Children with Special Healthcare Needs

Summary of the Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents: Promoting Health for Children and Youth with Special Health Care Needs

Introduction (pg.65)

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. In addition, an increasing number of children are receiving diagnoses of developmental disabilities and conduct disorders, which may indicate special health care needs.

Definition (pg.65)

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.”

- 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.
- 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.
- 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 (pg.66)

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.
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).

A 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.

**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 (e.g., 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.


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. 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.
An eco-map provides a concise visual representation of the many entities involved in caring for the child and family. (Figure 1) It enables practices and families to delineate the existing plan of care coordination, assess the current supports surrounding a family,

<table>
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<td><strong>Work Flow of a Family-Centered Team Approach to Care</strong></td>
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<td><strong>Roles of Care Partnership</strong></td>
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Palliative and Hospice Care (pg.70)

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.

- 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.
- 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.
- Pediatric palliative care focuses on pain and symptom management, information sharing, and advanced care planning; practical, psychosocial, and spiritual support; and care coordination.
- Both palliative care and hospice care can significantly enhance the care provided in the medical home.
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.

Families of these infants should be counseled about resources for long-term care as soon as practical during the hospital stay.

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.

The health care professional should explore with the family their understanding of their infant’s health condition, its effect on the family, and 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 identifying conditions that place the infant at risk of disability and warrant immediate referral to early intervention services or other community resources (Box 2).

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.

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.

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.

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.

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.
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.

- 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.

- 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.

- 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.

- 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.

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.

Promoting Health in Children with Special Health Care Needs (pg.73)

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.

- 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.
- 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.
- 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.

Promoting Health in Adolescents with Special Health Care Needs (pg.74)
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.
- 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.
- 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. Particularly important issues include discussion of academic performance, substance use, and sexuality.

Transitioning to Adult Care (pg.75)
- 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.
- 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.
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.

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.

This guideline summary is not all-inclusive of available guideline content. Please reference the full guideline for comprehensive content.