces confusion and duplication of effort
- Weekly meetings are held to discuss all admissions as a group
- Separate practice meetings are held to discuss management of common or recurrent clinical problems
- Information about children dependent on technology, kept in a central location in the practice, is available to the after hours triage nurse and is circulated in a binder at the weekly practice meeting. (It also could be managed in a hand-held computer.)
- The same data are given to the family to help them organize the information to present during an after hours telephone call

Managing Office Visits

Office visits for CSHCN should be managed differently from visits for typical patients. It is nearly impossible to fit the care of children with multiple severe issues into time slots for standard patients, and doing so is likely to lead to frustration for both providers and parents. Components of a successful system are indicated below.

Scheduled Visits

- Try to schedule patients during your least busy times - often early in the morning or just after lunch
- If your office has many CSHCN, consider setting aside an afternoon a month where you preferentially see four or five CSHCN while mixing in 10 - 20 of your most predictable brief encounters. Scheduling of this nature is often best done by a single, assigned medical assistant.
- To focus the visit, attempt to address the parent's single most pressing need and what you identify as the patient's most pressing medical need
- Do not try to address all problems in all visits; frustration will result
- Consider scheduling visits more frequently than the Early Periodic Screening Diagnosis and Treatment (EPSDT) guidelines dictate for health care screening and promotion as well as to address separate severe issues in more detail. This is acceptable practice as long as the separate issues are significant enough to warrant an office visit.
- Payment for these visits will depend on the patient's insurance coverage. Fee-for-service arrangements will reimburse, but payment under managed care will vary. Consider negotiating extra visits with the managed care organizations you contract with.

- "Bright Futures for Children with Special Health Care Needs," a guide for physicians, will have more specifics on managing office visits, including condition-specific health supervision, anticipatory guidance, and helpful Web sites

Urgent Visits

Urgent visits can be more challenging to manage than planned services. The suggestions below can help to organize staff and assist families to best utilize these encounters.

- Ask families to always call before coming to the office and give them the name of a specific nurse to ask for; this facilitates at least the start of the visit
- Help families ahead of time to understand what level of care can be provided in the office vs. the local hospital (office facilities often dictate this, e.g., availability of labs on site)
- Be sure that families are taught to recognize early stages and warning signs of illness and baseline care requirements for technology-specific procedures
- Include a list of likely complications, and general approach to the problems, in the patient's chart and in a central location in the practice
- Registration staff should know in advance if children with mobility issues or less obvious triage concerns (e.g., increased risk of infection, behavioral issues) should be ushered directly to a room

Gauging Benefits

Review the following components of care to help you gauge whether the children in your practice are benefiting from practice modifications.

- Examine hospitalization rates for CSHCN
  - ♦ Declining rates are an indication of success and can be used as evidence of the efficiency of enhanced services when negotiating enhanced coverage from insurers
- Examine "on-time" status of appointments
  - ♦ Declining lags in appointment times indicate increased efficiency and likely increases in patient satisfaction
- Review completeness of medical charts and poll providers in practice. Are IHPs and summaries with all needed information available in charts for use by covering partners in the practice?
  - Informal survey using a 1-5 multiple point scale can assess the ease with which providers can find information. This can be implemented with a simple index card clipped to the chart and placed in a box at the end of the appointment.
    - ♦ Improvements in documentation should lead to increases in efficiency
- Ask about questions that focus on quality of life/wellbeing such as school missed
    - ♦ Declines in school absences due to health enhances quality of life for families

Best Practice Tip—Communication Strategy

- Primary care providers are notified by fax whenever a patient registers for an emergency room visit, outpatient consultation or diagnostic test, with follow-up notification after the encounter
- Contact the provider relations department at your local hospital to discuss arrangements

Handling Telephone Calls

- Handle calls from selected families of CSHCN differently from other calls to minimize the risk that important issues will not be appropriately addressed
- Ask families to identify themselves immediately as a member of "your group name"
- Channel immediately all health-related calls to the "nurse-in-charge"
- Transfer calls for non-urgent, non-health-related matters to a dedicated voicemail line that is regularly monitored throughout the day

> “PACC helps our practice truly manage the care of children who are very medically complicated. We are able to play a much more effective role in their care.”
>
> –Physician at Hyde Park Pediatrics

SECTION 3

Reimbursement Strategies

edited by Michael L. Ganz, PhD, MS

Finding appropriate ways to obtain reimbursement for care unique to CSHCN can play an important role in the long term financial viability of your practice. This section examines:

- How your practice can maximize reimbursements, using traditional funding mechanisms
- Proper use of Current Procedural Terminology (CPT) codes
- Special considerations under capitation

Proper Use of CPT Codes

To maximize reimbursement, providers should utilize a wide range of CPT codes that properly capture the nature of the services rendered. Many higher-intensity evaluation and management (E/M) codes are appropriate but often go unused.

Try to avoid "down-coding" when billing for services rendered to CSHCN as the practice may suffer financially. Common causes of down-coding:

- Lack of knowledge of how to properly utilize CPT codes; and/or
- Insufficient documentation to justify the higher-intensity codes

Your practice can legitimately increase revenues by utilizing higher-intensity codes, but you must keep documentation to justify these higher codes. For example, proper documentation of the outpatient visit codes 99201-99205/99212-99215 should permit billing at the 4th and 5th level for most acute problems or treatment of technology-specific issues. Generally, the documentation guidelines for history taking are more difficult to meet than the guidelines for examination and decision making for CSHCN.

One quick method to determine if your practice is appropriately utilizing higher intensity codes:

- Examine the distribution of CPT codes used for all children compared to the distribution of CPT codes used for CSHCN
- The distributions should *not* be similar; if they are, the practice is not fully and appropriately utilizing the richness of CPT coding to capture the true nature of the services rendered to CSHCN

Additional Suggestions for Improving Reimbursement

- Double check with local carriers to see if they cover all the codes you are likely to use. Under fee-for-service payment systems, proper billing using the appropriate codes can legitimately increase revenues.
- Offset the cost of your PNP/care coordinator through proper billing. The PNP can help arrange, collect and document information needed to justify billing at higher-intensity levels.
- Bill for typically unreimbursed care whenever possible. Telephone calls and letter writing are a financial drain, especially with many CSHCN in a practice. Remember that time spent on the telephone, especially if that time precedes an office visit and if the visit is impacted by the telephone conversation, can be rolled into case management codes or can be bundled into the next office visit.

- Determine if uninsured children would be eligible to enroll in your state's Child Health Insurance Program (SCHIP). See *www.mchpolicy.org/issue5.html* for an analysis of state CHIPs with respect to CSHCN.

Billing Strategies for Routine Health Care Maintenance (RHCM)

When CSHCN are seen according to the EPSDT guidelines for routine health care maintenance, apply the age-specific preventive medicine codes 99381–99385/99391–99395 (see Table 1). Given that providing quality routine health care to CSHCN takes more time than providing routine care for their healthy peers, pursue two options for billing these services:

1) Apply prolonged service codes 99354 - 99355. When these codes are applied, note the actual clock time of face-to-face interaction in the chart.
2) If a single medical issue that is addressed during the visit rises over and above what would be considered routine management, apply both a preventive medicine and outpatient code for that visit

Two Codes/One Visit

A nine year old child with cerebral palsy and seizures comes to the office for routine health care but complains of rapidly escalating seizures and complications of her anticonvulsant medications which leads you to make treatment decisions affecting anticonvulsant management.

You can apply:

(prev. med) 99393
and
(mod.-severe outpatient visit) 99215

OR

(mod.-severe outpatient visit) 99215
and
have patient return for separate RHCM visit

If you intend to use time as a default for applying 4th and 5th level codes, note in the chart the actual clock time spent with the patient. (See Table 2 for codes not often used.)

Capitation and CSHCN

Under capitation payment systems, consider the following steps to increase reimbursement:

1) Request enhanced case management fees and ask for special consideration
2) Obtain rates that are adjusted by age and disabilities. Non-adjusted plans, especially for younger patients, need to be carefully evaluated.

Practices with significant numbers of CSHCN should be especially careful to do the following:

1) Determine what exactly capitation is responsible for
   - Accordingly, determine which patients can never fit under a capitation scheme
2) Define stop losses carefully–there are different thresholds for CSHCN
   - Understand how reinsurance works; set it up so one patient cannot surpass your budget cap. Certain schemes have a per member per month budget cap that is determined by age, sex and historical utilization patterns. Services are paid on a fee-for-service basis and at the end of the month accounts are reconciled. Providers may have to pay the insurer if the provider went over the budget cap.

For further reading on how to evaluate health care plans:
www.ichp.edu/managed/materials/purchaser

Table 1
Commonly Used Evaluation and Management (E/M) Codes[a,b]

Description	**E/M Codes**	
Preventive Medicine[c] **Age**	**New**	**Established**
0 – 1 year	99381	99391
1 year – 4 years	99382	99392
5 years – 11 years	99383	99393
12 years – 17 years	99384	99394
18 years – 39 years	99385	99395
Office/Outpatient Visits Level of Severity	**New**	**Established**
Straightforward	99201	99211
Low	99202	99212
Moderate	99203	99213
Moderate – Severe	99204 (45 mins)	99214 (25 mins)
Moderate – Severe	99205 (60 mins)	99215 (40 mins)
Preventive Counseling	**Individual**	**Group**
15 mins	99401	--
30 mins	99402	99411
45 mins	99403	--

Table 1 prepared with the assistance of Peter D. Rappo, M.D, F.A.A.P., and Gregory J. Young, M.D.

Table 2

Evaluation and Management (E/M)[a,b,c] Codes Generally Not Used but Appropriate for Use in Caring for Children with Special Health Care Needs

E/M Codes	Description
Prenatal Care[d]	
99401	15 minutes
99402	30 minutes
99403	45 minutes
99404	60 minutes
Telephone Advice	
99371	Simple/Brief
99372	Intermediate
99373	Complex/lengthy
Office/Other Outpatient Consultation	
99241	Office consultation, minor
99242	Office consultation, low severity
99243	Office consultation, moderate severity
99244	Office consultation, moderate high severity (60 mins)
99245	Office consultation, moderate high severity (80 mins)
Care Plan Oversight	**Use these codes once per 30 days**
99374	15-29 minutes; patient under care of home health agency
99375	30 minutes or more; patient under care of home health agency
99377	15-29 minutes; hospice patient
99378	30 minutes or more; hospice patient
99379	15-29 minutes; nursing facility patient
99380	30 minutes or more; nursing facility patient
Prolonged Services[e]	**Not Face to Face**
99358	Prolonged services, without contact, first hour
99359	Prolonged services, without contact, each additional 30 min
Prolonged Services[f]	**Face to Face**
	< 30 minutes – not reported
99354 x 1	30 – 74 minutes
99354 x 1 & 99355 x 1	75 – 104 minutes
99354 x 1 & 99355 x 2	105 – 134 minutes
99354 x 1 & 99355 x 3	135 – 164 minutes
99354 x 1 & 99355 x 4	165 – 194 minutes

continued next page

Table 1 prepared with the assistance of Peter D. Rappo, M.D, F.A.A.P., and Gregory J. Young, M.D.

E/M Codes	Description
Case Management	
99361	Physician/team conference, 30 min
99362	Physician/team conference, 60 min
99371	Physician phone consultation, brief
99372	Physician phone consultation, intermediate
99373	Physician phone consultation, complex
Home Services[g]	**Low Severity**
99341 (new)	Components are:
99347 (established)	problem focused history
	problem focused examination
	medical decision making, straightforward
Home Services	**Moderate Severity**
99342 (new)	Components are:
99348 (established)	expanded problem focused history
	expanded problem focused examination
	medical decision making, low complexity
Home Services	**Moderate to High Severity**
99343 (new)	Components are:
99349 (established)	detailed history
	detailed examination
	medical decision making, moderate complexity
Home Services	**High Severity**
99344 (new)	Components are:
99350 (established)	comprehensive history
	comprehensive examination
	medical decision making, moderate
Home Services	**Unstable or significant new problem requiring immediate physician attention**
99345 (new)	Components are:
	comprehensive history
	comprehensive examination
	medical decision making, high complexity

[a] Information for table extracted from *Current Procedural Terminology, CPT 2000*.
[b] Evaluation and Management is part of the CPT coding system.
[c] E/M codes, descriptions and numeric modifiers only are copyright 1999, American Medical Association. All rights reserved.
[d] Prenatal Care codes are the same as the Preventive Counseling codes.
[e] For extensive work related to the visit done before or after the visit, e.g., extensive telephone consultation to coordinate care with other physicians or with state agencies such as Department of Health.
[f] Bill for procedure code + add modifier "- 25" (extended service modifier.) Use these prolonged service codes as appropriate, depending on time spent.
[g] Under all Home Services codes, new patients require 3 components, established patients require 2 components.

> “Cases that are less complex medically often become extremely complicated due to other non-medical concerns such as language barriers and poverty. PACC has been vital in that it has led the families through the process of caring for a child with special health care needs not only medically but also socially.”
>
> –Martha Eliot Health Center Physician

Key Components of Family-Centered Care

by Linda Freeman, MBA, MS

Role of Parent Consultant

Parents who have experience raising a CSHCN can provide special support and empathy to families in your program. Providers should identify a parent in their practice whose child's medical condition is stable, and who seeks an opportunity to help other families and has sufficient time and energy to reach out. Although it is not necessary for the parent to have specific education or training in the social work disciplines, it is important to provide the parent with the tools and backup necessary to fulfill their role (see Supporting Your Parent Consultant.) Your parent consultant should receive a stipend (e.g., $150 per month) and reimbursement for any expenses.

Supporting Your Parent Consultant

Resources and technical assistance are available from:

Parents Helping Parents, www.php.com
NPPSIS: National Parent to Parent Support and Information Services
PO Box 907
Blue Ridge, GA 30513
800-651-1151; 706-632-8822
www.nppsis.org
e-mail: judd103w@wonder.em.cdc.gov

Supervision

The lead physician should meet with the parent consultant initially and then periodically, not only to reinforce the importance of this role, but also to monitor and adjust the specific guidelines for the parent consultant's interactions with the practice and the families. The care coordinator should arrange to talk by phone or meet weekly with the parent consultant and use this time to see that she or he is up-to-date on any specific resource needs or assistance required by families in the practice. The care coordinator and parent consultant together can decide who will be responsible for following through on specific needs. These exchanges can also address other general planning ideas such as arranging a spring picnic for families.

Parent consultants can fill the following roles:

1. Advisor to providers and the practice in general

- Family experiences and perspectives can inform many aspects of the practice, from the actual physical layout/accessibility of the office to the way staff interact with the families–on the telephone and during visits

2. Personal and direct support to families

- The volunteers can provide both enormous direct emotional support and practical advice to other parents, especially at the time of diagnosis. They need not be professional counselors, but should be trained in effective communication.
- Support can include: periodic telephone calls, connecting in person at events, and e-mails. Some parents prefer phone calls, others would rather attend an event.

3. Organizer and coordinator of family events

- Families have a great need for information about resources and for social connections with others in similar circumstances. A wide range of events will meet many needs from 1) social, "coffee hours"; to 2) informational meetings, e.g., financial planning for CSHCN; adapting toys, handling stress; and 3) family events such as music/art sessions, and holiday parties.

Tips on Organizing Family Events and Outreach

- Be sure to remind families early and often about upcoming events – telephone reminders work best
- Minimize barriers to attendance by arranging for free parking and/or transportation and volunteers who can help with care for the children
- Consider pooling resources with other practices if your office is small or serves a more rural area; it can be hard to find parent volunteers in these settings
- Ask for donations of goods and services; many speakers or organizations are responsive to events related to CSHCN

4. Information disseminator

- Distributing a newsletter three times a year is a great way to stay in touch with the families in your program. If that is not feasible, even brief, periodic memos can be helpful. Setting up bulletin boards in the waiting room to post important news is another option. Useful items to include by any of these methods are:
    - Information on upcoming workshops and programs
    - Resource tips such as summer camp guidance, where to find used durable medical equipment and specialized clothing
    - Updates about important legislation affecting children

Office Staff Training

Your office staff members make the first and sometimes most lasting impression on your patients and their families. Training and sensitizing them to the particular issues confronting families with CSHCN can make an enormous difference in their overall experience as a member of your practice. A single, one-hour session with some follow-up can effect useful changes. Excerpts from PACC's "Tip Sheet" and "Disability Etiquette" illuminate this work.

Staff Training Agenda

- A parent "consultant"– a parent known to the practice who has a CSHCN – is the best facilitator. A practice nurse or whomever is managing your care coordination should organize the meeting.
- Physician presence at all or part of the meeting sends a strong, positive signal to staff about your commitment to this patient population
- Holding the session during lunch or a regularly scheduled staff meeting minimizes office disruptions
- Strive to give staff a chance to learn more about what special challenges families face such as:
    - constant stress and exhaustion; difficulties associated with travelling with a child who uses medical equipment; dealing with "the public"
- Focus on special circumstances that may arise at the office (e.g., big enough exam room to accommodate wheelchair) and how to handle them
- Remind staff that simple courtesies such as making eye contact with children, smiling and addressing them directly, has a profound affect on families' office experience

Follow-Up

Recapping the work done in the meeting is essential to creating lasting change. Visual reminders often work best.

- Given this chance to brainstorm together, staff often display their ability to devise approaches and solutions to various situations that may cause discomfort or difficulty for families
- Consolidate these solutions and write them in a way that can be shared with current and incoming staff
- Simple suggestions for adaptations to office procedures include:
  - Posting the names of the families in your program near the telephones so staff can recognize and greet them by name; this is both appreciated by families and helpful for handling the call appropriately
- Physician support is critical to integrate modifications in day to day practice

These meetings can enhance the comfort level for staff in working with families with CSHCN and facilitate positive interactions on the telephone and in person.

Tips for Families to Identify Local Support Resources

- Identify any regional or local associations related to a particular special health care need (e.g., United Cerebral Palsy). The local library should have appropriate listings of organizations.
- Ask school nurses, guidance counselors, and the special education department about any groups serving families with CSHCN
- Call the town recreation department for any programs available to CSHCN; they may include sports activities as well as general recreational programs
- Contact the education department of any local colleges or universities (or any other relevant department such as physical therapy). Most institutions have social service/community organizations that may sponsor appropriate groups for children or provide volunteer support to families.
- Contact Exceptional Parent magazine at <www.eparent.com> to link with your state's Parent Training and Information Center and Parent to Parent program for names of people who can help in your own area

Community Support— Places Families Can Inquire for Home Modification Help

Contact fraternal organizations such as the Knights of Columbus, Kiwanis, Rotary Club, the Elks and Shriners.

- Often they provide wheelchair ramps, purchase other types of equipment, and facilitate access to transportation services. The non-profit organization Habitat for Humanity does home modifications/remodelling.
- Local lumber and hardware stores may contribute materials or labor for installing ramps or other home modifications

In-Office Conferences

Another way to enhance communication between parents and professionals is through in-office conferences. Attendees should include the pediatrician, pediatric nurse practitioner and parent/guardian(s). Not every practice may be able to set aside time accordingly but components of these meetings can be valuable for everyone. Below is a tested format and some outcomes:

- The PNP encourages parents to think ahead about what they wanted to mention and accomplish in the meeting
- Pediatrician meets with parent and PNP for 30-40 minutes to discuss particular parent concerns, and to review reports from the child's subspecialists and any relevant testing schedules
- PNP meets with the parent alone afterward for 45-60 minutes to review and update the IHP and to focus on goal setting for the child and family if the latter is not completed in the prior meeting
- The relatively unhurried nature of the encounter allows the physician to gain insight into the difficulties involved in caring for a CSHCN and to obtain important health information that otherwise might be missed
- The three way dialogue among parent, physician, and PNP is a very effective and efficient way to solve a host of different problems – an opportunity that doesn't present in typical office visits
- The parents are very pleased to have the extra time with the physician, and the forum helps the PNP to further a bond and connection to the family

Meeting the Needs of Culturally Diverse Populations

- Provide for interpreter services at office and home visits
- Have bi/multilingual providers available
- Understand cultural values and biases, acquire knowledge of cultural beliefs and practices
- Coordinate transportation and patient appointments
- Initiate telephone calls to durable medical equipment and home health companies; arrange physician/specialist appointments
- Assist with early intervention and special education referrals and with school transitions
- Advocate for families at special education evaluation team meetings at schools
- Incorporate extended family supports, when applicable, in patient teaching
- Inform families of available community resources

Disability Etiquette: Some Do’s and Don’ts — from the Parent’s Perspective:

Tips to Make the Office Visit Better for Everyone

The following suggestions have been compiled from parents of children with special health care needs across the country:

- ✓ DO respond positively to our children in your initial interaction. Tell us they are cute, sweet, cool, that they are wearing a neat hat. Let us know that you value them even if you can’t cure them.
- ✓ DO ask questions of our children, even if the child can’t speak. Show your recognition and respect. Don’t worry; his parent will find a way to facilitate the communication.
- ✓ DO look at our children when you are talking to them. Please make every effort to establish a personal connection.
- ✓ DO get down to our child’s level. For example, if our child is in a wheelchair, kneeling or sitting down will help make him feel more comfortable.
- ✓ DO realize that parents sometimes are very tired of telling their story over and over. Even though you may have your own personal medical interest, don’t ask if you don’t need to know. Be understanding if the parent shows frustration at telling his child’s “story” yet again.
- ✓ DO notice and be attentive to brothers and sisters. They have grown up in a situation where their sibling has, by necessity, received lots of extra attention. They don’t understand why they shouldn’t be just as entitled to a sticker or balloon.
- ✓ DO be aware that our grief and sadness may recur at any time and often does at transitional times — beginning pre-school or high school, the day of the senior prom, an anniversary of another loss. It’s never resolved entirely.
- ✓ DON’T ask questions or raise issues that could be painful for us (and our child) in front of our child. If you need to understand more about the birth history, for example, find a way to talk separately with the parent. You should never assume our child doesn’t understand or doesn’t have feelings.
- ✓ DON’T refer to our children by their diagnosis (e.g., “MR kid”, “Downs kid”); it’s a good habit to develop no matter with whom you are talking.
- ✓ DON’T judge parents; we are doing the best we can under often difficult circumstances. If we are impatient or rude, it may be that we are under particular stress.
- ✓ DON’T be surprised if we need instructions, procedures or explanations repeated several times, especially if the information is complicated, upsetting or unexpected. We are often thinking about a million other things and we are trying to synthesize what you have to tell us at the same time.

TIPS FOR OFFICE STAFF— AS DEVELOPED BY YOU!
The following tips were developed by Longwood Office Staff to help them better serve the needs of PACC families.

On the phone...

✓ Become familiar with the names of the PACC patients by keeping a list posted near your work area. When booking an appointment, note on the schedule that this is a PACC patient.

✓ PACC patients may have urgent medical needs but may not identify themselves on the phone as a PACC family. By recognizing them yourselves by name, you will be able to help them get what they need as quickly as possible.

- ◆ Also, your acknowledgment of a PACC family on the phone or in person with a friendly “Hi, Mrs. Ainsworth,” will be very much appreciated by these families, many of whom are in touch with the practice much more frequently than the average family.

- ◆ By recognizing a family’s name, you can avoid situations like putting them “on hold” when there could likely be an urgent need or asking a question that may not apply (e.g., “Is this a sick visit or a well visit?”).

Upon arrival...

✓ Be aware that the PACC family is coming in. Be prepared to acknowledge them when they sign in. A low-key but welcoming acknowledgment is very meaningful to families.

✓ When a PACC patient is coming in and will do best in a particular examining room (e.g. because of size of equipment with the child), remind the nurses so they can save that room.

✓ When the family signs in, write PACC next to their name.

✓ For some families, the waiting room experience is particularly difficult:

- ◆ Their child may have immune problems and should not be exposed to other sick children;
- ◆ The amount of equipment they bring with them is large and awkward; they don’t know where to head;
- ◆ There is nowhere to sit in the waiting room;
- ◆ They are uncomfortable with the stares and looks they may get in the waiting room from others unfamiliar with their child’s medical situation.

There are a number of ways in which you might help the family:

✓ If they are “struggling” with equipment or just maneuvering into the office, offer them assistance by asking, “How can I help you?” (Some families may prefer not to be helped, so by asking directly you are letting them decide what help they want.)

✓ Help find them a spot in the waiting room.

✓ Offer to have them go into a room immediately.

✓ If a doctor is running behind schedule, give the family the option of leaving (e.g. for a cup of coffee) and returning at a certain time. Many PACC families carry cell phones and you might ask if they are reachable that way.

In the examining room...

✓ Before getting started with any clinical procedures with the child, (e.g. weighing) ask the parent, “Before we get started, is there anything I should know about your child or what works best for him/her when he’s here at the office?”

- ◆ Another way to inquire about a procedure is, “How do we usually weigh Julie?” (Note: The parent may even want to speak with you out of earshot of her child.)
- ◆ Given the age/awareness of the child, it may be inappropriate for them to hear any discussions about current concerns.

✓ If you have any questions or concerns about what you are observing/learning from an exam, think carefully about whether to share this concern or to comment openly with the parent present. Again, these kinds of comments can be very painful for a parent.

✓ Some PACC families may be visting the the office because of some urgent need. You may want to consider delaying some of the routine aspects of the examination until after the parents’ anxiety has been attended to by the physician.

✓ In cases where a child is examined frequently and/or repeatedly, you may want to consider letting the physician decide whether it is necessary to undress the child or proceed with routine steps, such as weighing. This can spare the parent what in itself can be a challenging situation.

✓ Before assuming that a parent wants to receive a sheet of developmental milestones, give the parent the option of getting this information. For some parents, this sheet only serves as a painful reminder that their child is not developing typically.

SECTION 5

Benefits of Setting up a Consortium of Providers

Medical homes can be created by individual practices or as part of a consortium with other health care providers. Consortiums can offer the following enhancements.

Opportunities for hospital affiliation through its provider relations office, which can provide and support:

- Electronic access to hospital medical records and patient visits
- Creation of a daily report to inform your practice about admissions, emergency room visits, and clinic visits from the prior day
- A strong base from which to develop subspecialty referrals
- Professional Education Sessions to advance knowledge base in areas particular to CSHCN
  - Continuing Medical Education (CMEs) Sessions for physicians
  - Continuing Education Units (CEUs) for nurses

Collaboration/resource sharing with other physicians that can lead to:

- Opportunities to apply for public or private grant money
- Problem solving, case reviews with other physicians
- A more powerful voice in negotiations with insurers and state departments of health for financing for enhanced services for CSHCN
- Pooling of resources with other practices to host/sponsor family events, and write and develop newsletters/bulletins for families

Professional Education Programs for Physicians and Nurse Practitioners

An affiliation with a university-based, children's hospital is essential to hosting professional education sessions for credit.

Continuing Medical Education (CME)

Suggested Format

- Semi-annual sessions; 3 hours in length
- Three topics per class
- Case-based instruction whenever possible
- Presentations by subspecialists from affiliated hospital

Suggested Topics

- Evaluation of Genetic Mechanisms of Disease
- Nutritional Issues in CSHCN
- Function and Anatomy of Selected Craniofacial Conditions
- Common Orthopedic Problems in CSHCN
- Pediatric Dysphagia/Oral Motor Dysfunction
- Seizures in Children with Significant Developmental Delay
- Diagnosing and Treating Complex Developmental Disorders
- Creating Effective Coverage Plans for CSHCN
- Children Assisted by Medical Technology in the Community (e.g., gastrostomies, tracheostomies)
- Guardianship for Individuals with Special Health Care Needs/Mental Retardation
- Transition from School to Adult Life
- Estimating Utilization and Expenditure Patterns

Professional Education Sessions for Nurse Practitioners

Continuing Education Units (CEUs)

Consider beginning your Nurse Practitioner Training program with three half-day sessions in close succession.

Suggested Initial Topics

- Overview of Chronic Illness and Common Medical Problems
- Case Management
- Communication Issues for Children with Multiple Medical Needs
- Overview, Care and Management of: Tracheostomies; Gastrostomies; Clean Intermittent Catheters; Central Venous Catheters
- Genetics Evaluation Process; Pharmaceutical Interactions; Cultural Diversity and Community Resources

Suggested Subsequent Topics

Format: A three-to-four hour session every two months

- Neurological Assessments
- Pulmonary Complications
- Musclo-skeletal Assessments
- Gastrointestinal Issues
- Immunization Update
- Respiratory Home Care
- Development and Management of the Individual Health Plan
- Children with Chronic Illnesses and Disabilities in the School Setting
- Community Resources: state and local agencies; Public Housing; state Department of Public Health; state Medicaid; state Department of Mental Retardation

SECTION 6

Missouri Partnership for Enhanced Delivery of Services

Building Medical Homes for Children with Special Health Care Needs in Rural Settings

This booklet has described in detail the medical home model of the Pediatric Alliance for Coordinated Care project. There are other important programs around the country working on behalf of CSHCN. Below, we profile the Missouri Partnership for Enhanced Delivery of Services (MO-PEDS) initiative.

Overview

The Missouri Partnership for Enhanced Delivery of Services (MO-PEDS) is a three-year demonstration project designed to develop medical homes for CSHCN in rural settings. Funded since 1998 by the Robert Wood Johnson Foundation and the Title V program in the Missouri Department of Health, the project will serve approximately 125 children and adolescents with complex chronic health conditions and disabilities ages 0-17.

The project has identified the following barriers to medical homes in rural areas:

- Limited professional resources due to a shortage of primary care providers, pediatric nurse practitioners, mental health services, special education supports, and therapy services
- A lack of community-based specialty care, which decreases the likelihood of family-centered, continuous, and culturally competent care
- Fewer opportunities for family-to-family supports

Coalition Building

In partnership with the PACC program and with consultation from the Rural Medical Home Improvement Project (of New Hampshire, Vermont and Maine), MO-PEDS set out to develop its initiative in a nine-county region of central Missouri with extensive input from a broad-based consortium. Partners in the planning process included primary and specialty care physicians, families, a Medicaid managed care health plan, and public agency representatives, including the Title V program, the Division of Mental Retardation and Developmental Disabilities/Department of Mental Health, Missouri Medicaid/Department of Social Services, and the Missouri Division of Special Education.

Proposed Solutions

These stakeholders proposed the following solutions to the challenge of building a rural medical home:

- Care coordination by a social worker or other designated non-medical professional

This person partners with the medical staff to create an IHP, problem solves with families about their medical and non-medical needs, facilitates communication across multiple systems of care (e.g., schools, agencies, health plans), teaches families self-advocacy skills, and identifies local resources for family support. The Title V agency funds this position in the demonstration project and has expressed a willingness to consider additional support if outcomes are positive.

- Use of advanced telecommunications systems (e.g., interactive telehealth services, Internet links) to improve access to specialty care, enhance community providers' knowledge about chronic care management, and coordinate primary/specialty care

- An emphasis on the role of the parent consultant based in the practice, who can support families of CSHCN through direct contact, newsletter and Internet linkages, and family-oriented activities

Objectives

The project will be implemented at 3 primary care practices in central Missouri to:

- Facilitate coordination of primary/secondary care
- Foster parent/professional partnerships
- Support family access to non-medical services

MO-PEDS is currently enrolling families from a large general pediatrics practice associated with an academic medical center and two smaller community family practice clinics. Physicians report interest in assistance with written health care plans for CSHCN, billing procedures, information on chronic care management, and parent-to-parent and family support services. They have also requested additional supports to improve primary/specialty care communication and access to mental health services.

MO-PEDS will examine outcomes such as changes in access to care, provider and family satisfaction, and health care expenditures of children enrolled, as well as processes such the determining the number of children that a social worker can follow. These data will be shared with Missouri state agency partners to help shape a "best practice" model of care for rural CSHCN and their families.

For additional information, contact Janet Farmer, Ph.D., Principal Investigator of MO-PEDS, at (573) 884-2905 or e-mail Farmerje@health.missouri.edu

Appendix B provides a brief summary of several other innovative programs for children with special health care needs.

Conclusion

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 makes 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 population.

For further information, please contact:

Lisa A. Sofis, Project Manager
The Pediatric Alliance for Coordinated Care Project
Division of General Pediatrics
Children's Hospital Boston
300 Longwood Avenue
Boston, MA 02115
617-355-4678 or 617-355-6714
lisa.sofis@tch.harvard.edu

“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

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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 prinicipal 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

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

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

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

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

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

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

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

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

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

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

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

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

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.icondata.com/health/pedbase/index.htm

The Pediatric Database (PEDBASE) contains descriptions of more than 550 childhood illnesses. Click "here" to get to a list of the childhood illnesses. Clicking on one, such as congenital muscular dystrophy, provides brief information about the disease such as its epidemiology, clinical features and management.

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

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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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