



CLINICAL REPORT

Home Care of Children and Youth With Complex Health Care Needs and Technology Dependencies

abstract

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Children and youth with complex medical issues, especially those with technology dependencies, experience frequent and often lengthy hospitalizations. Hospital discharges for these children can be a complicated process that requires a deliberate, multistep approach. In addition to successful discharges to home, it is essential that pediatric providers develop and implement an interdisciplinary and coordinated plan of care that addresses the child's ongoing health care needs. The goal is to ensure that each child remains healthy, thrives, and obtains optimal medical home and developmental supports that promote ongoing care at home and minimize recurrent hospitalizations. This clinical report presents an approach to discharging the child with complex medical needs with technology dependencies from hospital to home and then continually addressing the needs of the child and family in the home environment. *Pediatrics* 2012;129:996–1005

INTRODUCTION

Enormous advances in neonatal, pediatric, and surgical care have led to the survival of a greater number of children and youth with special health care needs who are cared for at home.¹ The issues faced by these children and their families are often complex and include significant feeding and respiratory problems, often associated with technology dependencies. Many children and youth with special health care needs have intellectual disabilities, physical impairments, and sensory deficits that require specialized therapeutic and educational interventions. The overarching goal of home health care is to optimize each child's health and function while minimizing recurrent or prolonged hospitalizations through the provision of comprehensive, cost-effective, family-centered health care rendered in a nurturing home environment.² Caring for children with chronic conditions at home can be challenging to pediatricians but successful and rewarding when provided in the context of a coordinated, family-centered, and complete medical home.

Children and youth with special health care needs are defined as those who "have or are at increased risk of having 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."³ More than 10 million children in the United States meet this definition.⁴ Diagnoses common to children and youth with special health care needs are numerous and include

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KEY WORDS

children and youth with special health care needs, discharge planning, rehabilitative services, home care, medical home, technology dependency, tube feedings

ABBREVIATIONS

DME—durable medical equipment

PCP—primary care provider

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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preterm birth, congenital genetic and metabolic disorders, neurologic disorders, sequelae of severe infections, or trauma and malignancies. A subset of children with special health care needs has been recently termed “children with medical complexity,” as defined by substantial health care needs, 1 or more chronic conditions, functional limitations often associated with technology assistance, and health care use. Technology dependency refers to the use of medical devices without which—if they were to fail or be discontinued—adverse health consequences and hospitalization would likely follow.⁵ Examples include mechanical ventilators, intravenous catheters, tracheostomy tubes, enteral feeding devices, colostomy bags, and urinary catheters. The multifaceted medical, developmental, and psychosocial needs of children with such a diverse group of diagnoses typically require the expertise of many pediatric subspecialists and related health care providers in a coordinated system of care.⁶

Most children and youth with medical complexity are discharged to home after birth or hospital admissions for acute exacerbations or conditions because long-term hospitalization of such children is no longer a preferred option in our society.⁷ As the acuity of hospitalized children has increased over time, so too has the severity and complexity of the unresolved medical conditions present on discharge.⁸ Children are now frequently sent home to complete or continue interventions that formerly would have occurred in hospitals. They are discharged with complex medical interventions, including oxygen, tracheostomies with or without ventilators, enteral feeding tubes, intravenous infusions, dialysis, and complex medication regimens.

Part I of this report offers guidance on the hospital discharge of children and youth with medical complexity issues

to home. Part II discusses how to optimally care for children with complex, chronic conditions at home after hospital discharge. The focus of this report is on the medical rather than the financial aspects of pediatric home care and is intended to provide an easily accessible resource for pediatricians. A more detailed resource from the American Academy of Pediatrics (*Guidelines for Pediatric Home Health Care*) is available for those who seek more comprehensive guidance on this subject.⁹ Another resource discussing insurance changes helpful to families caring for children with special health care needs is the American Academy of Pediatrics clinical report “Parent-Provider-Community Partnerships: Optimizing Outcomes for Children With Disabilities.”¹⁰ This report addressed some of the changes mandated by the Affordable Care Act of 2009, the goal of which was to improve access to home care services for children with special health care needs.

PART I: TRANSITIONING FROM HOSPITAL TO HOME CARE

The primary care provider (PCP) should be intimately involved with discharge planning for children and youth with special health care needs. The 6 main issues to be addressed during this process are outlined in Table 1 and include the following: (1) establishing a partnership with the family and acute care providers to identify family and community resources available to support the transition process and ensure success at home; (2) defining, locating, and engaging a medical home; (3) ensuring adequate training of family and other care providers; (4) assisting in the selection of a home nursing agency and/or providers of supplies and equipment; (5) identifying respite care providers; and (6) opening communication with the school district so that the Individualized Education Plan

process for school services can be initiated. Discharge planning should commence in a timely way, preferably as soon as the child is admitted.

Evaluating the Child, Family, Home, and Community

Not every child with medical complexity can be cared for at home. Instead, some children and families opt for out-of-home care, including care in foster homes, extended specialty hospitals (long-term acute care), or pediatric skilled nursing facilities.¹¹ Although the number and availability of congregate care options have decreased in recent years and may not be geographically feasible in some cases, out-of-home care continues to play an important role for children with severe disabilities who cannot be cared for at home. Each child should be evaluated to ensure that he or she is medically stable for home care. Although there is no clear definition of “stability” given the numerous underlying and complex issues involved, the child should have had no major changes made to the medical regimen for at least several days before discharge and should be tolerating feedings and current medications and have no new fevers or worrisome respiratory problems noted. At the time of hospital discharge, the child’s care needs should be stable and predictable.

The needs, preferences, and resources of families of children with disabilities should be evaluated well in advance of hospital discharge.¹² A candid appraisal of the family’s desire to provide complex care at home and of their skills, time, and energies is essential. The home should be evaluated to ensure that it is an adequate, safe, and accessible environment. Architectural barriers, including the ability to accommodate equipment such as wheelchairs, lift systems, hospital beds, or medical equipment, must be considered. Local emergency medical services, as well

TABLE 1 Issues Related to Planning for Home Care Before Discharge From the Hospital

- A. Evaluating child, child's family, home, and community
 1. Child
 - a. Child is medically stable for home care
 2. Family
 - a. Family desires to have child at home
 - b. Family has learned the necessary skills
 - c. Family has the resources (time, energy, and finances) to provide care
 - d. Family has considered palliative care and end-of-life care options
 3. Home
 - a. The home environment is adequate, safe, and accessible
 - (1) Structure
 - (2) Electrical (eg, 3-pronged plugs, 220-V line)^a
 - (3) Access (eg, bathroom and ramps)
 - (4) Heat, hot water, clean water supply
 - (5) Air conditioning
 - (6) Driveway/road accessibility
 - (7) Other (eg, snow removal)
 - (8) Telephone access^b
 4. Community
 - a. Community health nurse
 - b. Home care nurses
 - c. Therapists (eg, physical and occupational therapy)
 - d. Ambulance/emergency medical services
 - e. Specialty care
 - f. Medical supply vendors
 - g. Pharmacist
 - h. School/early intervention program
 - i. Counseling
 - j. Support group(s)
 - k. Palliative and hospice care where indicated
- B. Finding a medical home
 1. PCP
 2. Roles and communication network
 3. Patient summary
 - a. Plan for emergency care
 - b. Medications
 - c. Equipment
 - d. Disposable supplies
 - e. Advance care plan, out of hospital do-not-resuscitate order, where appropriate
- C. Training the home caregivers
 1. Training schedule
 2. Actual care with supervision (trial home care)
- D. Arranging home care nursing and developmental/educational services
 1. Nursing care coverage is outlined
 2. Alternative plans are made if nursing care is not available
 3. Arrangements with school or preschool programs for ongoing educational needs
- E. Finding home care agencies for supplies and equipment
- F. Insurance coverage
 1. Verify that adequate coverage will be provided
 2. Pursue alternative or additional coverage and benefits such as Medicaid waiver program and SSI
 3. Evaluate ability of family to pay for uncovered care (eg, transportation, electricity)

^a Secondary power generators may be necessary; local power companies and emergency providers should be alerted on hospital discharge, to help prioritize responsiveness to emergencies.

^b Arrangements should be made with telephone companies to ensure uninterrupted services. Internet services may also be required, especially for those parents who are hearing impaired and cannot easily communicate via telephone.

as heating and electrical providers, should be alerted to the specialized needs in homes of children with high medical complexity and fragility. Safe, accessible, and predictable means of transporting the child and essential

equipment and supplies should be established. The community should be evaluated to ensure that it can provide the resources and support necessary to care for the child at home and support the family.

Finding a Medical Home

It is critical to identify a PCP who accepts the care of the child on hospital discharge and is willing to provide a medical home for the child with medical complexity as well as his or her family. Not every provider is proficient in managing children with complex, chronic conditions or willing to invest the time and energy that this responsibility demands.¹³ The PCP should be knowledgeable about the child's conditions and treatments as well as community support services. A detailed and immediately accessible care plan should be developed jointly by the family, the PCP, and other care providers, with continuous updates as indicated. The PCP for children with complex conditions and disabilities who receive home care support should be provided with a comprehensive discharge summary that includes details of all the issues and events of the hospitalization and an accurate list of medications, therapies, equipment, and services that have been arranged before the discharge. The PCP should also know how communication will take place with other subspecialists involved in the child's care and how frequently the child will need visits with other providers and therapists.¹⁴

Training the Home Caregivers

Before the child's discharge, the caregivers (usually the parents but occasionally the grandparents or other family and friends) will require appropriate training to be able to render care for the child at home. Caregivers should be taught and should demonstrate competency in the care and use of enteral feeding tubes, tracheostomy care, respiratory treatments and supports (eg, nebulizers, ventilators), wound care, intravenous line care, and medication management. Cardiopulmonary resuscitation training is generally advisable. In addition to teaching the home

caregivers how to render care, teaching assessment skills is also essential. For example, it is important to know not only how to suction or change a tracheostomy tube but also when a child needs this intervention. Home caregivers should also have a clear understanding of when and how to call the PCP or specialist, should problems arise. Family preferences should be considered when developing care regimens, including timings for feeding and medication administration. Hospital schedules of administering enteral feedings every 2 hours around the clock indefinitely are generally unsustainable expectations that families are expected to adhere to at home. After a prolonged hospitalization, it is strongly recommended that the parents stay overnight for 1 to 2 days before discharge, allowing them to render all the child's care independently but with the support of hospital staff for questions and problem solving before the discharge.¹² Parents must demonstrate competency in the use of monitors that may be used in the home in preparation of transitioning from hospital to home. Standardized criteria for caregiver competencies and ongoing demonstration of skills are much needed.

Arranging Home Care Nursing and Developmental/Educational Services

Some children and youth with special health care needs have requirements that are so time-consuming and complex that parents alone cannot meet those needs without home nursing support.¹² Children who require intensive respiratory supports, such as those with tracheostomy and ventilator dependencies associated with high suctioning requirements, are likely to require private duty home nursing rather than brief and periodic skilled nursing visits. A nationwide shortage of qualified pediatric registered nurses and licensed practical nurses often

complicates and delays discharge, as does ensuring coverage by insurance for such support.¹⁵ The unique needs of children with complex, chronic conditions and their families who reside in rural areas with limited nursing and community resources should be anticipated and addressed. Parents should be actively involved in determining the child's care plan to ensure that the plan is feasible from their perspective in the context of their community. For example, parents who must work outside the home often elect to have home nursing during the day, whereas other families elect to have nighttime nursing so that they can sleep. However, some nursing agencies will not allow the nurse to be the only adult in the home and require that a family caregiver be present as well. In some limited areas, providers specially trained in the care of children with medical complexity may offer an additional care option for parents who are employed outside the home or who are full-time students themselves. Families and providers should have well-established contingency plans that are responsive to unanticipated interruptions in caregiving (family or home nursing care).

Children from birth to 3 years of age should be referred to local early intervention programs for developmental services.¹⁶ Children with sensory deficits may require specialized referrals to programs that address visual and/or hearing impairments. Frequent and consistent communication between PCPs and early intervention providers is essential to optimize each child's medical, developmental, and functional outcomes. For school-aged children, it is often important to meet with the school, including the school nurse, to plan for appropriate educational, therapeutic, and medical services before discharge from the hospital.¹⁷ For children requiring care for their tracheostomy or enteral feedings in school,

training of the school personnel by hospital personnel should be considered before patient discharge.

Arranging Providers for Supplies and Durable Medical Equipment

Many large pediatric centers now have care coordinators/discharge planners (usually registered nurses) who arrange for home equipment such as oxygen, respiratory technologies, enteral feeding supplies, intravenous medications, specialized enemas, urinary catheters, and other durable medical equipment (DME) before discharge. The prescription of DME that supports safe and effective mobility, such as specialized beds, bath seats, lift systems, and adapted car seats, should also be completed collaboratively with interdisciplinary providers before hospital discharge.¹⁸ The child's insurance coverage usually dictates which DME providers may be accessed, further influenced by geographic considerations. Early and meticulous discharge planning is essential to ensure that the appropriate supplies are ordered and delivered in a timely way so that they can be readily available for training of caregivers and use on discharge.

Insurance Coverage for Care at Home

At times, third-party payers fail to cover the costs of specialized pediatric private duty home care, leading to delayed or even canceled hospital discharges for children with complex, chronic conditions and technology dependencies.¹⁹ Lack of coverage for home nursing or extended therapeutic services are not uncommon. Families may seek secondary insurance coverage through Medicaid to cover costs denied by primary commercial payers. Families often face financial hardship related to extensive medical bills from lengthy hospitalizations as well as lost revenue related to the need to reduce

employment outside of the home.²⁰ Some children with disabilities are eligible for Supplemental Security Income benefits, which may help meet the financial demands.²¹ The financial implications of caring for children with special health care needs is further discussed in the American Academy of Pediatrics clinical report on parent-provider-community partnerships.¹⁰

PART II: CARING FOR CHILDREN AND YOUTH WITH MEDICAL COMPLEXITY AT HOME

As complicated as sending a child home from the hospital may be, sustaining the child and family at home can be an even greater challenge. The most common reasons for failure of home care are the lack of community and family resources, lack of financial resources, and emotional depletion of the family.²² For simplicity, an approach to caring for children with complex, chronic conditions at home can be divided into 7 main areas: (1) defining the basic medical issues; (2) defining the developmental issues; (3) understanding the underlying diagnoses; (4) the role of the PCP and the medical home; (5) the needs of the family; (6) the ongoing home care agencies and services required; and (7) assessment of the community and educational services.

Defining the Basic Medical Issues

Nutrition is 1 of the most basic medical needs of every child. Many children with disabilities are unable to meet their nutritional requirements orally and rely on enteral or parenteral supports. At every visit, it is important to assess each child's growth by using readily available standardized growth curves.²³ It is important to consider the route of feeding as well as its safety and efficacy. For example, does the child who eats orally cough, choke, or demonstrate respiratory distress during or after meals? If so, obtaining

a specialized feeding and swallowing evaluation, including videofluoroscopic studies, may be indicated. Alternatives to oral intake include feeding via gastrostomy tube (ie, g-tube), nasogastric tube, nasojejunal or jejunal tubes, or via intravenous catheter, such as total parenteral nutrition. Feedings via gastrostomy tube may be given as boluses or continuous infusions by using feeding pumps. Jejunal tube feedings must be administered continuously because bolus feedings are associated with abdominal pain, diarrhea, and dumping syndrome. Some children require specialized formulas, such as elemental or higher-calorie formulas, or supplements to increase the caloric or nutritional density of the diet. Because enteral feedings and delivery systems are medically necessary, they are generally covered by third-party payers.²⁴ A balanced intake of fiber and fluid is recommended for optimal bowel motility and evacuations. The need for consultations with dietitians and gastroenterologists should be determined by the child's feeding tolerance, nutritional status, and related concerns (eg, gastroesophageal reflux disease, dysmotility, constipation).

Respiratory issues can be frequent and often life-limiting challenges for children and youth with special health care needs.²⁵ Chronic lung disease may follow preterm delivery or result from chronic aspiration of feedings and secretions in children with neurologic disabilities. Children with neuromuscular conditions, such as muscular dystrophy, may need ventilator assistance (via continuous positive airway pressure, bilevel positive airway pressure, and tracheostomies with ventilators). Oxygen supplementation is frequently indicated for children with neurologic impairments as well as for those with complex congenital heart disease. Airway issues related to severe chronic airway obstruction in children with craniofacial anomalies or severe

neuromuscular disorders may necessitate placement of a tracheostomy, often with continuous or intermittent ventilator support. Children may frequently require bronchodilators or long-term inhaled or systemic steroids, which can compromise growth and bone density. Other interventions such as regular pulmonary toilet, often with high-frequency chest wall oscillation (eg, the Vest Airway Clearance System [Hill-Rom, Minneapolis, MN] or Smartvest [Electromed Inc, New Prague, MN]) or mechanical insufflator-exsufflator (eg, CoughAssist [Phillips Respironics, Pittsburgh, PA]) devices, may be necessary. Typically, children with moderate to severe respiratory impairments benefit from ongoing input from pediatric pulmonologists. Preventive care should be a priority, including the provision of pneumococcal and annual influenza vaccines for at-risk children and their families.

Children with special health care needs receive 5 times the number of medications than do typical children.²⁶ These may include protein pump inhibitors for gastroesophageal reflux disease; prokinetic agents for dysmotility and remedies for chronic constipation; and bronchodilators, antiepileptics, spasmolytics, and behavioral medications such as stimulant, antipsychotic, or anxiolytic agents. All medications have the potential for adverse effects, and the use of multiple medications increases the risk of drug-drug interactions.²⁷ Maintaining current medication lists for the caregivers with clear dosing regimens is essential, and updated lists must be maintained in the medical home. This action facilitates timely refills, reduces risks of medication errors, and allows health care providers to regularly monitor for and address potential drug interactions. This is a critical role of the PCP in the care of children with complex conditions.

Complications of immobility can lead to secondary conditions in children

who are on bed rest or have decreased mobility.²⁸ Pediatricians and home care providers need to vigilantly avoid and otherwise identify and address early threats to skin integrity, such as decubitus ulcers²⁹ over pressure points, particularly the posterior occiput, sacrum, ischium, and heels. Immobility and lack of weight bearing also contributes to osteoporosis and increases the risk of pathologic fractures.³⁰ Musculoskeletal contractures and deformities can progress quickly; range-of-motion exercises should be routinely implemented in children who are nonambulatory, which may require input from the pediatric physical medicine specialist. Elimination disorders can be managed with careful attention to regular bowel and bladder emptying, facilitated with regular bowel programs, enemas, bladder irrigations, and intermittent catheterization as needed. Regulation of sleep-wake cycles is another strategy to minimize secondary conditions. Children may benefit from early intervention services and home occupational and physical therapy for the establishment of exercise regimens and to ensure that appropriate equipment is available to optimize mobility and minimize complications (eg, hospital beds, commodes, wheelchairs).

Pain in children with complex, chronic conditions may be caused by orthopedic, gastrointestinal, or neurologic issues. Their irritability and discomfort can be distressing to families and home care providers. It may be challenging to determine whether there is an underlying medical issue causing pain that requires intervention, particularly in a child with limited communication abilities.³¹ Validated and reliable measures can be useful in assessing pain in children with cognitive impairments, such as the FLACC (Face, Legs, Activity, Cry and Consolability) Scale and the Pediatric Pain Profile (<http://www.ppprofile.org.uk>).

Medical home providers may be called on to evaluate the child to rule out simple problems, such as otitis media, which may be easily treatable. Less obvious problems, such as urinary tract infections, dental abscesses, or pathologic fractures, may be contributing to discomfort and should be identified and treated. Consultations with palliative care providers might further benefit children with chronic pain and the families who care for them.³²

Defining Developmental Issues

Many children with special health care needs have intellectual and physical disabilities that affect their overall health and development. If developmental disabilities are suspected on the basis of history, underlying diagnosis, or developmental screening results, it is critical to ensure that children receive appropriate educational and related services through an early intervention or adapted preschool program, often in collaboration with medically based rehabilitative therapies. Referrals for individualized rehabilitative services often require prescriptions from PCPs, particularly when coverage is requested for medically based (as opposed to educationally based) therapeutic services, and pediatricians may need to advocate for these services.¹⁷ Lastly, barriers to development, such as impairments of vision and hearing, should be identified and managed promptly to maximize outcomes.

Understanding the Underlying Etiology of the Child's Conditions

Children and youth with special health care needs should be discharged from the hospital to home with a plan of care that clearly addresses the acute medical issues, any temporary or long-term changes to the chronic condition care plan, and family adaptation and training.³³ In addition, ongoing attention to the underlying chronic issues

should not be overlooked. For some children, home care may be defined by a course of antibiotics and wound care, with discharge on resolution of the primary concern. For other children, an episode of acute pneumonia will resolve, but long-term respiratory failure and ventilator dependency will persist and require ventilation titration. Children with dependency on medical devices (including pacemakers, ventriculoperitoneal shunts, intravascular catheters, colostomies, and other devices) warrant close monitoring for device-related complications.

There are multiple etiologies of chronic pediatric conditions associated with special health care needs and disabilities. Sometimes, the underlying diagnosis is straightforward, and the child's needs are well understood. However, some children are discharged to home without a clearly established diagnosis, and the medical workup may still be in progress at discharge. Differentiating among time-limited acute conditions, chronic but stable conditions, and progressive and life-limiting conditions in children receiving home care ensures that the care rendered is appropriate to the needs of each individual.³³

The Role of the Medical Home

Although pediatricians cannot be experts in every chronic condition of childhood, it is important that they update their knowledge regarding the individual children and youth with special health care needs in their practices. By reviewing the literature and consulting with specialists, pediatricians can quickly gain the needed expertise to manage and coordinate care, whether it is with interdisciplinary spina bifida or craniofacial teams or with individual specialists. Depending on the unique medical needs or community resources of a child, medical home providers may be either PCPs or pediatric subspecialists. An awareness of the recommended

frequency of follow-up visits with consultants further facilitates care coordination. Pediatric residency programs may need to reassess the training experiences for their residents so that future pediatricians have the needed expertise and comfort in providing medical homes for all children, including those with chronic conditions, disabilities, and complex home care needs. Medical homes should ensure coordination of care associated with technology dependencies among families of children and youth with special health care needs, home care providers, and community systems, including emergency medical services and utility companies.³⁴ Arrangements for uninterrupted power in homes of children with technology dependencies may include the provision of generators and prioritization by utility companies for immediate restoration of services in the event of disruptions.

The medical home office visit for children and youth with special health care needs, particularly with technology dependencies, needs to be carefully orchestrated, in terms of the frequency, duration, and content of visits. It can be useful to provide separate chronic condition management visits and well-child visits or schedule longer-than-routine visits, because acute issues too often crowd out much-needed time for routine pediatric care. A large examination room that accommodates the child, family, and caregiver (s) as well as wheelchairs and ventilators, as needed, should be available. Providers need to consider their own access to dietitians, care managers, social workers, and other support staff members who contribute substantially to the care of children and youth with special health care needs. A systematic method of communication among all providers should be established so that critical information is available during office visits. Electronic health records

are increasingly used for this purpose. A detailed problem list and care plan, including the names and contact information for consulting specialists, should be regularly updated in the medical record. The medical home should also maintain a record of medications and refills, the preferred pharmacy, home care orders, referrals, and letters of medical necessity.⁵ Home visits by pediatricians can offer a safe and efficient alternative to traditional office visits.

Each individual medical home needs to address payment for direct and indirect services rendered. A major disincentive in the current system of care is the lack of physician compensation for time invested in phone management, care coordination, completion of home care orders and recertifications, management of medication refills, and letters of medical necessity, although some insurance companies are starting to cover care coordination.³⁵ Children with chronic conditions and disabilities may be insured by Medicaid rather than by private insurance companies, and the effect of this policy on individual practices needs to be considered.

The Needs of the Family

Family-centered care is a critical component of the medical home for children and youth with special health care needs. Providers should periodically assess family caregiver skill and comfort in rendering care, particularly when technology dependencies are present, and offer opportunities to refresh or extend skills to grandparents and other close relatives or caregivers. The primary coordinator of care should be explicitly identified and may often be a parent. Providers should have regular conversations with the families regarding met and unmet home care staffing, equipment, and transportation needs.

The needs of parents in their roles as long-term caregivers as well as the

unique needs of siblings of children with complex, chronic conditions and disabilities should be recognized, with appropriate referrals to community agencies (eg, Supplemental Security Income, Family Voices, disease-specific organizations, adapted sports and recreational programs). Families and providers should partner in care planning and proactive discussions regarding their child's prognosis, including explicit statement of family preferences regarding resuscitation status and end-of-life care. Referrals to palliative or hospice care providers and wish-granting organizations may be arranged according to family preferences. Formal and informal opportunities for respite care should be identified and accessed whenever possible.

The presence of a child with complex medical and developmental needs associated with technology dependencies and long-term home care most certainly affects the physical and emotional health and well-being of the parents, siblings, and other family members.^{22,36} Siblings of children with disabilities may demonstrate behavioral problems or academic failures, as they often assume caregiving responsibilities and may have unmet needs for parental attention and support.³⁷ Family vacations may be canceled or postponed, parental attendance at important school or sports events may not occur, and sometimes even serious medical symptoms in the well sibling may go unattended. Siblings may sometimes be called on to assume caregiving roles for which they have not been appropriately trained or are not developmentally prepared. Pediatricians can assist these children and their families by being cognizant of these issues, seeing the well siblings for separate appointments where they can receive individualized attention, and sometimes meeting privately with the siblings to allow them to express their feelings. Because children

with disabilities are at increased risk of abuse and neglect, pediatricians should also be particularly attentive to child–family interactions and sensitive to early indications of maltreatment. In some instances, family support services and counseling are indicated.³⁸

Ongoing Home Health Care Needs

Some children and youth with special health care needs have chronic conditions associated with complete and irreversible dependence on technology. As a consequence, they may require lifelong private duty nursing care. The provision of uninterrupted home care is threatened by national nursing shortages, limitations in the availability of skilled pediatric nurses in rural areas, and lack of funding.¹⁹ Pediatric equipment is not universally available. Physicians need to provide frequent updates on orders, with an associated flurry of paperwork. Thus, home care services must be carefully monitored and maintained to ensure that the requirements of the children and youth with special health care needs and their families are safely and effectively met without interruption. Transitioning from pediatric to adult care providers also requires careful planning.

Community and Educational Services

Most children and youth with special health care needs are cared for by their families, with support from their medical homes, pediatric subspecialists, and communities. Community services should not be underestimated, as they offer developmental programs (eg, early intervention programs),¹⁶ educational services,³⁹ and recreational opportunities.^{10,40} Individualized education plans should include the provision of the nursing care (eg, enteral feedings, airway suctioning, medication administration) necessary during school hours so that each child can participate fully in

school programs. Programs of adapted sports and recreation, specialized vacation camps, and community-based religious or cultural services offer additional opportunities for child and family participation in their communities. Table 2 lists issues that are important to monitor for children who are receiving home care.

CONCLUSIONS

Children with complex medical and developmental issues comprise a significant percentage of hospitalized pediatric patients and are being discharged to home with an ever-expanding range of complex medical and technology dependencies. Medical homes for children with complex home care needs must coordinate a team of providers toward the overarching goal of optimizing each child's health, development, and well-being. Pediatricians must understand the complexities of the child's underlying conditions, including ongo-

ing medical needs, prognosis and end-of-life care, family needs, and available community resources. Medical homes may need to adapt routine practices and individualize their approaches to best orchestrate the multifaceted needs of children and youth with special health care needs, their parents and families, and health care systems. A systematic approach¹⁰ to pediatric care with explicit care coordination, family-centered care, and advanced planning ensures the best outcomes and most rewarding experiences for children and youth with special health care needs, their families, and providers.

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TABLE 2 Issues Related to Ongoing Monitoring of Home Care

1. Regular review of home care discharge plan to determine whether goals are being met or have changed
2. Child assessment <ol style="list-style-type: none"> Physical condition Appropriateness of current nursing care Developmental issues Advance care planning
3. Family assessment <ol style="list-style-type: none"> Strengths Problem identification Changes Family–provider communications Adequacy of current services
4. Financial <ol style="list-style-type: none"> Paperwork Policy benefit changes Family financial changes Adequate coverage
5. Equipment/supplies/medications <ol style="list-style-type: none"> Identification and tracking of current needs Prescriptions written Justification letters
6. Diagnostics ordered with appropriate interventions made, and referrals to specialists as needed
7. Follow-up appointments made <ol style="list-style-type: none"> To PCP To specialists Coordination of appointments and procedures whenever possible Communication with subspecialists in a timely way so that the child's changing needs are being addressed

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REFERENCES

- Perrin JM. Health services research for children with disabilities. *Milbank Q.* 2002; 80(2):303–324
- American Academy of Pediatrics Committee on Children with Disabilities. Guidelines for home care of infants, children, and adolescents with chronic disease. *Pediatrics.* 1995;96(1 pt 1):161–164
- McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics.* 1998;102(1 pt 1): 137–140
- Kogan MD, Strickland BB, Newacheck PW. Building systems of care: findings from the National Survey of Children With Special Health Care Needs. *Pediatrics.* 2009;124 (suppl 4):S333–S336
- Feudtner C, Villareale NL, Morray B, Sharp V, Hays RM, Neff JM. Technology-dependency among patients discharged from a children's hospital: a retrospective cohort study. *BMC Pediatr.* 2005;5 (1):8
- American Academy of Pediatrics Council on Children with Disabilities. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. *Pediatrics.* 2005; 116(5):1238–1244
- Healthy People 2020 objectives. Available at: www.healthypeople.gov/hp2020/Objectives/ViewObjective.aspx?Id=454&TopicArea=Disability+and+Secondary+Conditions&Objective=DSC+HP2020%e2%80%93110&TopicAreaId=17. Accessed April 18, 2011
- Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics.* 2010;126(4):647–655
- American Academy of Pediatrics. *Guidelines for Pediatric Home Health Care.* 2nd ed. Elk Grove Village, IL: American Academy of Pediatrics; 2009
- Murphy NA, Carbone PS; Council on Children With Disabilities; American Academy of Pediatrics. Parent-provider-community partnerships: optimizing outcomes for children with disabilities. *Pediatrics.* 2011; 128(4):795–802
- Prouty R, Lakin KC, Coucouvanis K, Anderson L. Progress toward a national objective of healthy people 2010: “reduce to zero the number of children 17 years and younger living in congregate care”. *Ment Retard.* 2005;43(6):456–460
- Graf JM, Montagnino BA, Hueckel R, McPherson ML. Children with new tracheostomies: planning for family education and common impediments to discharge. *Pediatr Pulmonol.* 2008;43(8):788–794
- Wise PH. The future pediatrician: the challenge of chronic illness. *J Pediatr.* 2007;151 (suppl 5):S6–S10
- Turchi RM, Berhane Z, Bethell C, Pomponio A, Antonelli R, Minkovitz CS. Care coordination for CSHCN: associations with family-provider relations and family/child outcomes. *Pediatrics.* 2009;124(suppl 4): S428–S434
- Buerhaus PI. Current and future state of the US nursing workforce. *JAMA.* 2008;300 (20):2422–2424
- Duby JC; American Academy of Pediatrics Council on Children With Disabilities. Role of the medical home in family-centered early intervention services. *Pediatrics.* 2007;120(5):1153–1158
- American Academy of Pediatrics. Committee on Children with Disabilities. The pediatrician's role in development and implementation of an individual education plan (IEP) and/or an individual family service plan. *Pediatrics.* 1999;104(1 pt 1): 124–127
- Sneed RC, May WL, Stencel C. Policy versus practice: comparison of prescribing therapy and durable medical equipment in medical and educational settings. *Pediatrics.* 2004;114(5). Available at: www.pediatrics.org/cgi/content/full/114/5/e612
- Committee on Child Health Financing, Section on Home Care, American Academy of Pediatrics. Financing of pediatric home health care. *Pediatrics.* 2006;118(2):834–838
- Murphy N, Christian B. Disability in children and young adults: the unintended consequences. *Arch Pediatr Adolesc Med.* 2007; 161(10):930–932
- Council on Children With Disabilities, Academy of Pediatrics. Supplemental Security Income (SSI) for children and youth with disabilities. *Pediatrics.* 2009;124(6):1702–1708
- Llewellyn G, Dunn P, Fante M, Turnbull L, Grace R. Family factors influencing out-of-home placement decisions. *J Intellect Disabil Res.* 1999;43(pt 3):219–233
- Sullivan PB, Lambert B, Rose M, Ford-Adams M, Johnson A, Griffiths P. Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study. *Dev Med Child Neurol.* 2000;42(10):674–680
- Committee On Child Health Financing. Scope of health care benefits for children from birth through age 26. *Pediatrics.* 2012; 129(1):185–189
- Seddon PC, Khan Y. Respiratory problems in children with neurological impairment. *Arch Dis Child.* 2003;88(1):75–78
- Fiks AG, Mayne S, Localio AR, Alessandrini EA, Guevara J. Shared decision-making and health care expenditures among children with special health care needs. *Pediatrics.* 2012;129(1):99–107
- Stone BL, Boehme S, Mundorff MB, Maloney CG, Srivastava R. Hospital admission medication reconciliation in medically complex children: an observational study. *Arch Dis Child.* 2010;95(4):250–255
- Kim CT, Moberg-Wolff E, Trovato M, Kim H, Murphy N. Pediatric rehabilitation: 1. Common medical conditions in children with disabilities. *PMR.* 2010;2(3 suppl 1):S3–S11
- McCaskey MS, Kirl L, Gerdes C. Preventing skin breakdown in the immobile child in the home care setting. *Home Healthc Nurse.* 2011;29(4):248–255
- Houlihan CM, Stevenson RD. Bone density in cerebral palsy. *Phys Med Rehabil Clin North Am.* 2009;20(3):493–508
- Hauer J. Identifying and managing sources of pain and distress in children with neurological impairment. *Pediatr Ann.* 2010;39 (4):198–205, quiz 232–234

32. Klick JC, Hauer J. Pediatric palliative care. *Curr Probl Pediatr Adolesc Health Care*. 2010;40(6):120–151
33. Elias ER. Children with multiple disabilities and special health care needs. In: Carey WB, Crocker AC, Coleman WL, Elias ER, Feldman HM, eds. *Developmental-Behavioral Pediatrics*. 4th ed. Philadelphia, PA: Elsevier; 2009:737–745
34. American Academy of Pediatrics; Committee on Pediatric Emergency Medicine and Council on Clinical Information Technology; American College of Emergency Physicians; Pediatric Emergency Medicine Committee. Policy statement—emergency information forms and emergency preparedness for children with special health care needs. *Pediatrics*. 2010;125(4):829–837
35. Antonelli RC, Stille CJ, Antonelli DM. Care coordination for children and youth with special health care needs: a descriptive, multisite study of activities, personnel costs, and outcomes. *Pediatrics*. 2008;122(1). Available at: www.pediatrics.org/cgi/content/full/122/1/e209
36. Carnevale FA, Alexander E, Davis M, Rennick J, Troini R. Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. *Pediatrics*. 2006;117(1). Available at: www.pediatrics.org/cgi/content/full/117/1/e48
37. O'Brien I, Duffy A, Nicholl H. Impact of childhood chronic illnesses on siblings: a literature review. *Br J Nurs*. 2009–2010;18(22):1358–, 1360–1365
38. Hibbard RA, Desch LW; American Academy of Pediatrics Committee on Child Abuse and Neglect; ; American Academy of Pediatrics Council on Children With Disabilities. Maltreatment of children with disabilities. *Pediatrics*. 2007;119(5):1018–1025
39. Cartwright JD; American Academy of Pediatrics Council on Children With Disabilities. Provision of educationally related services for children and adolescents with chronic diseases and disabling conditions. *Pediatrics*. 2007;119(6):1218–1223
40. Murphy NA, Carbone PS; American Academy of Pediatrics Council on Children With Disabilities. Promoting the participation of children with disabilities in sports, recreation, and physical activities. *Pediatrics*. 2008;121(5):1057–1061

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