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**Enhancing Collaboration
Between Primary *and*
Subspecialty Care
Providers *for* Children
and Youth with Special
Health Care Needs**



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Enhancing Collaboration Between Primary and Subspecialty Care Providers for Children and Youth With Special Health Care Needs

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To the reader who reaches for this guide, may you find the tools we present to be useful for your efforts in developing Medical Homes, all the while realizing that the process of providing Medical Home-based care begins in your consciousness. May you embrace this concept and work to bring it to fruition.

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Introduction

Building a New Kind of System of Care

Over 15 years ago, dissatisfaction with the way families with children and youth with special health care needs (CYSHCN) were served led to a new vision of the systems of care in our nation. Families and service providers were frustrated with the fragmentation of services, the frequent need for families to travel long distances to obtain needed help, and the lack of sensitivity for families' knowledge and needs. The vision that developed was for a system of care that is community based, comprehensive, and coordinated. This system must also recognize that the family is at the center of caring for a child with special needs and must respect the family's cultural values and viewpoints.

The federal Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) defines children and youth with special health care needs as those who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally.¹ In response to *Healthy People 2010*, the national health care agenda for the United States of America, the federal MCHB has identified six key outcomes for CYSHCN and their families. These six outcomes have now been clearly articulated by President Bush in the New Freedom Initiative²:

- 1** Families of CYSHCN will participate in decision making at all levels and will be satisfied with the services they receive;
- 2** CYSHCN will receive ongoing, comprehensive care within a Medical Home;

- 3** CYSHCN will have adequate private and/or public insurance to pay for the services they need;
- 4** Children will be screened early and continuously for special health care needs;
- 5** Services for CYSHCN and their families will be organized in ways that families can use them easily; and
- 6** Youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence.

Although all six outcomes are interdependent, this guide focuses especially on outcomes 2 and 5. Creating a true Medical Home and making the services in a community easy to use for families require an effective collaboration between primary and subspecialty health care professionals and organizations.

What Is a Medical Home?

The American Academy of Pediatrics, in collaboration with families, other professionals, and public agencies, has developed a model of care called the Medical Home³. A medical home is an approach to providing comprehensive primary care in a high-quality and cost-effective manner. In a medical home a primary care child health professional works in partnership with the family/patient to assure that all of the medical and non-medical needs of the patient are met. Through this partnership, the primary care child health professional can help the family/patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child/youth and family.

Continued

What Is a Medical Home? Continued

The Medical Home is a model of providing care to patients and families that is:

- Accessible,
 - Care is provided in the child’s community
 - All insurance, including Medicaid, is accepted by the provider
- Continuous,
 - The same primary care pediatric health care professionals are available from infancy through adolescence
 - Assistance with transitions (to school, home, and adult services) is provided
- Comprehensive,
 - Health care is available 24 hours a day, 7 days a week
- Preventive, primary, and tertiary care needs are addressed
- Family-centered,
 - The family is the principal caregiver and the center of strength and support for children
 - Unbiased and complete information is shared on an ongoing basis
- Coordinated,
 - Families are linked to support: for example, educational and community-based services
 - Linkages to appropriately trained pediatric subspecialists are assured
 - Pertinent medical information is centralized and available to all care providers with appropriate confidentiality ensured
- Compassionate
 - Concern for the well-being of child and family is expressed and demonstrated
- Culturally effective.
 - Family’s cultural background is recognized, valued, and respected

Who Coordinates Medical Care?

An essential component of the Medical Home model is the ability to provide services that are coordinated. But who is responsible for coordinating care?

Without question, the family and patient are the principal coordinators of care. However, it is vital that all providers within the Medical Home model of care understand their interdependent roles and effectively serve the child and family. Indeed, the collaboration between primary and subspecialty providers is a critical aspect of coordinated care within a Medical Home model.

Goals of This Guide

The goals of this guide are to discuss the complementary roles of generalist and subspecialist physicians in providing coordinated and effective care for CYSHCN. We will emphasize the centrality of family-professional partnerships. We also will describe various models for collaboration among generalist and subspecialist physicians and families. Ultimately, the value of this guide will be to serve as a framework for discussion about how primary and subspecialty care physicians can work collaboratively to enhance the quality of care that CYSHCN and their families receive. While it is essential to appreciate the structural and functional differences among various health care delivery systems, a core expectation for creating Medical Homes is that each system and community will embrace the critical components underlying collaboration outlined in this guide.

Why Is Collaboration Between Primary and Subspecialty Care Providers Important?

The Health Professional Perspective

Policy makers have emphasized the importance of collaboration among all providers of care in the past several years. In 1999, the AAP identified it as a central principle of care coordination.⁴ More recently, the AAP has identified this collaboration as one of 10 services central to providing a Medical Home for children with special health care needs (CSHCN).³ In its report, *Crossing the Quality Chasm*, which dealt more broadly with the quality of health care for children and adults, the Institute of Medicine (IOM) noted, “Although good coordination and communication are essential for all care, they are especially important for chronic care.”⁵ Furthermore, this IOM report made the case that the only way to significantly reduce the frequency of errors occurring in the health care system is to fundamentally change the way care is delivered at the system and community levels. Most recently, the IOM report *Priority Areas for National Action* clearly articulated that a central focus for improving the quality of health care delivery needs to be on the provision of care coordination services, especially for patients with chronic illnesses.⁶ A fundamental component underpinning care coordination is effective communication.

There has been much debate about the respective roles of primary care and subspecialty care physicians in providing a Medical Home to CSHCN. By way of functional definition for this guide, *primary care* is the point of access to the health care system for all new needs and problems. It provides person-focused (not disease-specific) care over time, provides care for

all but very uncommon or unusual conditions, and coordinates care provided by others in the system.⁷ *Subspecialty care* is the component of the health care system that provides disease-specific care for patients. Subspecialty physicians typically have additional training in specific disease entities. However, subspecialists may provide primary care services in addition to their subspecialty activities.

In its recent policy statement defining a Medical Home, the AAP does not limit the assignment of the role of the primary care provider (PCP) to that of a generalist pediatrician. In fact, as long as the operational elements of a Medical Home are provided, the role of the PCP can be fulfilled by either a generalist or a subspecialist physician.³ Furthermore, a recent *Clinical Report* acknowledged that inpatient care for children has become increasingly complex. The AAP summarized the responsibilities of the PCP, the inpatient attending physician, and other specialists involved in caring for hospitalized children to ensure that the care is coordinated and comprehensive, and that it is provided within the context of the child’s Medical Home.⁸

Serious gaps in medical care can occur when a number of medical providers are involved in a child’s care acting in an uncoordinated fashion. Pediatric subspecialty teams providing disease-specific care may not be focused on the primary care needs of children under their care, or some services that might be provided by either generalists or specialists may be done by neither physician. There is lack of consensus about whether the PCP or the specialty pediatrician is best suited to be the preferred provider, highlighting the need for closer communication and dialogue

between providers. The pediatric subspecialist may be best suited to address the categorical and disease-specific needs of CYSHCN, whereas the generalist is in the best position to deal with primary care issues (and to address such local issues as coordination with schools and linkage to community-based organizations). This still leaves the question of who should address non-categorical needs, such as care coordination, routine laboratory monitoring, and acute illness care.

Navigating the Referral System: One Family's Experience

Tres writes: *"When our pediatrician makes all our referrals, and usually to people he knows and has a rapport with, it makes things MUCH easier from the outset. A way to communicate that has been great for us is when the specialist sends an e-mail to our PCP after the visit and I'm cc'd. Then, if there are follow-up questions or clarifications needed, or if I just want to know what my PCP thinks, there's a loop created that we're all part of that's very quick and easy to maintain.*

"My PCP also helps me get in for appointments more quickly than if he gave me a name and I was left to go through the main number to reach them myself. Usually, if he wants me to see someone, he'll call them (or page them) while I'm in his office. He'll tell them what's going on and why he thinks Lauren needs to be seen. This way, when it comes from another physician, it seems more important, and the specialist is often able to see Lauren quickly. (It's often something like, "Can they stop by the office today after lunch?" and they squeeze us in.)

"My PCP has even e-mailed specialists that we need to follow up with if I have a hard time getting a timely appointment, just to let them know that he thinks Lauren needs to be seen and that I've been trying. This usually results in the specialist's office calling me to set something up.

"Finally, there is nothing better than a sit-down, team meeting-type session when the situation calls for it. My PCP has had lunch with specialists when they are deciding what would be the best course of action. We've all met briefly when weighing a difficult decision. This way everyone's views and concerns are addressed. This can also be done via e-mail to make scheduling easier."

What Do Families Need?

The experience of Tres' family reflects the following needs for families:

- **Preparing for a visit with a new provider.** When a family has an established, comforting relationship with a PCP, it can be frightening to venture out with a new provider. Going to see a new provider means having to learn a new practice and how it works and dealing with a new style of interacting. The family needs to know what to expect and that their PCP is actively engaged in this consultation process. The PCP also should let the family know how she will stay in touch with the specialist and the role she will play after the consult.
- **Timely and ongoing communication between PCP and specialist.** Too often, going to a new health care professional means having to "tell one's story" all over again, from the beginning. Families need their PCP to communicate with the specialist before they have an appointment, to share the pertinent background information about their situation. Such communication ensures that details that are critical to the consultation are included and that accurate medical information is shared. On the other side, families need the subspecialist to provide timely feedback to them and to their PCP so that critical decisions can be made and new treatments begun. When there is a long lag between the visit to the subspecialist and the report back, families are left to worry about the negative impact on their children.
- **Appropriate clinical information and previous test results received by the consulting physician before the family's visit.** Families need the specialist to know the reason for the consult and to have the appropriate medical records, films, and test results ready. Having this information readily available can benefit the families and the specialist. It is very frustrating for families to arrive at an appointment with a specialist to find that they are starting from scratch. In such instances, the specialist needs to get basic information and may need to repeat tests and other work-ups that have been done previously, because no information has been organized and shared.

- **PCP follow-up with patients/families after their visit with a specialist to help interpret the consult and make decisions.** The PCP has a long-term relationship with the family and has developed, in partnership with them, the goals and priorities for their child’s care. Families appreciate making important decisions about treatments or understanding information about new diagnoses within the context of this ongoing relationship.
- **Help from the PCP when specialists may offer divergent points of view about needed treatments or the sequence for interventions.** Sorting through complex and conflicting advice from specialists is very hard and frustrating for a family. A sit-down session, as Tres described previously, not only helps the family make a decision, but also can save time in back-and-forth telephone calls. Such a session also can potentially reduce or even eliminate any dissatisfaction with a physician’s treatment recommendation.
- **A bedside visit from the PCP when a child is in the hospital, being treated by specialists.** This visit not only reassures the family that their PCP is up to date on their child’s medical situation and is fully “in the loop,” but it is also emotionally very comforting at a difficult time. It also supports the PCP’s involvement with care provided by hospital-based team, and it facilitates the role of the PCP and family working collaboratively at discharge planning.
- **Help with “out-of-panel” referrals when the physician’s office negotiates a contract with managed care organizations (MCOs).** Under some MCO contracts, requesting an “out-of-panel” consultation may have a direct adverse financial impact on the primary care practice or provider. CYSHCN are likely to require more referral services than other children. Therefore, practice managers should think twice about approving these types of MCO contracts if the practice wishes to service a substantial number of CYSHCN.

Benefits of Collaboration Among Health Care Professionals

Focus groups of families with CSHCN in Ohio report that they have multiple health care providers with whom to coordinate care. They receive little assistance outside of their own family in coordinating care, not by their own choice⁹. A national survey in 2000 of families of CYSHCN reported that 80% of families felt that their child’s primary care physician (PCP) had the appropriate level of skill to care for their child. However, they further reported that about 30% of these PCP’s were not easy to reach in an emergency or for telephone advice. Only about 30% had contact with the child’s or youth’s school or Early Intervention Program¹⁰. So, what can be gained by building collaborative relationships to support medical homes?

The benefits of collaborative care provided within a Medical Home model are numerous:

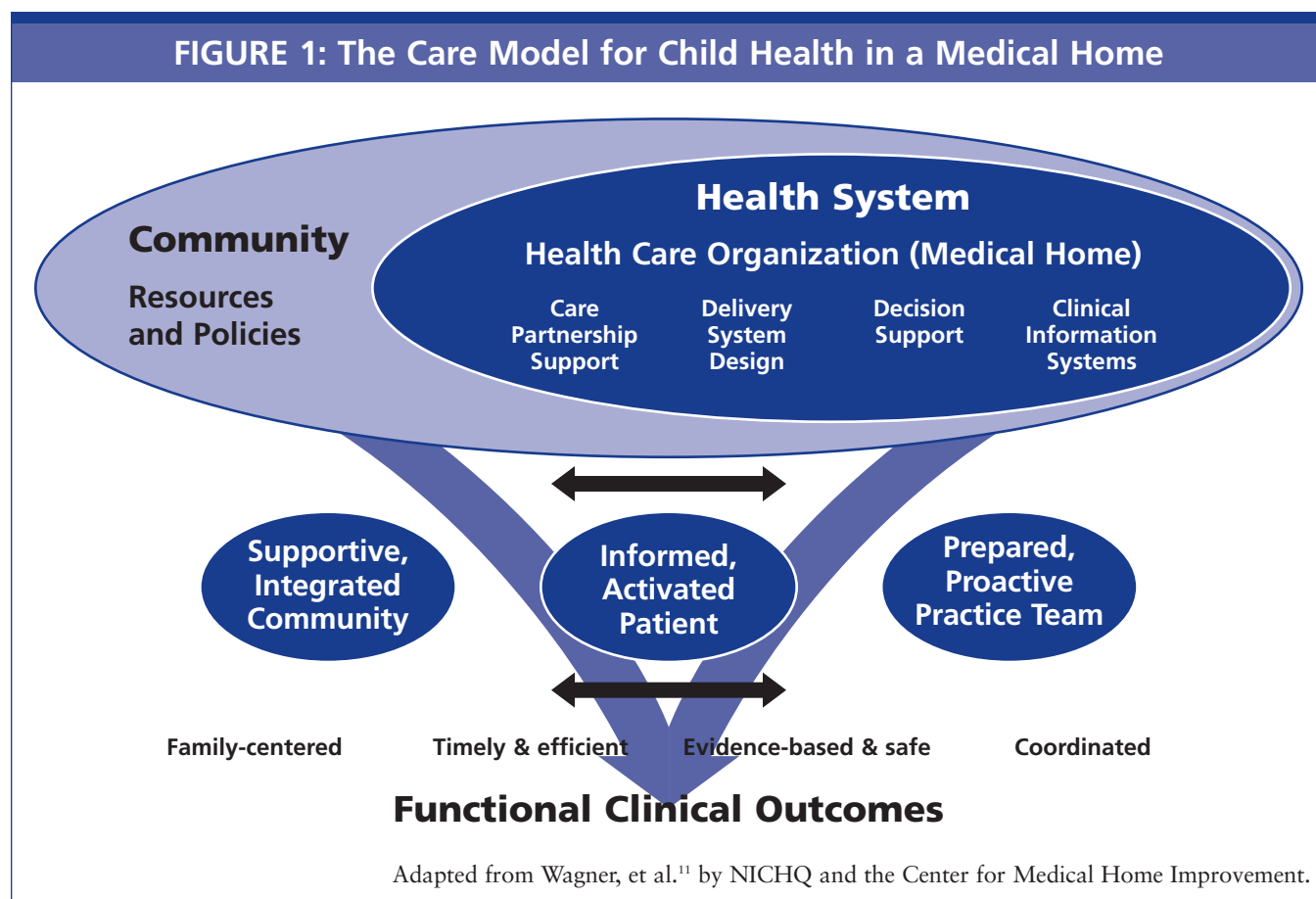
- **Benefits to Families**
 - Care system that is easily accessible
 - Care that is coordinated across health care providers including primary and tertiary care
 - Care that is family centered
 - Families accepted as true partners in the care for their children
- **Benefits to Physicians**
 - Less redundancy
 - Fewer errors
 - Higher satisfaction
 - Greater efficiency and productivity
 - More appropriate use of physician expertise
- **Benefits to Payers**
 - Enhanced cost efficacy
- **Benefits to Community-Based Organizations**
 - Closer collaboration with health care providers and families
 - Resources focused on filling gaps in care with less redundancy

What Is the Framework for a Collaborative Model of Care for CYSHCN?

A Systems Perspective

Wagner and colleagues have developed a model of caring for adults with chronic conditions.¹¹ The faculty of the National Medical Home Learning Collaborative, a joint project of the National Initiative for Children’s Healthcare Quality (NICHQ)¹² and the Center for Medical Home Improvement (CMHI) transformed the core elements of this model into a care model for CYSHCN.¹³

Figure 1, “The Care Model for Child Health in a Medical Home,” depicts the features of this care model within a broad, system-wide organizational context. The system is population-based and creates practical, supportive, evidenced-based interactions between an informed, activated patient and a prepared, proactive practice team. The domain of Decision Support applies particularly to the collaboration among family, PCP, and specialist.



Evidence About Collaboration: What Models Work?

Several investigators have reported good success with models to improve collaboration in some settings. Strategies to improve the broad system of care so that collaboration can occur across a variety of settings and a variety of generalist-subspecialist models have yet to be developed. Successes mainly have been reported in programs involving a single specialty or in specialized, labor-intensive programs serving relatively small numbers of children. Nonetheless, it is possible to learn from some of the successes that have been described.

Models of Shared Care

Because CYSHCN may have a variety of conditions of differing levels of severity, no “one-size-fits-all” model of collaboration can be adopted. Hack presents a spectrum of models that may be useful for providers as well as families.¹⁴ In one model, the generalist serves as the primary manager with occasional specialty consultation. A second model creates a “co-management” relationship with close involvement of each provider. A third involves care provided principally by the specialist for most services, with the generalist acting only as “gatekeeper” or single point of entry to the care system. Appropriate use of each model depends on 1) the severity and complexity of the child’s condition; 2) the expertise, interest, and availability of each type of provider; 3) the access of families to the various providers; and 4) the comfort of families and providers with different care situations.

The case of a child with moderately severe asthma, who is managed primarily by a generalist with occasional consultation from a specialist, is an example of the *generalist as manager model*. The efficacy of this model presumes that the generalist and family feel mutually comfortable with implementing a comprehensive care plan, the family’s access to the generalist is good (or access to specialty

care is limited) and the child’s clinical course is relatively straightforward. This model also presumes that there is a collaborative linkage between the generalist and the subspecialist.

The *co-management model* might be most appropriate in the case of a child with Type I diabetes and attention deficit hyperactivity disorder (ADHD). In such a case, the generalist manages behavioral issues and most acute illnesses, but the specialist primarily undertakes the long-term management of the child’s diabetes. This model requires that the family have reasonable access to each type of provider. Clearly, the success of this model requires well-orchestrated coordination of care and communication among providers.

The *specialist as manager model* might be best for some children with particularly rare or complex conditions, such as those with some congenital metabolic diseases or with malignancies. In this model, the clinical skills necessary to manage the child may be so specialized that only the subspecialist has the necessary training to provide comprehensive care. In order for the child to receive a comprehensive, Medical Home-based plan of care within this paradigm, the subspecialist must be able to coordinate all aspects of the child’s medical and non-medical service needs. Alternatively, the subspecialist must clearly delineate those needs that will be delegated to a collateral provider (a primary care or another subspecialty provider). Of course, the family must be fully aware of which provider is responsible for what elements of care.

Another example in support of a subspecialist as primary manager model is the child with myelomeningocele, in which a multispecialty team at a referral center manages multiple complex problems. This scenario presumes that the family has easy access to the center. It also presumes that a very busy generalist is not able to provide the extra time that the family needs.

Choosing the Model

Choosing the appropriate model must be done on a family-by-family basis, relying on a mutually deliberative process among the providers in partnership with the family. A number of factors influence the decision:

- **Factors Related to the Child or Youth**
 - Complexity of the condition
 - Acuity of the condition
 - Chronicity of the condition
- **Factors Related to the Family**
 - Family’s preference
 - Family’s transportation resources
 - Family’s support needs
 - Family’s insurance benefit package
- **Factors Related to the Health Care System**
 - Primary Care
 - Capacity
 - Access
 - PCP’s level of training/comfort with the condition of CYSHCN
 - Ease of linkage to tertiary care system
 - Subspecialty Care

- Capacity
- Access
- Ease of linkage to primary care system

- **Factors Related to the Community**
 - Resources accessible to families and CYSHCN
 - Availability of Title V services

Table 1 demonstrates the determinants for each model of care. It is essential that the family be actively involved with the choice of a co-management model.

Increased generalist-specialist collaboration is increasingly preferred by families and providers. Recent studies seem to favor co-management, as described below:

- Generalists who receive more support and education from specialty programs report increased comfort with co-management¹⁵; and
- Some studies report families favoring the generalist as point of first contact for all routine needs (and many disease-specific needs), especially if children had a lower severity of disease¹⁶.

TABLE 1: Patient, Provider, and Community Characteristics as Determinants of Models of Co-Management for CYSHCN

Model	Access to Primary Care	Access to Subspecialty Care	Complexity of Condition	Access to Specialized Services
PCP as Primary Manager	adequate	adequate or limited	low-moderate	limited or adequate
PCP/SP Co-Management	adequate	adequate	moderate-high	adequate
SP as Primary Manager	adequate or limited	adequate	high	adequate

PCP = primary care provider; SP = subspecialist

Implementation of Collaborative Care Between Primary and Subspecialty Care Providers

Setting the Agenda for Comprehensive, Collaborative Care for CYSHCN

A key element of the Medical Home model of care is a comprehensive needs and strengths assessment developed in conjunction with the family. The information from this assessment and the resulting care plan will support effective collaboration within the medical system and among community partners. The assessment should include a thorough review of the medical and non-medical needs. Many tools exist that can be used to perform this needs assessment. Figure 2, “Medical Home Assessment Information,” shows the range of items that support a Medical Home-based needs and strengths assessment. Other tools have been developed that present families with an open format for discussing their needs (Figure 3, “Nashaway Pediatrics Pre-Visit Survey,” and Figure 4, “Nashaway Pediatrics—Children’s Pre-Visit Survey”). The use of these tools represents an opportunity to communicate to families the message that the providers of the Medical Home model value their input; validate the ability to share all concerns, medical and non-medical; and encourage interactions that begin with open-ended agendas. Indeed, the Pre-Visit surveys shown in Figures 3 and 4 were developed, piloted, and implemented by the family partners within that pediatric practice. Assessments of the specific cultural and/ or linguistic needs of the child or youth and family also must be documented on the communication tools that are generated by the members of the care team.

Following this thorough needs and strengths assessment, a Medical Home-Based Care Plan is developed to guide the provision of services to the child or youth and family. Depending on the composition of the pediatric office, the personnel responsible for collecting the needs data can vary from clinical support staff, to physicians, to a dedicated care coordinator. In other models of care delivery, community-based personnel may play an important role as facilitators. These include public health nurses, Title V-funded care coordinators, Early Intervention specialists, child care providers, emergency response personnel, and school-based clinic staff. Care plans are composed of several components: 1) a medical summary of the child or youth, 2) an emergency care plan and 3) an action plan.

The *medical summary* includes patient demographics, diagnoses, medications, medication allergies, and other pertinent historical and contemporary medical, surgical, and rehabilitative information. The medical summary is useful as a portable archive, so that accurate data is readily available when the child or youth is evaluated by covering PCP’s, by consulting subspecialists, or by other providers (eg, Early Intervention specialists, school-based nurses, case managers, and Title V personnel involved with care coordination). It is essential that the medical summary be kept up-to-date. In addition, the family and youth must be aware of the content of the summary and approve what data is shared with which affiliated providers. An example of a medical summary template is shown in Figure 5.

FIGURE 2: Medical Home Assessment Information

Name: _____ Medical Record Number: _____
 Date of Birth: _____ Sex: _____ Telephone Number: _____
 Parent/Caregiver Name: _____ Relationship: _____
 Primary Diagnosis: _____ Secondary Diagnosis: _____
 Primary Care Physician: _____
 Dentist: _____
 Specialist(s): _____
 Insurance: _____
 HMO PPO CCS Medi-Cal Healthy Families Share of cost? Other _____
 Insurance ID/Group Number: _____
 Health History: _____

QUESTIONS:

1. Services received by client/family (check and complete any that apply):

<input type="checkbox"/> DCFS: _____	<input type="checkbox"/> Special Education: _____
<input type="checkbox"/> Food Stamps: _____	<input type="checkbox"/> Special Care Center: _____
<input type="checkbox"/> WIC: _____	<input type="checkbox"/> SSI: _____
<input type="checkbox"/> TANF (AFDC): _____	<input type="checkbox"/> Mental Health: _____
<input type="checkbox"/> CCS: _____	<input type="checkbox"/> MTU: _____
<input type="checkbox"/> Head Start: _____	<input type="checkbox"/> Other: _____

2. Other services requested by parent/caregiver (check and complete any that apply):

<input type="checkbox"/> Child/Dependent Care: _____	<input type="checkbox"/> Shelter/Energy: _____
<input type="checkbox"/> Education: _____	<input type="checkbox"/> Support/Counseling: _____
<input type="checkbox"/> Food/Nutrition: _____	<input type="checkbox"/> Training: _____
<input type="checkbox"/> Health/Medical: _____	<input type="checkbox"/> Transportation: _____
<input type="checkbox"/> Income Assistance: _____	<input type="checkbox"/> Dental Care: _____
<input type="checkbox"/> Mental Health: _____	<input type="checkbox"/> Other: _____

3. What are your concerns about your child’s health/medical care? Explain.

Continued

FIGURE 2: Medical Home Assessment Information Continued

3. What are your concerns about your child's health/medical care? Explain.

4. Do you feel you are able to get all the care you need for your child? Explain.

5. Do you have any concerns about your child's behavior or development? Explain.

6. Are there any family problems/concerns that might affect your child? Explain.

Plan: _____

Rx referral completed.

Other _____

Signature of person completing form: _____ Date: _____

Adapted from: Los Angeles County Department of Health Services, California Children Services Caregiver Contact Triage Form.

Funded by the Department of Health Services Maternal Child Health Bureau Grant No. MCJ-06IS02-01-0

Downloaded from <http://www.medicalhomeinfo.org/tools/assess.html> 7/15/05

FIGURE 3: Nashaway Pediatrics Pre-Visit Survey*

This survey is to be used as a tool to help you organize your thoughts concerning your child(ren) and family. Completing it will enable our practice to assist you with any needs or concerns. Completion of the form is voluntary and you may decide if you wish to have it placed in your child's record, or you may take it with you.

Child's Name: _____ Date of Birth: _____

1. During the past 6 months, how much of the time did you worry about your child's health?

- none of the time
- a little of the time
- most of the time
- all of the time

2. Do you have any concerns about the following issues for your child?

- development differing peers
- ability to learn
- falling behind in school
- sleeping
- loneliness
- behavior
- substance use or abuse
- other(s)
- being independent
- self-care issues
- the future
- making/keeping friends
- participation in activities
- self-esteem
- eating or diet concerns
- sibling issues

3. Of the above concerns, which are the two most on your mind today?

- a. _____
- b. _____

4. What are your family's greatest strengths?

- communication
- fun/play/sports
- artistic
- other

5. What are your child's greatest strengths?

- communication
- fun/play/sports
- artistic
- other

6. Do you need help coordinating any aspects of your child's care? YES NO

If so, with what do you feel you need assistance?

- healthcare
- childcare
- insurance
- mental health
- education
- other

7. Are any of the following issues troubling your family at this time?

- divorce/separation
- substance abuse
- sexual abuse
- domestic abuse: physical verbal
- other
- death in the family
- sickness in the family
- lay-off/unemployment
- lack of insurance

8. Would you like this to be part of your child's record? YES NO

Initial here _____

**The Nashaway Pediatrics parent Advisory group (PAG) developed this survey. The PAG is a group of parent volunteers who serve as advisors to the staff of Nashaway Pediatrics. If you would like to become a member of our PAG, please speak with your pediatrician.*

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FIGURE 4: Nashaway Pediatrics Children's Pre-Visit Survey*

As you wait to see the pediatrician or nurse practitioner today, you may fill out this paper. You may also choose to share it with us. The grown-up who came with you today can help you answer the questions.

Name: _____ Date of Birth: _____

What I like about myself

- | | |
|-------------------------------------|-------------------------------------------|
| <input type="checkbox"/> How I Look | <input type="checkbox"/> My School Work |
| <input type="checkbox"/> My Family | <input type="checkbox"/> My Body's Height |
| <input type="checkbox"/> My Friends | <input type="checkbox"/> My Body's Weight |

Other things I am good at _____

Things I might worry about

- | | |
|-------------------------------------|-------------------------------------------|
| <input type="checkbox"/> How I Look | <input type="checkbox"/> My School Work |
| <input type="checkbox"/> My Family | <input type="checkbox"/> My Body's Height |
| <input type="checkbox"/> My Friends | <input type="checkbox"/> My Body's Weight |

Other things I might worry about _____

I wish I were better at _____

If you would like, please use the back of this paper to draw a picture of yourself doing anything you choose.

**Developed by Nashaway Pediatrics, Parent Advisory Group*

Revised 02/03

The *emergency care plan* is a vital (and potentially life-saving) tool that needs to be portable and immediately available to personnel working with CYSHCN in hospital emergency departments, clinic settings, community settings (eg, school, child care, athletic venues, or other social settings), and even in the home of the child or youth. Be aware that the target audience for the emergency care plan includes nurses, physicians, and community-based Emergency Medical System (EMS) personnel. The content of this care plan must reflect the potential variability of the experience and training of the emergency responders. Figures 6 and 7 represent templates for emergency care plans.

The *action care plan* becomes a clear road map for supporting the needs of the family and child or youth. The mutual efforts of the family, associated community-based organizations (CBOs), and the health care team, (reflecting all the care elements within the Medical Home), are brought together in the action plan. The *action care plan* defines the explicit care needs at a given point in time; indicates the locus of responsibility for pursuing the action items; the expected outcomes for each action step; and the time frame in which each step should occur. It defines the framework for communication, coordination, and partnership among the family, PCP, subspecialists, and allied care providers within CBO's.

Action care plans are valuable for tracking progress within the primary care office setting as well. For example, following a visit with the primary care provider, the family may encounter a barrier in pursuing a particular referral. The family member contacts the office, and the assigned contact responds to the inquiry by reviewing the *action plan*. Problem solving is facilitated because the intent of the action plan is explicit and clear and the office-based resource (e.g., nurse, care coordinator, referral manager) is able to help the family work toward the expected outcome. This function of care coordination may or may not necessitate direct physician involvement. Figure 8 is an example of a diagnosis-

specific action care plan pertinent to asthma. The critical elements of monitoring of the patients' clinical status, the family-based response for given levels of symptom severity, and explicit descriptions of communication linkages and accountability make this document extremely valuable as a guideline for on-going surveillance and intervention. Note that the use of this action plan serves as a vital tool in teaching the CYSHCN and the family about chronic disease-specific management. The *action plan* must be monitored for timeliness as the patients' and families' needs and circumstances change with respect to condition severity and resource availability.

Action Care plans can also be non-diagnosis specific (i.e., non-categorical). Figure 9 is an example of such an *action plan*. It has general utility in any acute, episodic visit, but it can also be used for planned chronic condition management visits with a broad range of needs to be addressed. It is portable, dynamic, and is critical in defining outcome expectations, role responsibilities, time frames, and follow-up goals. It can easily be adapted to be community-specific with regard to frequently utilized resources. Copies are kept in the chart of the CYSHCN at the PCP's and subspecialists' offices, sent home with the family, and can be shared with appropriate allied Medical Home providers.

The Medical Home-Based Care Plan as a Tool for Enhancing Collaboration

The value of a comprehensive Medical Home-Based Care Plan cannot be overstated. Indeed, the care plan becomes a core component of the collaborative relationship between the primary and subspecialty care providers. Working in concert with the families and CYSHCN, the primary and tertiary care physicians can amend each of the components of the care plan at any time. Thus, the Care Plan becomes a dynamic tool reflecting the evolving service needs and resource allocation within the patient's Medical Home.

FIGURE 5: Hitchcock Clinic Concord—Pediatric Care Plan

PART I

Child's Name: _____ Nickname: _____ DOB: _____
 Parent (Caregiver) _____ (Relationship) _____
 Address _____
 Phone #(home) _____ (Blocked? Y__N__) Best time to reach _____ E-mail _____
 Mom Alternate Phone _____ Dad Alternate Phone _____

 Emergency Contact _____ Phone _____ Relationship _____
 Emergency Contact _____ Phone _____ Relationship _____
 Health Insurance/Plan _____ Identification # _____

Diagnose(s): Emergency Plan Yes No **Complexity Level** _____
 Primary _____ ICD9 _____ Primary _____ ICD9 _____
 Secondary _____ ICD9 _____ Secondary _____ ICD9 _____
 Secondary _____ ICD9 _____ Secondary _____ ICD9 _____

Allergies/reaction: _____

Medications/dose: _____

PCP _____ Phone _____ Fax _____ E-mail _____

#1 Specialist/Specialty Clinic/Hospital Phone	Other (fax, e-mail, etc.):
#2	Other (fax, e-mail, etc.):
#3	Other (fax, e-mail, etc.):
#4	Other (fax, e-mail, etc.):

Nurse Service/Respite _____ Phone _____

Continued

FIGURE 5: Hitchcock Clinic Concord—Pediatric Care Plan Continued

PART II: CHILD DESCRIPTION

Child's Name: _____ Nickname: _____ DOB: _____

Child's Assets & Strengths _____

Vital Sign (baselines)

Ht _____ Wt _____ Temp _____ Other _____

Challenges (check all that apply, please explain on lines below)

- | | | |
|--------------------------------------------|-----------------------------------------------------|------------------------------------------|
| <input type="checkbox"/> Behavior | <input type="checkbox"/> Learning | <input type="checkbox"/> Stamina/Fatigue |
| <input type="checkbox"/> Communication | <input type="checkbox"/> Orthopedic/Musculoskeletal | <input type="checkbox"/> Respiratory |
| <input type="checkbox"/> Feed & Swallowing | <input type="checkbox"/> Physical Anomalies | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Hearing/Vision | <input type="checkbox"/> Sensory | <input type="checkbox"/> Other _____ |

Procedures/foods/activities to be avoided: _____

Prior surgeries/procedures:

_____ Date _____	_____ Date _____
_____ Date _____	_____ Date _____
_____ Date _____	_____ Date _____

Most recent labs/diagnostic studies:

Labs _____	EEG _____
_____	EKG _____
_____	X-rays _____
Drug Levels _____	C-Spine _____
_____	Other _____
_____	Other _____
MRI/CT _____	_____

Continued

FIGURE 5: Hitchcock Clinic Concord—Pediatric Care Plan Continued

PART II: CHILD DESCRIPTION

Equipment/appliances/assistive Technology (Please check all that apply and use the lines below to explain on lines)

- Gastrostomy Adaptive Seating Wheelchair
- Tracheostomy Communication Device Orthotics
- Suction Monitors: Apnea O2 Crutches
- Nebulizer Cardiac Glucose Walker
- Other _____

School System/Child Care:	Contact Person/Role:	Phone:
_____	_____	_____
_____	_____	_____
_____	_____	_____

Family Information:

Caregivers _____

Siblings _____

Other important facts _____

Special Circumstances/Comment/What you would like us to know:

_____ Parent/Caregiver Signature & Date	_____ Primary Care Provider Signature & Date
-------------------------------------------------------	------------------------------------------------------------

FIGURE 6: Specialized Emergency Information Hitchcock Clinic Concord

Child's Name: _____ Nickname: _____ Date: _____

Common Presenting Problems/Findings with Specific Suggested Managements

() See specialist letter(s) Attached

Problem #1	Presenting Signs & Symptoms
Suggested Diagnostic Studies	Treatment Considerations:

Problem #2	Presenting Signs & Symptoms
Suggested Diagnostic Studies	Treatment Considerations:

Problem #3	Presenting Signs & Symptoms
Suggested Diagnostic Studies	Treatment Considerations:

Comments on child, family, or other specific medical issues:

Physician/Provider	Signature	Print Name
Family/guardian signature giving consent for release of this information to the emergency room		Print Name

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FIGURE 7: Emergency Information Form for Children With Special Needs

	Date form completed	Revised	Initials
	By Whom	Revised	Initials

Name:		Birth Date:	Nickname:
Home Address:		Home/Work Phone:	
Parent Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		

Physicians:	
Primary care physician:	Emergency Phone:
	Fax:
Current Specialty physician: Specialty:	Emergency Phone:
	Fax:
Current Specialty physician: Specialty:	Emergency Phone:
	Fax:
Anticipated Primary ED:	Pharmacy:
Anticipated Tertiary Care Center:	

Diagnoses/Past Procedures/Physical Exam:	
1. _____	Baseline physical findings: _____
_____	_____
2. _____	_____
_____	_____
3. _____	Baseline vital signs: _____
_____	_____
4. _____	_____
_____	_____
Synopsis: _____	_____
_____	Baseline neurological status: _____
_____	_____
_____	_____

*Consent for release of this form to health care providers

Continued

FIGURE 7: Emergency Information Form for Children With Special Needs Continued

Diagnoses/Past Procedures/Physical Exam Continued:		
Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):	
1. _____	_____	
2. _____	_____	
3. _____	_____	
4. _____	Prostheses/Appliances/Advanced Technology Devices:	
5. _____	_____	
6. _____	_____	
Management Data:		
Allergies: Medications/Foods to be avoided	and why:	
1. _____	_____	
2. _____	_____	
3. _____	_____	
Procedures to be avoided	and why:	
1. _____	_____	
2. _____	_____	
3. _____	_____	
Immunizations		
Dates	Dates	
DPT	Hep B	
OPV	Varicella	
MMR	TB status	
HIB	Other	
Antibiotic prophylaxis:	Indication:	
_____	Medication and dose:	
_____	_____	
Common Presenting Problems/Findings With Specific Suggested Managements:		
Problem	Suggested Diagnostic Studies	Treatment Considerations
_____	_____	_____
_____	_____	_____
Comments on child, family, or other specific medical issues:		

Physician/Provider Signature:		Print Name:
_____		_____

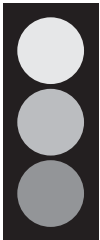
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FIGURE 8: Asthma Action Plan

Massachusetts Asthma Action Plan

The colors of a traffic light will help you use your asthma medicine.

Name:		Date:
Birth Date:	Doctor/Nurse Name	Doctor/Nurse Phone #
Patient Goal:		Parent/Guardian Name & Phone
Important! Avoid things that make your asthma worse:		



Green means Go Zone!
Use controller medicine.

Yellow means Caution Zone!
Add quick-relief medicine.

Red means Danger Zone!
Get help from a doctor.

Personal Best Peak Flow: _____

GO – You’re Doing Well! ➔ **Use these daily controller medicines:**

You have **all** of these:

- Breathing is good
- No cough or wheeze
- Sleep through the night
- Can go to school and play



Peak flow from _____ to _____

MEDICINE/ROUTE	HOW MUCH	HOW OFTEN/WHEN

CAUTION – Slow Down! ➔ **Continue with green zone medicine and add:**

You have **any** of these:

- First signs of a cold
- Cough
- Mild wheeze
- Tight Chest
- Coughing, wheezing, or trouble breathing at night



Peak flow from _____ to _____

MEDICINE/ROUTE	HOW MUCH	HOW OFTEN/WHEN

CALL YOUR DOCTOR/NURSE: _____

DANGER – Get Help! ➔ **Take these medicines and call your doctor now.**

Your asthma is getting worse fast:

- Medicine is not helping
- Breathing is hard and fast
- Nose opens wide
- Ribs show
- Can’t talk well



Peak flow from _____ to _____

MEDICINE/ROUTE	HOW MUCH	HOW OFTEN/WHEN

GET HELP FROM A DOCTOR NOW! Do not be afraid of causing a fuss. your doctor will want to see you right away. It’s important! If you cannot contact your doctor, go directly to the emergency room and bring this form with you. DO NOT WAIT.

Make an appointment with your doctor/nurse within two days of an ER visit or hospitalization.

Doctor/NP/PA Signature: _____ Date: _____

I give permission to the school nurse, my child’s doctor/NP/PA or _____ to share information about my child’s asthma

Parent/Guardian Signature: _____ Date: _____

****SEE BACK OF SCHOOL COPY FOR STUDENT MEDICATION ADMINISTRATION AUTHORIZATION****

Continued

FIGURE 8: Asthma Action Plan Continued

****IMPORTANT INSTRUCTIONS: SEPARATE THIS PAGE BEFORE WRITING****

Consent for administration of medication in school:

I consent to have the school nurse or school personnel designated by the school nurse administer the medication as prescribed the reverse side of page.

Parent/Guardian Signature _____ DATE _____

Authorization for student self-administration of medication in school:

I have instructed this student in the proper way to use his/her medications. Medications administered must be consistent with school policy and a medication plan must be developed with the school nurse in accordance with the Massachusetts Regulations Governing the Administration of Prescription Medications in Public and Private Schools (105 CMR 210.000), as printed below. Translated copies of the regulation can be obtained from the Massachusetts Department of Public Health 250 Washington Street, Boston, MA 02118. It is my professional opinion that this student may self-administer the medication and may be allowed to carry and use his/her medications by him/herself.

COMMENTS/SPECIAL INSTRUCTIONS:

SIGNATURES

DATE

Student's Doctor/Nurse _____

Parent/Guardian _____

Medication administration plan completed _____

School Nurse's approval _____

SIGNATURE

Listed below are regulations governing the self – administration of Prescription medication 105 CMR 210.006

- (A) Consistent with school policy, students may self-administer prescription medication provided that certain conditions are met. For the purposes of 105 CMR 2100.000, "self administration" shall mean that the student is able to consume or apply prescription medication in the manner directed by the licensed prescriber, without additional assistance or direction.
- (B) The school nurse may permit self medication of prescription medication by a student provided that the following requirements are met:
 - (1) the student, school nurse and parent/guardian, where appropriate, enter into an agreement which specifies the conditions under which prescription medication may be self administered;
 - (2) the school nurse, as appropriate, develops a medication administration plan (105 CMR 210.005 (E) which contains only those elements necessary to ensure safe self administration of prescription medication;
 - (3) the school nurse evaluates the student's health status and abilities and deems self-administration safe and appropriate. As necessary, the school nurse shall observe initial self-administration of prescription medication;
 - (4) the school nurse is reasonably assured that the student is able to identify the appropriate prescription medication, knows the frequency and time of day for which the prescription medication is ordered, and follows the school self administration protocols;
 - (5) there is written authorization from the student's parent or guardian that the student may self medicate, unless the student has consented to treatment under M.G.L. c. 112,§ 12F or other authority permitting the student to consent to medical treatment without parental permission;
 - (6) if requested by the school nurse, the licensed prescriber provides a written order for self administration;
 - (7) the student follows a procedure for documentation of self-administration of prescription medication;
 - (8) the school nurse establishes a policy for the safe storage of self-administered prescription medication and, as necessary, consults with teachers, the student and parent/guardian, if appropriate, to determine a safe place for storing the prescription medication for the individual student, while providing for accessibility if the student's health needs require it. This information shall be included in the medication administration plan. In the case of an inhaler or other preventive or emergency medication, whenever possible, a backup supply of the prescription medication shall be kept in the health room or a second readily available location;
 - (9) the school nurse develops and implements a plan to monitor the student's self-administration, based on the student's abilities and health status. Monitoring may include teaching the student the correct way of taking the prescription medication, reminding the student to take the prescription medication, visual observation to ensure compliance, recording that the prescription medication was taken, and notifying the parent, guardian or licensed prescriber of any side effects, variation from the plan, or the student's refusal or failure to take the prescription medication;
 - (10) with parental/guardian and student permission, as appropriate, the school nurse may inform appropriate teachers and administrators that the student is selfadministering a prescription medication.

Copyright 2001, Massachusetts Health Quality Partners, Massachusetts Asthma Action Plan.
 The Massachusetts Asthma Action Plan was developed by Massachusetts Health Quality Partners (MHQP) and the New England Public Health and Managed Care Collaborative. MHQP is a broad-based coalition of physicians, hospitals, health plans, purchasers and government agencies working together to promote improvement in the quality of health care services in Massachusetts.

FIGURE 9: Nashaway Family-Centered Health Care Plan

<p>NASHAWAY PEDIATRICS—UMassMemorial Health Care P.O. Box 639 Sterling, MA 01564 Phone (978) 422-6900 Fax (978) 422-7561</p>		<p>Richard C. Antonelli, MD, FAAP Kathleen Cleary, MD, FAAP Lucille Kanjer Larson, MD, FAAP Deborah Francis, MD, FAAP Elizabeth Madden, PNP</p>	
<p>Medical Home Family-Centered Health Care Plan</p>			
<p>Prepared for: _____ Prepared by: _____ Nashaway Contact Person: _____</p>		<p>Date Prepared: _____</p>	
<p>Problem</p>	<p>Activity</p>	<p>Who will do</p>	<p>When</p>
			<p>Expected Outcome</p>
			<p>Follow-Up</p>
<p>Resources</p> <p>UMIMHC Early Intervention DPH Case Management Memorial Rehab Family TIES</p>		<p>CHADD (Leominster) SSI Eligibility Federation for Children with Special Needs MSPCC Parents as Teachers Program Nashaway Pediatrics: www.nashawaypediatrics.yourmd.com NICHY (Information Center)</p>	
<p>Downloaded from http://www.medicalhomeinfo.org/tools/assess.html on 7/15/05.</p>			

Within the framework of the chosen model of management, the care plan is an important tool for transmitting information about a child or youth to each member of the care team. The document defines the inter-dependent linkages among families, the children or youth, CBOs, primary and subspecialty care providers, and Title V programs. The information can be recorded and transmitted electronically or in hard copy format. Copies must be distributed in a timely fashion to all appropriate care team members with the permission of the family and youth.

Creating Key Relationships

Effective communication and coordination are based on collaborative relationships. For the families, it is helpful for the PCP to create a familiar circle of specialists with whom you collaborate on an ongoing basis. Of course, families should always have a choice, but you can explain the value of your ongoing relationship with the specialist to enhance coordination of care. This carefully selected circle of partners helps facilitate team building and enhances communication between the PCP and the specialist. A closer working relationship between the PCP and the specialist will benefit both the PCP and the family. The PCP will have the needed information, and the family is more likely to follow through with plans when they know they can turn to their PCP for guidance and reassurance.

Take opportunities to meet the specialists in person. If they are local, try to meet them when you are in the hospital at rounds, at staff meetings, at grand round sessions, or at local educational or other meetings. Use integrated care networks through hospitals or MCOs to make those contacts. If you are in an area where families have to travel longer distances for specialty care, consider making a visit to the consulting specialists or inviting them to do a continuing education event in your community. Telephone calls are also a way to build the relationship.

PCPs can turn to specialists for supports needed in co-management of CYSHCN because of their closer working relationships. Shared management systems

in which generalists are given the opportunity to provide much disease-specific care for children who live far from a referral center can be effective if appropriate supports are in place for the PCP. Supports include education about protocols, 24-hour access to consultation, computerized tools to navigate complex treatment plans, educational manuals, or continuing medical education courses.

Creating Effective Communication Strategies

Effective communication among the PCP and the subspecialist and the family is critical to coordinated, collaborative care. The first part of the communication process occurs when the PCP requests a consult from the subspecialist or seeks ongoing involvement in the patient's management. This communication should be seen as being on behalf of the family to make sure that the visit to the specialist is efficient and productive. Key medical information as well as family questions or concerns should be conveyed. Figure 10, "Elements of Information Exchange: Primary Care Physician to Subspecialist," presents the essential elements for communication from the PCP to the subspecialist. Note that some of these elements are contained within a standard Care Plan. Therefore, the consultation request and response forms may exclude this summary if each provider and the family already hold the most up-to-date care plan.

The other part of the communication process is from the subspecialist to the PCP and the family. This part of the process may be seen as the subspecialist's response to a request for consultation from the PCP. But in cases in which the subspecialist is the primary care manager, the communication may be related to aspects of care that are not being addressed by the subspecialist and that need to be performed or facilitated by the PCP. For example, the community PCP may best address routine immunizations or school-related health requirements. Figure 11, "Elements of Information Exchange: Subspecialist to Primary Care Physician," reflects the key elements of communication from the subspecialist to the PCP.

FIGURE 10: Elements of Information Exchange: Primary Care Physician to Subspecialist

- Patient Name
- DOB
- Reason for Referral
- Summary of pertinent past medical history, family history, and social history
 - Including medication history and drug allergies
- Questions to be addressed by consultant as determined by family, youth, primary care physician (PCP), and other service providers (e.g., teachers, counselors, and others)
- Requested role of subspecialist (SP) as consultant:
 - Occasional consultation with PCP
 - Active co-management
 - SP to be primary care manager
 - To be determined prospectively
- Mode of communication link to PCP
 - Telephone
 - Fax
 - Electronic
 - Written report by mail
- Mode of communication link to family/patient
 - Directly to family/patient
 - Through PCP as liaison
- Request for educational materials
 - Brochures for family, youth, and children
 - Technical articles for PCP
 - Information about community-based resources

Underlying all role definitions of the PCP and the subspecialist is the presumption that the family/ youth will be integral to developing the overall Care Plan and will approve the roles of the respective providers.

In addition to the basic information, communications should include information that will facilitate the co-management model chosen and will help the family understand who will be responsible for the various aspects of the care plan. When recommendations are made for follow-up testing, the provider must be explicit and clear about who will be responsible for ordering the test, who will seek the results, and who will report the results of the test to the family and provider team. Similarly, responsibility for following up on therapeutic interventions must be predetermined. Except under extraordinary circumstances, it is advisable for providers to transmit copies of consultative letters directly to families as well. Such

FIGURE 11: Elements of Information Exchange: Subspecialist to Primary Care Physician

- Patient Name
- DOB
- Reason for Referral
- Summary of pertinent history, physical examination, laboratory
 - including medication history and drug allergies
- Suggested role of subspecialist (SP) as consultant:
 - Occasional consultation with primary care physician (PCP)
 - Active co-management
 - SP to be primary care manager**
 - To be determined prospectively
- Mode of communication link to SP by family/youth and by PCP
 - Telephone
 - Fax
 - Electronic
 - Pager
- Mode of communication to family/patient
 - Directly to family/patient
 - Through PCP as liaison

**When the SP will be the primary care manager, the suggested role of the PCP must be made clear to the PCP and to the family/youth. Specifically, the SP should clarify:

- whether the PCP will coordinate all other aspects of care besides what the SP will provide; or
- whether the PCP will provide liaison support to the SP and the SP will provide for all medical and non-medical needs while functioning as the Medical Home coordinator.

information will provide a tool to help organize a later discussion between the family and affiliated providers. Various technologies for transmitting information are typically used. Generally, time urgency should dictate the mode of communication. For example, telephone contact should be used for emergent issues; fax and electronic mail for expedited transfer. Traditional “hard copy” on letterhead sent via external mail service is quite slow.

Identify a general process for communication that is efficient and that provides a structure for a rapid communication response. One approach is a “clinical fax-back sheet” that should include your fax, voicemail, and back-office telephone numbers. Encourage the consultant to briefly respond with the same form as soon as possible, preferably before sending the full consultation report. Figure 12 presents a template for such a tool.

FIGURE 12: Referral Fax Back Form

Practice Name

Telephone #

Fax #

Referral Fax Back Form

Thank you for participating in the care of our patient.

Patient Name _____ DOB _____

Parents Name _____

Primary Insurance _____ Secondary _____

Diagnosis _____

Problem List 1 _____ 2 _____ 3 _____

Reason for Referral _____

Current Medications 1 _____ 4 _____

2 _____ 5 _____

3 _____ 6 _____

In an effort to facilitate future care, please complete the information below and fax this form back to our office.

Diagnosis _____

Needs Identified _____

Referrals needed for follow up:

Referral to: _____ Diagnosis/Reason _____

Referral to: _____ Diagnosis/Reason _____

Laboratory tests to be performed _____

Radiology studies to be performed _____

Signature/Date _____

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When a good communication relationship exists between subspecialist and PCP, the PCP will be up to date and in the best position to help the family interpret the consult. Focus on whether the family understood the information they received and whether they felt generally well cared for.

Patient Confidentiality Issues

In April 2003, the Health Insurance Portability and Accountability Act (HIPAA) was implemented. Designed to safeguard personal, confidential, medical information, HIPAA regulations require that personal health information (PHI) be transmitted only with the explicit permission of the patient (or family/guardian, in the case of a minor).¹⁷ In general, when referrals are made among physicians, there is implied permission for information exchange. However, there may be elements of a patient's history for which health care providers must seek explicit permission for information release. The referring physician must ensure that certain sensitive information is released only with the permission of the family and/or patient. Certain types of information require the specific permission of the patient exclusively for release. This includes, for example, information about pregnancy in adolescents.

If the patient or family has not given permission for information release, health care providers may only exchange information that has no specific patient identification data attached. This scenario may be especially useful when one physician is requesting an informal consultation from another about a specific condition rather than about a particular patient.

Patient Protection Issues

In addition to broader confidentiality issues dealt with by HIPAA, providers need to be sensitive to the protection of patient information exchange as dictated by the mode of communication. For example, when providers send faxes, they must ensure that recipients are permitted to view protected health information. Electronic mail must occur by encrypted technologies only. In general, the Internet is

not an appropriately safeguarded environment in which to share PHI. Check the HIPAA compliance plan of your practice or organization to determine appropriate and efficient ways to share information.

Changing Practice Organization and Culture to Promote Effective Collaboration

Cultural and organizational changes within the Medical Home practice are needed to promote more effective collaboration. Many practices traditionally focus on acute illness care and well child care. However, Medical Home practices must embrace a collaborative teamwork approach and incorporate strategies for chronic condition management. To address needed changes, practices might consider:

- Delegation of certain care coordination functions to non-physician members of the practice team, freeing up physician time for more clinically-based collaborative activities;
- Reorganization of practices to accommodate needs of patients requiring more time;
- Systematic attention to informational and behavioral needs of patients and families;
- Ready access of providers to necessary expertise and information support;
- Explicit plans of care that are evidence based; and
- Practice-based parent advisory groups to initiate and sustain a quality improvement program.
- Specific linkages between CBO's and practice-based staff and families serving to assess and improve quality of collaboration
- Creation of registries of CYSHCN to facilitate communication and tracking for purposes of educational and clinical supports

In addition, specific office practices are helpful to support effective communication and collaboration and to ensure that families do not get lost in the process. Develop an office system to track whether patients have been seen and when consultation information has been received. Try to use consultants who make the effort to conscientiously respond to the PCP.

Special Challenges and Opportunities

Transition for Youth With Special Health Care Needs

The paradigm of care that supports the transition of youth with special health care needs from pediatric to adult health care systems will be enhanced by improved communication between primary and subspecialty physicians. Multiple reports from families and youth with special health care needs indicate that it is very difficult to find adult-focused primary and subspecialty care physicians to support their needs. Such providers must have the necessary skills to provide comprehensive care plans for these patients with relatively complex pediatric disorders. Adult specialists may not encounter these disorders frequently in their practice or in their training. Therefore, defining communication linkages between primary and subspecialty care providers across the transition ages may provide patients with more

effective care. These linkages should focus on communication among PCPs (from pediatric to adult care), as well as among subspecialty providers across the age spectrum.

Lack of Access to Specialty Care

When access to specialty health care providers is systemically lacking, the only way to close the gap may be by forging close collaborative linkages between primary care and subspecialty care providers. Pediatric mental health and dental health are two areas in which these enhanced collaborative linkages are vital to meet the current level of need nationally. Still, much work must be done at the systems development level to create an environment in which these collaborative relationships can be initiated and sustained.

Measures of Health Care Quality

Evaluating a clinical process as individual and interpersonal as generalist-specialist collaboration is difficult. Perrin outlined the difficulties with measuring quality of care for CYSHCN, pointing out that research about the quality of care in general for children with disabilities is sparse, and that even conducting systematic reviews to establish guidelines for care for specific conditions has been difficult because of a lack of evidence.¹⁸ To date, most of the measurement research has focused on accurate and practical identification of CYSHCN. However, no measure has focused primarily on the degree to which physicians or other health care providers collaborate in care, in the Medical Home, or in other areas.

Most measures of health care quality focus on service utilization, such as hospitalization, or on discrete clinical outcomes, such as improvements in blood pressure. Many of these “traditional” measures are either far removed from the process of generalist-specialist interaction, or they are not useful measures for children. Therefore, they may not reflect better or worse physician collaboration. The epidemiology of chronic conditions in children is characterized by a relatively large number of conditions affecting small subgroups of children. This situation makes it difficult to describe a “typical” subgroup for the purpose of broadly prescribing standards of care across types of chronic conditions. We are several steps away from being able to adequately evaluate the quality of collaboration in the Medical Home, and its impact on patient care and health. We must first agree on what the essential elements of good collaboration are, and then we must find a way to

measure them: timely communication, cooperation to increase the proportion of “met needs” for families, and establishment of a care plan by multiple providers. These elements are all possible components being examined by investigators. When measures are established, health outcomes must be defined and health care process measures that are sensitive to the quality of collaboration must be employed. Examples may include use of emergency or inpatient care, duplication of laboratory testing, and family report of met vs. unmet needs. Only then will we be able to measure the quality and impact of physician collaboration sensibly.

Several questionnaires exist that measure both Medical Home quality and family and provider satisfaction with care.¹³ However, these tools have included only a few questions that address physician collaboration, and these have not provided much detail. Questions asked include an overall perception of how providers communicate, whether parents act as partners in this process, and how well care for CYSHCN is coordinated in general (not necessarily between generalist and subspecialist physicians). High-quality generalist-specialist collaboration, although likely to be affected by factors in the larger practice environment and health care system, takes place largely at a personal level. Therefore, successful instruments to measure this collaboration will need to examine care in detail at the level of the individual provider or practice, while assessing the impact of the system of care on this collaboration. Expansion of parts of these published instruments may be one way to address the issue.

Conclusions

In order to achieve the outcome goals of the New Freedom Initiative with respect to caring for CYSHCN, efforts to address quality measurement and improvement within systems of care must be designed and implemented. Specifically, the collaboration between primary care and subspecialty care providers is an essential element of care coordination, which in turn is a critical component of Medical Home provision. The reality of limited access to many different pediatric subspecialties across the nation can and must be addressed within the framework of enhanced linkages between primary and subspecialty care providers. By partnering with families and youth as advisors, Medical Home providers will be able to address the challenges inherent in assessing and enhancing systems of care for CYSHCN.

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Resources and Tools to Enhance Collaboration in Caring for CYSHCN

SHARED RESPONSIBILITIES TOOLKIT: Tools for Improving Quality of Care for Children With Special Health Care Needs

A Publication of New England SERVE, 2002

The Shared Responsibilities Toolkit is designed to assist **health plans** in improving their systems of care for children with special health care needs (CSHCN). However, the tools are designed to be easily adapted for use by provider groups, among others. The utility of the toolkit is based on the premise that health plans share responsibility for planning, supporting, and improving health services for this population with other partners, including providers.

The toolkit is divided into three sections (Identify, Collaborate, and Improve). Specialists will find two tools in the Collaborate section most applicable to their practice.

- **Family Survey:** This self-administered questionnaire is designed as a mailed survey for pre-identified families caring for CSHCN. The tool is designed to collect family experiences of care and to assess satisfaction in seven domains: Primary Care, Mental Health, Specialty Care, Care Coordination, Inpatient and Emergency Care, Other Health and Therapeutic Services, and Medical Supplies or Equipment.
 - Available as a Word document from www.neserve.org/publications/srt_learnmore.html
The tool can be easily adapted and modified.

- **Primary Care Provider Survey:** This self-administered questionnaire is designed as a mailed survey to pediatric primary care providers to collect their experiences and to assess their satisfaction in providing care to CSHCN. It is intended to be used in conjunction with the Shared Responsibilities Family Survey. Findings from families and providers can be compared in the same seven domains described above.
 - Available as a Word document from www.neserve.org/publications/srt_learnmore.html
The tool can be easily adapted and modified for the specialist/subspecialist population.

Very Useful Web Sites

<http://www.medicalhomeinfo.org>

American Academy of Pediatrics hosted site that provides many useful tools and resources for families and providers

<http://www.medicalhomeimprovement.org>

web site designed to offer tools for assessing and improving quality of care delivery, including the Medical Home Index, and Medical Home Family Index

<http://www.hrtw.org>

Healthy and Ready to Work Website, designed to support youth with special health care needs and their families

<http://www.improvingchroniccare.org>

Website with tools and information for designing improved systems of care for patients with chronic illness

<http://gucchd.georgetown.edu/nccc>

National Center for Cultural Competence site that provides information about issues of diversity and disparity

