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A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs

American Academy of Pediatrics, American Academy of Family Physicians and
American College of Physicians-American Society of Internal Medicine
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AMERICAN ACADEMY OF PEDIATRICS

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A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs

ABSTRACT. This policy statement represents a consensus on the critical first steps that the medical profession needs to take to realize the vision of a family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent health care system that is as developmentally appropriate as it is technically sophisticated. The goal of transition in health care for young adults with special health care needs is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. This consensus document has now been approved as policy by the boards of the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine.

INTRODUCTION

Each year in the United States, nearly half a million children with special health care needs cross the threshold into adulthood.¹ One generation ago, most of those with severe disabilities died before reaching maturity; now more than 90% survive to adulthood.² Most young people with special health care needs are able to find their way into and negotiate through adult systems of care.³ However, many adolescents and young adults with severe medical conditions and disabilities that limit their ability to function and result in complicating social, emotional, or behavioral sequelae experience difficulty transitioning from child to adult health care. There is a substantial number whose success depends on more deliberate guidance.⁴

Children grow up within complex living arrangements, communities, and cultures and receive medical care within an equally complex, interlocking set of relationships that includes social services, education, vocational training, and recreation. Clearly, no single approach will work equally well for all young people, and the health care sector cannot work in

isolation from the other professionals and networks that impact these young people.⁵ By focusing on the health care sector in this policy statement, we do not ignore other critical relationships. Rather, we are acknowledging that physicians have an important role in facilitating transitions to adulthood and to adult health care for young people who are least likely to do it successfully on their own.

The goals of this policy statement are to ensure that by the year 2010 all physicians who provide primary or subspecialty care to young people with special health care needs 1) understand the rationale for transition from child-oriented to adult-oriented health care; 2) have the knowledge and skills to facilitate that process; and 3) know if, how, and when transfer of care is indicated.

WHAT IS MEANT BY "HEALTH CARE TRANSITIONS"?

Transitions are part of normal, healthy development and occur across the life span. Transition in health care for young adults with special health care needs is a dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination.

Physicians are of special importance in this process because of the frequent contact with many of these young people and the close relationships that often develop with them and their families.

A well-timed transition from child-oriented to adult-oriented health care allows young people to optimize their ability to assume adult roles and functioning. For many young people with special health care needs, this will mean a transfer from a child to an adult health care professional; for many others, it will involve an ongoing relationship with the same provider but with a reorientation of clinical interac-

The recommendations in this statement do 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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tions to mirror the young person's increasing maturity and emerging adulthood.

Whether the transition entails a transfer of care or not, all adults with special health care needs deserve an adult focused primary care physician. This is not to say that the child health specialist will not have an ongoing role. Rather, it is to affirm that just as children receive optimal primary care in a medical practice experienced in the care of children, so too adults benefit from receiving care from physicians who are trained and experienced in adult medicine.⁵ Whether or not a transfer of care occurs, successful transition requires communication and collaboration among primary care specialists, subspecialists, young adult patients, and their families.

WHY IS PLANNING FOR TRANSITIONS IMPORTANT NOW?

*Healthy People 2010*⁶ established the goal that all young people with special health care needs will receive the services needed to make necessary transitions to all aspects of adult life, including health care, work, and independent living. Just as the Individuals With Disabilities Education Act of 1997⁷ requires a plan for education transition, so too there should be a plan for health care transition. The challenges faced by health care professionals include ensuring age-appropriate care, advocating for improved health insurance coverage, and negotiating adequate compensation for services provided.

Optimal health care is achieved when every person at every age receives health care that is medically and developmentally appropriate. The central rationale for health care transition planning for young people with special health care needs is to achieve this goal by ensuring that adults receive primary medical care from those trained to provide it.

CRITICAL FIRST STEPS TO ENSURING SUCCESSFUL TRANSITIONING TO ADULT-ORIENTED HEALTH CARE

1. Ensure that all young people with special health care needs have an identified health care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health care planning. This responsibility is executed in partnership with other child and adult health care professionals, the young person, and his or her family. It is intended to ensure that as transitions occur, all young people have uninterrupted, comprehensive, and accessible care within their community.
2. Identify the core knowledge and skills required to provide developmentally appropriate health care transition services to young people with special health care needs and make them part of training and certification requirements for primary care residents and physicians in practice.
3. Prepare and maintain an up-to-date medical summary that is portable and accessible. This information is critical for successful health care transition and provides the common knowledge base for collaboration among health care professionals.

4. Create a written health care transition plan by age 14 together with the young person and family. At a minimum, this plan should include what services need to be provided, who will provide them, and how they will be financed. This plan should be reviewed and updated annually and whenever there is a transfer of care.
5. Apply the same guidelines for primary and preventive care for all adolescents and young adults, including those with special health care needs, recognizing that young people with special health care needs may require more resources and services than do other young people to optimize their health. Examples of such guidelines include the American Medical Association's *Guidelines for Adolescent Preventive Services (GAPS)*,⁸ the National Center for Education in Maternal and Child Health's *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*,⁹ and the US Public Health Service's *Guidelines to Clinical Preventive Services*.¹⁰
6. Ensure affordable, continuous health insurance coverage for all young people with special health care needs throughout adolescence and adulthood. This insurance should cover appropriate compensation for 1) health care transition planning for all young people with special health care needs, and 2) care coordination for those who have complex medical conditions.

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