Paradigms of Care for Children With Special Healthcare Needs

CHERYL H. HACK, MD

Children with special healthcare needs (CSHCN) are increasing in number because of improvements in medical care. More children are surviving complex and previously catastrophic medical conditions. Five percent to 10% of the pediatric population is currently thought to have some functional limitation due to chronic medical issues or disabilities. Some of these children require a disproportionately large amount of time and healthcare expenditures over long periods. The goal of medical care provided to CSHCN is to allow the child to function in a state of maximal health and to reach his or her maximal potential for independence and participation in society. Pediatricians must have a plan for providing care to this growing population of children.

EDUCATIONAL OBJECTIVES
1. To provide models of care that can be used for children with special healthcare needs.
2. To present information regarding the physician's role in educational management of children with special healthcare needs.
3. To discuss basic issues in psychosocial support of children with special healthcare needs.

SCOPE OF THE PROBLEM
Caring for CSHCN challenges the diagnostic and management skills of the primary care physician and his or her ability to locate resources and to communicate effectively and sensitively. It requires keeping up with new information in a variety of specialties, monitoring for associated medical problems, managing coexisting problems, understanding how specific treatments may affect other treatments, and helping families choose from an overwhelming number of...
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MODELS OF CARE MANAGEMENT

Three general models are possible for the primary care provider to use in caring for CSHCN: (1) be the primary manager with specialist intervention as needed only to solve specific issues; (2) be a gatekeeper; and (3) be a co-manager with specialist direction. The choice of style in managing CSHCN must be based on the physician's ability to adequately meet the needs of patients. Meeting these needs includes additional time required to see children with complex, multiple, and overlapping problems, and a commitment to gain knowledge in the multiple medical specialties, educational issues, and community resources that will support the child and family physically, emotionally, and otherwise. Let us examine the options.

Pediatricians may choose to manage care independently and refer to specialists only for management of a specific issue. The pediatrician choosing this option will need to learn about all the factors involved in the management of the medical condition. They will need specific plans for keeping up with expanding knowledge and treatments from multiple disciplines in medicine and related fields such as psychology, audiology, physical therapy, and occupational therapy. They will need to commit additional time to seeing CSHCN, who often require two to three times as much time usually required for a follow-up office visit, especially if multiple problems are being handled. The generalist will need to identify community resources and develop creative ways to access those not listed in the directories. Specialists in the area or outside the area who provide specific management techniques will need to be identified. The practitioner will be responsible for all choices and options of care and for the appropriateness of the selected therapeutic intervention because it is assumed the specialist chosen will provide only the services requested. This style of management will be time-consuming and leaves the responsibility for continuing education and total management of care in the realm of the generalist for what may be a very limited population of affected patients.

The second care plan is for the generalist to be a gatekeeper offering access to resources as guided by the specialists and allowing for the full care of the CSHCN to be done in specialty settings. The physician must have knowledge of who the specialists in
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The community are and what their areas of expertise include. The specialist would devise and implement a plan of care that would effectively anticipate and deal with the medical problems with an eye to prevention of complications and long-term sequelae. Depending on the medical issue, the generalist may have an arrangement with the specialist regarding management of acute illnesses (e.g., the pulmonologist may handle respiratory tract infections in the child with cystic fibrosis) or preventative services. The primary care physician, trusting in the specialist’s grasp of the medical condition, would then approve whatever plan was proposed in its entirety. They would allow the specialist to carry out the management plan independently. This option minimizes the time commitment of the generalist and his or her involvement with the child and family. It also limits the ability of the practitioner to learn more about the condition and how to manage it.

The third care option is to serve as co-manager with a specialist (or group of specialists if multiple major medical problems are involved). In this model, the specialist or specialists would see the child a limited number of times during the year depending on the severity of the problems and the need for ongoing adjustment of management issues. During each visit, the specialist would devise a plan of care and make the necessary arrangements for its provision. Ongoing care could be provided or monitored primarily through the generalist’s office. This model requires that communication must be clear as to what both the generalist and the specialist will do and the criteria for specialist involvement in complications and new medical issues. The specialist may be responsible for ordering of supplies and special equipment, training for use of special equipment, training of special care techniques, monitoring equipment, assessing function in school and social settings, and identifying and connecting families with community resources. The generalist may provide all acute care and preventive services with some guidance from the specialist on issues specific to the medical condition of the child. The primary care physician and specialist co-manager will need to develop skills that allow them to work together effectively, with both partners being responsible for communication and management issues. There must also be adequate exchange of information regarding monitoring laboratory studies related to medications or disease process. This style of management allows for shared responsibilities, a reasonable investment in time, and the opportunity for the primary practitioner to learn on a continuing basis from the specialist about management issues and cutting-edge changes in care and diagnosis.

EDUCATIONAL PLANNING: THE PHYSICIAN’S ROLE

Once the generalist has chosen which care management style will be used with a patient, he or she must establish mechanisms to make that care plan optimal for the particular patient and his or her family. Communication strategies, educational input, community resources, developmental monitoring, and psychosocial issues need to be planned for as well as basic medical care in the generalist’s office and specialist care. An effort should be made to limit or eliminate fragmentation of services. Recordkeeping will be an important component to ensure that all issues are dealt with. Communication is the basis for making any plan of care work and may be accomplished by telephone contact, letters, reports, or meetings. Establishing a mechanism for communicating about care and obtaining permission to make contact among the physician’s office, specialist’s office, school, and community agencies on a continuing basis is important. The generalist must be willing to share responsibility for communication and clearly identify the mechanism to be used. For the physician, the most time-effective communication for care management is likely to be written materials of some kind that can be added to the medical record.

Physician input to schools is essential for CSHCN. Federal law mandates school services for the child “with an identifiable condition that has the potential to interfere with his or her educational process and normal school performance to the extent that special education services are required.” Most CSHCN qualify for special services through the public schools as physically or otherwise health impaired. Some may qualify as hearing impaired, visually impaired, mentally impaired, or learning disabled. Physicians must provide the diagnosis that qualifies the child for services. In addition, the American Academy of
Pediatrics has developed position statements encouraging pediatricians to be further involved in the educational process through involvement in making or reviewing Individual Educational Plans (IEPs) for children 3 years and older and Individual Family Service Plans (IFSP) for those under the age of 3.5-8. The IEP/IFSP is a legal document that is developed to identify the plan of service for a child. It requires evaluation by a multidisciplinary team, educational resources in the least restrictive environment, provision for related services as necessary, and protection of the parents’ and child’s rights by due process. The physician’s formal role in regard to the IEP/IFSP is to provide a medical diagnosis of any condition that will affect functioning in the educational setting.

In reality, physician input to the IEP/IFSP for CSHCN may involve much more than the diagnosis.6-10 For many educators and administrators, CSHCN are a perceived burden and the physician may need to advocate for the child to be in the least restrictive environment (ie, the regular classroom). The physician may need to provide information about medications being used, their potential side effects, and possible effects that are expected but not of medical concern. The physician will need to identify medical procedures that must be done during the school day and ensure that school personnel have training to safely and appropriately complete these procedures.6,9,11 Functional limitations will need to be identified and communicated based on the individual’s current medical condition. Assistive devices that allow the child to function, such as wheelchairs, augmentative communication devices, or computers, may need to be prescribed. Medical treatments may be ongoing or anticipated. Input on the absences that will result from these treatments should be communicated to the school to minimize their impact on the educational process. For children with physical impairments, such transportation issues as the need for an attendant to supervise the child and the child’s ability to tolerate the proposed transportation might need to be addressed. Effort should be made to minimize the impact of midday medical treatments on educational activities. This must be accomplished by a dialogue between the physician and the school staff.

PSYCHOSOCIAL BASICS

Increasingly and appropriately, families are the primary caregivers for CSHCN. Their success in this endeavor will affect the child throughout his or her lifespan. The primary care physician is in a unique position to assist the family with this process. They are present at the time of diagnosis and may be one of the only professionals who is available to the family consistently over the years. By accentuating the positives and supporting family strengths, the physician can assist in the development of patterns of thought and behavior that will minimize handicaps and acknowledge the child’s and family’s need for independence, mastery, and control.12,13

When a child is diagnosed with a medical problem, he or she may be perceived by the family to be “ill.” Parents treat their children differently during illnesses. They hold them less accountable for difficult behavior, excuse them from expected household activities such as chores, and often have decreased expectations for the child’s independent functioning.14 Parents may also show a more emotional side to their nature at this time. On a short-term basis, these accommodations are excellent adaptations that can help the child learn many lessons of social interaction, but they can be counterproductive and destructive to the family when adopted on a long-term basis. The physician must help the family overcome these perceptions of illness and normalize their expectations and goals for the child to promote the child’s growth and independence.

Ongoing support of CSHCN and their families is vital to facilitate acceptance, encourage positive coping strategies, and improve the quality of life. In 1987, C. Everett Koop, MD, ScD, proposed the development of family-centered, community-based, coordinated care for CSHCN.5 This philosophy acknowledged the importance of the family in providing care to CSHCN and the importance of providing meaningful support to families to allow them to function effectively. It was found that support should be aimed at balancing the special needs and responsibilities related to the child’s medical condition with other family needs. It should encourage flexibility, social integration, reframing of situations in positive perspectives, and effective communication among family members and between the family and professionals with whom they interact.12 It should be grounded in the knowledge that most families remain together and will eventually cope effectively with having CSHCN.3,15 Cooley aptly states that “the success of family caregiving is dependent on past experience, coping skills of the family members, caregiving demands, and the way society values and supports this important family activity.”12 Formal and informal supports must share the goals and objectives to promote optimal caregiving.
CONCLUSION
General pediatricians as primary care providers should assume a greater role in the care of CSHCN. That role can take the form of primary responsibility, gatekeeping, or co-management. For some physicians, the experience will be a comfortable one and for others there may be a sense of being forced into taking care of these children. Whichever option is selected and no matter how they feel, the physician must still provide support to the family and input to the school. By becoming aware of these issues and incorporating them into their practice, pediatricians can contribute to the quality of life of this ever-increasing population of children who are surviving and living with special healthcare needs.

REFERENCES
5. AAP Committee on Children with Disabilities. Pediatrician’s role in the development and implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP). Pediatrics. 1997;99:340-347.