Ethics for the Pediatrician: Children Who Have Special Health-care Needs: Ethical Issues
Alex Okun
Pediatrics in Review 2010;31:514
DOI: 10.1542/pir.31-12-514

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://pedsinreview.aappublications.org/content/31/12/514
Children Who Have Special Health-care Needs: Ethical Issues

Alex Okun, MD*

Introduction
Nearly one in five children in the United States has special health-care needs, including chronic medical conditions and developmental disabilities that require care well beyond the needs of children who are developing typically and are in good health. For a minority of such children, these needs are multiple and complex, requiring significant help from health professionals and the use of medical technology in the home. Raising and caring for children who have special health-care needs (CSHCN) require substantial time, knowledge, and commitment on the part of families and professionals alike, as well as willingness to grapple with unique and complex ethical issues. Many of the topics in bioethics that the American Board of Pediatrics (ABP) (1) has determined that its diplomates should master are germane to the care of CSHCN. These issues include decision-making in special medical circumstances regarding critical care, the limiting of nonbeneficial interventions toward the end of life, the pediatrician’s role in allocation of health-care resources, and the patient-parent-pediatrician relationship and other subtopics in professionalism. The Section on Bioethics of the ABP offers an extensive annotated bibliography. (2)

Issues Faced by Parents, Families, and Caregivers

Duties and Obligations
The duties and obligations of families to care for CSHCN dominate their day-to-day responsibilities. Their efforts can lead to triumphs that bring pleasure to the entire family and at other times can be so burdensome as to reach crisis proportions.

Despite the support they receive from an array of community-based services, personnel, and technological advances, families find that the responsibilities of raising CSHCN at home far exceed those associated with raising typically developing, healthy children. (3) The enormity of such obligations may constrain families’ capacity to nurture their children as fully as they wish. Families raising CSHCN often find that they must sacrifice attention to siblings, limit their own employment opportunities, forgo recreation and respite, and make other choices that undermine family stability.

Limits to Familial Autonomy
As they pursue the best interests of their CSHCN, families may curtail efforts to pursue all available avenues for treatment when doing so would restrict opportunities in the lives of other family members or degrade the integrity and overall interests of the family unit. (4) For example, families living in rural settings who have the opportunity to move closer to a metropolitan medical center where needed services are available may opt not to if doing so would cause a loss of valued connections and support in the home community. Not infrequently, parents find

---

*Associate Professor of Clinical Pediatrics, Division of General Pediatrics, Department of Pediatrics, Albert Einstein College of Medicine/Children’s Hospital at Montefiore, Bronx, NY.
themselves apart from their CSHCN during hospitalizations if accompanying them involves neglecting the needs of others at home.

At the same time, families are held responsible for meeting the educational and medical needs of their CSHCN and for adhering to complex care regimens. Failure to do so may be considered neglectful to the extent that reports to child protective services are triggered. For most families who are not able to maintain adherence with all recommended treatments, specialty consultation, and follow-up care, this failure constitutes neither abject medical neglect nor trivial oversight of unimportant activities, but lies somewhere in a “gray zone” between these extremes. Some liberties enjoyed by families of typically developing, healthy children, such as the freedom to decline specific immunizations or traditional medical interventions with a strong evidence base of effectiveness, are restricted for families who have CSHCN because the consequences of exercising these freedoms amount to a high risk of direct harm to their children.

Decision-making Amidst Uncertainty
For CSHCN living with one of the more common chronic conditions, such as asthma, diabetes, sickle cell disease, cerebral palsy, attention-deficit/hyperactivity disorder, or autism spectrum disorders, fundamental treatment choices have been examined closely and clinical practice guidelines have been formulated by groups of medical experts, with varying degrees of evidence-based consensus. Yet, many CSHCN have a condition, or combination of conditions, for which evidence-based treatments are extremely limited. Those who have severe neuromuscular disabilities, for example, have high rates of swallowing disturbance, nutritional depletion, progressive lung disease, scoliosis, soft-tissue contractures, and other orthopedic deformities, for which many preventive or ameliorative therapeutic offerings pose significant associated risks but have little or no evidence for benefit. Professionals must appreciate how difficult it is for families to feel confident in their decisions in the face of all the information they are provided about the risk of complications and adverse effects associated with proposed treatments.

Advance Care Plans
Among the most difficult decisions faced by families caring for CSHCN are those that address the risk and projected timing of their children’s deaths. Outside of neonatal intensive care settings, oncology services, and critical care units, where previously healthy but severely injured children are treated, it is in the lives of families who have CSHCN that the bulk of advance care plans, also called advance directives, are made. Deliberations about forgoing life-prolonging medical and surgical interventions, including decisions not to attempt cardiopulmonary resuscitation, demand the establishment of explicit goals of care that families who have typically developing and healthy children never have to consider. In one intervention at a long-term care facility for CSHCN, families appreciated the opportunity to discuss do not resuscitate orders, and many decided to put these orders in place. (5)

Challenges to Health Professionals
The fulfillment derived from intensive, long-term work with families and their CSHCN can be great, but inherent challenges can test the limits of health professionals’ altruistic commitment to meet a variety of obligations. Shortfalls in professionals’ training, limited evidence for treatment efficacy, and inadequacies of health-care financing combine to perpetuate these challenges.

Limited Expertise in Counseling and Informing
Working with families of CSHCN requires a commitment of time and energy to counsel about issues for which professionals may feel inadequately trained or experienced. Most primary care pediatricians are not well prepared to talk about end-of-life care choices, provide genetic counseling, inform children and adolescents about the nature of devastating conditions, or involve patients in complex treatment decisions. Professionals who treat adolescents may be more accustomed to including patients fully in these conversations, as the American College of Physicians (9) and the AAP (7) suggest they should.

Some particularly challenging counseling responsibilities derive from policy statements of the AAP. For example, pediatricians are strongly encouraged to disclose human immunodeficiency virus status to school-age children who are infected but asymptomatic and to all symptomatic children and adolescents, (10) but it is not clear to whom, among professionals and family members in the child’s life, this obligation best falls or how to fulfill it. In the care of children who have developmental disabilities, pediatricians are urged to engage families in dialogue about sexuality and reproductive function near the time...
of the appearance of secondary sexual characteristics, (11) another topic for which most professionals have little background with this population.

Professionals have more challenging obligations to help children and families examine the likelihood of benefit and harm from major surgical and medical treatment options when there are no empirically derived clinical practice guidelines to follow compared with clinical situations in which therapeutic recommendations are clear-cut. The duty to promote beneficence and nonmaleficence requires that professionals share the moral burden of difficult decision-making with families. As the saying goes, professionals must not simply tell children and families what can be done, but rather help them decide if what can be done should be done.

Allocation of Resources and Advocacy for Patients

Despite calls for greater transparency in coverage decisions on the part of insurers (12) and opportunities for “members” to appeal specific elements of health insurance policies, (13) professionals who treat CSHCN are often burdened by the effort needed to write and re-write letters of justification and to make numerous telephone calls to company representatives on behalf of patients. Complicating these obligations are complexities and idiosyncrasies of the workings of different payers and the determination, in each individual patient’s situation, of how to assess the strength of justification for the requested service and what alternatives should be considered.

In the care of CSHCN, especially those who have complex or life-threatening disorders, it may be in the child’s best interests to receive specialty medical or surgical treatment outside the primary care pediatrician’s institution or the usual network that a pediatrician uses or the child’s insurer covers. Referral outside of established networks can create conflict for the primary care pediatrician by threatening loyalty to specialists at his or her affiliated institution and by demanding a substantial investment of time and effort to obtain authorization. The greater the potential difference projected in care outcomes within and outside these networks, the more strongly professionals are obligated to advocate on the child’s behalf.

With health-care costs escalating at rates that far outpace inflation, the imperative for professionals to uphold justice by acting as “good stewards” in the distribution of limited health-care resources (14) is least clear in the care of individual patients, in part because physicians in the United States have no say as to where the expenditures that are saved ultimately are put to use. (15) Fee-for-service systems of payment offer no incentive to restrict the ordering of additional tests or provision of expensive therapies. In cost-sharing systems inherent in certain managed care arrangements, in which professionals’ remuneration is tied to limiting health expenditures, the incentive to reduce spending on patient care exists but is of dubious ethical integrity and should be eliminated. (9)(13)(14)

Sometimes families request referrals or authorizations for treatments that the pediatrician feels have no potential to benefit the child or offer no advantages over less costly alternatives. When professionals decline to authorize or advocate for such services or treatments, it is their obligation to explain their reasons for doing so to families (9) in what can be uncomfortable or confrontational exchanges.

Inadequate Compensation for Substantial Incremental Work

The only means of compensating professionals for the extra time and effort required to care for CSHCN are to charge proportionally higher fees for services rendered, to bill for case management work performed outside patient care visits, or to demand that managed care plans adjust capitated rates for case-mix differences. (16) In most current systems of payment, such measures do not come close to closing the gap with what a professional could have earned in the same amount of time spent in the office seeing a greater number of patients whose needs are less complex. Although the AAP and American College of Physicians have declared that physicians’ “sense of duty” (9) and “unselfish regard or devotion to the welfare of others” (17) should take precedence over such financial concerns, this lack of support undoubtedly influences professionals’ choices about the extent to which they devote time and effort to the needs of certain patients and families.

Many pediatricians wish for the existence of accessible alternatives to their own practices to which these responsibilities could be transferred and from which families raising CSHCN could obtain primary care that incorporated intensive care coordination and expert case management. Some would cherish the opportunity to care for a greater number of CSHCN in their practices, as long as the time and resources needed to do so were assured. Even in academic medical centers, where many specialized primary care programs are located, the needs of most CSHCN in the population served by the center cannot be met. All primary care pediatricians care for CSHCN and need to reconcile their fiduciary obligations to pa-
tients and families with financial effects on their practices.

**Lack of Guidance in Effective and Efficient Aid for Children and Families**

The extent of extra help, advocacy, and counseling needed by different families whose children otherwise seem to have comparable levels of disability, comorbid medical disorders, and physiologic lability can vary. Frustration characterizes patient-family-professional relationships in which professionals devote extensive efforts over long periods of time, but little direct benefits to the child or family seem to follow. No current practice guidelines can advise professionals in the most effective and efficient approaches to help some of the neediest CSHCN and their families. In dealing with these and the other previously described professional challenges, teamwork with other health professionals and reflective practice can lead to more informed decision-making and greater satisfaction at work.

**Summary**

- Raising CSHCN involves obligations and duties that families who have typically developing and mostly healthy children seldom face.
- Decision-making amidst uncertainty about the benefits and burdens of proposed interventions poses extreme challenges for families of CSHCN and the professionals involved.
- Caring for CSHCN tests the limits of professionals’ altruistic obligations through a lack of support for the time, effort, and training required to counsel and share information and to advocate fully for children’s needs.

**References**

Ethics for the Pediatrician: Children Who Have Special Health-care Needs: Ethical Issues
Alex Okun
Pediatrics in Review 2010;31;514
DOI: 10.1542/pir.31-12-514

Updated Information & Services
including high resolution figures, can be found at:
http://pedsinreview.aappublications.org/content/31/12/514

References
This article cites 13 articles, 8 of which you can access for free at:
http://pedsinreview.aappublications.org/content/31/12/514#BIBL

Subspecialty Collections
This article, along with others on similar topics, appears in the following collection(s):
Development/Behavioral Issues
http://pedsinreview.aappublications.org/cgi/collection/development:behavioral_issues_sub
Psychosocial Issues
http://pedsinreview.aappublications.org/cgi/collection/psychosocial_issues_sub
Ethics/Bioethics
http://pedsinreview.aappublications.org/cgi/collection/ethics:bioethics_sub

Permissions & Licensing
Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:
http://pedsinreview.aappublications.org/site/misc/Permissions.xhtml

Reprints
Information about ordering reprints can be found online:
http://pedsinreview.aappublications.org/site/misc/reprints.xhtml