



PLANNING FOR THE FUTURE: 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 in DC by providing appropriate health care services that continue without interruption from adolescence to adulthood. **Unfortunately, only 24% 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 indicators¹ 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 profile of the District of Columbia'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 National Survey of Children with Special Health Care Needs 2005/2006, available at the federal Maternal and Child Health Bureau's Data Resource Center for Child and Adolescent Health.

DC Adolescents with Special Needs

In Washington, DC, 17% of adolescents – about 5,200 – have a special health care need. A broad range of conditions affect these young people, including many rare conditions such as spina bifida or cancer and common conditions such as asthma, ADD/ADHD, depression, or developmental disabilities. According to DC parents whose adolescents have special needs, half report that their teens' conditions cause moderate or severe difficulties, and one fifth report significant activity limitations.

Transition from Pediatric to Adult Health Care

The District of Columbia ranks last among states on this national transition outcome. Compared to the U.S. average of 41%, the District is 17% lower, as shown in Table 1.² Adolescents least likely to meet the transition core outcome are Black, in families with incomes below 200% of poverty, publicly insured, and/or without a medical home.

The National Alliance to Advance Adolescent Health, with funding support from DC's Community Health Administration, is seeking to identify the barriers that adolescents and parents/caregivers face in making a smooth transition from pediatric to adult health care. This will be accomplished through focus groups with adolescents and young adults with special needs, parents whose teens have special needs, and surveys of pediatricians, internists, and family physicians. In the coming months, a DC Health Care Transition Resource Center website (www.dchealthcaretransition.org) will be available at Family Voices-DC.

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 low transition ranking.

Table 1. Adolescents with Special Needs Receive Services Needed to Make Transition to Adult Health Care		
	DC (%)	U.S. (%)
Total meeting this outcome measure	24	41
Gender		
Male	27	39
Female	20	44
Race/Ethnicity		
Black	19	29
White	49	47
Hispanic	NA	26
Income		
0%-199% FPL	17	30
200-299% FPL	NA	41
300%-399% FPL	NA	46
400% or greater FPL	41	54
Insurance		
Private insurance only	37	49
Public insurance only	12	28
Both private and public	NA	32
Uninsured	NA	18
Presence of a medical home		
With a medical home	40	57
Without a medical home	18	29

NA = sample size too small for reliable estimates.

- 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, 40% of adolescents with special needs have a family physician as their primary care provider, compared to 25% 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, and 46th 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 74% 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 58% have discussed changing health needs as they become adults, only 21% say that their doctors or other health care providers have discussed the actual transition to adult health care, and only 25% have received any guidance about how to maintain health insurance coverage as a young adult.

For more information about the DC health care transition efforts, please contact Katherine Rogers (krogers@thenationalalliance.org).

Endnotes

¹ These 6 core outcomes are: (1) families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive; (2) children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home; (3) families of CSHCN have adequate private and/or public insurance to pay for the services they need; (4) children are screened early and continuously for special health care needs; (5) community-based services for children and youth with special health care needs are organized so families can use them easily; and (6) adolescents with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

² The transition outcome is a composite measure made up of 4 questions: 1) have doctors or other health care providers encouraged the adolescent to take increasing responsibility for self care, 2) have doctors or other health care providers discussed changing health needs as the adolescent becomes an adult, 3) has the doctor or other health care provider discussed transition to adult health care, and 4) has anyone discussed with the family how to maintain health insurance coverage as adolescent becomes an adult. All 4 questions must be answered affirmatively to indicate that needed transition services were provided.