

Aging Out Of Coverage: Young Adults With Special Health Needs

Expanding access to this population depends on the creation of a new eligibility standard based on the urgency and expense of a person's health need, not a person's employability.

by Eliot Fishman

ABSTRACT: Young adults with disabilities and chronic conditions have high uninsurance rates, while Medicaid and Medicare are closed to many of them. Federal legislation to allow states to offer Medicaid to employed persons with disabilities has met with an unenthusiastic reaction thus far in the states, with few using the Medicaid options and low enrollment levels even in those states. Nevertheless, these Medicaid changes do move us toward a more basic solution: replacing employability with insurability and dependence on health interventions as the eligibility standards for public coverage for adults.

254

COVERING
YOUNG
ADULTS

A LARGE NUMBER OF YOUNG AMERICAN ADULTS lack health insurance: twelve million, or 30 percent of persons ages nineteen to twenty-nine (twice the rate of uninsurance among those ages thirty to sixty-four).¹ Young workers disproportionately lack employer-sponsored insurance, and college-based insurance is rare among persons with low and moderate incomes. Young adults, of course, tend to be healthy as a group. But for young adults with disabilities or with chronic illnesses, the lack of health insurance can be devastating.

Persons with disabilities and chronic conditions often have private or public coverage as children. A large majority of parents of adolescents have employer coverage, and the State Children's Health Insurance Program (SCHIP) or Medicaid provides categorical coverage for poor and near-poor children and for virtually all foster children. However, turning nineteen, twenty, or twenty-one can bring a treacherous transition from parental or public coverage.

In this paper I first present previously unpublished data on young adults with disabilities and describe the insurance gaps among young adults with serious chronic illnesses. I then discuss three existing state policies—extensions of Children with Special Health

Eliot Fishman is a senior research associate at the Institute for Medicare Practice, Mount Sinai School of Medicine, in New York City.

Care Needs” block grants to adults, regulation of private insurance, and Medicaid options authorized in the late 1990s—which although promising have helped only small numbers of people. Almost all of these programs are tiny, short on outreach, and thus far grossly inadequate to the problems that exist. Most states have not implemented the new Medicaid options, and those that have implemented them have largely failed to enroll people outside the cash assistance system. Even if fully implemented, these expansions would not reach many young adults with serious chronic conditions who cannot get private insurance but who are not functionally disabled.

Nevertheless, the halting, incremental adjustments to Medicaid eligibility described here have begun a move toward a more fundamental solution. The recent Medicaid options have the potential to break the connection between public coverage and cash assistance for persons with disabilities, just as it has been broken for children through Medicaid changes in the past fifteen years. That so many young persons with disabilities and chronic illnesses lack health insurance points to the need to base adults’ eligibility for public coverage on the urgency of health needs and insurability, rather than on lack of employability and receipt of income support. I conclude with some ideas to move policy more firmly in that direction.

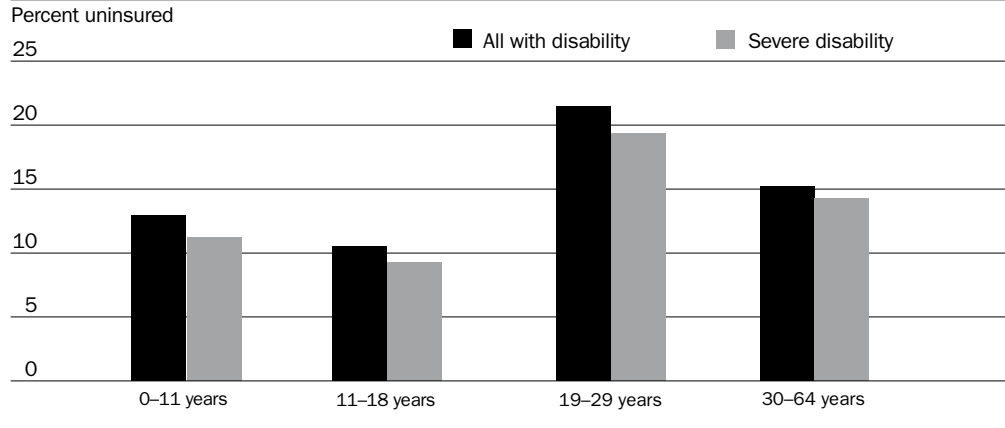
■ **Data and methods.** There have been little analysis or few data published on the insurance status of the young adults discussed here. While the Survey on Income and Program Participation (SIPP) and the National Health Interview Survey (NHIS) each include detailed sets of questions on disability and insurance status, this paper is the first to publish data on insurance coverage for those ages nineteen to twenty-nine with varying levels of disability, using SIPP. No similarly comprehensive and well-defined national survey data are available for persons with chronic illnesses, but there is enough information to indicate enormous gaps in coverage among persons with acute health care needs. To examine the impact of previous reforms in coverage policy, I have surveyed program administrators in states that have used the new Medicaid options or have extended Title V programs to adults.

DATAWATCH 255

Levels Of Uninsurance

■ **Young persons with disabilities.** For younger adults (ages 19–29) with disabilities, insurance coverage is poor: Almost 22 percent are uninsured, a proportion much larger than is the case for similarly disabled children (age eighteen and younger) (Exhibit 1). About 36 percent have public coverage, and 42 percent have private insurance (Exhibit 2).² The approximately 2.3 million young adults with disabilities that are defined by the Bureau of the Census as

EXHIBIT 1
Uninsurance For Persons With Disabilities, By Age And Level Of Disability, 1996



SOURCE: Survey of Income and Program Participation, 1999.

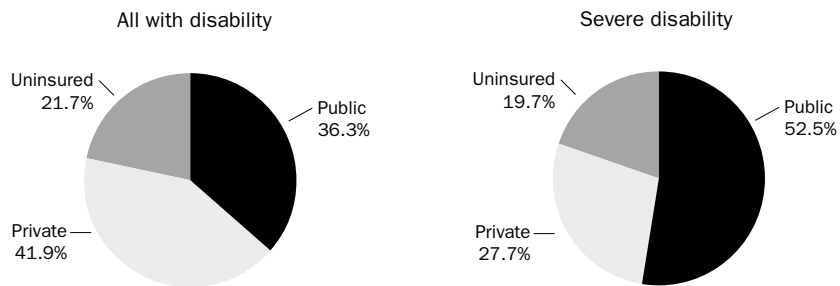
256

**COVERING
 YOUNG
 ADULTS**

“severe”—substantial developmental or physical disabilities or chronic mental illness—also had a high level of uninsurance (19.8 percent) but somewhat higher levels of public coverage.

When all working-age disabled adults (ages 18–64) are considered, the statistics are still disturbing. About 16 percent lack health insurance (4.4 million persons), even though half of them are employed.³ Of the 9.3 million adults with a long-term disability that limits their ability to work, 15 percent (1.4 million) are uninsured. Approximately 40 percent of these more severely disabled uninsured persons manage some employment.⁴ Adults with disabilities who work but lack health insurance are mostly low income: 30 percent are poor, and 62 percent make less than 200 percent of the federal poverty level.⁵

EXHIBIT 2
Insurance Coverage Among Persons With Disabilities, Ages 19–29, 1996



SOURCE: Survey of Income and Program Participation, 1999.

NOTE: Percentages do not add to 100 because of rounding.

Children with disabilities fare better in terms of coverage than their young adult counterparts do, in several ways. Private parental coverage covers many more children than young adults because of the limits on most family coverage policies. SCHIP covers children only up to age nineteen. Medicaid has relatively generous coverage of children: Most important, it covers all children in households with incomes up to 100 percent of poverty (or much more in many states). Moreover, in states offering coverage for “Katie Beckett” children (the great majority of states), Medicaid covers community-dwelling children meeting the Supplemental Security Income (SSI) standard for disability regardless of parental income, if they are receiving care that would be provided in an institution. But Medicaid coverage of adults with disabilities in almost all states is limited to the SSI program and “medically needy” options. Finally, the SSI disability standard for children is more liberal in certain respects than that for adults—most explicitly, adults who earn more than \$700 a month are considered ineligible for SSI as a rule, regardless of their medical expenses. In 1997 and 1998, 35–40 percent of eighteen-year-olds with disabilities applying to continue their previous SSI coverage were turned down; this likely led to the loss of Medicaid coverage for some 35,000 young adults in those two years.⁶

■ **Young persons with chronic illnesses.** Many children with serious, chronic health conditions depend on Medicaid for their health coverage. This is so both because poor and near-poor children are disproportionately burdened with these conditions, and because the high health expenditures these conditions impose can help families to “spend down” to Medicaid eligibility in most states. Yet most of these children will not qualify for Medicaid when they turn nineteen. The main path for such coverage, as discussed above, would be SSI eligibility. But SSI focuses on employability and functional problems rather than serious health problems as such.

This is reflected in statistics on children enrolled in Medicaid—even those with serious chronic conditions generally get Medicaid because of their age rather than by qualifying for both Medicaid and cash payments through SSI. The prevalence of severe, chronic health conditions is three to five times higher among Medicaid-insured than privately insured children.⁷ These conditions include cancer, cystic fibrosis, severe asthma, human immunodeficiency virus (HIV) infection, and sickle-cell anemia. However, 74 percent of the children in Medicaid who have a severe medical condition do not receive SSI, even under SSI’s relatively generous eligibility rules for children, and a similar majority of children in SSI have disabilities that are not severe medical conditions.⁸ SSI eligibility is typically determined by level of functional loss or, in some cases, medical

severity, rather than the costs of medical treatment. A medical condition may be under control and nondisabling yet very expensive to treat.⁹ A 1997 study of Medicaid-enrolled children in California, New York, Georgia, and Michigan found that 2 percent had one of these conditions but were not enrolled in SSI.¹⁰ If this proportion is similar in other states, about 400,000 of the twenty million children enrolled in Medicaid have a serious, chronic health condition but no SSI. When these children turn nineteen, they are likely to have enormous health costs with no Medicaid eligibility.

Shortfalls In Existing Coverage Policy

Except in a handful of states with broad Medicaid waivers, public coverage for nonelderly adults is available only to very low-income parents, to those receiving income support by reason of disability from either Social Security or SSI, or to some of those who gain employment after having received income support for their disability. The regulatory definition of disability includes a substantial list of serious illnesses, but the illness must be sufficiently advanced to constitute a work disability. The provision of publicly financed health insurance to persons with disabilities and serious illnesses, then, has traditionally been based upon unemployability. Three areas of policy that have seen some efforts to change that traditional standard are Medicaid reforms; adult add-ons to Title V programs; and regulation of private coverage. None has had much of an impact thus far.

258**COVERING
YOUNG
ADULTS**

■ **Medicare and Medicaid eligibility and enrollment.** Three million persons with disabilities ages eighteen to sixty-four received Medicare in 1995.¹¹ People receiving Social Security checks and their dependents are eligible for Medicare coverage, including those eligible for Social Security Disability Insurance (SSDI), although SSDI recipients must wait two years before their Medicare eligibility kicks in. Adults with disabilities under age sixty-five can only get Medicare through SSDI if they have an employment history but are now disabled, or if they are the dependent child of a Social Security beneficiary. They also must be severely disabled under Social Security rules, meaning that they are not able to work and earn significant income. Nevertheless, former Medicare beneficiaries who begin working can get free Medicare coverage for eight and a half years after returning to work; after that they can take advantage of a buy-in option created by the new Ticket to Work legislation.

Medicaid is the public alternative for the larger number of young adults with disabilities who cannot qualify for Medicare because they never worked and do not have retired parents. About 4.9 million persons with disabilities ages eighteen to sixty-four are in

Medicaid.¹² (Of these Medicaid beneficiaries, 800,000 receive Medicare as well, meaning that there were 7.1 million disabled Medicaid and Medicare beneficiaries ages eighteen to sixty-four in 1995.) They can qualify for Medicaid through SSI if they make less than \$700 per month in earned income after subtracting certain expenses, along with some other income and asset restrictions.

Once qualified for SSI, young adults can retain Medicaid coverage even if they get a job and earn a modest income: Under rules in place since 1980, Medicaid coverage must continue for employed former SSI recipients if their income is below state-specific limits. In 2000 this provision allowed 83,000 persons with disabilities to receive Medicaid after their income disqualified them for SSI; 25,000 were age twenty-nine or younger.¹³

In a small number of states, adults with disabilities with higher incomes can in principle qualify without ever having been on SSI through two new, optional Medicaid eligibility categories. One provision, passed in 1997, allows states to give Medicaid coverage to employed persons with disabilities earning up to 250 percent of poverty who meet the other SSI eligibility standards because of the severity of their impairment.¹⁴ A second optional Medicaid extension, another piece of 1999's Ticket to Work law, extends the 1997 law to become completely open-ended, allowing states to offer Medicaid to anyone disabled enough for SSI at whatever income the state chooses. States can even extend coverage to those working persons with disabilities whose conditions have improved medically to the point that their severe impairment no longer meets the SSI standard. The law only loosely restricts cost sharing and premiums. As of August 2001 only fifteen states had implemented one of these optional Medicaid extensions.

Even in the states that have implemented these two optional Medicaid provisions, programs have so far mainly helped those coming off the SSI rolls—that is, those who find jobs after they had been deemed unemployable and thereby gained SSI or SSDI eligibility. Partial figures show that almost all of the enrollees in the new programs had already qualified for Medicaid and SSI before they started working (Exhibit 3). All states with information on enrollees indicate that almost all of them were prior Medicaid beneficiaries, and few have incomes high enough to trigger cost-sharing requirements. This is largely true of those states that have achieved relatively high initial enrollments, with the partial exception of Minnesota. These states have adopted these Medicaid expansions as welfare-to-work supports for SSI beneficiaries rather than as health insurance expansions.

■ **Private insurance.** The individual insurance market is pro-

EXHIBIT 3
Medicaid “Employed Persons With Disabilities” And “Ticket To Work” Programs, In
Eleven States

State	Inception	Enrollment as of June 2001	Income maximum (with SSI exclusions)	Premiums	Percent with no or minimum cost sharing	Outreach to non-SSI population
Alaska	6/99	99	250% FPL	Sliding scale above 100% FPL	- ^b	Minimal; emphasis on “comprehensive benefits planning, not program-specific outreach”; most enrollees were on Medicaid before
Arkansas	2/01	30 ^a	250% FPL	Copayments: Medicaid below 100% FPL, above 100% FPL higher	- ^b	None as yet; advocacy groups doing outreach; enrollment currently exceeding budget
California	10/99	250 (flat growth)	250% FPL	\$20–\$250 per month; premium based on income	86%	900,000 fliers sent to disability advocates, state health and rehab agencies
Connecticut	10/00	1,274 (growth of 100 per month)	Up to \$75,000	10% of marginal income over 200% poverty	Over 90%	Started with Medicaid spend-down enrollees, then outreach through rehab services, Dept. of Mental Health
Iowa	3/00	2,711	250% FPL (unearned not counted)	Premiums over 150% FPL	78%	89% from other Medicaid categories, although this includes spend down and QMB/SLMB
Maine	8/99	473 (growth of 10–20 per month has leveled off)	Earned income 100% FPL, unearned 250% FPL	\$10–\$20 per month between 150–250% FPL	Over 90%	80–90% from other Medicaid categories; limited outreach: some training, fliers at vocational, rehab, other agencies
Minnesota	- ^b	6,103	None (\$22,000 asset limit)	10% of marginal income over 200% poverty	92%	About 60% from other Medicaid; outreach through brochures, Web, advocacy groups
Mississippi	- ^b	75 (flat growth)	250% FPL (must be working >40 hours a month)	None	- ^b	None: beneficiaries assigned to program as they apply for Medicaid
Nebraska	6/99	85 (flat monthly growth)	Up to 250% FPL	Sliding scale from 200–250% FPL, 2–10% of income	Over 90%	None (meetings with several advocacy groups)
New Jersey	10/00	140	Up to 250% FPL, unearned up to 100%	Premium \$25–\$50 over 100% FPL	Over 95%	Majority from other Medicaid. No outreach yet, but PR campaign is now budgeted and planned
New Mexico	1/01	223	250% FPL	Copayments (up to a sliding maximum-based)	- ^b	Predominantly not from other Medicaid categories

EXHIBIT 3**Medicaid “Employed Persons With Disabilities” And “Ticket To Work” Programs (cont.)**

State	Inception	Enrollment as of March 2001	Income maximum (with SSI exclusions)	Premiums	Percent with no or minimum cost sharing	Outreach to non-SSI population
Oregon	2/99	472 (growth of 10–15 per month)	250% FPL (unearned income not counted)	Premium for income above \$2,200 per month (\$532 unearned)	Unearned income—45% (mostly SSDI) no premium—99%	Training with advocacy and consumer groups; 85% of enrollees have prior Medicaid
South Carolina	10/98	40 (flat growth)	250% FPL	None	— ^b	Distributed a flier to local vocational rehab and other agencies
Vermont	1/00	320	250% FPL	Above 185% FPL, \$12–\$25 monthly premium	— ^b	Mainly enrolling off of SSI as a welfare-to-work program
Wisconsin	3/00	1,500 (flat monthly growth)	250% FPL	3% of income above 150% FPL, 100% FPL unearned income	78%	Initially aggressive outreach, including town meetings; now at budgeted enrollment

SOURCE: Author’s survey of state administrators.

NOTES: FPL is federal poverty level. SSI is Supplemental Security Income. SSDI is Social Security Disability Insurance. QMB is qualified Medicare beneficiary; SLMB is specified low-income Medicare beneficiary.

^a After three weeks.

^b Not available.

hibitive for persons with serious health problems.¹⁵ For young adults aging out of their parents’ private coverage, there are in principle several options aside from the unregulated individual insurance market and Medicaid or other public programs: coverage in a family plan that covers dependent adult children with disabilities (once a rare level of family coverage but one now mandated for plans not subject to the Employee Retirement Income Security Act, or ERISA, in forty-four states); coverage in a family plan as a full-time student; Consolidated Omnibus Budget Reconciliation Act (COBRA) coverage (typically limited to thirty-six months for children aging out of coverage); state high-risk pools or community-rated markets; and gaining a “certificate of portability” into an employer or individual plan based on the Health Insurance Portability and Accountability Act (HIPAA) of 1996, for those applying immediately after having been covered by a different plan for eighteen months.

None of these paths to private coverage offers help to the vast majority of uninsured young persons with disabilities or chronic illnesses. Dependent coverage for disabled adults in family health

plans, including coverage now mandated in most states, almost always requires the dependent to be unemployable, as does SSI. Indeed, previous SSI enrollment is one of the primary sources of documentation that insurers use to determine initial eligibility. Student dependent coverage usually ends in the early twenties and requires a full-time course load that persons with disabilities and chronic illnesses often cannot maintain, and persons from low-income families often cannot afford. The other three options—COBRA, high-risk pools and community-rated markets, and HIPAA portability certificates—all involve high premiums, because of adverse selection and the lack of employer subsidy. Moreover, the uninsured with disabilities and chronic illnesses are a predominantly low-income population, with 62 percent of the uninsured with serious disabilities making less than 200 percent of the federal poverty level, an income that is not much more than the premium for a community-rated policy. Uninsured young adults, if anything, have even lower incomes.

■ **Condition-specific Title V program extensions.** Twenty-one states operate condition-specific coverage programs for adults with one or more genetic diseases. These are primarily programs for children that use federal Title V block-grant funding (state programs dating back to “Crippled Children’s” programs in the 1920s and 1930s) that states have extended to adults, generally using state funds. But while most of those programs cover a substantial number of children with a wide variety of conditions, adult enrollment is typically limited to those who have one or one of two specific conditions, and it may be limited as well to those who were enrolled in the program as a child (because they were ineligible for Medicaid) or to those using specific providers and medical centers (Exhibit 4). Most of these program extensions are quite small. Because Title V is a block-grant program, moreover, expansions of Title V programs are almost always with state-only funds, while Medicaid receives an open-ended federal match of 50–80 percent. If states are going to expand eligibility, it is more likely to be through Medicaid.

A New Standard For Public Coverage?

Substantial employment with significant income generally keeps persons with disabilities and chronic illnesses from gaining eligibility for Medicare and Medicaid, since the disability standard is defined around inability to work. That keeps many people uninsured and also a large number unemployed: The 1994 Harris Survey of Americans with Disabilities found that 31 percent of those who are unemployed find loss of health insurance or long-term services to be a work barrier.¹⁶

EXHIBIT 4 State Health Insurance Programs For Adults With Genetic Disabilities

State/ program name	Adult enrollees	Coverage limitations	Income requirements	Funding
Many conditions				
California: Genetically Handicapped Persons Program	Ca. 2,000	Program covers many genetic diseases	None	State-only
New Hampshire: Catastrophic Illness Program	Ca. 900 (600 active)	Cancer, CF, spinal cord injury, hemophilia	\$13,500 + \$1,000 per additional member of household, \$30,000 in assets	State-only
Pennsylvania: Special Health Care Programs	5,051 (4,772 ESRD)	Anemia, CF, ESRD, hemophilia, spina bifida, brain injury	Below 300% poverty	State-only
Cystic fibrosis (CF) and other rare conditions				
Arizona: Children's Rehabilitative Services	25	CF or sickle cell	Below 200% poverty	State-only
Connecticut: Children with Special Health Care Needs	Ca. 20	Those enrolled as children with CF	Below 300% poverty	Title V block grant
Idaho: Children's Special Health Program	33	CF	None	State-only
Indiana: Children's Special Health Care Services	<100	CF	Below 250% poverty	State-only
Louisiana: Children's Special Health Services	Ca. 40	CF	Case-by-case analysis	State-only
Michigan: Children's Special Health Care Services	359	CF and hemophilia; only services related to conditions ^a	None	State-only
Minnesota: Children with Special Health Needs	60	CF and hemophilia: CF transitioning to Medicaid	Ca. \$40,000 per year	State-only
Mississippi: Children with Special Health Care Needs	100-200	Those enrolled as children with CF, hemophilia, or sickle cell	None	Title V block grant
Missouri: Genetics Program	Ca. 120	Limited to CF, hemophilia, PKU, and sickle cell	Below 185% poverty	State-only
Nebraska: Genetically Handicapped People Program	40-50	CF, hemophilia, or sickle cell	Case-by-case	State-only
New Jersey: Pharmaceutical Assistance for Adults with Cystic Fibrosis; Hemophilia Program	CF: 85; hemophilia: 50	CF and severe hemophilia (home infusion)	CF: \$33,966; hemophilia: \$22,000	State-only
New Mexico: Children's Medical Services	Ca. 30	CF only	None	Title V block grant
New York: Cystic Fibrosis Program	95	CF only; must be ineligible for Medicaid	Spend down of 7% of income	State-only
North Carolina: Children's Special Health Services	Ca. 100	CF and hemophilia only	Below 100% poverty	State-only
Ohio: Bureau for Children with Medical Handicaps	158	CF only	None	State-only
Texas: Children with Special Health Care Needs	- ^b	CF only	Below 200% poverty with assets less than \$6,000	- ^b

EXHIBIT 4
State Health Insurance Programs For Adults With Genetic Disabilities (cont.)

State/ program name	Adult enrollees	Coverage limitations	Income requirements	Funding
Cystic fibrosis (CF) and other rare conditions				
Vermont: (no program name)	100	CF only	None	State-only
Virginia: Children with Special Health Care Needs	108	CF and hemophilia only	Below 200% poverty	Title V block grant

SOURCE: Author's survey of state programs.

NOTES: Twenty-two states also offer specific programs offering coverage for people with end-stage renal disease (ESRD), most of whom categorically qualify for Medicare. Such programs typically include some coverage of prescriptions, Medicare premiums and cost sharing, and/or other benefits. PKU is phenylketonuria.

^a Pays entire capitation for Medicaid managed care-enrolled beneficiaries.

^b Not available.

So far, the most promising avenue toward shifting away from the employability standard—Medicaid options aimed at employed persons with disabilities—has had disappointing results even in states that have adopted it. These states appear to be uncertain what standards to use to enroll working people with disabilities into Medicaid. The Centers for Medicare and Medicaid Services (CMS, formerly HCFA) has clearly stated that enrollees need not go through the SSI/SSDI disability determination process. The CMS has added, however, that states should enroll those who would be eligible for SSI except for the fact that they are working. Yet three of the five steps in determining eligibility for SSI have to do with unemployment and the inability to work. The CMS, then, has instructed the states to make Medicaid available to working people based on standards that are supposed to indicate an inability to work. A Connecticut program administrator stated that he has instructed enrollment officers to use the following broad standard: “People who work through extraordinary efforts even though their disability is substantial enough that they would be justified in not working and collecting SSI are eligible.” In practice, this apparently has meant enrolling recent SSI beneficiaries.

While the fact that these programs have been enrolling straight out of the SSI rolls sidesteps the problem of disability determination, it also greatly limits the reach of the federal legislation. The very existence of this definitional problem, however, derives from a more fundamental problem in American health policy, the same fundamental problem that leaves so many young people with disabilities and chronic conditions uninsured: Employability does not mean insurability. The unemployability standard is a legacy of Medicaid's connection to welfare. But the employer health coverage system often excludes bad health risks, persons with low incomes, and persons in part-time jobs—all characteristics typical of the

young adults discussed in this paper.

More specifically, the unemployability standard excludes two groups of people who cannot access private insurance. First, it excludes persons with functional disabilities who can work, but cannot work in a full-time job that offers them coverage. Second, it excludes persons with chronic conditions and illnesses that are expensive to treat but do not limit or only partly limit their ability to work. Legal, social, and medical advances have allowed more persons with disabilities and chronic medical conditions to work. But because of their disability or health condition, their work will often be part time and may not offer benefits, particularly for young persons in entry-level jobs. Also, the individual and small-employer health insurance markets are inaccessible to persons with serious health problems in ways that are difficult to address with market regulation.

In principle, a loosening of the unemployability standard is all that is needed to reach the first group—those with functional disabilities who can and should work but whose disability is a strong risk factor for lack of access to jobs with benefits. To reach persons with chronic illnesses, however, focusing on employability is off target: Their claim on public coverage stems from the urgency of their health needs and their unattractiveness to private insurers. These criteria ought to be the basis of a new eligibility standard, although such a standard would need to balance the need to cover the uninsurable against the risk of turning public coverage into an all-purpose dumping ground for people who get sick.

Medicaid may be a poor vehicle to accomplish this change in eligibility standards. Although Medicaid is a natural choice given its current enrollment of persons with disabilities who are not former workers, there is already substantial experience that many states will refuse optional Medicaid expansions, particularly expansions to expensive populations. And even if expansions are made mandatory, the means-tested, state-administered Medicaid model has had trouble reaching employed people in many states, as evidenced by underenrollment problems among mothers and children in recent Medicaid expansions and SCHIP.

BOTH ONE-FIFTH OF ALL YOUNG ADULTS with disabilities and one-fifth of those with severe disabilities are uninsured. Close to half of uninsured persons with disabilities work. And three-quarters of Medicaid-eligible children with a severe, chronic health problem do not even have SSI and therefore in all likelihood will also lose their Medicaid coverage when they turn nineteen. Indeed, turning nineteen and getting a job often means losing eligi-

bility for SSI and Medicaid without a private-sector alternative. If the problem of the young uninsured adult with special health needs is to be addressed, eligibility for adults with disabilities must move from an unemployability standard to an “acuity and insurability” standard, based both on employability at a job with benefits and on the urgency and expense of individuals’ health needs.

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NOTES

1. K. Quinn et al., *On Their Own: Young Adults Living without Health Insurance* (New York: Commonwealth Fund, May 2000).
2. Unpublished data from the Survey of Income and Program Participation, 1996 (Wave 11), personal communication, Bureau of the Census.
3. J. Meyer and P. Zeller, *Profiles of Disability: Employment and Health Coverage* (Washington: Kaiser Commission on Medicaid and the Uninsured, September 1999). (These figures are from the NHIS. The figures for those ages 19–29 in the previous paragraph are from SIPP.)
4. Ibid.
5. J. McNeil, *Americans with Disabilities: 1997*, Current Population Reports, Pub. no. P70-73 (Washington: Bureau of the Census, 1997). This report uses SIPP data.
6. R. Schulzinger, “Youth with Disabilities in Transition: Health Insurance Options and Obstacles,” *Healthy and Ready to Work Policy Papers* (Washington: Maternal and Child Health Bureau, June 2000), 5.
7. B. Burwell et al., “Children with Severe Chronic Conditions on Medicaid” (Washington: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, November 1997).
8. Ibid.
9. The 1999 Ticket to Work Act offered \$250 million for Medicaid demonstration programs to offer coverage for nonelderly adults with conditions that will likely disable them if not treated, before they become disabled.
10. Burwell et al., “Children with Severe Chronic Conditions,” Tables 1 and 2.
11. Meyer and Zeller, “Profiles of Disability,” 10.
12. Ibid.
13. Office of Policy, Office of Research, Evaluation and Statistics, *SSI Disabled Recipients Who Work*, Quarterly Report of the Social Security Administration (Washington: Social Security Administration, December 2000).
14. States may also use “less restrictive methodologies” in excluding income or imposing buy-in premiums.
15. K. Pollitz, R. Sorian, and K. Thomas, *How Accessible Is Individual Health Insurance for Consumers in Less than Perfect Health?* (Menlo Park, Calif.: Henry J. Kaiser Family Foundation, June 2001).
16. B. O’Day, “Policy Barriers for People with Disabilities Who Want to Work,” *American Rehabilitation* (Spring 1999): 8–15.