

INTRODUCTION

In 1984, US Surgeon General C. Everett Koop, MD, cohosted a national invitational conference with Undersecretary of Education Madeline Will, focusing on the needs of older adolescents with chronic and disabling conditions.¹ For the first time, issues of health care transition were on the national radar. This new attention was brought about by dramatically improved survival rates during the 1970s and early 1980s for children born with chronic and disabling conditions. That conference was followed 5 years later by the 1989 Surgeon General's Conference titled "Growing Up and Getting Medical Care: Youth with Special Health Care Needs."² That conference set forth a national agenda in training, research, and program development with a goal of establishing a seamless health care system that would allow young people with special health care needs to move from child-centered to adult-centered services.

Today, nearly 2 decades after the first invitational conference, the process of transitioning youth with special health needs to adult health care appears to be only marginally further ahead of where it was at that time. No doubt, there is more awareness today of the issues facing older adolescents and young adults with special health care needs than there was a generation ago. So too, our knowledge of impediments to and factors that facilitate the transition process has been more clearly established. But it is equally clear that the medical community, specifically, and the health care community, more broadly, have yet to put into place a set of changes needed to ensure that young people most dependent on coordinated health care services are able to make the transition to the adult health care system and still receive the services that they need.

It is against this backdrop that in September 2001, the American Academy of Pediatrics sponsored a national invitational conference to bring together leaders from the primary care specialties of pediatrics, internal medicine, and family practice; subspecialties of adolescent medicine, physical medicine and rehabilitation, and neurology and neurodevelopmental disabilities; psychiatry; and the professions of social work, psychology, and nursing as well as parents of young adults with disabilities. The conference was supported by the Maternal and Child Health Bureau of the US Department of Health and Human Services, Health Resources and Services Administration, which has set health care transitions as 1 of its 6 action steps to help ensure that by the year 2010, comprehensive community-based service systems are in place for all children and youth with special health care needs.³ In addition, the Johnson Foundation provided support that allowed the meeting to be held at its educational conference center Wingspread in Racine, Wisconsin. Thirty-eight indi-

viduals met from Friday evening until Sunday afternoon to craft a national policy statement on health care transitions.

THE CONSENSUS STATEMENT ON HEALTH CARE TRANSITIONS

The policy statement (see pages 1304–1306) represents a consensus for the critical first steps that the medical profession needs to undertake if 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 is to be realized. This consensus document has now been approved as policy by the boards of directors of the American Academy of Pediatrics, the American Academy of Family Practice, and the American College of Physicians-American Society of Internal Medicine.

THE COMMISSIONED PAPERS

In preparing for the conference, 4 papers were commissioned that together deepen our understanding of the health care transition process, the financial factors that complicate that process, and models of care coordination that have the promise of facilitating it.

In their article, "Health Care Transition: Destinations Unknown," Reiss and Gibson review the evolving policies in the United States related to health care transition from the first conference that was held through a 1999 meeting titled "Transition Revolution." In the 1999 meeting, it was recommended that youth with special health care needs participate as decision makers and partners in the planning process for their own health care. Additionally, participants urged that all youth with special health care needs have identified medical homes that are responsive to their needs. They saw Title V of the Social Security Act⁴ as a vehicle to facilitate the development of transition systems for children, youth, and young adults with special health care needs and their families, and they identified as a priority the need to provide youth with special health care needs accessible and affordable insurance coverage. Reiss and Gibson provide data from youth, parent, and provider focus groups that identify factors that impede and that promote health care transition in 3 domains: service needs, structural issues, and personal preferences and interpersonal dynamics. They conclude that there is no clear model for health care transition in the United States for young adults with special health care needs. Rather, some continue to receive care from pediatric providers and facilities, others receive health care from pediatric and adult providers, and others transition to receiving all care from

adult providers, facilities, and programs. Most significantly, a large number of young people with special health care needs drop out of the health care system and have no provider once they transition from pediatric services.

The authors put forth 5 core recommendations to facilitate transition: 1) have an orientation that is future focused and flexible; 2) anticipate change and develop a flexible plan for the future; 3) foster personal and medical independence and creative problem solving; 4) develop a specific and detailed transition plan; and 5) celebrate transitions.

The article by Scal, "Transition for Youth With Chronic Conditions: Primary Care Physicians' Approaches," compliments the work by Reiss and Gibson. Scal set out to undertake a survey of primary care providers who were nominated by parents of young adults with special health care needs as individuals who provide prototypic services. Despite the fact that nearly 6500 surveys were sent out, primarily through e-mail, only a handful of nominations were returned. According to Scal, many more parents responded by sharing the frustrations and difficulties they have encountered in trying to obtain transition services for their adolescents and young adults with disabling conditions.

Despite the limited response, there are certain themes in Scal's article that resonate with that of Reiss and Gibson, including: 1) fear and ambivalence tend to characterize the health care transition process; 2) transition is a process and not an event; 3) providers need to orient to the future—adolescents and parents respond to providers' sense of optimism and future orientation.

Primary care physicians who do provide transition services appear to have been sensitized to the need for these services by an issue or an experience that was personal or patient related. These physicians indicate that there are 2 critical elements that a young person must have to be able to successfully transition to adult health care settings: 1) an understanding of and an ability to describe the signs and symptoms requiring urgent medical attention, and 2) an understanding of the implications of their condition and treatments on their sexual and reproductive health.

Although providers indicate family and adolescent resistance are among the most significant barriers to health care transitions, these are not the ones that are insurmountable. Far more often, the problems of institutional support (eg, insurance or hospital cutoff age and the inability to find an adult primary care provider) are the true rate-limiting steps in developing an organized transition plan.

The article by White, "Access to Health Care: Health Insurance Considerations for Young Adults With Special Health Care Needs/Disabilities," provides us with a far deeper understanding of the health insurance issues faced by young people with special health needs and their families. White reviews the public and private insurance mechanisms that cover youth with disabilities. What becomes clear is that what is available varies greatly from state to state, as does eligibility for specific plans. It also is clear how poorly reimbursed, if at all, is the

care coordination that Reiss and Gibson, as well as Scal, underscore. White puts forth a call to action dealing with health insurance and payment issues. Specifically, she argues that we need 1) good data on "leavers" of the State Child Health Insurance Plan (SCHIP), looking specifically at adolescents and young adults; 2) studies that would model private and public insurance system expansion to include young adults who are currently uninsured and underinsured; 3) new models of insurance pooling to incorporate those with serious chronic conditions so as to make health insurance more affordable; 4) assessment to better understand why states do not take advantage of federal programs currently available; 5) child and adult providers to collaborate with the Ticket to Work legislation and the new technical assistance centers authorized by that legislation, helping to define "disability" and "medically improved" so as to improve the work and health care coverage options for young adults with special health care needs; and 6) ongoing advocacy at the state and federal levels to ensure that issues of financing of health care services for adolescents and young adults with special health needs remain visible and on the agenda. Otherwise, the needs of other populations larger in number are more likely to overwhelm the legislative agenda.

Finally, the article by Kelly et al, "Implementing Transitions for Youth With Complex Chronic Conditions Using the Medical Home Model," provides a concrete example of how a care coordination program can address and overcome many of the barriers identified in the other 3 articles. Kelly et al lay out a framework for evaluating complexity of need, which they indicate is a critical first step in providing comprehensive care to young adults. The framework that they use explores complexity in 4 domains: the medical condition, family strengths, health care services and needs, and education. They describe a model of a medical home, the U Special Kids Program, and present 2 cases of how health care transitions were facilitated through this model. Interestingly and importantly, these cases highlight many of the principles that Scal and Reiss and Gibson articulate in their articles. Kelly et al also highlights the need for accurately synthesized complex medical information so it is accessible and available to family members and adult health providers. Such information is a cornerstone to successful health care transitions; the authors provide a template for such an information system, and a template is provided for a chart summary.

CONCLUSION

From a medical perspective, great advances have been made over the past 20 years in improving the survival rates and medical outcomes for a large number of children and adolescents with special health care needs. The policy statement that is now brought forward is submitted with the hopes not only that every major health professional organization will "sign on," but much more importantly, that the critical first steps needed to realize the vision of successful transitions to adult care for all young people,

whether or not they have special health care needs, will begin to be implemented.

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