

## Promoting Health for Children and Youth With Special Health Care Needs

Caring for children and youth with special health care needs is a growing responsibility for health care professionals. Advances in medicine and technology and the expansion of pediatric home care mean that more children with special needs are surviving into adulthood and integrating successfully into home and community settings.

Nearly 20% of the childhood population—about 14.6 million children—have special health care needs, which include birth defects, inherited syndromes, developmental disabilities, and disorders acquired later in life, such as asthma. Each age or stage presents the child with different developmental tasks, and these may be complicated for children with special health care needs.

Along with their particular medical and developmental issues, children and youth with special health care needs have many of the same health supervision needs as typically developing children. The Bright Futures visit provides an opportunity for health care professionals to provide regular preventive and primary care, along with care for the unique needs related to a child's condition.

### SUPPORTING FAMILIES OF CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

- 1. Use a comprehensive approach that balances care for the child's special health care needs as well as regular health supervision needs**  
The medical home considers the unique trajectory of the child with special health care needs and his or her family, along with the preventive and primary care needs that are consistent with those of all children and families.
  - Use surveillance, screening, and attention to parental concerns to identify and monitor special health care needs as well as to highlight typical developmental milestones and achievements.
  - Ensure that the child's needs for overall health supervision, the identification of strengths and protective

factors, and anticipatory guidance receive sufficient time during the visit, along with focused attention on the unique needs of the child.

- Learn coding requirements for billing and reimbursement to ensure payment for evaluation and management services that may be added to the health supervision visit.
- 2. Jointly develop a shared plan of care (SPoC)**  
An SPoC is a team-based, integrated, continuously updated plan of care that links activities from visit to visit. The SPoC coordinates the child's or adolescent's care across the health care continuum and provides a place where the child or adolescent and family can describe their priorities and plans for supporting health. Recognizing that children with special health care needs often have multiple care professionals, the SPoC is a mechanism for developing a plan of care in partnership across these care provider organizations.

### ABOUT BRIGHT FUTURES

Bright Futures is a national health promotion and prevention initiative, led by the American Academy of Pediatrics (AAP) and supported by the Maternal and Child Health Bureau, Health Resources and Services Administration. The *Bright Futures Guidelines* provide theory-based and evidence-driven guidance for all preventive care screenings and well-child visits. Bright Futures content can be incorporated into many public health programs such as home visiting, child care, school-based health clinics, and many others. Materials developed especially for families are also available. Learn more about Bright Futures and get Bright Futures materials by visiting [brightfutures.aap.org](http://brightfutures.aap.org).



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An SPoC is important, especially for children with complex medical needs, because it:

- Enables all members of the care team to operate from the same family-centered perspective.
- Helps everyone be accountable for desired outcomes.
- Supports continuity and longitudinal care needs as critical primary care functions.
- Extends the medical home and makes use of community partnerships and resources.

- The team monitors progress against goals, provides feedback, and adjusts the SPoC on an ongoing basis to ensure that it is effectively implemented.
- Team members anticipate, prepare, and plan for all transitions (eg, early intervention to school, hospital to home, pediatric to adult care).
- The SPoC 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.
- Care is subsequently well coordinated across all involved organizations and systems.



## MAKE THE MOST OF HEALTH SUPERVISION VISITS BY USING THE BRIGHT FUTURES TOOL & RESOURCE KIT

The *Bright Futures Tool & Resource Kit*, 2nd Edition, provides the forms and materials that health care professionals need to carry out preventive health supervision and health screening for infants, children, and adolescents. These forms can be adapted for use with children with special health care needs.

The **Previsit Questionnaire** allows the health care professional to gather pertinent information before the visit, providing a foundation for discussion and anticipatory guidance during the visit. The **Visit Documentation Form** is a convenient resource for documenting activities during the visit, including the SPoC. This form can be adapted for use in electronic health record systems. The **Parent-Patient Handout** reinforces the discussion and provides additional information for the family to take home after the visit.

Example: 3 Year Visit Previsit Questionnaire

Example: 3 Year Visit Documentation Form

Example: 3 Year Visit Parent Education Handout

### 3. Follow the guiding principles<sup>1</sup> of the SPoC

- Children, youth, and families are actively engaged in their care.
- Communication with and among their medical home team is clear, frequent, and timely.
- Health care professionals or team members base their patient and family assessments on a full understanding of child, youth, and family needs, strengths, history, and preferences.
- Youth, families, health care professionals, and their community partners have strong relationships characterized by mutual trust and respect.
- Patient- and family-centered care teams can access the information they need to make shared, informed decisions.
- Patient- and family-centered care teams use a selected SPoC characterized by shared goals and negotiated actions; all partners understand the care planning process, their individual responsibilities, and related accountabilities.

<sup>1</sup> Reproduced in Hagan JF et al., 2017w, with permission from McAllister JW. Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs: An Implementation Guide. Palo Alto, CA: Lucile Packard Foundation for Children's Health; 2014.

## Additional Resources

- [\*Promoting Health for Children and Youth with Special Health Care Needs\*](#). This health promotion theme in the *Bright Futures Guidelines*, 4th Edition, provides additional information about Care Coordination and collaborative care.
- [National Resource Center for Patient/Family-Centered Medical Home](#). The National Resource Center carries out programs and activities to ensure that all children and youth with special health care needs receive care within, and have access to, a medical home.
- [AAP Agenda for Children: Medical Home](#). This website describes AAP's medical home principles and current activities.
- [STAR Center](#). This AAP website provides resources and training about screening for social determinants of health for the entire practice team, including [Screeningtime.org](#)—an interactive e-learning course.
- AAP's [Periodicity Schedule](#). This schedule is an easy way for health care professionals to stay up to date with AAP recommendations for health supervision screenings and assessments.



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Content for this Tip Sheet has been adapted from  
*Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*, 4th Edition.

Last updated: April 2019

Downloaded from: <http://brightfutures.aap.org>

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**HRSA**

This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$5,000,000 with 10 percent financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, HRSA, HHS, or the U.S. Government. For more information, please visit [www.HRSA.gov](http://www.HRSA.gov).