The Transition to Adult Health Care for Youth With Special Health Care Needs: Do Racial and Ethnic Disparities Exist?

abstract

Although the transition to adulthood for youth with special health care needs (YSHCN) has been gathering attention, the impact of racial and ethnic disparities on this process has been relatively unexamined. In this review, we explore evidence of disparities in the transition to adulthood for YSHCN, which is important because the problems that YSHCN face in transitioning to adulthood are, in large part, caused by interrupted access to high-quality health care and minority YSHCN and adults have many well-described gaps in access to quality care. Understanding the disparities in the transition process is essential to ensure that interventions designed to improve this transition will meet the needs of this high-risk population. We reviewed research on transition preparation and outcomes for YSHCN to find evidence of racial and ethnic disparities. The results of our review indicate that few YSHCN are receiving adequate transition preparation, and some evidence indicates that this situation is worse for racial and ethnic minorities. Furthermore, young adults, including YSHCN, have poorer access to care than children. Moreover, at some ages, this age-related decline in access is worse for Hispanic and black young adults than for others. Finally, low-income YSHCN are at higher risk than other YSHCN of experiencing gaps in access to care as they age into adulthood. Possible causes of racial and ethnic disparities in health care transitions are related to insurance, living in low-income communities, and sociocultural factors. Significant efforts in research, policy change, advocacy, and education of providers and families are needed to ensure optimal transition preparation and adult outcomes for YSHCN from all racial and ethnic backgrounds. Pediatrics 2010;126:S129–S136
As more children with complex and chronic conditions survive to adulthood, growing attention is being paid to what happens to this population as its members leave childhood. Youth with special health care needs (YSHCN) are at risk of experiencing difficulties as they transfer from pediatric to adult health care systems. Because of their reliance on health care services to maintain their quality of life, YSHCN are susceptible to gaps in access to high-quality health care services because of lack of support with the transition process.

Even before they reach the age at which they might need to transfer to adult care, YSHCN from racial and ethnic minorities face disparities in access to and quality of care compared with white YSHCN. This subgroup of YSHCN is also likely to experience difficult transitions to adulthood.

In this article, we review evidence of disparities in the transition of YSHCN to adult health care. We present a general framework for thinking about growing into adulthood for YSHCN and, using this framework, we review data on the transition to adult health care for YSHCN. Because data on racial and ethnic disparities in the transition to adult health care are limited, we summarize evidence about transitions to adult health care among all youth and highlight available evidence of disparities. We then explore possible reasons for disparities in transitions to adult health care and describe actions that are needed to address these gaps.

**CONCEPTUAL TRANSITION FRAMEWORK**

The transition to young adulthood takes place over multiple areas of the lives of YSHCN and their families (see Fig 1). Most YSHCN need to shift their primary care provider from a pediatric to an adult medical care provider, although some continue to receive care from pediatric providers if their pediatrician cares for young adults or no adult-trained providers with expertise in the young adult’s condition (eg, inborn errors of metabolism) are available to provide the needed care. Changes in insurance coverage are common between the ages of 18 and 25 years, because private and public insurance carriers have different eligibility criteria for children and adults. Also, as YSHCN grow up, most take on more responsibility for self-care, including ordering and taking medications, scheduling doctor appointments, cooking, and doing laundry. Another typical transition for YSHCN entering adulthood is leaving high school and entering a junior college or 4-year university or joining the workforce. As they make the transition to adulthood, YSHCN also experience more general changes in development, psychology, physical maturation, and relationships with family members, friends, and their community.

All YSHCN, regardless of health, socioeconomic status, or race or ethnicity, must negotiate some, if not all, of these changes. For example, a girl with a kidney transplant who is in high school and has private insurance coverage from her parent’s employer would be likely to face changes in all of the areas described above. In other cases, transitions may only be needed in some domains. For example, youth with severe cognitive impairments, with the help of their families, will need to negotiate changes to adult-oriented providers and programs although they may never be able to carry out all self-care tasks independently.

Transition preparation and the identification of desired outcomes are important for ensuring long-term access to medical care and insurance for YSHCN. Transition preparation consists of planning activities (eg, counseling by providers about upcoming changes in all of the functional transition domains, including medical providers, insurance, self-care, and school and vocational opportunities) conducted in the pediatric health care system by pediatric health care providers. Important transition outcomes for adults who have aged out of the pediatric health care system include uninterrupted access to high-quality medical care and maximized quality of life.

For this review, we provide an overview of data on 2 transition phases—preparation and outcomes—in medical care and insurance. Other transition factors, such as self-care and education and vocational issues, are equally important but are beyond the scope of this article. In each section, we describe the evidence on racial and ethnic disparities.
PREPARATION

Most studies of transition preparation or planning have been qualitative assessments of patient or provider attitudes or preferences. Few studies have compared receipt of transition preparation among different racial and ethnic groups.

The only study to examine the frequency of transition preparation at the national level has been the National Survey of Children With Special Health Care Needs (NS-CSHCN). Fielded in 2001 and 2005 by the National Center for Health Statistics, the NS-CSHCN is a nationally representative telephone-based survey of children and youth from birth to the age of 18 years who have a special health care need.10–13 In 2001, survey personnel asked parents and guardians whether their 13- to 17-year-old sons and daughters (1) discussed changing health care needs in adulthood with their health care providers and, if so, (2) whether these YSHCN had made plans for the change, and (3) whether these YSHCN had discussed the need to see doctors who treat adults.12 Overall, only 15.3% of respondents reported “yes” to all 3 questions. The investigators found no significant differences according to race or ethnicity in a multivariate analysis after controlling for other socioeconomic and health care access factors. Factors associated with achieving the study’s transition-performance outcome (an answer of “yes” to all 3 questions) included older age and having a medical home.

In 2005, NS-CSHCN personnel asked parents or guardians of YSHCN aged 12 to 17 years whether they or their children had talked to providers about the youth’s changing health care needs, receipt of care from adult versus pediatric providers, health insurance eligibility, and encouragement of youth self-responsibility.13Parents or guardians had to report a need for transition-related discussions for their child’s results to be included in the study’s performance-outcome calculation. Overall, 41.2% of YSHCN achieved the transition-performance outcome of having had all 4 of these discussions.

Unlike the 2001 survey, the 2005 survey revealed significant racial and ethnic disparities in receipt of transition counseling. Although 47.6% of non-Hispanic white youth achieved the 2005 transition-performance outcome, only 28.7% of non-Hispanic black youth and 26.3% of Hispanic youth achieved this outcome. In multivariate analyses, compared with non-Hispanic white youth, non-Hispanic black youth had 1.5 times and Hispanic youth had 1.43 times the odds of not achieving the transition outcome (differences significant at \( P < .05 \)). In the same model, after the investigators controlled for race and ethnicity, respondents who did not speak English in the home had 2.45 the odds of not achieving the transition outcome compared with English speakers. The 2005 sample had more respondents overall and more YSHCN of color than did the 2001 survey. These results indicate that fewer than half of YSHCN receive transition preparation and that YSHCN of color and from non–English-speaking families are even less likely to have discussions with their health care providers that could help prepare them to meet their health care and insurance needs as adults.

These disparities in transition preparation are similar to the disparities in pediatric care that racial and ethnic minority populations with special health care needs experience.9 For example, Strickland et al10 found that Hispanic and non-Hispanic black children with special health care needs (CSHCN) were significantly less likely to have a medical home; both groups had \( \sim 1.6 \) the odds of not having access to a medical home of non-Hispanic white CSHCN. This finding did not change when the investigators took into consideration other socioeconomic factors, disease severity, or insurance coverage. In these analyses, having a medical home significantly lowered the odds of having delayed or forgone care, having unmet health care needs, having an unmet need for family support services, or missing 11 or more days of school because of illness. Thus, transition-preparation disparities must be examined and addressed in the larger context of pediatric care disparities.

OUTCOMES

In this conceptual framework, good transition outcomes for YSHCN include ongoing access to appropriate health care providers and comprehensive health insurance that meets their needs in young adulthood. Although the outcomes of racial and ethnic health care disparities for older adults have been well documented,14 fewer studies have examined the outcomes of disparities in young adults undergoing health care transitions. We review here the evidence on transition outcomes for YSHCN and highlight the racial and ethnic disparities described in the literature.

Studies have revealed that young adults tend to have high uninsurance rates and those from ethnic and racial minority populations experience worse access to insurance. An analysis of data from the 2002 and 2003 National Health Interview Survey revealed that full-year insured rates followed a U-shaped curve in adolescence and young adulthood, falling from a high of 87% among 13- to 14-year-olds to a low of 61% among 23- to 24-year-olds before rising to 75% among 31- to 32-year-olds.15 This study also revealed that rates for Hispanic people followed the same curve, but
this population had significantly lower insured rates than those for white people of the same age group, even after the investigators controlled for confounding variables. In addition, the gap between white and Hispanic youth increased from 16 percentage points at 13 to 14 years to 32 percentage points at 19 to 20 years. After controlling for other socioeconomic factors, the investigators found that white and black disparities in insurance coverage across age groups were only significantly different at ages 19 to 20 years (74% [white youth] vs 59.8% [black youth]) and 21 to 22 years (68.1 [white youth] vs 58.1% [black youth]).

Young adults with chronic health conditions may not be protected from age-related loss of insurance coverage. Callahan and Cooper,16 who also used data from the National Health Interview Study, found similar uninsurance rates among the 4.7% of individuals aged 19 to 29 years with disabling chronic conditions (on the basis of self-report) and those without such conditions: 26% for those with chronic conditions and 28% for those without. However, those with disabling chronic conditions were more likely to have Medicaid coverage (27.2%) than those without such conditions (5.3%). In addition, young adults without insurance were more likely to delay medical care because of cost, not obtain needed medical care because of cost, not be able to afford to fill a prescription, have no usual source of care, and have had no contact with a health professional in the previous year. The authors did not report on racial or ethnic disparities. In another study in which the same data set was used, Callahan et al17 found differences in access to health care among various Hispanic subgroups; noncitizens were at the highest risk of poor access to care.

Two smaller studies examined the transition to adulthood from a longitudinal perspective. The 2007 Survey of Adult Transition and Health followed a national sample of YSHCN identified in the 2001 NS-CSHCN. This sample of 10,933 former YSHCN now aged 19 to 23 years is not nationally representative (because of the low response rate). The study revealed that 25% of these young adults had lost a usual source of care and 18.8% had lost insurance coverage since they turned 18. Although the study found no racial or ethnic differences in access to care, results of a multivariate analysis showed that low-income young adults had poorer health care access than those with incomes higher than 400% of the federal poverty level (unpublished data).

The second study examined access to care for young adults who had aged out of a program for children with chronic conditions.7 Among the youth in this group, 65% had at least 1 poor transition outcome; they had no usual source of care, had forgone or delayed care in the previous 6 months, had no insurance, or had experienced a gap in insurance coverage since leaving the program for children. Although most of those surveyed had insurance, 24% did not have a regular health care provider for their health condition. The study authors could not evaluate racial and ethnic disparities because of the small sample size and the fact that 52% of the sample was nonwhite.

The results of these studies suggest that, similar to all young adults, those with special health care needs have a high risk of having no health care coverage and that lack of coverage is associated with poor access to care. Furthermore, young adults with special health care needs from traditionally underserved communities have an even greater risk of experiencing health care barriers. Preparing for the transition to adulthood and obtaining continuous access to high-quality health care is a challenge for all YSHCN but is probably more difficult for members of racial and ethnic minority groups, although data on this issue are limited. Although the extent of the racial and ethnic health disparities in the transition to adulthood for YSHCN has not been fully defined, this preliminary evidence indicates that such disparities exist.

**POSSIBLE CAUSES**

The underlying causes of disparities in health care transitions are probably multifactorial. Some issues that are likely involved include access to insurance, living in low-income communities, and sociocultural factors. Health care providers need to be aware of these factors to alter their practice to meet the needs of minority YSHCN.

**Health Insurance Factors**

Access to health insurance is nearly a prerequisite for access to high-quality health care, and youth from all racial and ethnic backgrounds experience challenges in obtaining access to insurance during the transition from childhood to adulthood. Compared with CSHCN, young adults with chronic conditions (especially those with a low income, which disproportionately affects members of minority groups) have more limited private and public insurance options. Recent policy changes in access to insurance coverage enacted with passage of the Patient Protection and Affordable Care Act (PPACA) of 2010 will significantly change the landscape for both public and private coverage options for low-income minority YSHCN.18,19 In the sections that follow we describe current limitations on access to insurance for minority youth and young adults with special health care needs and upcoming changes that will be enacted with passage of the PPACA (either by 2010 or in 2014 when full implementation of the law goes into effect).
Private insurance coverage through an employer is the most common type of insurance coverage for both adults and children (through their parents) in the United States. Most CSHCN (60.3% according to the 2005 NS-CSHCN), similar to their typically developing peers, have private insurance coverage. Historically, this dependent coverage typically ends when they turn 18, although full-time students may be eligible for longer coverage, depending on state laws. Because YSHCN, particularly minority youth, are less likely than other youth to continue with formal education after high school, they are more likely to lose parental coverage at an earlier age. Beginning in September 2010, new rules under the PPACA require insurance plans to continue to offer dependent coverage until the age of 26 years regardless of financial, residential, and student status, thus benefiting minority youth whose parents have private coverage. Youth who are permanently disabled and who continue to be dependents of their parents after the age of 26 will continue, as in the past, to maintain coverage through their parents into adulthood.

Young adults can obtain private insurance coverage through their own employment, but access to jobs with benefits is typically lower for young people generally and especially for young adults from low-income minority backgrounds. During the current economic recession, access to employment in general, and full-time employment with benefits especially, has been even more difficult for young adults who are newly entering the job market. Although private insurance is available for purchase by people who do not receive coverage through an employer, obtaining such coverage has been virtually impossible in the past for young adults with chronic conditions, especially those with a low income, because of the prohibitive costs of such coverage and the frequent exclusion of beneficiaries with a preexisting condition. Beginning in 2014, the PPACA will create significant changes in the nonemployment, self-purchased insurance-plan market for all low-income young adults. Health plans will be prohibited from limiting coverage or charging much higher premiums for those with preexisting medical conditions. Furthermore, health insurance exchanges will create new options for private coverage with premium subsidies and caps on out-of-pocket expenses for low-income individuals.

Currently, significant age-related challenges to eligibility for public sources of insurance (eg, Medicaid, State Child Health Insurance Programs [SCHIPs], and Medicare) also exist. Although it is relatively generous to poor children, all individuals, regardless of health status, are considered “adults” under Medicaid and SCHIP after the 19th birthday. Adult Medicaid coverage has been limited to low-income adults who meet federal disability criteria or are very low-income parents of young children. Beginning in 2014, the PPACA expands Medicaid to all adults up to 133% of the federal poverty limit (approximately $14,000 per year for an individual, and $30,000 per year for a family of 4), regardless of disability or parental status. As it has been in the past, young adults are only eligible for Medicare (a program for those older than 65) if they have end-stage renal disease or are dependents of Medicare beneficiaries.

In the past, this age-related disparity in access to public insurance has had a disproportionate impact on young minority adults, who are more likely to be publicly insured as children than their nonminority peers. Specifically, according to the 2005 NS-CSHCN, 51% of black YSHCN and 44% of Hispanic YSHCN younger than 18 years had public insurance in 2005, compared with 20% of white CSHCN. Thus, the PPACA’s Medicaid expansion will likely have a significant impact on a large number of low-income minority YSHCN who currently cannot continue their childhood Medicaid coverage because they are not sick enough to meet disability criteria. These challenges in access to public insurance are compounded for YSHCN who are not US citizens. Although some (limited) public coverage may be available to noncitizen CSHCN, their eligibility typically ends when they become adults because, for example, Medicaid only covers adults who are US citizens. Furthermore, these YSHCN are less likely than their US citizen peers to hold jobs that offer private insurance coverage.

Living in Low-Income Communities

The fact that minority YSHCN are more likely than nonminority YSHCN to live in low-income communities also creates challenges in the transition to adulthood. For example, low-income communities typically have fewer resources for youth development, such as schools with resources to meet the needs of YSHCN who are often absent from school because of illness, might have mental health service needs (eg, for depression and posttraumatic stress disorders), and often have other special education needs (such as cognitive or attention problems because of the disease’s impact on brain development). Underresourced schools are also less likely to offer career and college-preparation services, which are key resources for any youth leaving high school. YSHCN might have difficulty accessing the services of local community-based groups because of periods of illness and some of the sociocultural factors described below.
Sociocultural Factors

Several sociocultural factors tend to have a negative impact on the successful transition of minority YSHCN to adult health care. Health care providers are often not aware of cultural traditions that are important to this population, which can lead to a mismatch between patient or family and provider expectations and needs. Investigators have studied these factors in minority children, adolescents, and adults in general, but few empirical studies have examined the impact of these sociocultural factors on transition preparation or outcomes.

The most obvious sociocultural factor that can impose barriers to successful transitions to adult health care for minority YSHCN is language. Discussions between youth, their parents, and health care providers about health care transitions can be difficult in English and are even more challenging when language barriers exist. According to the 2005 NS-CSHCN, 12.5% of parents of CSHCN speak a language other than English in the home. The impact of language barriers in pediatric settings generally has been well described, and these findings are probably also relevant to the transition setting. Using a child as an interpreter is especially problematic in the context of conversations about the long-term health problems and self-care skills of youth. Parents might be uncomfortable asking difficult questions (eg, about long-term health issues or problems with their child), and children might “selectively interpret” information from their parents or provider to avoid “getting into trouble” or to protect their parent from bad news.

In navigating between the old, familiar pediatric health care system and the new, unfamiliar adult system, patients and families need to interact with many people in addition to their doctors and nurses, including unknown office staff members, insurance providers, and community service workers. Language barriers make conversations with these individuals challenging and could lead to misunderstandings and gaps in the transfer of services.

Lower educational attainment (eg, not completing high school), which is more common in minority groups, can result in barriers for YSHCN and their families in navigating the transition to a complex new adult health care system. Interpreting and responding to information from health insurance companies, medical offices, and hospitals is particularly challenging for family members with limited formal education. Given the complexity of the US health care system, navigating changes for patients with multiple needs can be challenging even for well-educated patients and families; for those with low education levels, these challenges can result in significant gaps in care. Specifically in terms of racial and ethnic minorities, studies have revealed that patients from racial and ethnic minority groups are less likely than their nonminority peers to have a sense of trust in their providers. Trust in health care providers plays a large role for YSHCN and their families, who often have a special bond with their pediatric provider who, in many cases, has helped them address life-threatening issues. Leaving this protective relationship can be difficult for all YSHCN. Yet, forming new relationships with adult-oriented providers may take longer for minority YSHCN and family members who share the lack of trust of health care providers found in other racial and ethnic minority groups of patients. Although some skepticism about unknown providers may be appropriate, in extreme it could cause problems such as not following up on a referral to a new physician or resistance to following recommendations for care from that provider. This could result in missing needed follow-up care. YSHCN and their families might delay leaving the pediatric provider until forced to do so by some urgent circumstance (eg, an admission to an adult floor of a hospital) without the benefit of past relationship-building or transfer of past records or other key information.

ELIMINATING DISPARITIES IN TRANSITIONS TO ADULT HEALTH CARE FOR YSHCN

Significant research, policy change, advocacy, and education efforts involving providers and families are needed to make progress in eliminating racial and ethnic disparities in the transition to adult health care for YSHCN.

Future research efforts should provide a clearer understanding of racial and
ethnic differences in the transition-preparation needs of YSHCN. Important research questions include whether Hispanic parents have different expectations from white parents for their YSHCN when they become adults, how these expectations influence the transition-planning support they should receive, and the characteristics of culturally effective transition. Longitudinal studies of transition outcomes in access to care could help identify youth at the highest risk of poor outcomes. Other research should test the efficacy of tools and interventions (such as interventions that connect tertiary medical center services to community-based services) to improve transition preparation and outcomes.

Policy changes at several levels could prevent gaps in health care after YSHCN make the transition to adult care. Expanding access to public and private health insurance for low-income individuals who are not disabled but have special health care needs (as will begin under changes enacted by the PPACA) is essential to ensure that all youth and young adults with special health care needs receive the care they need.\(^\text{19,23}\) Other policy changes to support transition preparation include improved reimbursement for care-coordination services, including support for the comprehensive medical home model and transition preparation.\(^\text{36}\) Increased access to, and utilization of, medical homes for YSHCN could help eliminate disparities in transitions to adult health care, just as access to medical homes has reduced racial and ethnic disparities in access to, and quality of, care for the general population of adults.\(^\text{37}\) In addition to its changes in access to health insurance coverage, other policy changes in the PPACA could increase the availability of high-quality medical homes for everyone, including those in this population.\(^\text{38}\) In addition, changing health insurance policies to allow a period of comanagement by pediatric and adult providers could be helpful to some YSHCN. Although all of these changes would benefit all YSHCN, the extra support is likely to be most valuable to YSHCN of color because of their greater need for assistance during the transition period. Advocacy at the federal, state, and local levels will be necessary to eliminate disparities in transition. As described above, many of the reforms in the PPACA begin to address these policy needs, but careful monitoring will be required to ensure that the PPACA has its intended effects.\(^\text{18,19}\)

Finally, educational efforts are needed in this area. YSHCN and their families need access to professional interpreter services to permit nuanced discussions among providers, parents, and youth about the transition to adult health care. Educational initiatives for adult and pediatric providers should build awareness of the cultural aspects of the transition to adulthood and add to the growing health care provider awareness of cultural effectiveness.\(^\text{39}\) Targeted educational efforts for parents and YSHCN can help promote effective transitions to adulthood.

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The Transition to Adult Health Care for Youth With Special Health Care Needs:
Do Racial and Ethnic Disparities Exist?
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