

Promoting Health for Children and Youth With Special Health Care Needs

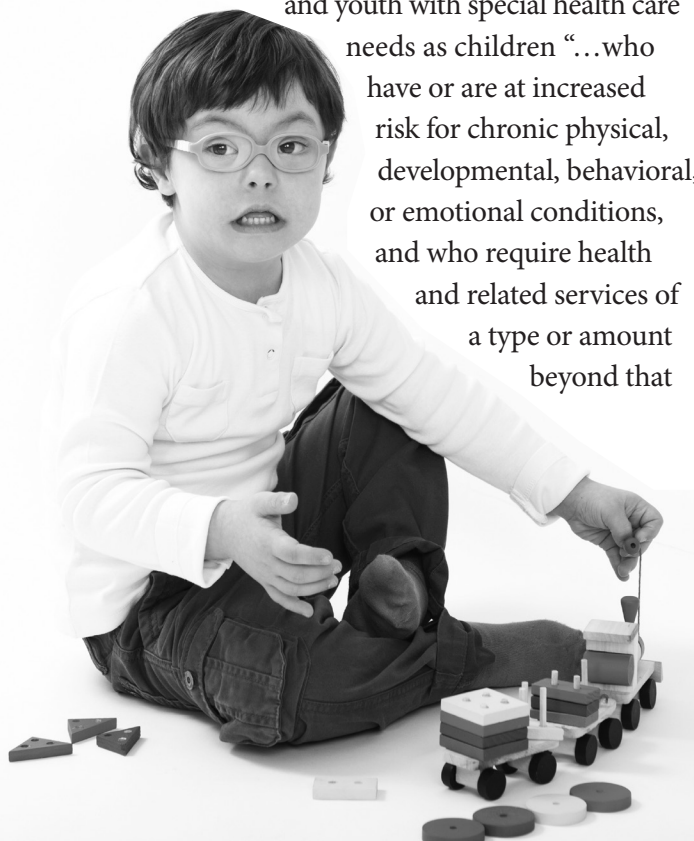
Children and youth with special health care needs share many health supervision needs in common with typically developing children. They also have unique needs related to their specific health condition. Birth defects, inherited syndromes, developmental disabilities, and disorders acquired later in life, such as asthma, are relatively common; children with special health care needs represent nearly 20% of the childhood population, or 14.6 million children.¹ In addition, an increasing number of children are receiving diagnoses of developmental disabilities and conduct disorders, which may indicate special health care needs.

The US Department of Health and Human Services Maternal and Child Health Bureau defines children and youth with special health care needs as children “...who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions, and who require health and related services of a type or amount beyond that

required generally.”² Children with special health care needs and their families represent an increasing responsibility for primary care practices. The growing numbers of children with special health needs and the increasing complexity of their care demand new practice models for care and support for families. For example, infants diagnosed prenatally or at birth may have complex morbidities and conditions that were not previously cared for in the primary care setting. Although children with special health

care needs may present unique challenges for care provision, their survival and integration into home and community settings reflect enormous advances made in the basic sciences and technology and the expansion of pediatric home care in the recent past.

Approximately 0.1% of children and youth with special health care needs may need assistance from various forms of technology for some or all of the day and may need the help of multiple health and community providers. Among children with chronic health conditions who require hospitalization, more than 40% depend on technology, including medications, devices (eg, feeding tubes, central venous catheters, and tracheostomies), or both.³ This includes 12% to 20% of hospitalized children with special needs who require devices, one-third of children who require medications, and 10% of children who require devices and medications. Hospitalization rates for children with more than one complex condition are significantly higher than for children with only one complex condition.⁴





In the previous century, many children with severe disorders did not survive, much less achieve adulthood or function as active members of a family. Now they and their families receive services in the community and schools that were previously unavailable and often rely on their medical home as a primary support. However, the necessary resources are all too often not introduced or discussed, not accessible, or not coordinated, and many families are not connected to adequate support systems in their communities. When referred for supportive services, many families experience difficulties following through because of misunderstandings, misgivings, financial concerns, perceived inadequate support through the process of referral and engagement, and other challenges.

Each age or developmental stage presents children and families with different developmental tasks. Developmental progress and medical management can be complicated for children with special health care needs. The medical home considers the unique trajectories of the child and his family along with the regular preventive and primary care needs of the child and family according to the guidelines for all children.

Implementing a Shared Plan of Care and Care Coordination

The individual health care professional or practice cannot meet the needs of the child with special needs and her family alone. High-quality pediatric care occurs when children, families, and professionals forge trusting, caring partnerships that fully use the knowledge and expertise of all. Frequently, a multidisciplinary team designed to meet multiple interdisciplinary needs must be involved in the child's care, thereby creating the structure of an integrated medical home that collaborates with community partners. This kind of integrated medical home can develop a team-based,

integrated, continuously updated plan of care for the child or youth with special needs. Such a plan can be an effective tool that links activities from visit to visit and coordinates the child's care across the health care continuum.^{5,6} A shared plan of care (SPoC) typically is developed in partnership with the family and multiple care providers and describes the child and family's priorities and plans to support optimal health (Box 1).⁷ It takes into consideration the child's medical information, development plan, Individual Family Service Plan for young children, and educational plan (ie, the Individualized Education Program).

An SPoC enables all partners to operate from the same family-centered perspective and to be accountable for desired outcomes. Parent partnerships with professionals can be achieved through the mutual sharing of goals, timely communication, and planned monitoring of care plans with targeted follow-up. Family-centered team care in the SPoC model enables the primary care team and the family to capitalize on blended family and provider goals and draw on supportive community resources and supports. This process is known as care coordination.

Care coordination provided within the medical home supports continuity and longitudinal care needs as critical primary care functions.^{5,8-10} A care coordination framework builds on characteristics and functions consistent with the primary care medical home.¹⁰ Pre-visit assessments or pre-visit contacts with the family can help team members prepare for a visit that effectively addresses the child's health care needs. Such pre-visit contact can assist the family to prepare for a visit, describe what to expect in preventive care, and identify topics about which they may wish to ask questions.¹¹ All children need routine health supervision as well as sick or condition-related care. Pre-visit planning allows time to review progress in achieving identified goals and follow-up from referrals. Families

**Box 1****Principles for Successful Use of a Shared Plan of Care**

1. Children, youth, and families are actively engaged in their care.
2. Communication with and among their medical home team is clear, frequent, and timely.
3. Providers or team members base their patient and family assessments on a full understanding of child, youth, and family needs, strengths, history, and preferences.
4. Youth, families, health care professionals, and their community partners have strong relationships characterized by mutual trust and respect.
5. Family-centered care teams can access the information they need to make shared, informed decisions.
6. Family-centered care teams use a selected plan of care characterized by shared goals and negotiated actions; all partners understand the care planning process, their individual responsibilities, and related accountabilities.
7. The team monitors progress against goals, provides feedback, and adjusts the plan of care on an ongoing basis to ensure that it is effectively implemented.
8. Team members anticipate, prepare, and plan for all transitions (eg, early intervention to school, hospital to home, pediatric to adult care).
9. The plan of care is systematized as a common, shared document; it is used consistently by every health care professional within an organization and by acknowledged health care professionals across organizations.
10. Care is subsequently well coordinated across all involved organizations and systems.

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can be asked about their family needs and expectations in culturally sensitive ways and about roles they wish to play in shared decision-making. Visits can therefore focus on obtaining a medical history, administering questionnaires or screening tools, reviewing the existing SPoC, performing a

physical examination, entering into discussions, providing anticipatory guidance, and planning next steps. Responsibilities should be clarified and accountability determined for the various condition-specific health care and follow-up and resource needs.



Table 1 depicts the work flow of a family-centered team in partnership with the family; pre-visit, visit, and post-visit activities are detailed.

Highly effective care coordination extends the medical home and makes use of community

partnerships and resources, building a relationship among families, specialty health care professionals, schools, and community resources. An eco-map provides a concise visual representation of the many entities involved in caring for the child and family.

Table 1

Work Flow of a Family-Centered Team Approach to Care			
Roles of Care Partnership	Pre-Visit Activities: Anticipation and Preparation	Visit Activities: Building Partnership Relationships	Post-Visit Activities: Following Through With Accountability
Care Coordinator, or Providers of Care Coordination	<ul style="list-style-type: none"> Reach out to patient/family Complete a pre-visit assessment Review priorities Review and/or initiate a plan of care; summarizing progress/gaps Huddle with team Communicate/share ideas, concerns 	<ul style="list-style-type: none"> Assess and discuss needs, strengths, goals, and priorities Educate and share information Inform the plan of care in real time Facilitate communications Set time for next visit or contact 	<ul style="list-style-type: none"> Update/share the plan of care and implement accountable tasks Ensure quality access and communication loops with resource contacts Create opportunities for the ongoing engagement of patients/families <i>Repeat these steps accordingly</i>
Youth and Family	<ul style="list-style-type: none"> Prepare for visit or contact, review recent events, insights, expectations, goals, and hopes Review existing plan of care for progress, gaps, successes, failures, and frame questions Prioritize topics to address at visit 	<ul style="list-style-type: none"> Share priorities with team Discuss care options together Contribute to current plan of care development and/or revision Ask for/acquire needed caregiving/self-care skills Offer feedback and ideas Set time for next visit/contact 	<ul style="list-style-type: none"> Review care information and instructions Access and communicate with team as desired or needed Use, share, and implement the plan of care with health partners Complete tasks responsible for <i>Repeat these steps accordingly</i>
Pediatric Clinician	<ul style="list-style-type: none"> Huddle with team Review pre-visit assessment data Review plan of care and other data Identify the need for a plan of care if none exists Attend to team readiness/gaps for holding a prepared/planned visit 	<ul style="list-style-type: none"> Meet with family, engage them as part of the medical home core team Complete screenings and/or assessments Evaluate, listen, learn, and plan Frame family and clinical goals: bio-psychosocial, functional, environmental Co-create, update plan of care Link with referrals/resources Set time for next visit or contact 	<ul style="list-style-type: none"> Update/implement the plan of care completing accountable tasks Monitor communications Huddle with team frequently Help guide team conferences Supervise continuous care coordination and ensure plan of care oversight <i>Repeat these steps accordingly</i>

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It enables practices and families to delineate the existing plan of care coordination, assess the current supports surrounding a family, and identify gaps in services. Creating the eco-map brings together the team of resource and service providers that can potentially care for the child and family, including caregivers (day, night, weekdays, and weekends);

physicians; legal and financial consultants and institutions; psychological and counseling support; diet and nutrition support; hearing, vision, speech therapy; physical therapy; occupational therapy; toileting; and school, religious, educational, and community supports. Figure 1 shows an example of a completed eco-map.

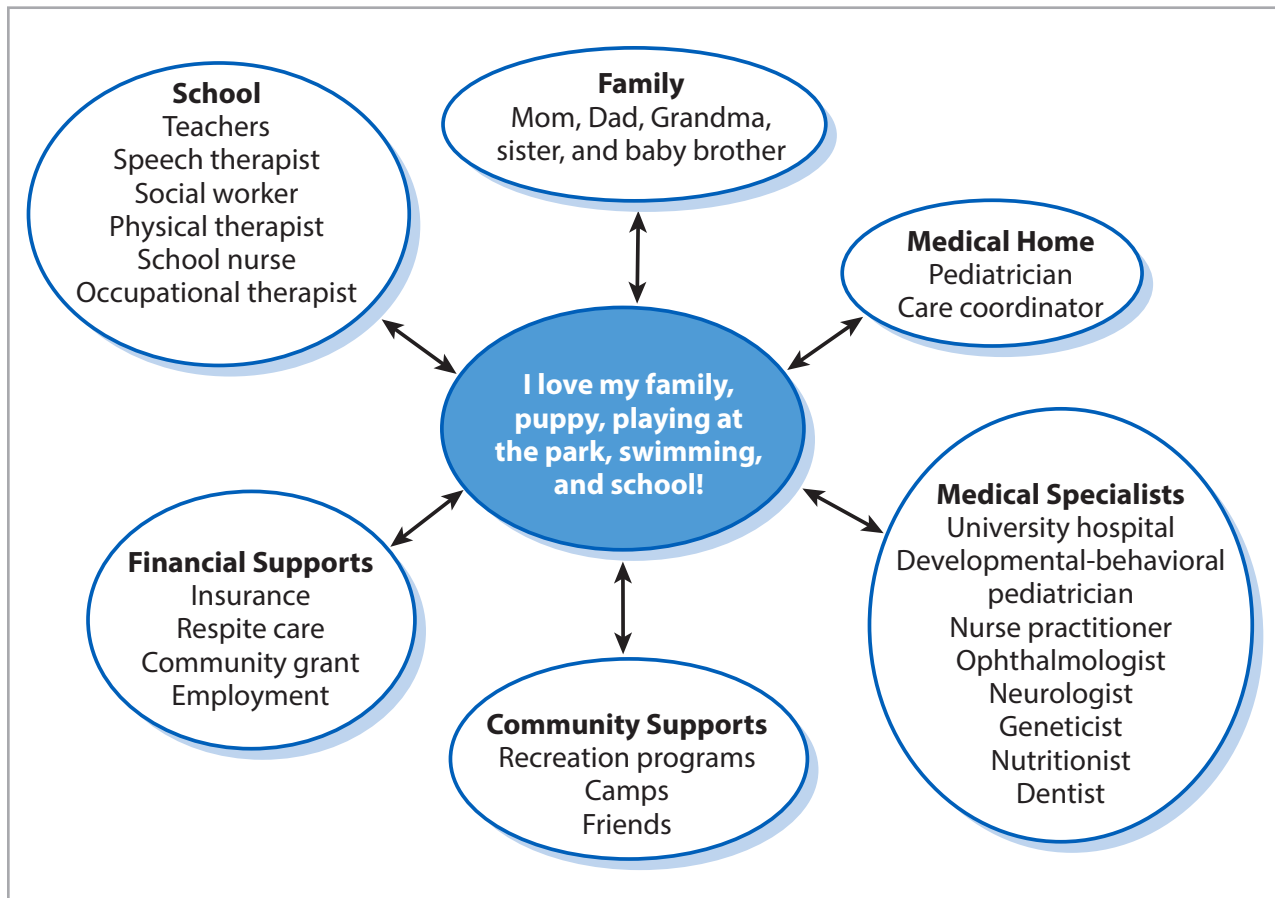


Figure 1: Example of Care Coordination Eco-Map



Palliative and Hospice Care

Infants, children, and adolescents with chronic, life-threatening, or life-limiting conditions may benefit from palliative care, and consultation with experienced palliative care providers can be considered.¹² The goal of palliative care is to improve the life of the affected child and of the family that cares for him and is ideally integrated into the care plan as soon as possible after the child's condition is recognized.¹³ The principles, goals, and priorities of palliative care are best integrated into the care of all children with special health care needs, regardless of prognosis for shortened life expectancy. In focusing on the needs of the child and family, palliative care recognizes that a chronic health condition in a family member affects the entire family. If the life improvement goal is to be achieved, the physical needs of the child must be cared for in a comprehensive manner, and the needs of the child's family must be identified and addressed. Pediatric palliative care focuses on pain and symptom management, information sharing, and advanced care planning; practical, psychosocial, and spiritual support; and care coordination. It acknowledges the inevitable effect on the physical and mental health of parents, siblings, and the extended family and seeks to support these essential persons.

Hospice care is palliative by nature, but it differs because it is reserved for patients for whom curative treatments are no longer available or chosen and for whom death in the foreseeable future would not come as a surprise to caregivers and health care professionals. The primary treatment goal shifts from cure to comfort, while continuing the management of the special health care need. Emphasis is focused on assisting the family and, when possible, the child to identify goals for care and living that account for their needs for comfort and support and prioritizes their wishes and desires. Special attention is given to pain management; alleviation of nausea, shortness of breath, and other

uncomfortable symptoms; management of disturbed sleep; and alleviation of anxiety in the patient. The family is helped with their own uncertainty, anxiety, and grief, and supports are identified. The needs of siblings are addressed and end-of-life planning is discussed. Both palliative care and hospice care can significantly enhance the care provided in the medical home.¹²⁻¹⁴

Promoting Health in Infants With Special Health Care Needs—Birth Through 11 Months

Infants born preterm, at a low birth weight, or with birth defects require special attention. The joy of having the new baby is tempered by the fact that many of these infants have chronic health care and developmental needs. Parents and caregivers of an infant with a chronic health condition will need support and guidance in nurturing the infant and fostering family cohesion.

Families of these infants should be counseled about resources for long-term care as soon as practical during the hospital stay. The first health care transition for a child with special health care needs and their family occurs when parents take their infant home from the hospital and experience the benefits of a supportive and coordinated plan of care among all health care professionals and community agencies. This transition sets the stage for the parent-professional partnership and builds trust that the health care system will provide support when parents have questions and concerns.

Anticipatory guidance should be structured around the parents' concerns, goals, and expectations. Specific guidance can include information on growth and development, feeding concerns, specialized health care needs for the infant, expectations and plans for achieving developmental milestones, and any specific vulnerability that the family will need to address. Health care professionals also



can discuss the infant's integration into the family structure and family dynamic and ways other children in the family can be introduced to the possibility that their sibling can have different challenges because of her disability and circumstances.

The health care professional should explore with the family their understanding of their infant's health condition, its effect on the family, their expectations on issues such as family supports and care coordination, and their cultural beliefs and their hopes for the child. The health care professional plays an important role in helping the family develop expectations and plans for their child's future. Many families may need assistance with referrals to community services, financial assistance, and other types of supports. This assistance is vital because many high-risk infants with chronic disorders have significant unmet health care and resource needs.¹⁵ The health care professional plays an important role in identifying conditions that place the infant at risk of disability and warrant immediate referral to early intervention services or other community resources (Box 2). It is important for the medical home team to follow up to be sure that connections to community services have been successful. Health care professionals should note children who require enhanced developmental surveillance and

periodic standardized developmental screening to permit the earliest identification of their need for intervention services.

The health care professional also plays an important and continuing role in providing informed clinical opinion in determining the scope of services that are needed by the child and family and in helping the family meet state, federal, or insurance company eligibility criteria for appropriate services. Hospital-based integrated primary care and specialty care teams for infants with medical complexity are available in some communities.¹⁶ Care coordination of services, follow-up, and collaboration with other community agencies in the context of the medical home are important.

Professionals should be aware that some families may not recognize the early developmental delays or concerns of the pediatrician or may not view early intervention as positive. They may see efforts to screen and evaluate as efforts to stigmatize their child, or they may belong to a culture or religion in which differences are tolerated and accepted and are not addressed. Each family experiences readiness for developmental intervention services differently. However, they may be open to other support services and resources, such as culturally competent parent supports.

Box 2

Program for Infants and Toddlers with Disabilities (Part C of Individuals with Disabilities Education Act)

Children from birth–age 3 years who exhibit, or are at risk of, delays in development are eligible under federal law for early intervention services that will foster age-appropriate development. The Program for Infants and Toddlers with Disabilities (Part C of IDEA) assists states in operating a comprehensive, statewide program of early intervention services for infants and toddlers with disabilities, from birth–age 3, and their families. A diagnosis is not necessary for enrollment in early intervention programs. Children can be on waiting lists for an evaluation while receiving services. Children from the age of 3–school age and beyond also are eligible for early intervention services through the educational system (Part B of IDEA, also called Section 619) or through developmental services. Eligibility criteria for infants, children, and adolescents can be found at <http://ectacenter.org>.

Abbreviation: IDEA, Individuals with Disabilities Education Act.



Developmental surveillance, screening, and observations are important in all aspects of any child's growth and development. Formal developmental evaluation is indicated if a developmental screen is failed and if any signs of developmental delay exist, if the parents express concern or questions about their child's development, or if the child is at risk of developmental challenges because of factors such as prematurity or prenatal exposure to alcohol, drugs, or other toxins. *(For more information on this topic, see the Promoting Healthy Development theme.)*

Many parents are aware of developmental delays or irregularities before they are told about them by a health care professional. Their concerns must be promptly addressed and appropriate evaluation must be initiated. This evaluation might begin in the primary care office and might include an immediate referral to an early intervention program, a developmental specialist, or, for most cases, both. Follow-up of referrals with the parents is especially important in case delays in accessing intervention services occur or if the infant's condition is determined ineligible. In this situation, the health care professional can help parents obtain other sources of support and intervention.

The parent-child relationship is the most important factor in supporting every child's development, particularly for infants or children with chronic health conditions or special health care needs. Yet parents may be under significant stress related to the provision of their infant's care needs. The health care professional plays an important role in assessing the family's strengths and their predicament, including concerns about the parent-child relationship or parental lack of knowledge about parenting or infant care, which may place the infant at further risk of developmental, behavioral, or physical disabilities and that warrant referral to early intervention services or other community supports.

Long-term outcomes for all infants are improved when the strengths of the infant and families are

recognized and opportunities are provided for parents to have early physical contact through rooming-in, breastfeeding, holding skin-to-skin, cuddling the infant, and understanding infant cues and sleep and awake states. Infants with special health care needs frequently provide parents with cues or signals that are more difficult to interpret, poor sleep, crying and fussiness, and feeding challenges. These concerns need to be addressed, and they may indicate the need for early intervention.^{17,18}

Promoting Health in Children With Special Health Care Needs: Early Childhood—1 Through 4 Years

Health care professionals who take care of children between the ages of 1 and 4 years have a responsibility to follow through with addressing known disorders and to diagnose and manage new special health care needs as they arise over time. Because children in this age group grow and progress rapidly, parents anticipate and analyze how their child is reaching developmental milestones such as walking, talking, and socializing. Developing pleasurable activities for the child and family and keeping a sense of the joy of childhood accentuates the child's strengths and achievements.

When parents express concerns about how their child is developing, the health care professional should listen and observe carefully. A wait-and-see attitude will not suffice, particularly if the child falls into an at-risk group. A proactive approach is essential. Some disorders have well-organized societies, such as the National Down Syndrome Society¹⁹ to offer specific guidance on Down syndrome, while other problems or less common congenital anomalies may require individualized expertise.

Parental concerns are highly accurate markers for developmental disability. The health care professional must be sensitive to these concerns. Several



tools are available to assess parent concerns about learning, development, and behavior. If developmental screening suggests problems or if developmental delay or disability is suspected, a referral should be made to an appropriate early intervention program or developmental specialist for evaluation. If significant developmental delay or disability is confirmed or if a delay in diagnostic confirmation is likely, the child also should be referred for early intervention services matched to the child's and family's needs. With the appropriate services in place, the primary health care professional provides a medical home for the child and, in partnership with the family, assists with ongoing care planning, monitoring, and management across agencies and professionals. The primary care practice team carries out these activities by providing care coordination services while at the same time helping with the normally encountered developmental hurdles and health supervision, including timely immunization. Participation in enjoyable activities like playgroups, singing, reading, and games to the extent of the child's abilities should be emphasized. Barriers to easy access to these services, such as inadequate health care coverage plans, family finances, access to resources, parental health and well-being, and sibling issues, also must be addressed.

Young children with special health care needs often have working parents and require child care and preschool just like typically developing children of the same age. As in all settings where these children spend their time, accommodations will be needed. Coordination with all caregivers and family members, including siblings, and a clear plan for how to manage acute problems, such as hypoglycemia or a seizure, lessen the fear that such events always entail. Families whose young children have special health care needs usually find that referrals to parent-to-parent support programs and family organizations are helpful. The transition between services described in Part C of the Individuals with Disabilities Education Act and

Part B (see Box 2) can be an especially difficult time for parents as they learn to negotiate the system requirements, which now include education, or find that their child's condition is no longer eligible for services.²⁰ The pediatric provider must understand the importance of this transition and provide parent support or alternative community supports for the family.

The health care professional caring for a child with a special health care need, while perhaps having received little training in this domain during residency, will come to an understanding of the crucial roles that additional professionals play in the lives of these children. These include occupational, physical, speech, behavioral, and respiratory therapists; education and child life specialists; personal care aides and assistants; and home care licensed practical or registered nurses. The medical home may be the ideal setting for responses to requests for guidance, clarification, or attention to concerns raised by all these home care personnel. The extent of responses will be influenced by the capacity of the health care professional or practice to provide care coordination if sources of support for the time and work required are limited or absent.

Promoting Health in Children With Special Health Care Needs: Middle Childhood—5 Through 10 Years

Middle childhood is a critical time for children with special health care needs to be actively involved in their own care so they can adapt successfully to their conditions. Two major transitions occur during this period—entrance into kindergarten at the beginning of middle childhood and entrance into middle school at the end. These are significant milestones for parents and the child as they adapt to increasing educational and social demands and the child begins to assume self-care responsibilities. During this period, children with special needs continue to define their sense of self and improve



their ability to care for their own health, supported by their interactions with their care providers. Children adapt best to chronic illness when health care professionals, families, schools, and communities work together to foster their emerging independence. Inclusion in school and community life allows children with special health care needs to feel valued and to integrate their specific care needs with other aspects of their lives. Many children and youth with special health care needs require extra support from their schools, including resource room services, special classes and aides, and adaptations in the school environment, including accommodations for physical activity and sports. They and their families may experience prejudice and misunderstanding, both in the social and academic worlds. Their families frequently experience increased levels of emotional and financial stress and isolation.

It is important to discuss family perspectives because families may have various beliefs and values regarding the independence of children with special health care needs based on culture and history. Further, families should have appropriate supports if they need to cope with certain difficult tasks, such as hospitalizations or painful tests, illness, or possibly death.

When families have children with special health care needs, the health care professional may need to work with the family to provide information to the school and teachers on how best to meet the child's needs. Information effectively shared about what issues are and are not expected because of the underlying condition may help improve a child's school performance and schoolmate acceptance. Parents and child care providers should be sensitive to these issues and responsive to the needs of medically fragile children and their healthy siblings. At the same time, children with special health care needs should not be given special privileges simply because of their condition. Instead, outlining rules and responsibilities is extremely important for the child's development and the family's functioning.

Child care providers and teachers can play an important supportive role and be a source of information for parents and their children.

Promoting Health in Adolescents With Special Health Care Needs—11 Through 21 Years

As children with special health care needs enter adolescence and experience puberty and rapid physical and emotional development, new levels of functionality in the face of their special need can bring important and remarkable gains in independence and autonomy. Alternatively, limitations related to their illness can further underscore their physical dependence and threaten autonomy, which can limit the development of emotional independence. Pubertal development may be affected, influencing healthy sexual development and perceived sexual autonomy.

Careful assessment of medical conditions, strengths, and risk-taking behaviors, followed by sensitive discussions of the youth's perceived needs and goals, can assist the adolescent with a special health care need to maximize physical and emotional development and support the attainment of full emotional development and maturity. Assessing physical abilities and carefully analyzing risks can foster participation in adaptive or interscholastic sports activities. The health care professional's expectations and opportunities for the adolescent to take active roles in their care decisions are important.

Entrance into high school is a significant transition for youth and their parents as they experience adapting to increasing educational and social demands, assumption of self-care responsibilities, and greater independence with the long-term goal of a happy, rewarding adolescence. The pediatric health care professional must understand the importance of this transition and provide parent support or alternative community supports for the family. Just as in the care of adolescents whose



overall health status and development are more typical, adolescents with special health care needs require time alone with the health care professional to discuss, as able, topics germane to reproductive health, sexuality, relationships, mood, and the use of nicotine, alcohol, marijuana, and other drugs. Particularly important issues include discussion of academic performance, substance use, and sexuality.

Transitioning to Adult Care

Optimal health care for youth includes a formal plan for the transition to an adult health care provider. Transition is a flexible process, allowing youth to move to increasing levels of adult specialty care as they are ready, with the anticipation of completing the process by 25 years of age. Successful transition involves the early engagement and participation of the youth and family with the pediatric and adult health care teams in developing a formal plan. Health care professionals who care for adolescents with special health care needs and providers of pediatric specialty care for issues such as human immunodeficiency virus (known as HIV), chronic illness, and other special health care needs should have a policy for the transfer of the adolescent to adult care. The plan can be introduced to the youth in early adolescence and modified as the youth approaches transition.

Before initiating the transfer to adult care, it is important to assess developmental milestones to define the youth's readiness to assume responsibility for her own care. A successful transition from pediatric- to adult-oriented health care depends on the youth acquiring disease self-management skills, except for youth who lack the decisional capacity to guide their own health care and are under legal guardianship. The process should be as seamless as possible. Communication between the adolescent and adult care professionals is essential and may include personal contact and a written medical summary.²¹

It may be difficult to identify health care professionals with the expertise that the family and youth have experienced in the pediatric arena. Youth may find that the adult care services may not be as nurturing in providing support as they are accustomed to in the pediatric and adolescent medicine settings. Although the literature describes several transitioning care models, no research exists comparing these models or the patient satisfaction attributed to each.²²



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