

# DC FACT SHEET ON TRANSITION TO ADULT HEALTH CARE FOR ADOLESCENTS WITH SPECIAL HEALTH CARE NEEDS

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## Introduction

Transition to adult health care is a process, not a single event. The aim of health care transition is to maximize the potential of each young person by providing appropriate health care services that continue without interruption from adolescence to adulthood. **Unfortunately, only 34% of DC adolescents with special needs are receiving needed support to effectively transition from pediatric to adult health care.**

The transition core outcome is one of six indicators used by DC's Department of Health and the federal government to monitor progress toward the goal of a comprehensive, patient- and family-centered, community-based system of care. It is measured in terms of whether adolescents' doctors have usually or always encouraged increasing responsibility for self-care and, when needed, have discussed transition to adult health care, changing health care needs, and how to maintain health insurance coverage.

This fact sheet provides a current profile of DC's status in meeting the national transition outcome for adolescents with special health needs, ages 12 through 17. These are youth with chronic physical, developmental, behavioral, or emotional conditions who require health and related services to manage their condition. The national transition outcome calls for all adolescents with special health care needs to receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. In this profile, DC and U.S. transition results are compared by gender, race/ethnicity, income, insurance status, and the presence of a medical home. Information for this fact sheet comes from the 2009-10 National Survey of Children with Special Health Care Needs.

## DC Adolescents with Special Needs

In Washington, DC, 22% of adolescents – over 8,000 – have a special health care need. A broad range of conditions affect these young people, including many rare conditions such as spina bifida, sickle cell anemia, and cancer and common conditions such as asthma, ADHD, depression, and developmental disabilities. According to DC parents whose adolescents have special needs, about one quarter report their their teens' condition causes significant functional limitations, and as many as 16% of DC youth with special needs have 4 or more chronic conditions.

## Transition from Pediatric to Adult Health Care

Although DC has improved its transition ranking over the last several years, it still remains among the five states with the lowest scores on this national transition outcome. Only 34% of DC adolescents are receiving needed transition assistance. Compared to the U.S. average of 40%, the District scores 6% lower. Adolescents in DC who are least likely to meet the transition core outcome are Black, in families with incomes below 200% of poverty, publicly insured, and without a medical home. Drawing on information from the National Survey of Children with Special Health Care Needs, we have identified several issues that may be influencing DC's improvements, as well as its persistently low transition ranking.

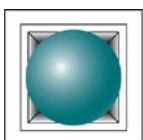
- Fewer teens in DC are being served by family physicians than in other states and, as such, more DC teens have to change health care providers when they become adults. Nationally, 35% of adolescents with special needs have a family physician as their primary care provider, compared to 22% in Washington, DC.
- A larger proportion of DC's adolescents with special needs are minorities, with low incomes, and receiving public insurance -- populations who fare much worse on this transition measure, compared to white, higher-income, and privately insured teens.
- DC also ranks last among states whose adolescents with special needs receive coordinated, ongoing, comprehensive care within a medical home, but has risen to 30<sup>th</sup> among states whose families report partnering in decision-making and being satisfied with the care they receive. Consistently, teens without a medical home and without family-centered care are much less likely to receive needed transition support.
- Even among DC adolescents with special needs who report that they receive care within a medical home and who partner in decision-making, the majority are not receiving assistance on transition to adult health care.
- While 78% of DC adolescents with special needs report that their doctors or other health care providers encourage them to take increasing responsibility for self-care, and 52% have discussed changing health needs as they become adults, only 18% say that their doctors or other health care providers have discussed the actual transition to adult health care, and only 27% have received any guidance about how to maintain health insurance coverage as a young adult.

### **DC Health Transition Efforts**

The National Alliance to Advance Adolescent Health, with funding support from DC's Community Health Administration, has been working to identify the barriers that adolescents and parents/caregivers face in making a smooth transition from pediatric to adult health care. Through focus groups with adolescents and parents whose teens have special needs and surveys of pediatricians, internists, and family physicians, we have learned that few adolescents carry information about their chronic condition, such as a list of medications, a medical history, or an emergency number, and few carry their health insurance information. In addition, few teens and parents have planned for transition or have talked with their teen's health care providers about eventually seeing an adult doctor. Both parents and adolescents are interested in receiving more information and support on health care transition.

Health care providers in DC identified several barriers to transition, including lack of available adult doctors, lack of knowledge about community resources to support older teens and young adults, and lack of sufficient time to provide transition services. They recommended a health care transition pocket guide, training on and reimbursement for transition, more identification and communication between pediatric and adult health care providers.

In response to these identified barriers and suggestions, The National Alliance to Advance Adolescent Health is operating a quality improvement initiative that involves teams of physicians, consumers, and care coordinators from Children's National Medical Center, Georgetown, Howard, and George Washington. These sites are piloting new transition tools and clinical approaches to improve transition from pediatric to adult health care. For more information about health care transition efforts, please refer to the health pages on [www.dctransition.org](http://www.dctransition.org).



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