"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
(Children's Hosp. Med. Ctr [CHMC] ####)
Date of Birth
Address/Phone/Parent

Last Revision 2/2/00

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.<br>NPO as of 12/12/97. 840 kcal daily.<br>Pediasure with Fiber<br>Vision: Cortically blind<br>Hearing: Moderate bilat. conductive loss<br>Communication: No words, cries/smiles<br>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<br>Cardiac, Renal, Endocrine: No known problem<br>Orthopedic: Hip/knee contractures. Grade IV IVH.<br>Neurologic: Profound gross/fine motor impairment. Profound cognitive impairment. Multiple seizures per day of mixed types. Phenobarb + VPA levels q 4 weeks.<br>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