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Caring for Children Who Have Special Health-care Needs: A Practical Guide for the Primary Care Practitioner

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Author Disclosure

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Background

Advances in the care of children who have chronic illness have allowed many more children to survive and live longer. Although there are many definitions of chronic illness, the American Academy of Pediatrics (AAP) has endorsed the broad definition proposed by the Maternal and Child Health Bureau (MCHB), which defines children who have special health care needs (CSHCN) as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” (1)

For the purposes of this article, we define CSHCN broadly by adopting this MCHB definition. CSHCN does not encompass just those children who have complex disorders or who require technology; children who have attention-deficit/hyperactivity disorder, diabetes, emotional disorders, and autism also can be included in this broad definition. CSHCN are estimated to comprise 13% of the pediatric population and account for 70% of pediatric health-care expenditures. Based on the MCHB definition and the prevalence of CSHCN, all child health clinicians will care for children who have special health-care needs at some time during their practice experiences.

Good evidence shows that care for CSHCN delivered in specialized centers can improve clinical outcomes, as measured by hospitalizations, emergency department use, and detection of rare complications. Unfortunately, such speciality centers frequently are confined to academic centers that may be far from the community in which CSHCN and their families reside. The specialized care may be inaccessible to many families because of such barriers as language, culture, distance, cost, and transportation. There also is evidence that some of the basic primary care needs of CSHCN and families may not be well addressed in these subspecialty settings. (2)

Primary care physicians and families who find themselves caring for increasing numbers of CSHCN often have inadequate support and knowledge of community resources and limited capacity for care coordination. Recognizing this paradox, the AAP advocates that care for all children, including CSHCN, be provided in a medical home. (3) The medical home requires a partnership between physicians and families and collaboration with the community. Although the medical home may be based in a specialist’s office, it most often is based in the child’s primary care office. The primary care office may offer advantages such as being located in the child’s community and having a clinician who knows the child’s family and is able to provide continuity of care as well as coordination with schools and local community resources.

What is a Medical Home? Why is it Needed?

The AAP defines care given in the context of a medical home as care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. A medical home is not a structure or a building; rather, it is an approach and philosophy to providing care. A medical home is a partnership with families that promotes access to all of the services and community supports necessitated by their children’s care. The medical home approach does not simply entail change on an individual level, with physicians single-handedly working harder or faster. Rather, providing a medical home requires change on a systems level, including practice changes as well as improved communication and collaboration with families, schools, specialists, and community agencies.

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Care coordination is a key ingredient of the medical home. Coordinated care is a shared process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health. Often, the care coordinator is the parent, and the responsibility can be overwhelming. At other times, care must be coordinated by the physician, who frequently has no training in care coordination or resources. Most often, however, the role is a shared responsibility of the physician and the parent. Such an integrative effort can be facilitated more successfully by a designated care coordinator, either from agencies such as Title V or Early Intervention or by a trained individual within the practice, such as a nurse or social worker.

Care delivered in the medical home is family-centered. In this setting, the physician takes adequate time to listen to the concerns of families and to accommodate and respect cultural needs. Family-centered care is collaborative, with shared decision making by the physician and family. The family is embraced as a full partner in care and as the ultimate expert on their children.

Why should primary care physicians be interested in providing a medical home? First, all primary care physicians who care for children will care for some CSHCN. Also, better care using the medical home approach can improve outcomes for CSHCN and their families. These effects may include decreased emergency department visits and hospitalizations, fewer missed days by the child from school and the adult from work, improved family function, and reduced family stress. (4)

What Do Families of CSHCN Need?

According to the 2001 telephone data from the National Survey on Children's Health, Children with Special Health Care Needs, the unmet needs of families of CSHCN include mental health care for the patient and family, communication and mobility aids, specialized equipment, dental care, respite care, family support, and care coordination.

In addition, families of CSHCN have significant financial needs. The added time and economic burden of caring for their children sometimes can impoverish families. (5) For approximately 30% of CSHCN, the parent who is the primary caregiver has to reduce work hours or stop working completely to care for the child. (6) Families who have CSHCN are more likely to have more out-of-pocket costs and other expenses associated with caring for their children. Insurance may not cover durable medical equipment and home nursing and may have additional limits and exclusions. (2)

Table 1. Steps to Develop a Medical Home

1. Develop a database of CSHCN.
2. Develop a chart identification system (eg, color-coding).
3. Designate a care coordinator.
4. Change forms in the chart (eg, care plans, problem lists).
5. Train the staff about the needs of CSHCN and the medical home concept.
6. Consider an advisory board for the practice.
7. Develop resource guidelines.

CSHCN=children with special health-care needs

Care for CSHCN is complicated by their use of multiple points of entry into the health-care system, such as the hospital, office, or emergency department, and potential varying insurance coverage among entrance sites. In addition, categorical criteria often are used to determine the availability of funding and services among public and private payers, resulting in reduced support services for some CSHCN.

Accessing and navigating complex networks of physicians and resources can be daunting for families. Primary care physicians can play a vital role in this process in concert with the family by partnering with schools and community agencies around the delivery of services to CSHCN and their families and by assisting with communication and coordination among all health-care practitioners and providers involved in the child's care.

Sounds Good, But How Can I Do This in My Office?

Helpful first steps include identifying yourself as a medical home, identifying the CSHCN in your practice, and creating a way to involve parents in your practice, whereby families can provide input and are viewed as partners. Tables 1 and 2 summarize additional key steps to building a medical home.

Strategies for Identification of CSHCN

The first step to building a medical home is to identify the CSHCN within a practice. Knowing which patients require more time and coordination results in better flow and efficiency for the physician and better care for all patients. Understanding the number of CSHCN within a practice and their specific needs also may help demonstrate the necessity of additional supports such as care

Table 2. **Online Tools to Develop a Medical Home**

- Adolescent Autonomy Checklists. <http://www.depts.washington.edu/healthtr/Checklists/intro.htm>
- Washington State Medical Home Checklists and Tools. http://www.medicalhome.org/physicians/checklist_tools.cfm
- Coding and Documentation. <http://www.medicalhomeinfo.org/tools/Toolkits.html>
- Partnering with Families. Family Voices. <http://www.familyvoices.org/>
- Utah MedHome Portal. <http://www.medhomeportal.org>
- The National Center of Medical Home Initiatives for Children With Special Needs. <http://www.medicalhomeinfo.org>
- The University of Illinois Division of Specialized Care for Children. *A Medical Home Primer for Community Pediatricians and Family Physicians*. <http://internet.dsc.uic.edu/forms/medicalhome/MedHomeCMEMonograph.pdf>
- Silva TJ, Sofis LA, Palfrey JS. 2000. *Practicing Comprehensive Care: A Physician's Operations Manual for Implementing a Medical Home for Children with Special Health Care Needs*. Boston, Mass: Institute for Community Inclusion, Boston. <http://beta.communityinclusion.org/publications/pdf/compcare.pdf>

coordination, nursing care, or administrative support to either administrators or funding sources. Eventually, this information may help to justify enhanced reimbursement by payers. Most important, understanding the CSHCN caseload acknowledges that the practice needs to begin to accommodate the needs of CSHCN and ultimately benefit all patients.

For existing patients whose conditions are known, many clinicians rely on recall to identify CSHCN, making a list from memory. Others may do a chart review or abstract by diagnoses from billing or problem lists. One useful strategy is to allow families to identify CSHCN by using a phone script. Nurses or schedulers can ask parents calling the office, "Does your child have any special needs we should know about?" Finally, validated screening tools, such as the "CSHCN Screener" (http://www.markle.org/resources/facct/doclibFiles/documentFile_446.pdf), can be completed by families in the waiting room.

In the medical home, the primary care physician also should monitor patients for developmental delays to ensure that CSHCN are diagnosed and treated early. Recognizing that developmental surveillance using informal measures identifies only 30% of children who have developmental delays, the AAP recommends periodic use of formal, validated screening tools. (7)

Physicians can strategize with office staff to find an approach to identify CSHCN easily within the practice for record-keeping and quality-of-care purposes. Among the options are use of a different colored chart, an identifying sticker, or some other method to flag the chart. An acronym (eg, SKIP—Special Kids in Pediatrics) can be added to the computer system, physician schedule, problem list, or chart. Parents can be encouraged to self-identify as SKIP families when they arrive at or call the office.

Management of Chronic Conditions

CSHCN should be scheduled to see the clinician more frequently for managing their chronic conditions when they are well. Such additional visits can be used to review medications and specialty visits and assess resource needs. This approach allows the clinician to anticipate problems, coordinate care, and ideally, prevent emergency department visits and hospitalizations. Because CSHCN often require more time, schedulers might offer longer appointments to CSHCN when possible or schedule them at less busy times (often the beginning or end of the day). (8) Office visits for CSHCN should be scheduled with their primary care practitioner whenever possible. Continuity of care is important for all children, but perhaps more so for CSHCN. The primary care practitioner has the best knowledge of the family, the child, and his or her specific medical needs.

Communicating With Families—DARE to be a Better Partner

As noted earlier, caring for CSHCN can be very stressful for families. Sometimes, families express this burden openly; sometimes, they keep it hidden. The medical home practitioner can create a comfortable and safe place where parents can share and vent such feelings. Motivational interviewing techniques can be applied as a therapeutic tool to help families and practitioners become better partners. The "DARES" model can be particularly helpful:

- Describe: Give parents the opportunity to share what has been on their minds. Use reflective listening to describe your understanding of the situation. Summarize your understanding of the problem while acknowledging its difficulty.

- **Avoid Argumentation:** Give families room to vent their feelings to relieve some of their frustration.
- **Roll with Resistance:** When families are experiencing intense emotions, they may not be very receptive to suggestions; be patient.
- **Express Empathy:** Acknowledge that while you may not be able to know exactly what it is like to live with a child who has a chronic illness, you understand that this can be difficult.
- **Support Self-efficacy:** Identify and support what is working well for families and help them find the internal and external supports that can help them to make changes.

Communication With Specialists

CSHCN often require the care of multiple specialists. Besides providing and following up on referrals to specialists, primary care physicians can work with families to coordinate care with their specialists. That role could include preparing families for what to expect from the visit with the specialist, providing updated information about the child to the specialist before the visit, meeting with the family after the visit to discuss the specialist's recommendations, and assisting families in planning care. It is important for primary care physicians and specialists to communicate effectively and efficiently and to assign roles and responsibilities between specialty and primary care. (9)

Community Resources

The significant role that appropriate, accessible, and family-centered community resources play in supporting the care of CSHCN cannot be underestimated. Community supports can augment medical care and identify and address many of the issues facing families. Asking about and assessing the nonmedical support needs of families who have CSHCN is important for primary care physicians. These needs may include respite, home health, financing, transportation, support groups, and durable medical equipment. Resources needs assessment can be incorporated into the medical visits by having families fill out a questionnaire prior to the visit or by using a tool such as "The Well-Child Guidelines," which was developed to facilitate discussion of nonmedical needs between physicians and families during an office visit (http://www.neserve.org/maconsortium/pdf/Medical%20Home/Well-Visit_Guidelines.pdf). This instrument provides a list of topics and specific questions that can delineate unmet needs of CSHCN.

Among the strategies that can improve the primary care physician's capacity to support coordinated care is to

become familiar with the resources in the community, making a list of what is available and how to connect with them. Families can serve as sources of information, recommending agencies they use for home nursing, durable medical equipment, recreation, family support, and care coordination. It also is helpful to identify a person to help coordinate care. For children younger than 3 years of age, Early Intervention can fill this role. In many states, Title V and other state agencies provide care coordination for CSHCN. A staff member or nurse in the office may fill this role, providing information about community-based resources and facilitating communication with schools and community agencies. Finally, it can be helpful to develop a file of templates for correspondence frequently needed by families of CSHCN, including letters of medical necessity for enteral feedings or disposable diapers as well as letters requesting school evaluations. Templates available on the Internet can be personalized for individual families (<http://www.medicalhomeinfo.org/tools/index.html>).

Partnering With Families

Families can provide valuable input on the delivery of care to their children and help pediatricians improve their knowledge of community resources and understand family concerns. (10) It is essential to find a way to give families of CSHCN a voice in the practice, such as a suggestion box in the waiting room or via a family survey. Survey findings can be used to guide the CSHCN practice. Parents can be invited to form a family advisory group or families can be included in existing initiatives to encourage dialogue and to give parents a consistent voice in the practice.

Helping Families Work Better With Schools

When not at home, most CSHCN spend the greatest amount of their time attending school. Coordinating pediatric care with the school often is challenging, partially due to lack of communication. Because schools generally are the one "agency" in the community with whom most or all CSHCN interact, it is essential that schools become partners with the child's primary care physician and medical home.

The school team for CSHCN may include the principal, teacher, school nurse, therapists, and others. Among the challenges to effective communication with the team is difficulty in reaching them because of time or inability to contact them after school hours. It can be helpful to develop a brief care plan with the family that lists the child's medical issues, medications, allergies, and specialists. This plan should include a list of nursing needs in

school and medical issues that are most likely to surface during the school day and contact information for the school to reach the pediatrician or office. This plan can be adapted for other settings so parents can share it with community agencies, other health and human service providers, or emergency department physicians. Sample plans are available online (<http://www.medicalhomeinfo.org/tools/assess.html>), and additional guidance can be found in the book by Porter and associates. (11)

Understanding Disability Law and Educational Rights

Several resources offer overviews of disability law and educational rights of CSHCN (<http://www.medicalhomeinfo.org/health/Downloads/EIBrochureF.pdf> and <http://www.doe.mass.edu/sped/links/Advocacy.html?section=ma>). Early Intervention programs are funded from birth until age 3 years under part C of the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004. These programs are designed to meet the developmental needs of infants and toddlers who have disabilities and, in some states, children at risk for developing disabilities. After children reach 3 years of age, provision of these services is the responsibility of the public school system. Primary care physicians can assist families by advocating for school services and helping families understand their educational rights.

Under the IDEIA of 2004, schools are required to provide eligible students with “free and appropriate public education” in the “least restrictive environment,” meaning placement in the same class as typical or non-disabled students whenever possible. Children eligible for special education should have an individual education program (IEP) plan that specifies which services will be implemented. Once a family makes a request for an IEP, the family must provide written consent for an evaluation. The law states that an evaluation must take place within 30 school days of the consent, and a meeting of the IEP team with the family needs to occur within 45 school days. Families should request a copy of the evaluation IEP; they will have 48 hours before their meeting to review it. Parents have a right to receive a written IEP report, and they have 30 days to consent to or reject the IEP. They do not need to sign the IEP at the time of the meeting. The IEP must be reviewed annually, and the team needs to repeat the evaluation every 3 years, at a minimum.

Parents have the legal right to participate in the IEP team meeting and in the development of the IEP. Recommendations should be based on the child’s evalua-

tions. For example, the evaluation may include a functional behavioral analysis to develop positive behavioral interventions and supports and procedural safeguards. IEPs are required to address transition to adulthood issues, beginning at age 14 years, with specific services that prepare youth for independence and employment starting at age 16 years. Youth ages 14 and older should be invited to participate in their IEP meeting.

Parents of children who have disabilities and are not eligible for special education services can request accommodation under Section 504 of the Rehabilitation Act of 1973 to meet the needs of their CSHCN. This civil rights law prevents discrimination against individuals (including students) who have a physical or mental impairment that substantially limits one or more major life activities. It entitles a student to receive special accommodation and other related services to ensure access to the general educational curricula. Examples of such accommodations include: 1) use of assistive technology, 2) special seating arrangements, 3) wheelchair ramps, 4) permission to type assignments instead of writing them by hand, and 5) permission to hand in assignments late due to illness or hospitalization.

Publicly funded special education is available until age 22 years. However, the young adult who has a chronic disability may be eligible to receive continued services through other programs. The Rehabilitation Act, the Americans with Disabilities Act (ADA), and Supplemental Security Income (SSI) may provide continued support for the disabled young adult in obtaining employment, workplace accommodations, and financial assistance.

Transitions

As the family’s needs change over time, existing plans for support need to be updated. Such changes or transitions can be times of great stress and vulnerability for families. Major times of transition include going from hospital to home, from home to early intervention program, from early intervention to preschool, from preschool to school, and from school to adulthood. Continual access to a medical home that embraces parents as full partners in planning can help to manage the inherent challenges during these transitions and ensure an easier experience for everyone.

Transition to Adulthood: Talking With Youth

Clinicians can use open-ended questions to engage conversation, moving from less sensitive to more sensitive issues. Periodically asking the youth to describe his or her day can provide a better understanding of the needs and concerns of the youth and family. Specific questions can

Table 3. Preparation for Transition

Health Care

- Assure that the adolescent understands his or her health condition and medications.
- Initiate discussion about transfer to an adult health-care practitioner.
- Identify possible adult care practitioners, and initiate communication with the adult practitioner the family has selected.

Education

- Remind the adolescent of his or her right to be present and participate in the educational planning meetings required by special education law.
- Make sure that the adolescent and family know that starting at age 16 y, services must be included in the student's IEP.

Employment

- Encourage the adolescent and family to explore community vocational opportunities and to become familiar with vocational services, even if additional education is planned.
- Discuss with the adolescent and family the importance of early work experiences and job-related skills such as resume preparation and interviewing.

Recreation

- Discuss in-home and community recreation options.
- Help families to develop strategies to foster friendships and avoid social isolation.

Internet Resources

- Healthy Ready to Work. www.htrw.com
- National Center of Medical Home Initiatives for Children with Special Health Care Needs. <http://www.medicalhomeinfo.org/health/trans.html>

From Porter S, Freeman L, Griffen L. *Transition Planning for Adolescents With Special Health Care Needs and Disabilities: A Guide for Health Care Providers*. Boston, Mass: Institute for Community Inclusion/UAP at Children's Hospital Boston; 2000.

cover what assistance is needed for activities of daily living (dressing, mobility, bodily functions, hygiene), what supports already are in place, and how the constellation of services needs to change during and after the transition. The practitioner must be honest, supportive, and open. He or she should ascertain what is working and what is not working and what additional resources and supports are necessary.

Transition to Adult Life

Frank and honest discussions with families over time can address the very real concerns of parents and caretakers of CSHCN about the future (Table 3). The issues of parental wills and guardianship must be discussed openly. As the child who has special health-care needs becomes an adolescent, clarification of roles and responsibilities around self-care and household chores can foster independence. The primary care physician also can encourage greater youth involvement in the development of their 504 plans or IEPs by asking them what they want to do when they finish school. Primary care physicians can play an important role in supporting a youth's aspirations and in promoting peer socialization and recreation. Youth

should be encouraged to examine their needs and to seek help when needed. The primary care physician can be an advocate by addressing health issues in school and ensuring that these issues are not interfering with learning.

Sexual health also must be discussed, and the physical changes of puberty need to be reviewed. Concerns that may be unspoken, such as acne, sex, physical appearance, and masturbation, need to be addressed. Youth and patients must discuss how to recognize, report, and prevent sexual abuse. Contraception should be discussed and resources offered to increase awareness of the importance of safe sexual behavior. (12) Teens may be assessed for psychosocial problems and risk behaviors by using the American Medical Association's *Guidelines for Adolescent Preventive Services* (GAPS) (13) or the HEADSS assessment proposed by Goldenring and Rosen. (14)

Finally, the issue of transition to adult health-care practitioners should begin by age 14 years. Not surprisingly, primary care physicians can have difficulty letting go of patients after so many years of caring. Further, the transition may be intimidating to the youth and family. Adult medicine can be very different from pediatric medicine. Pediatrics tends to be more nurturing, family-

centered, and interdisciplinary and has a developmental focus. Adult medicine tends to be more disease-focused and stresses individual autonomy. (15) Some families opt to have care remain with the pediatrician while subspecialty care is transferred and coordinated with adult-oriented clinicians. As the patient develops a relationship with the adult subspecialist and becomes familiar with local adult practitioners, primary care can be transferred. Others transfer care to an adult-oriented generalist who is skilled in the needs of young adults who have a chronic illness, while keeping the pediatric subspecialists until the family and the practitioners are comfortable making a change.

Although the transition to adult health care is individualized, successful transition has some common features. Focus groups of physicians and families undergoing health-care transition have reported that envisioning the CSHCN as an adult at an early age can help families with future planning. A gradual transfer of responsibility to the CSHCN in such areas as activities of daily living, medical procedures, and communication with the primary care physician can help the process. It is important to recognize a developmental continuum that occurs in practitioners, patients, and the family and the key role of a trusting relationship among the practitioners and patient during the transition. (16)

Bringing It All Together

Children who have special health-care needs require more time, coordination, and resources. Caring for CSHCN can be challenging, but it also is very rewarding. By making small changes in a practice and getting to know the resources in the community, the primary care physician can build a medical home for all patients. The National Center of Medical Home Initiatives for Children with Special Needs has a Web site (www.medicalhomeinfo.org) that can help the individual physician find specific resources in specific states.

Evidence-based Medicine Summary

- Based on some research evidence and consensus, care for children and youth who have special health-care needs can be poorly coordinated and result in unmet needs that place a financial and emotional burden on families. (4)(5)(6)
- Some research evidence suggests that practitioner and family perceptions and expectations can differ. (10)
- According to some research evidence and consensus, these children and families are cared for best in a medical home that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. (3)(9)

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