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## Primer on Health Care Access for Young Adults with Disabilities

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Today, 90% of children with disabilities or special health care needs survive into adulthood, and they account for one-half of all health care expenditures for children, even though they represent about 15%–18% of all American children. These children receive health care coverage through a variety of public and private programs. For most, their health issues will follow them into adulthood. Yet, as they pass the legal age of consent, typically age 18, their access to health care changes dramatically. This brief, based on Patience Haydock White and Leslie Galloway's chapter in *On Your Own without a Net: The Transition to Adulthood for Vulnerable Populations*, edited by D. Wayne Osgood, E. Michael Foster, Constance Flanagan, and Gretchen Ruth, offers a primer on the changing eligibility and access that young adults with disabilities face as they enter adulthood.

### Public Insurance

Medicaid is the major source of health insurance for low-income youth, and, as of 1999, it was the source of health insurance for 80% of adults under age 65 with severe disabilities. Eligibility and services vary by states, and in most states, Medicaid covers youth until age 21 so long as the family meets state income eligibility criteria. Once they are 21, however, youth risk losing Medicaid coverage unless they have children of their own who qualify or they are eligible for Supplemental Security Income (SSI). Estimates are that 400,000 youth in the Medicaid program with serious chronic health conditions are at risk of losing Medicaid and are unlikely to qualify for SSI.

SSI is a means-tested program designed to supplement Medicaid and other public benefits. Children under age 18 who meet the Social Security Administration's (SSA) definition of disability and whose parents meet the SSI income criteria are covered. After age 18, many states redetermine eligibility based on adult criteria, including that the individual must be unable to work. SSA estimated in 2001 that 30% of those who had SSI as a child were no longer eligible as adults because they were able to work and/or earned more than \$700 per month. Many of these youth who lose SSI would also lose Medicaid. On the other hand, some youth whose families earned too much for the youth to be eligible for SSI as a child might become eligible at age 18, so long as they could not work. In 1997, the Balanced Budget Act allowed working youth to continue to receive SSI if their earnings disqualified them from Medicaid. If individuals meet SSI disability criteria and have a net income below 250% of the federal poverty line, they can buy into Medicaid. However, these programs are in jeopardy because of state budget shortfalls.

Another program available to working disabled adults is Social Security Disability Insurance (SSDI), which operates in a manner similar to insurance. Young adults are eligible for benefits if they have paid their premiums by working for at least 5 of the last 10 years.

The State Children's Health Insurance Program (SCHIP) offers Medicaid or, in some states, private managed care insurance, to those under age 19 in families with incomes less than or equal to 200% of the federal poverty line. However, the managed care benefits are often narrower for prevention and chronic care services than the Medicaid programs and are unavailable to those young adults over age 19.

One of the few ways a youth with serious health conditions can be eligible for medical coverage is through the Adult Disabled Child (DAC) benefit. A child who was disabled before age 22 and is unable to work is eligible for a DAC if his or her parent contributed enough to Social Security before the parent became disabled, retired, or died. The

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amount of support received is based on a percentage of the parent's benefit amount. Often the DAC is greater than SSI. Thus, if a youth opts for DAC, he or she would lose SSI and Medicaid.

Many working youth with disabilities are eligible for Old Age, Survivors, and Disability Insurance (OASDI) benefits. The program is not needs based and has no income or asset test. Eligibility is based on youths' own work history or that of their parents who are receiving social security benefits. In addition, after 2 years in the program, individuals are automatically eligible for Medicare. A disabled adult dependent who has received Medicaid for at least 24 months but who has recently become ineligible for Medicaid could become eligible for some Medicare benefits. However, the package lacks coverage for long-term care and prescription drugs.

## Private Insurance

Two-thirds of children with disabilities are covered through their parents' health plan.<sup>1</sup> Of course, they often lose eligibility under their parents' plan when they enter adulthood. To maintain eligibility, they must either not work or they must be a full-time student. Maintaining a full school load is often difficult for young adults with disabilities. If they choose to work and thus lose their health coverage under their parent's plan, they often face less extensive benefits and higher costs under their employer's plan. Further, part-time work often does not offer health benefits and it is exempt from the requirement.

Obtaining one's own insurance as an adult is often prohibitively expensive, and many insurers turn down individuals with conditions such as asthma, HIV, or cancer, or they face premium surcharges. Some states have created high-risk pools to cover individuals who require extensive care. However, various restrictions have limited the numbers in these pools to only about one million. About half the states offer condition-specific coverage for one or more genetic diseases such as cystic fibrosis, hemophilia, and sickle cell disease. However, eligibility requires that the young adult be enrolled since childhood. In short, many private plans are either too expensive, have limited benefits, and are often offered for a limited time.

## Policy Options

Short of a massive overhaul of the health insurance system, the authors offer several policy changes that could significantly affect the transition to adulthood for youth with serious health problems. States, they argue, should require private insurers to extend coverage through age 25. This would assist in covering an estimated 500,000 to 1 million unmarried, dependent youth under age 22. Congress should also require states to extend Medicaid and SCHIP coverage to age 23, which could assist 2.6 million uninsured young adults (aged 19–25) with poverty-level incomes. States should also expand SCHIP benefits for youth with special health care needs. Congress should also extend the redetermination age for Social Security to 23 to allow youth to obtain enough skills to find a job with health care benefits. Alternatively, Congress could change SSI's "unemployability" standard for Medicaid eligibility for young adults. New models are needed that incorporate those with serious chronic illnesses so they can participate in large insurance pools that can make health care more affordable. Finally, states should ensure that Medicaid and SCHIP cover appropriate preventive services for adolescents with disabilities.

*Based on Patience Haydock White and Leslie Gallay, "Youth with Special Health Care Needs and Disabilities in Transition to Adulthood," in On Your Own without a Net: The Transition to Adulthood for Vulnerable Populations, edited by D. Wayne Osgood, E. Michael Foster, Constance Flanagan, and Gretchen Ruth (forthcoming fall 2005, University of Chicago Press). The editors are members of the Network on Transitions to Adulthood, supported by the John D. and Catherine T. MacArthur Foundation.*

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<sup>1</sup> E. Fishman, "Aging Out of Coverage: Young Adults with Special Health Needs," *Health Affairs*, vol. 20 (2001), pp. 254–66.

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The Research Network on Transitions to Adulthood and Public Policy examines the changing nature of early adulthood, and the policies, programs, and institutions that support young people as they move into adulthood. Significant cultural, economic, and demographic changes have occurred in the span of a few generations, and these changes are challenging youth's psychological and social development. Some are adapting well, but many others are floundering as they prepare to leave home, finish school, find jobs, and start families. The network is both documenting these cultural and social shifts, and exploring how families, government, and social institutions are shaping the course of young adults' development. The Network is funded by the MacArthur Foundation and chaired by University of Pennsylvania sociologist Frank Furstenberg.