Health Care Services and the Transition to Young Adulthood: Challenges and Opportunities

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ABSTRACT

OBJECTIVE: The aim of this study was to examine the potential role of the health care system in the successful transition to young adulthood for all adolescents, with emphasis on adolescents with special health care needs (ASHCN), and to evaluate the system's status in filling that role.

METHOD: Research and conceptual frameworks addressing successful transitions and functioning were reviewed. A framework describing a role for health care services in the transition was presented. The health care system's status in promoting healthy transitions was evaluated, including National Survey of Children with Special Health Care Needs 2005–2006 analyses of key outcomes for ASHCN.

RESULTS: Although most national efforts to define skills needed for the transition have focused on career/vocational skills, a few frameworks integrate broader issues such as health, psychosocial development, and civic engagement. Adolescent transitional issues have generally received little attention; however, these have been articulated for ASHCN. Nevertheless, only 2 in 5 ASHCN receive transitional care, and ASHCN fare poorly on other core outcomes. ASHCN with mental health conditions fare worse on outcomes than those with physical health conditions. Our framework for healthy transitions includes the following: 1) adolescents can access a comprehensive health care system, 2) preventable problems are avoided, and 3) chronic problems are managed. The present health care system falls short of accomplishing these.

CONCLUSIONS: Health care services can potentially play a role in facilitating a healthy transition to young adulthood; however, many gaps exist. Although the health care reform act addresses some gaps, efforts that integrate adolescents' developmental needs and address mental health issues are needed.

KEYWORDS: adolescents; special health care needs; transition; prevalence

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ADOLESCENCE IS A period of significant transition involving biological, psychosocial, and cognitive development. During adolescence, young people become increasingly independent and begin assuming adult roles and responsibilities, a process that continues as they transition to young adulthood. Given a nurturing environment, with policies and positive community environments that support young people and their families, most adolescents make a successful transition into young adulthood, in which they are healthy, productive, and meaningfully engaged in society. Young people need support from many sectors during this period. Certain populations of adolescents require additional support, including adolescents with special health care needs (ASHCN).

Health, and by extension access to health care services, are critical components of a successful transition to young adulthood. This paper examines the potential role of health care services in fostering a successful transition, with emphasis on the ASHCN population. We review research and conceptual frameworks from numerous fields, with an overall goal of articulating an integrated approach to this transition. The first section introduces the complex issues involved in the transition to young adulthood. The second section focuses on ASHCN, presenting an analysis of national data on health care received by ASHCN. The third section offers a framework for assessing health care services during this critical period of transition and assesses the existing health care system that serves adolescents. The paper concludes with recommendations for advancing research and policy to improve transitional health care services to adolescents, including ASHCN.

TRANSITIONS AND HEALTH CARE SERVICES

THE SOCIAL AND ECONOMIC CONTEXT

The transition to young adulthood changed significantly in the second half of the 20th century, with a shift to a postindustrial economy. This economy requires greater skills, resulting in more young people pursuing postsecondary education. The importance of higher education has led to a large gap in achievements between those with and without a college degree. The prolonged transition to adulthood for men and women, combined with women's greater workforce participation, have contributed to later marriage and childbearing. At the same time, there has been a substantial increase in single motherhood, both absolutely...
and relative to marital childbearing. These changes have resulted in numerous paths to adulthood, with varied sequencing of education, work, marriage, and parenthood. As they navigate this transition, young adults also face a significant weakening of the safety net and other support systems that serve adolescents.

In this changing context, there is limited consensus on what it means to be “ready” for adulthood. Some national efforts have defined skills and assets needed to succeed in a postindustrial economy. Although most of these efforts focus primarily on career/vocational skills, a few focus more broadly on health and well-being. Two relevant frameworks come from the Institute of Medicine (IOM) and the Forum for Youth Investment. A 2002 IOM report identified 4 broadly defined assets that predict adult success and facilitate youth development: 1) physical development (including good health habits and good health risk management skills), 2) psychological and emotional development, 3) intellectual development, and 4) social development. The Forum for Youth Investment has developed Ready by 21 based on outcomes of healthy adult functioning in 3 areas: 1) economic self-sufficiency; 2) healthy habits and healthy relationships; and 3) civic engagement through volunteering, political activity, or community or religious group participation.

TRANSITIONS AND HEALTH CARE SERVICES

As part of normative development, adolescents become increasingly independent and may initiate and experiment with adult behaviors. These behaviors, in areas such as driving, sexuality, substance use, and diet and exercise habits, affect health status in the short- and long-term. Research using nationally representative data also suggests adolescence is a critical period for the emergence of mental health issues. Progress in adolescent clinical preventive services reflects consensus among professional medical organizations on adolescents’ need for developmentally based services. Since the early 1990s, several organizations have issued guidelines that emphasize screening and counseling related to risky behaviors for young people through age 21. These early guidelines also recommended that adolescents receive confidential care or “time alone” with a clinician. In 2008, the American Academy of Pediatrics (AAP) issued the third edition of Bright Futures, a consensus document supported by professional organizations involved with the care of adolescents. Initiatives to improve quality of care in the broader fields of health and medicine also recognize the unique needs of adolescents. The Health Plan Employer Data and Information Set, a widely used performance measurement tool, includes the following measures for adolescents: annual well visit with anticipatory guidance, alcohol use screening, immunization, and chlamydia screening in sexually active females. The U.S. Preventive Services Task Force recommends obesity screening and depression screening for adolescents.

Professional organizations recognize the need for a workforce skilled in serving adolescents. In the early 1990s, the Residency Review Committee for Pediatrics introduced an adolescent-specific requirement into pediatric programs: an intensive 1-month experience in adolescent medicine and an additional month with exposure to adolescent patients. The respective committees for family medicine and internal medicine have general statements about exposure to adolescent medicine, but no specific requirement.

Although recognizing adolescents’ developmental needs, these advances in general adolescent health generally do not acknowledge the need for transitional health care services, with some exceptions in the 2008 Bright Futures. By contrast, the field of children of special health care needs (CSHCN) has focused on transition services since the 1980s. In 2002, a consensus statement on health care transitions was issued by the AAP, the American Academy of Family Physicians, and the American College of Physicians–American Society of Internal Medicine, with a goal of “maximizing lifelong functioning and potential” for ASHCN transitioning to young adulthood. The statement, subsequently endorsed by the Society for Adolescent Health and Medicine, presents 6 steps to guide clinicians in providing transition services to ASHCN, summarized here:

- ensure a medical home for primary care
- identify core knowledge and skills (clinician, adolescent, and parent, as appropriate)
- prepare and maintain portable medical summary
- create a health care transition plan
- provide primary and preventive care
- ensure health insurance

Transition services are highlighted as a necessary component of quality care for ASHCN and are included in the Maternal and Child Health Bureau (MCHB) 6 core outcomes that are the focus of the following section.

PREVALENCE AND QUALITY OF CARE FOR ASHCN: A LIFESPAN APPROACH

This section examines care received by ASHCN and is guided by the CSHCN definition developed by the MCHB. This broad definition includes those who have or are at risk for developing a special condition. In so doing, it adopts a preventive approach and recognizes that some conditions can be better managed or even prevented with quality medical services. Children and adolescents with special health care needs (SHCN) often require a constellation of services and generally use health care services at higher rates than their peers without SHCN.

The MCHB has developed 6 core outcomes to assess systems of care for CSHCN. The final outcome is that adolescents with SHCN receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. Other outcomes, relevant for the entire CSHCN population, include the following:

- families of children and youth with SHCN partner in decision making at all levels and are satisfied with the services they receive;
• children and youth with SHCN receive coordinated ongoing comprehensive care within a medical home;
• families of CSHCN have adequate private and/or public insurance to pay for the services they need;
• children are screened early and continuously for SHCN;
• community-based services for children and youth with SHCN are organized so families can use them easily.

Using these outcomes as a framework, a large body of research has addressed all CSHCN, yielding helpful findings for improving systems that serve these children and adolescents. Many studies present outcomes for younger children and adolescents separately. However, relatively few focus specifically on how adolescents differ from younger children. To begin addressing this gap, these analyses examine prevalence of SHCN and assess quality of care by age group.

Analyses in this section were conducted using the 2005–2006 National Survey of Children with Special Health Care Needs (NS-CSHCN), a nationally representative survey sponsored by MCHB and conducted by the Centers for Disease Control and Prevention. It is part of the Local Area Integrated Telephone Survey program and included 40,723 parent/guardian interviews of CSHCN. Details of the survey and methodology have been presented elsewhere. All analyses presented here utilized statistical weights to provide nationally representative population estimates and included adjustment for the complex survey design. Analyses of estimates of the prevalence of CSHCN (as defined by MCHB) and of the MCHB 6 core outcomes utilized variables that were developed by MCHB and available in the data sets. We categorized ages into the following 6 groupings for specific analyses: 0 to 2 years, 3 to 5 years, 6 to 8 years, 9 to 11 years, 12 to 14 years, and 15 to 17 years. To explore types of conditions within the CSHCN population and how the 6 core outcomes might vary by condition types, we developed 2 general categories from caregiver reports of specific conditions: physical health (eg, allergies, asthma, diabetes) and mental health (eg, emotional problems, attention-deficit/ hyperactivity disorder, autisms) problems. Analysis of the 6 core outcomes by type of condition for adolescents aged 9 to 17 years included 26,336 adolescents.

Figure 1 shows SHCN prevalence across 3-year age groupings (0–2 years through 15–17 years), using the MCHB definition. The prevalence of having a SHCN increases steadily across each age up to 9 to 11 years and remains stable thereafter at approximately 17%. This suggests that 1 in 6 adolescents has a SHCN and, thus, will likely have transitional care needs specific to his or her condition.

Figure 2 presents attainment of MCHB 6 core outcomes across the age categories. Generally speaking, rates on the 6 outcomes are slightly lower for ages 9 to 17 years, compared with younger children. Nearly 9 in 10 families of ASHCN report that systems of care are well organized. Roughly 2 of 3 report that adolescents have received screening early and continuously, and that their adolescent’s insurance is adequate.

Adolescents fare worse on measures of family engagement and receipt of a medical home. Despite the critical role that parents and families play in adolescents’ lives, close to half of families of ASHCN report that parents are not partners in decision making, nor are they satisfied with the services they receive. Fewer than half of ASHCN have a medical home, indicating that the child may lack a usual source of care or a personal clinician, or the child may have problems receiving family-centered care, obtaining referrals when needed, or receiving help in coordinating health and health care.

Only 2 in 5 families of 12 to 17 year olds report that they have received transition services. These include discussions of transferring to adult care, future health care and insurance needs, and encouragement to take responsibility for health care. Among these, Lotstein and colleagues found that encouragement to take responsibility occurred most frequently and discussion of insurance occurred least frequently. These findings demonstrate considerable room for improvement in providing ASHCN and their families with needed transition services to facilitate healthy adult functioning.
Condition types and severity vary widely among CSHCN and influence the types of services and resources needed during the transition to adulthood. As noted above, adolescence is a critical period for the emergence of mental health problems. For CSHCN, the prevalence of having a physical health problem is approximately 75% across the 6 age groups and remains stable (Figure 3). By contrast, the prevalence of mental health conditions is lower at earlier ages, increases to roughly 54% by age 9 to 11 years, and remains above 50% throughout adolescence. By age 9 to 11 years, more than one third of CSHCN have both a physical and a mental health problem (not shown), increasing the complexity of care coordination and issues to be managed in the transition to adulthood.

Given the greater prevalence of mental health problems among adolescents, we examined the 6 core outcomes by 3 categories of adolescents: 1) those with a physical condition only, 2) those with a mental health condition only, and 3) those with both a physical condition and a mental health condition. This analysis (see Table) found that adolescents with a mental health condition only or with both types of conditions fared significantly worse on the outcomes than those with only a physical health condition. This suggests that ASHCN with mental health conditions are especially likely to experience gaps in access and quality of care.

**Transition Services for Adolescents: Framework, Challenges and Opportunities**

Health care services can play an important role in promoting a successful transition from adolescence into adulthood, especially if they complement educational and workforce policies that recognize the changing context of young adulthood. This section begins with our proposed 3-part framework to assess the quality of the health care system for adolescents during the transition. We then briefly assess the current system, drawing on the NS-CSHCN analyses and other national research. By most measures, this system falls considerably short of ideal. This section also summarizes the implications for adolescents of the federal Patient Protection and Affordable Care Act, or the Affordable Care Act (ACA), as it is commonly referenced, enacted in 2010. The framework is presented here.

1. Adolescents have the capacity to access a comprehensive health care system:
   - a comprehensive system exists—this system would include necessary specialty care and care coordination;
   - financing for this system is adequate;
   - adolescents have skills to negotiate the system.

2. Preventable problems will be prevented.

3. For adolescents with chronic conditions, these conditions are managed and the transition to adult care is assured.

The first component broadly outlines a comprehensive system. For the first 2 areas, a comprehensive system and adequate financing, a large body of research and numerous recommendations exist. We introduce a third area, adolescents’ skills, which has received relatively less attention. Adolescents’ transition into adult functioning requires them to have the capacity to manage their health care; this involves using health care services independently and appropriately and maintaining a relationship with a clinician. The second and third components articulate outcomes that such a system would achieve in young adulthood. These 2 components, prevention and management of chronic illness, are complementary needs for ASHCN.

**Comprehensive System Exists**

Numerous efforts have articulated features of a comprehensive health care system for adolescents. The IOM report, *Adolescent Health Services: Missing Opportunities*, summarizes this large literature and presents recommendations for improving the service delivery system in areas such as strengthening primary care services to provide health management, referral, and care management, among other areas; and coordination of specialty services in multiple settings. The report documents significant shortcomings in creating a comprehensive health care system for adolescents, describing the current system as consisting of “separate programs and services that are often highly fragmented, poorly coordinated and delivered in multiple public and private settings.”

*Adolescent Health Services: Missing Opportunities* also documents a shortage of clinicians trained in providing services to adolescents. The MCHB 6 outcomes also offer a framework for comprehensive services. The NS-CSHCN analyses show significant shortcomings in health care quality for the ASHCN population. Fewer than half of ASHCN have a medical home.

The NS-CSHCN analysis and the IOM report also suggest it is particularly difficult to access mental health services, a critical issue during adolescence. Several factors make care coordination difficult for ASHCN whose needs relate to mental health conditions, including inadequate coverage of needed adolescent mental health services, managed care arrangements that “carve out” mental health services into separate systems, and a shortage of mental health professionals trained to serve adolescents.
The ACA includes several provisions that aim to improve the quality of the health care system. These include support for development of integrated models of care such as "medical homes, team management of chronic disease, and integration of physical and mental health services," according to a recent analysis. Support for training in areas such as primary care and new models of interdisciplinary mental and behavioral health may help address the shortage of clinicians trained to serve adolescents. The ACA also requires the establishment of an essential benefits package. Although the detail of the package remains to be determined, the ACA specified that the package must include mental health and substance use disorder services, and chronic disease management. These provisions hold promise for improving care coordination for the ASHCN population, especially those with mental health needs.

Adequate Financing

As with people of any age, insured adolescents fare better on many indicators of access; compared with their uninsured peers, they are more likely to have a past-year visit, a usual source of care, and fewer unmet needs. Although adolescents have seen some progress over the past 2 decades, due primarily to expansions in public insurance programs, Adolescent Health Services: Missing Opportunities documents many gaps in adolescents' financial access to services. The NS-CSHCN analysis shows that more than 1 in 3 ASHCN lack adequate insurance. Young people fare poorly as they transition to adulthood. Until the recent passage of ACA, insurance rates dropped dramatically in the late teen years, as many adolescents abruptly lost eligibility for their family's employer-based insurance and/or the public programs that cover adolescents. Before ACA's passage, young adults were least likely to be insured of any age group in the lifespan, with rates remaining low until the late 20s. Young adults with disabilities report extra barriers in financial access to care, such as delaying care due to costs and inability to afford to fill a prescription.

The ACA has several provisions that aim to expand financing significantly for adolescents and young adults. Starting in 2010, adolescents can remain on their parents' plan until age 26. Beginning in 2014, low-income young adults are likely to benefit from significant expansions in Medicaid eligibility and the creation of state or regional health insurance exchanges to provide insurance to low- and moderate-income adults.

Adolescents Have Skills to Negotiate System

The concept of adolescents' skills has received less focus in research and policy relative to service systems and financing. We were unable to locate studies using national data in the peer-reviewed literature that measure competence in this area or adolescents' receipt of guidance in effective use of health care services. The concept of skills development is implicit in clinical guidelines that recommend confidential care for adolescents. Time alone affords adolescents the opportunity to develop and manage a relationship with a clinician and assume increasing responsibility to manage their health with appropriate clinical guidance. Confidential care also allows adolescents to develop skills in self-disclosure, especially for sensitive issues that frequently emerge during adolescence, such as sexuality and substance use.

Several studies have yielded low rates of time alone, suggesting that adolescents do not have the opportunity to learn skills in self-disclosure and managing a relationship with a clinician. An analysis of nationally representative data found that less than 40% of teens with a past-year preventive visit received confidential care, with even lower rates for Hispanic youths and younger teens, especially females.

Skills needed by adolescents are more explicitly articulated in research and programs related to ASHCN. For example, a 2009 AAP publication on transitional services offers a list and timeline of skills to be developed in adolescence and related activities. Skills include the capacity to describe one's illness, including knowledge of medication and dosages; knowing when to contact a clinician for...
behavior. Although parents often play an important role in adolescents' transition to young adulthood, this is a relatively neglected area of research. The findings from the NS-CSHCN broad self-report measures of family participation suggest room for improvement.

PREVENTABLE PROBLEMS PREVENTED, CHRONIC CONDITIONS MANAGED, TRANSITION ASSURED

Overall, research assessing how clinical services may help achieve these "outcomes" is extremely limited. In the area of preventing problems, national data show that many of the preventable problems of adolescence worsen in young adulthood. Rates of homicide, motor vehicle mortality, substance use, drinking and driving, and many sexually transmitted infections peak in young adulthood. Studies using national and smaller samples yield low rates for delivery of recommended clinical preventive services to adolescents, demonstrating limited adherence to professional guidelines. Several studies among ASHCN, in the United States and internationally, also yield low delivery of clinical preventive services, despite significant evidence that ASHCN engage in a range of risky behaviors, including substance use, violence, and unsafe sexual behavior.

Similarly, data assessing effective management of chronic conditions in young adulthood are limited. A small literature suggests that young adults with chronic conditions face barriers in accessing care and report unmet need and delayed care. Although there is evidence that improved patient self-management of asthma results in decreased hospitalizations, research is lacking on how skills in managing health conditions affect readiness to work and assuming other adult roles.

Although literature specifically linking adolescent health to "readiness for work" is scarce at best, a quick review of the health issues that contribute to loss of productivity suggests that health issues that arise in adolescence affect work performance of adults. Research indicates that chronic conditions, including mental illness, substance use, cancer, diabetes, and obesity, contribute substantially to sick days and suboptimal performance ("presenteeism"). Research on depression indicates that depression is related to self-reported work performance and lost days of work, and that treating depression may improve attendance at work and effective work hours per week.

RECOMMENDATIONS AND CONCLUSION

This paper takes a broad look at issues in adolescents' transition to young adulthood, especially those faced by ASHCN. This transition is complex and has received relatively little attention in the general adolescent health care field. For ASHCN, by contrast, transitions have been a focus of programs and research for over 20 years. However, the analyses presented here suggest improvement is needed in the system that serves this population. Future efforts to facilitate a transition should recognize the changing social and economic context that presents challenges to all adolescents and address the needs of the ASHCN population, especially those with mental health issues.

This review of our transition framework suggests several areas needing improvement, including the service system; health care services research; and overall transition research, programs, and policy. The ACA holds promise for addressing many limitations in comprehensive care and financing. In the coming months and years, laws and regulations to implement the ACA will be developed in areas such as the essential benefits package, training of primary care physicians, and development and testing of new models of integrated care and medical homes. The latter may be especially helpful in integrating physical and mental health services. Those who advocate on behalf of adolescents will need to remain vigilant to ensure that changes recognize the special needs of adolescence.

The review suggests several areas of health care research that would improve health care services during transition. Some of these areas may fall under the training and development of new models of care to be supported by the ACA. In the area of workforce development, research is needed to identify optimal methods to train clinicians in providing comprehensive care for ASHCN as they transition to young adulthood. Effectiveness studies should evaluate the impact of clinical preventive services for different groups of adolescents and young adults.

Measures of adolescents' competence and skills in managing their health and using services need greater focus, if ASHCN are to function optimally as adults. Programs need to identify effective methods of engaging parents in areas such as health care decisions during adolescence and adolescent management of chronic conditions and appropriate health care utilization.

Finally, facilitating a successful transition for adolescents will require research and programs that test models of integrating health with education and workforce issues. In integrating health with other fields, it may be helpful to draw on prior efforts to link health care services to early childhood development and the transition to school. National attention focused on the need to provide early childhood support that enabled children to be "Ready to Learn." Child health advocates took advantage of this focus to advance a health care agenda, by articulating a role for health care services in helping children be prepared to succeed in school. Initiatives included programs to support identification in clinical settings of conditions that could impede a child's ability to learn. This concept could be adapted to young adulthood, by identifying health problems that could impede a successful transition. Research questions might include the links between different health issues and youths' trajectories in the transition to young adulthood. One effort that has linked health to other areas is the Healthy and Ready to Work program, which integrates transitional health care services for ASHCN with support in other areas critical for young adult
functioning, such as work and education.48 This could serve as a useful model for expanded comprehensive, integrated initiatives that benefit both individuals and the workplace by addressing health factors involved in a successful transition to young adulthood.

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