



HEALTH CARE TRANSITION FOR DC ADOLESCENTS AND PARENTS: A FOCUS GROUP STUDY

Katherine Rogers, Aileen Collins, Doreen Hodges, and Margaret McManus
The National Alliance to Advance Adolescent Health
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Introduction

Obtaining the perspectives of adolescents with special health care needs and parents whose teens have special needs is critically important for understanding how health care transition is working in the District of Columbia. It is also very helpful for designing new strategies for improving transition support.

This report presents findings from focus groups with 31 adolescents and young adults, ages 13 to 23, and 19 parents, conducted in March and April 2010. All of the participants were low-income and Black or Hispanic. A total of four focus groups were held with seven to eight adolescent participants, and four focus groups with one to nine parent participants. Half of the adolescents in our focus groups had parents also participating in our focus groups. Adolescents in our focus groups had a variety of special health care needs, including asthma, hearing and vision impairments, mental health conditions such as bipolar disorder and ADHD, and developmental disabilities. The topic areas addressed included reliance on pediatric health providers as their usual source of care, teens' knowledge about their health conditions, perspectives and experiences on transition to adult care, and recommendations for transition support. The National Alliance to Advance Adolescent Health worked with Family Voices-DC to organize the focus groups.

Teens' Reliance on Pediatric Providers as Their Main Source of Care

Overall, teens in our focus groups reported a mixed picture. Some teens, particularly younger teens, reported seeing doctors that treat only children. Others were not sure about whether or not their doctors treat only children. The majority of parents in our focus groups reported their teenage children with special health care needs see pediatricians for their care.

Teens' Knowledge about Their Health Conditions

Although most teens said they felt able to take care of their chronic condition(s), responses varied when it came to specific skills. For example, most expressed comfort in recognizing signs and symptoms and knew how to find help if needed, but most reported that their parents schedule their health care appointments. Some reported being comfortable with taking their medications, but others reported needing reminders from parents. Few adolescents reported carrying information about their chronic condition, such as a list of medications, a medical history, or an emergency number, and few reported that they carry their health insurance information. As one younger male participant said, "I don't take my medicine unless my mom tells me." Conversely, an older male teen reported taking on more responsibility for his own care as he got older, saying "When you were younger, your mother had to basically do everything for you, give you your medicine and

everything. Now it's like basically like you're doing a lot of stuff on your own so it's totally different."

Parents described their teens' knowledge and skills similarly to the teens in the focus groups. Some parents felt their adolescent children were increasingly comfortable with self-care but indicated that they need reminders. For example, one parent reported that she maintained her daughter's insurance information and medical records, but her daughter was able to manage her medications and knew how to respond to signs and symptoms of her illness. Few parents reported their children carrying any health or insurance information with them.

Transitioning to Adult Health Care

When asked about how health care might change when an adolescent becomes 21 or 22 years old, few teens in the focus groups appeared to have thought about this. One teen commented that he knew it would change but wasn't sure how. Some adolescents actually expressed comfort with the idea of making a health care transition, with only a few articulating nervousness; the remainder had no opinion. Adolescents reported that it "seems manageable" and "change happens." The few teens who expressed concern were nervous about seeing a new doctor.

A few parents, particularly those with older teens, had started to think about how their child's health care might change as they grew older. These parents mentioned changes in doctors or location of care. Just as the teens reported, few parents expressed nervousness about their child's transition process, though some stated that they felt they had some time to plan (due to child's age). The concerns that were raised were about Social Security eligibility after age 18, insurance continuity, adolescents seeing doctors alone without a parent, and discomfort around teens' physical exams. A few parents expressed some difficulty "letting go," stating that they would like to continue significant involvement in their child's care as he or she grows older. One Spanish-speaking participant noted that she would prefer to talk with the doctor about transition issues and then have that discussion with her daughter, rather than having the doctor speak directly with her daughter. Parents of adolescents with more severe disabilities expressed greater reservations about this. As one parent said, "I have taken care of her all her life – I take her wherever I go."

Neither adolescents nor parents report developing a written health transition plan with their doctor, although several parents indicated they thought such a plan would be helpful to them or their child. In addition, few adolescents or parents in the focus groups reported seeing posted signs or hearing information about an age limit in the practice.

Transition Support

Both parents and adolescents indicated an interest in receiving more information about doctors – their quality, background, and availability – as well as insurance. They would also like information on their child's practice age limits and transition support.

When asked about the best ways to get transition information, help, and support to make a smooth transition to adult health care, most adolescents reported that internet-based information would be the best way to reach them. Some also thought written information from a doctor's office would be helpful, while others preferred face-to-face information exchange (with their doctors or with small groups of adolescents) over written material. Adolescents also mentioned multimedia and

interactive approaches (games, videos). Some adolescents expressed interest in text messaging for a variety of purposes.

Most parents preferred interpersonal means of getting information about transition, such as group meetings, “transition appointments” with providers, or conversations including doctors and their adolescent child. One parent also suggested a “transition kit” with information for parents/caregivers of younger children to read through and digest before transition plans are made. Spanish-speaking parents also noted that interpreters and Spanish-language materials should be available as they sometimes confront this additional barrier in receiving care.

Conclusions

The subject of health care transition was a new topic for DC teens and parents alike in our focus groups, even among older teens. Most, however, appeared to be informed about education transition. As our results indicate, strategies to address this knowledge gap should begin early in adolescence and include a variety of face-to-face, internet-based, and informational strategies involving teens and parents.