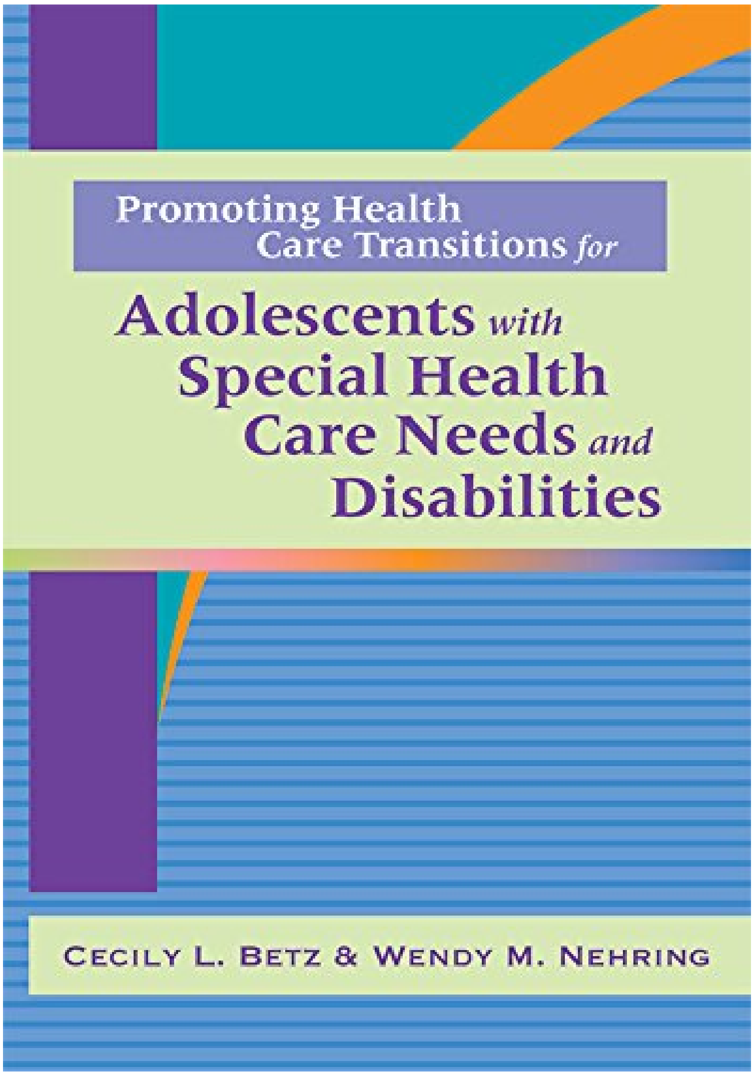
Promoting Health Care Transitions for Adolescents With Special Health Care Needs and Disabilities



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From Brand: Brookes Publishing : Promoting Health Care Transitions for Adolescents With Special Health Care Needs and Disabilities before purchasing it in order to gage whether or not it would be worth my time, and all praised Promoting Health Care Transitions for Adolescents With Special Health Care Needs and Disabilities:

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An essential resource...fills a significant gap in the literature and provides practitioners with practical information. --University of FloridaThe National Center for Health Statistics reports that more than 9 million U.S. children have special health care needs. This book is driven by the premise that when those children reach adulthood, they often face difficult transitions from pediatric care to adult medical care.The authors, who have academic and nursing credentials, address those challenges in a text that's appropriate not only for health care professionals and educators, but also parents.The solutions they offer include developing workable health care transition plans from start to finish; helping families locate and select adult medical and health care providers; and assisting young people with obtaining accessible accommodations in school and at work. --questAn excellent resource...provides readers with cutting edge knowledge, assessment and management tools. --University Dean and Distinguished Professor, Indiana University School of NursingThe National Center for Health Statistics reports that more than 9 million U.S. children have special health care needs. 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Previously, she held administrative and faculty positions at Rutgers, The State University of New Jersey, Southern Illinois University at Edwardsville, and the University of Illinois at Chicago, and a faculty position at Illinois Wesleyan University. She received her doctorate in nursing science from the University of Illinois at Chicago, her master's degree in pediatric nursing from the University of Wisconsin-Madison, and her bachelor's degree in nursing from Illinois Wesleyan University. Dr. Nehring is nationally and internationally known in the field of intellectual and developmental disabilities. She wrote one of the only history books on nursing in the field of intellectual and developmental disabilities. She and her colleagues revised the Scope and Standards of Practice in this specialty in 2004 for American Nurses Publishing and the American Association on Mental Retardation. Dr. Nehring is also the editor of a core curriculum for nurses and health professionals specializing in the field of intellectual and developmental disabilities (Jones Bartlett, 2005), an evidence-based practice book on specific health promotion topics and the research that was conducted on these topics with persons with intellectual and developmental disabilities (American Association on Mental Retardation, 2005). She also co-edited a book with Cecily L. Betz on the health concerns of adolescents with special health care needs and disabilities making the transition into adulthood (Paul H. Brookes Publishing Co., 2007). She has written, presented, and consulted widely on this nursing specialty, as well as received internal and external funding for her research on people with Down syndrome and neural tube defects. Dr. Nehring is a fellow of the American Academy of Nursing and the American Association on Intellectual and Developmental Disabilities (AAIDD). In 2009, she received the Leadership Award from the AAIDD.Dr. Betz has worked with children, adolescents, and families for more than 30 years in a variety of roles as a clinician, educator, administrator, and researcher. She has served as the editor-in-chief of the Journal of Pediatric Nursing, the official journal of the Society of Pediatric Nursing and Pediatric Endocrinology Nursing Society, since the mid-1980s. She has published extensively on topics pertaining to pediatric nursing, developmental disabilities, and health care transition planning for adolescents with special health care needs. Her textbook Pediatric Nursing Reference (Mosby, 2008) is in its sixth edition; this textbook and others she has authored have been translated into three languages. Dr. Betz has been the principal investigator for a number of extramurally funded federal and state grants and has served on a number of regional, state-level, and national professional committees representing the interests of pediatric nurses and adolescents with special health care needs and disabilities. She also served as one of the organizers and founding members of the Society of Pediatric Nursing, a national pediatric nursing association founded nearly 2 decades ago. She is a fellow of the American Academy of Nursing of the American Nurses Association and was formerly the Chair of the Child and Family Expert Panel. In 2008, Dr. Betz received the Margaret S. Miles Service Award from the Society of Pediatric Nurses for her service and contribution to pediatric nursing.Excerpt. copy; Reprinted by permission. All rights reserved.Excerpted from Chapter 1 of Promoting Health Care Transitions for Adolescents with Special Health Care Needs and Disabilities, edited by Cecily L. Betz, Ph.D., RN, FAAN, Wendy M. Nehring, Ph.D., RN, FAAN, FAAIDDCopyright copy; 2007 by Paul H. Brookes Publishing Co. All rights reserved. No part of this excerpt may be reproduced or reprinted without permission in writing from the publisher.DEFINING HEALTH CARE TRANSITIONSWhat is meant by health care transitions? This question can be answered by examining the professional literature and policy statements formulated by several professional associations and governmental agencies. The transition, including health care transition to adulthood, occurs over an extended period time and cannot be considered a discrete event (White, 1997). As will be discussed throughout this book, transition planning is a lifelong process as each successive developmental achievement enables an individual to evolve through the stages of childhood and adolescence and into adulthood. For the purposes of this chapter, health care transition is conceived as a dynamic process (NCYD, 1995) with a beginning, a middle, and an end. The beginning phase includes the decision to begin or prepare for the transition. The middle phase, transition readiness, includes logistical and other efforts of preparation for and implementation of the transition. Transition readiness is defined as the specific decisions made and actions taken in building the capacity of the adolescent and those in his or her primary medical system of support (parental caregivers/family and providers) to prepare for, begin, continue, and finish the process of transition (Telfair, Alexander, Loosier, Alleman-Velez, Simmons, 2004). The final or end stage occurs when the adolescent or young adult not only transfers to an adult care setting but also is actively participating in adult care activities, such managing as independently as possible the daily requirements of his or her treatment regimen, working with providers to plan his or her own medical care, deciding if a provider to whom he or she is referred is someone with whom he or she can work, and, if necessary, finding and choosing a different provider.Given this reality, transition experts have defined the term transition from a number of different perspectives depending on their disciplinary focus, research or clinical experience, and time period (see Table 1.1 for a sampling of transitionrelated definitions). There are several commonalities in these definitions. All definitions agree that transitioning is a process involving the services and support of one or more health care professionals who have specialized expertise in transition planning. Another area of agreement is that the primary goal of health care transitions is the successful transfer of the adolescent from pediatric care providers to adult care providers. Although not explicitly stated, the definitions also imply that the transfer of care entails the establishment of an acceptable, workable relationship between the provider(s) and the new patient. As research has demonstrated, an important measurement of transfer success is continued patient contact with the health care providermdash;whether it be an adult specialty or primary care physician or nurse practitionermdash;after the initial office visit. Beyond these areas of consensus, differences emerge. Some experts view health care transition planning as focused on medical needs (Anderson, Flume, Hardy, Gray, 2002; Nasr, Campbell, Howatt, 1992; Pacaud, McConnell, Huot, Aebi, Yale, 1996) whereas others have more expansive perspectives, suggesting that transition be viewed not just from a sole provider's perspective of transfer of care from the pediatrician to the internist and adult medical specialists, but as a comprehensive approach to learning new developmental competencies and the new systems of care for health, education, employment, and community living (Rettig Athreya, 1991; Sawyer et al., 1998; Scal, et al., 1999). Those with a more encompassing concept of transition planning embody more fully the emerging consensus of transition experts described in the following section. It is apparent that the question of what constitutes effective transition planning is only beginning to be answered from an empirical perspective. However, the growing interest and attention in the health care system to the issue of transition planning is creating a collective effort to describe the principles of best practices. That is, it is becoming clear that transitioning is more than a transfer process from one provider to another, and the explanatory emphasis of health care transition planning should be placed on the growing evidence of what constitutes best practices.Several professional associations have taken a leadership role in describing a framework of best practices related to health care transition planning. The AAP, American Academy of Family Physicians (AAFP), and American College of Physiciansndash;American Society of Internal Medicine (ACPndash;ASIM) issued A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs (AAP, AAFP, ACP#8211ASIM, 2002). The major provisions of this joint statement include having care coordinator, a transfer health summary, a transition health care plan, provision of adequate primary and preventive care, and health insurance coverage. The details of this joint statement by the AAP, AAFP, and the ACPASIM (2002) are displayed below.Have a care manager who coordinates health care planning between pediatric and adult health care providers. Provide transition training to enhance the knowledge and skills of primary care adult physicians. Formulate a medical summary for transfer to adult primary and specialty physicians. Develop a health care transition plan beginning at age 14. Ensure primary and preventive care based on accepted medical guidelines are provided. Ensure continuous health insurance coverage once pediatric eligibility terminates.Statements of transition practice issued by the AAP (AAP, Committee on Children with Disabilities, 2000, 2001; AAP, Committee on Children with Disabilities and Committee on Adolescence, 1996), the National Association of Pediatric Nurse Practitioners (NAPNAP; 2001), the Society of Adolescent Medicine (Rosen et al., 2003) and the DCSHCN share a number of similar recommendations. These recommendations advocate the following: The responsibility for transition service coordination and referral is assigned to one member of the youth's specialized health care team who has expertise in case management (e.g., social worker, nurse). Adolescents are active participants and are fully engaged in transition planning, which includes shared decision making, direct input during the planning process, and evolving primary responsibility for managing their condition on a long-term basis. Families of transition#8211age adolescents are provided supports and services to assist them in dealing with their feelings of "letting go" and learning to better support their children's developing self-reliance during the transition process. Services are based on the developmental needs of the adolescents, emphasizing strengths rather than deficits. Transition planning is a lifelong process with formalized transition services provided beginning at age 14. Transition planning begins at the time of diagnosis based on the belief that goals for adulthood are necessary and achievable based on the skills and capabilities of the adolescent. Service coordination includes determination of eligibility and referral to transition and adult services, including Supplemental Security Insurance (SSI) and Medicaid. Referrals to transition and adult services are not relegated to health care needs only but to the comprehensive array of services and programs that will assist the adolescent in achieving his or her goals for the future, such as living independently, being employed, and having a social network of friends and family. The service coordinator assists the youth to identify and obtain needed accommodations based on health/disability#8211related needs in education, work, and community settings. Transition planning ensures a smooth and coordinated transfer from pediatric to adult health care providers and services. This coordination process will involve the active engagement of both pediatric and adult health care providers to achieve success with the transfer to adult care providers and services. Clinical experts and researchers have contributed to the expanding body of knowledge and have offered a number of suggestions for developing and implementing transition service models. It is widely accepted that health care transition planning needs to be implemented according to a preplanned and structured process incorporating benchmarks of achievement. A best practices approach for transition planning incorporates timelines, identification of goal achievements, and processes for skills and knowledge achievement that can guide the practice of pediatric health professionals. As part of the structure and function of the medical care program, there be must good working relationships and communication between pediatric and adult providers (e.g., primary care providers, specialists, adjunct providers). Such relationships must be tempered with realism for a given setting since such relationships are more easily described than created or maintained (Betz Redcay, 2002; Clare, 1998). Education of the adolescent, his or her family, other providers from multiple disciplines, and community members needs to emphasize outcomes that demonstrate knowledge and skills obtained. The goals of the program for support in the form of case management need to clearly describe relevant activities (Wojciechowski, Hurtig, Dorn, 2002). Listening; demonstrating respect for opinions, concerns, and cultural values of the young person, family, and community; providing advice specific to problem solving; and including family and significant others in decision making are all important in providing support to the adolescent in transition.