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Access to Health Care: Health Insurance Considerations for Young Adults With Special Health Care Needs/Disabilities

Patience H. White, MD

ABSTRACT. Youth with special health care needs/disabilities want what all youth in America want: independence, health, friends, and jobs. Yet, between 19 and 23 years of age (depending on the state), youth with special health care needs/disabilities often find little availability of health insurance or health providers that were an essential part of why they survived and now are looking to participate in adult society. This article reviews the complex system of health insurance options that young adults with special health care needs/disabilities face as they move from pediatric to adult health insurance systems. Yet because of a maze of different eligibility criteria, many of these options are not available to young adults with special health care needs, and they are left with out health insurance. Similarly, the issues surrounding health provider reimbursement often leave the young adult with special health care needs without health care professionals who can manage their complex health conditions as they transition into adulthood. In conclusion, this article outlines what steps could be taken by associations and the health policy, advocacy, and governmental communities to improve the situation. *Pediatrics* 2002;110:1328–1335; *access, health insurance, Medicaid, Medicare, transition.*

ABBREVIATIONS. NCHS, National Center for Health Statistics; SCHIP, State Children's Health Insurance Program; SSI, Supplemental Security Income; HIV, human immunodeficiency virus; CMS, Center for Medicare and Medicaid Services; OASDI, Old Age, Survivors, and Disability Insurance; HIPAA, Health Insurance Portability and Accountability Act; COBRA, Consolidated Omnibus Budget Reconciliation Act; CPT, *Current Procedural Terminology*.

INTRODUCTION

Today, more than 90% of children with disabilities survive into adulthood. This is a tribute to the capability of modern medicine and early intervention strategies. In contrast, the health care financing and delivery systems for children and young adults with special health care needs have not kept pace. Adequate funding is a critical component for establishing and maintaining health care services for young adults with special health care needs/disabilities. Young adults with special health care needs/disabilities and their health care providers need adequate resources so health services will be

available. The following 2 central questions should be kept in mind when considering the costs of medical care for young adults with special health care needs/disabilities:

1. Are there enough financial resources within the health system to ensure that young adults with special health care needs/disabilities have access to the appropriate services?
2. Are there adequate financial incentives so young adults with special health care needs/disabilities will not be denied needed care?

This article will define the gaps in health insurance coverage for young adults with special health care needs/disabilities who are seeking flexible ways to participate in the larger society and keep their health insurance. In addition, this article will explore the current issues around adequate reimbursement to providers for services offered during the transition process from child-centered care to adult health care services. Finally, a discussion of suggestions for needed data, research, technical assistance, advocacy, and development of new models to improve the situation will conclude this article.

DEFINITION OF DISABILITY AS USED TO CHARACTERIZE WHO HAS INSURANCE

The number of persons who are classified as having a disability depends on the definition. Thus, as with many definitions of disability, it is important to know which is being used when interpreting the data presented. For example, one of the most inclusive definitions is that used by the National Center for Health Statistics (NCHS), which provides much of the data about characteristics of health insurance for those with disabilities. The NCHS definition classifies someone as having a disability if he or she has any of the following:

- a specific physical, functional, or mental or emotional disability or limiting condition;
- significant limitations in performing daily self-maintenance activities;
- need for the use of special equipment or devices, such as a wheelchair or breathing aid;
- limitation in a major or other life activity because of physical, mental, or emotional problems;
- income or insurance based on disability;
- other indicators of disability, such as poor overall health status, use of specialized programs or services, or other behavioral indicators of disability or developmental delay.¹

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Under this NCHS definition, 1 in 10 children (0–16 years of age), 18% of school-aged children (5–17 years of age) and 17% of nonelderly adults (18–64 years of age) have a disability. Recently, the statistics on children with special health care needs/disabilities were validated by a preliminary report from a national survey that was completed by the NCHS in 2001. For analysis purposes, large databases such as the NCHS often do not separate young adults (18–24 years of age) with disabilities from all nonelderly adults (18–64 years of age). The distribution of who has a disability shows that 7 in 10 people with disabilities are children or working-aged adults. The population with disabilities is diverse, and their disabilities range from the most common consisting of physical impairments (27 million) to mental health problems (10 million).

Newacheck,² using a different definition, calculated that in 1989, 6% of adolescents (10–18 years of age) had a serious chronic condition. Analysis of the *National Health Interview Survey* indicated an increase in prevalence of activity limiting chronic conditions from 1.8% in 1960 to 3.8% in 1981.² This increase continues today with a marked growth in the number of children with chronic illnesses, such as asthma and diabetes.

People with disabilities are more likely to be economically disadvantaged, to have less education, and to work part-time than are their peers without disabilities. All of these characteristics make them less able to afford health insurance. Sixty-two percent of working adults (19–64 years of age) with disabilities have income less than 200% of the federal poverty level (the federal poverty level was \$13 738 for a family of 3 in 2000).³ Nearly 40% of people with disabilities have family incomes below 200% of the federal poverty level, compared with 22% of those without disabilities. Fifty-two percent of the working-aged population with disabilities is employed, compared with more than 80% of those without disabilities. The likelihood of being uninsured irrespective of disability status increases as income decreases; more than 36% of the poor and 26% of the near poor are uninsured, in contrast to 6% of people with incomes at or above 300% of the poverty level (or \$41 000 per year for a family of 3).⁴

HEALTH INSURANCE

The majority of Americans (67% in the year 2000) without disabilities obtain their health insurance from their employer.¹ In contrast, some people with disabilities may have private insurance, but many rely heavily on Medicaid for their health coverage. This is most likely attributable to their high rate of unemployment, inability to pay the high health insurance premiums, or not having been offered employer-based health insurance.

One in 6 working-aged adults with a disability and 1 in 5 young adults (19–29 years of age) with a disability are without health insurance.⁵ This compares with 100% of individuals with disabilities older than 65 years who are covered by Medicare. In Fishman's analysis of the *Survey on Income and Program Participation* focusing on insurance coverage for in-

dividuals 19 to 29 years of age, he found that 12 million or 30% of all young adults (18–24 years of age) lack health insurance, and an even larger number do not have dental insurance.³ They are more likely to be uninsured, compared with all Americans (Tables 1 and 2). Similar data about the uninsurance rate for young adults with disabilities are not routinely available.^{6,7} Table 3 shows the source of health insurance coverage for persons with any disability by age. Of note, in comparing people 5 to 17 years of age with those 18 to 64 years of age, the older cohort has more uninsured, because fewer are covered by Medicaid and private insurance. Many parents of children and adolescents with disabilities have employer-based health insurance that covers their children. The children and adolescents may also qualify for Medicaid or the State Children's Health Insurance Program (SCHIP). However, when the adolescent turns between 19 and 23 years of age (depending on the state), they may have to leave their parents' or public insurance coverage and have few options for obtaining their own health insurance.

Why do young adults with special health care needs face a gap in their health care coverage between childhood and 65 years of age? A general survey of available health insurance for the different age groups reveals a complex maze of state, federal, and private insurance plans with eligibility criteria that change as the youth turns 18 to 23 years of age (depending on the state). For example, young adults age out of SCHIP at 18 years of age, Medicaid age limits are state-dependent, and coverage under parents' private insurance ends at age 23 or when the youth is no longer a full-time student. Often, this aging out of the childhood health insurance program results in a loss or change to a less comprehensive form of health coverage.

A popular misconception by the public is that people without health insurance will obtain the medical care they need. In fact, uninsured individuals are much more likely than are persons with insurance coverage to go without needed care. They also receive fewer preventive services and less regular care for chronic conditions than do people with insurance. Thus, early intervention that could save in health care costs in the future is forgone.⁸ Finally, those without health insurance often have to pay higher prices for services and drugs than do those with health insurance, creating another barrier to seeking care.

The following section of this article will outline the

TABLE 1. Percentage of the Population Younger Than 65 Years Who Are Uninsured, According to Age

Age	Uninsured (%)
0–17	13.9
18–24	29.0
25–34	23.2
35–44	16.5
45–54	13.4
55–64	14.5

Source: General Accounting Office. *Analysis of March 2000 Current Population Survey of Nonelderly (Under 65)*. Washington, DC: General Accounting Office; 2000.

TABLE 2. Insurance Status by Age (Young Adults), 1999

Age	Uninsured (%)	Employer (%)	Medicaid (%)	Other Public (%)	Other Private (%)
18–21	52.9	8.8	1.8	11.1	25.3
22–24	48.2	6.5	2.0	8.8	34.45

Source: General Accounting Office. *Analysis of March 2000 Supplement, Current Population Survey of Young Adults (18–24-Year-Olds)*. Washington, DC: General Accounting Office; 2000.

public and private possibilities for health insurance for young adults with special health care needs.

PUBLIC HEALTH INSURANCE

Medicaid for Children With Special Health Care Needs/Disabilities

The single largest public source of health care financing for people with disabilities is Medicaid. A General Accounting Office report stated that 80% of adults younger than 65 years with severe disabilities reported using Medicare or Medicaid for their health insurance. Individuals with disabilities insured by Medicaid are substantially more impaired than similar individuals with private health insurance.⁹ Medicaid is a means-tested individual entitlement program paid for by state and federal dollars. There are extensive rules for determining eligibility in the areas of financial requirements (income and resources) and nonfinancial requirements (categories of individuals, such as welfare and Supplemental Security Income [SSI] recipients) that vary by state. The result of state flexibility in the Medicaid program is a large number of eligibility pathways into the program. The breadth of services offered by Medicaid is greater than those offered by private insurance and children's health insurance programs that are separate from Medicaid. In particular, separate SCHIP programs contracting with managed care organizations offer benefits that are narrower than those under Medicaid for preventive and chronic care services.¹⁰ The comprehensive nature of the benefits offered under Medicaid is often essential to maintain the function and independence of those with disabilities. Medicaid programs are required to offer early and periodic screening, diagnostic, and treatment services; basic hospital and physician care; laboratory and radiography services; nursing facilities for adults; and home health services.

Children can qualify for Medicaid in a variety of ways and do not have to qualify on the basis of a disability. Therefore, Medicaid in most states covers children with and without disabilities from 18 to 23 years of age in different states as long as income criteria are met by the family. For example, families with youth who have chronic illnesses, such as cystic fibrosis, diabetes, or sickle cell disease, often "spend down" their income to meet the Medicaid eligibility criteria, because the child's health expenses are high and the child does not meet the disability criteria of SSI. Of note, 74% of children on Medicaid with a severe medical condition do not receive SSI, and an equal number of youth SSI for cognitive limitations and do not have severe medical conditions.^{11,12} In contrast, Medicaid does not cover most poor adults

TABLE 3. Source of Health Insurance Coverage for Persons With Any Disability, by Age

Age	Uninsured (%)	Medicare (%)	Medicare and Medicaid (%)	Medicaid (%)	Private (%)
0–4	7	0	0	42	47
5–17	11	0	0	28	58
18–64	16	8	3	15	55
Total	15	5	2	20	55

Source: *National Health Interview Survey, 1994 Supplement Booklet: Disability, Phase 1*. Hyattsville, MD: National Center for Health Statistics, Centers for Disease Control and Prevention; 1996.

without children unless they meet the Social Security Administration's eligibility criteria for a disability. Only 9 states to date have expanded their Medicaid eligibility to adults without children (see Table 4). Thus, a low-income child with a disability that did not meet SSI criteria for disability could receive Medicaid coverage but would lose that coverage once they became an adult in most states. There are, for example, many medical conditions for which treatments are expensive, but if well controlled, the conditions may not be disabling. Examples include severe asthma, diabetes, human immunodeficiency virus (HIV) infection, cancer, and cystic fibrosis. When youth with such conditions turn 19 to 24 years of age, they continue to have high medical expenses without Medicaid coverage, including prescription drugs, as they did as a child. Fishman estimated that 400 000 of the 20 million children enrolled in Medicaid have serious chronic health conditions, do not have SSI, and are at risk of losing their Medicaid coverage at the age of 19 years.³

A recent concern for youth with special health care needs is that states are lobbying the federal government for more flexibility with their Medicaid programs. The Center for Medicare and Medicaid Services (CMS) is allowing states, through Medicaid waivers, to decrease Medicaid benefit packages to free up money to cover more youth and families. For states, this solution is particularly attractive, because the recent economic downturn has left more children eligible for Medicaid as their parents are without employment and health insurance.

During an economic downturn, state Medicaid budgets are pulled between the need for increased coverage and spending and erosion of state revenues and constraints on state budgets. As of December 2001, 39 states were reporting budget deficits for fiscal year 2002. Similarly, employer coverage de-

TABLE 4. Medicaid Coverage for Adults Without Children

State	Income Eligibility Level
Delaware	100% federal poverty level
Hawaii	100% federal poverty level
Massachusetts	133% federal poverty level
Minnesota	175% federal poverty level
New York	100% federal poverty level
Oregon	100% federal poverty level
Tennessee	No income threshold
Vermont	150% federal poverty level
Washington	No income threshold

creases as employers find the cost of covering their workers increasing, and when they pass the increased costs on to the employee, the employee can no longer afford the health insurance offered. The Urban Institute, using Congressional Budget Office estimates of 2002 Medicaid enrollment of children and nonelderly adults of 44.7 million when unemployment is at 4.5%, has projected that an increase in unemployment to 6.5% would increase Medicaid enrollment by 3.2 million people to a total of 47.9 million.⁴

For a child with disability, there are additional ways to obtain Medicaid coverage.¹³ These pathways include SSI; 209(b) states; medically needy and home- and community-based waivers; foster care; and title and nontitle IV-E. In addition, there are pathways for a young adult with special health care needs to obtain Medicare through Title II and Disabled Adult Child programs. Of note, the benefit package in Medicare lacks coverage for long-term care and prescription drugs that are covered in Medicaid. Both benefits are often crucial to the health of the young adult with special health care needs.

Medicaid Eligibility for SSI Recipients

One of the major pathways to Medicaid is through SSI eligibility. Most states except the 209(b) states offer automatic Medicaid coverage to children with SSI whose parents meet the income criteria. Starting in 1998, states that received funds under section 209(b) of the Social Security Act elected to apply more restrictive income and resource standards than those non-209(b) states.

Today, all 18-year-olds on SSI must go through a redetermination process under the adult criteria for eligibility of SSI as an adult. The adult criteria differ from the pediatric criteria in that they depend on the applicant's inability to work, which is often not the case in a young adult with special health care needs. Currently, approximately 30% of those who had SSI as a youth will lose it at redetermination.¹⁴ Consequently, some young adults who lose their SSI payments no longer may be eligible for Medicaid coverage.

At 18 years of age, some youths with a disability will be redetermined by the Social Security Administration and found to be continuously eligible for SSI as long as they do not earn more than \$700 per month after taking into account certain expenses and other income and asset limits. Others will apply for SSI for the first time, because until their 18th birthday, their family income and assets were too high to qualify. Regardless of when individuals enter the SSI program, they must follow a basic SSI rule that requires them to apply for and accept any other benefits for which they may be eligible before collecting SSI benefits. SSI is a means-tested program designed to supplement other income sources, including other public benefits. Sometimes the amount of benefits from the other public programs will negate the SSI benefit and even the Medicaid benefit.

Medicaid for Young Adults With Special Health Care Needs/Disabilities

Eligibility criteria for the pathways into Medicaid for young adults with disabilities are detailed else-

where.¹³ Of note, individuals receiving SSI benefits can take advantage of different work incentive programs that will let them work and still qualify for Medicaid insurance. To receive SSI and Medicaid, the young adult must be unemployed or, if working, earn below what is called substantial gainful activity. As earnings increase, SSI payments decrease.

Under section 4733 of the Balanced Budget Act of 1997, states can create a new optional "categorically needy" eligibility group. Under this law, states can provide medical coverage to workers with disabilities who would not qualify for Medicaid because of earnings. If the individual meets SSI disability criteria and has a net income below 250% of the federal poverty level, they can buy into Medicaid.

In 2000, Congress passed the Ticket To Work legislation. It allows states to offer medical insurance to individuals with a disability without qualifying on income criteria of SSI. The Department of Health and Human Services awarded funds, called Medicaid Infrastructure Grants, to 24 states and the District of Columbia as part of an overall effort to encourage individuals with disabilities to return to work without fear of losing their health benefits (Kaiser Daily Health policy report, October 27, 2000). To date, because of budget shortfalls, a little more than half of the states have not enacted these grants (Kaiser Daily Health policy report, March 22, 2002). In addition, states can offer Medicaid to people whose disability has improved so they are no longer totally disabled but the standards for defining disability in this situation are unclear. Most states have only enrolled people from SSI roles in Medicaid without addressing the disability determination. Thus, the Ticket To Work legislation has had limited enrollment and, therefore, limited effect on uninsured young adults with disabilities. As of mid-2001, 11 states have taken up either option and because of the complexity of the SSI work incentive rules, few young adults opt to use them (for a list of states, see Fishman³[p260]).

Medicare Eligibility Under Title II

People with disabilities are often eligible for benefits under Title II of the Social Security program, known as the Old Age, Survivors, and Disability Insurance (OASDI) program. Title II benefits are not needs based and have no income or asset test; they trigger eligibility for Medicare after a 2-year waiting period. Young people with disabilities may be eligible for OASDI benefits on their own or they may be eligible on the basis of the work history of their parents who are deceased or receiving social security benefits.

Monthly cash benefits paid by Social Security programs are based on the amount of time worked and the amount of earnings in "covered" work. Most work is now covered, although some state government employees are still not covered by the Social Security system. For OASDI, an individual must work a minimum amount of time. For example, for retirement, a person must earn at least 40 work credits. Work credits are earned for work exceeding a certain amount (\$830 in 2002), and individuals may earn up to 4 work credits per year. For most workers,

disability insurance requires that the individual have earned 20 work credits in the last 10 years. A young person with severe disabilities may also earn eligibility for OASDI with fewer years in the workforce than an older worker without a disability. In this case, the individual may still receive SSI and Medicaid.

Disabled Adult Child Eligibility for Medicare and Medicaid

A youth is eligible as a disabled adult child (DAC) once a parent has become disabled, has retired, or has died, and the adult child receives benefits as a dependent of the parent. The DAC benefit is based on the parent's benefit amount. Often, the DAC benefit is greater than the maximum allowable SSI benefit, resulting in the loss of SSI and the automatic Medicaid eligibility that goes with SSI. The DAC will be eligible for Medicare after a 24-month period. Some years ago, Congress amended the Medicaid statute to permit people who lose SSI because of DAC eligibility or because of an increase in DAC benefits to be "grandfathered" into Medicaid eligibility as long as they remain SSI eligible because of their disability. This requires state determination of eligibility. In addition, some states have adopted options in Medicaid that allow workers with disabilities to "buy into" Medicaid as long as the young adult meets the disability criteria for SSI.

PRIVATE INSURANCE COVERAGE

Underinsurance

Two thirds of children with disabilities have private health insurance coverage. However, this does not mean their needs are adequately met. The issue of "underinsurance" for these children is common. This means families possess coverage that is limited in scope. A recent study found that 40% of children with special health care needs/disabilities also had secondary health plan coverage, most of which was public Medicaid.¹⁵ In a recent survey led by the NCHS, 16% to 20% of children with special health care needs/disabilities had insurance coverage that did not always meet their needs.

Out-of-Pocket Spending

The level of out-of-pocket spending can be a gauge of the adequacy of health coverage. Among adults younger than 65 years, out-of-pocket expenses were lowest for those covered by Medicaid. This is most likely attributable to the comprehensive nature of the Medicaid benefit package and cost-sharing limits. Those who were uninsured and had chronic conditions were found to have higher expenses and were 5 times less likely to see a health care provider than those with insurance.¹⁶ Similarly, Newacheck¹⁷ found that adolescents living in families with incomes below the poverty level without health insurance experienced higher charges for medical services than those families with incomes above the poverty line with health insurance.

Employer-Based Coverage

Most Americans obtain private group health insurance through their employer. Yet, as mentioned pre-

viously, many people with disabilities who are employed are not offered health insurance because they work part-time for a small employer who cannot afford to offer insurance, or cannot afford the insurance premium offered by their employer. People with disabilities often look to public insurance programs to find affordable health insurance.

Employment-based and public health insurance programs are not coordinated, but they historically have influenced each other. Medicaid expansions have offset some of the loss of employer-based coverage that occurred before 1994. Thus, with expansions of Medicaid eligibility and the availability of SCHIP, a small proportion of uninsured people who were eligible for employer-based insurance and those who had insurance have opted to enroll in public programs. Since 1997, however, the number of people who are leaving employer-based health insurance for public programs has diminished. This phenomenon is also called "crowd out," and public officials have concluded that crowd out is less of a problem if families earn less than 150% of the federal poverty level.⁹

Individual Market and High-Risk Pools

Most private health plans have an upper age limit for children after which the child can no longer be covered under the parent's plan. For young adults with disabilities to stay in the private insurance market, the plans need to be less expensive and have fewer or no significant restrictions. A young adult with a disability can try to obtain health insurance from the unregulated individual insurance market. However, a study from June 2001 showed that adults with such conditions as asthma, HIV infection, and cancer face barriers such as denial of coverage, limits on benefits, and premium surcharges in the individual insurance market.¹⁸ Regulation of the individual insurance market comes under state jurisdiction, and many states have enacted high-risk pools in response to these access problems. However, state high-risk pools are always more expensive than comparable private insurance policies that cost, on average, \$3000 per year for an individual. In addition, many states restrict covered benefits or cap enrollment to hold down costs. Thus, only approximately 1 million individuals are currently enrolled in state high-risk pools nationwide. This low number brings into question whether these plans can meet the need of uninsured young adults with a disabilities as they are currently structured.¹⁹ A few states such as New York have tried to make coverage in the individual market more evenly available to consumers, but this raised the insurance cost for young healthy consumers to cover a reduction in cost for those with chronic conditions.

Health Insurance Portability and Accountability Act (HIPAA) Benefits

Young adults with disabilities can continue coverage under their parental health insurance plan. First, the young adult with a disability can qualify for continued coverage in a family plan only if the adult child does not work. This option is mandated under

HIPAA for non-Employee Retirement Income Security Act plans and is available in 44 states. Thus, if young adults with special health care needs/disabilities start working, they will jeopardize their health coverage under their parental insurance plan. This discourages the attainment of essential developmental milestones for being successfully employed as an adult. Second, if young adults are full-time students, they can stay on their parents' insurance, but many young adults with disabilities are unable to take a full course load and, as a consequence, they lose this option. In addition, HIPAA offers coverage to individuals with disabilities who have been working for the previous 18 months, even when they have past or current problems. Often, the cost of these plans is prohibitive, and they have minimal benefit packages. Many young adults do not have jobs with benefits, so this law does not apply.

Coverage Under the Consolidated Omnibus Budget Reconciliation Act (COBRA)

In 1985, Congress passed a law to provide temporary access to health insurance for qualified individuals who lose their coverage as a result of a change in work or family status. Under Title X of COBRA, an employer with 20 or more employees must provide those employees and their families the option of continuing their coverage under the employer's group insurance plan in the case of certain events. The coverage generally lasts up to 18 months or, in some instances, up to 36 months, and the beneficiary can be required to pay up to 102% of the premium.²⁰ Thus, coverage under COBRA is expensive and short lived.

Disease-Specific Plans

Twenty-one state Title V programs offer condition-specific health coverage. States operate these programs for 1 or more genetic diseases such as cystic fibrosis, hemophilia, and sickle cell disease. To be eligible as a young adult, many require the individual to have been enrolled as a child. These programs are limited to a few genetic diseases (for a list of these programs, see Fishman^{3(p263)}).

In summary, many private plans are too expensive, have limited benefits, require that the young adult not participate in the workforce, and are offered for a limited time. Thus, the private market, as it is today, will be unable to provide many young adults with disabilities affordable and comprehensive health insurance like what they had as a child.

PROVIDER REIMBURSEMENT FOR TRANSITION SERVICES

Besides the lack of health insurance, another barrier to health care for young adults with special health care needs/disabilities relates to health care provider reimbursement. Health care providers strive to offer a medical home for children with special health care needs/disabilities in their practices. A major obstacle is that health plan providers have difficulty obtaining appropriate compensation for their professional work. The reimbursement coding system for clinical care is rooted in procedures. Much of the work to assist a family with

a child with special health care needs/disabilities to transition to adult health care is based on coordination, shared management, and prolonged service episodes. These nonprocedural services are poorly reimbursed, if at all. Thus, health care providers often do not receive adequate reimbursement for their time and services offered in care coordination, which further diminishes any incentive there might be to provide these services.

Given the limits on reimbursement, health care providers can face financial difficulties unless they limit the number of children with special health care needs/disabilities they see. This problem was documented in a recent study that showed that the proportions of physicians providing charity care dropped from 76% to 72% between 1997 and 1999, with reductions in all types of physician practices.²¹ In addition, many Medicaid managed contracts can require health care professionals to accept full risk capitation. This is problematic, because there are no reliable predictive risk-adjusted methods for understanding cost for the care of children or young adults with special health care needs/disabilities.

Nonprocedural Services

Managed care organizations and other insurers often do not reimburse for *Current Procedural Terminology (CPT)* codes that are needed to adequately care for a child or young adult with special health care needs/disabilities, such as prolonged physician service without patient contact, team conferences, telephone calls, care plan oversight services, or preventive services with individual or group counseling. In addition, few insurers reimburse on the resource-based relative value scale, which attempts to recognize health care providers' work in managing care.²² Finally, as many children and some young adults with special health care needs/disabilities are covered by Medicaid, the *CPT* reimbursement is between 58.3% and 72.6% of the Medicare reimbursement. Medicare reimbursement is considered by many to be insufficient.²³

The American Academy of Pediatrics, together with The Maternal and Child Health Bureau, has strived to address this situation in several ways. They convened an expert group that documented the current issues in providing care for children with special health care needs/disabilities in the current insurance market. The Academy provides information in the yearly updated coding resource for pediatrics on ways to code with maximum benefit as well as provide training to health care professionals on these issues. The Maternal and Child Health Bureau convened a group to develop a framework to determine costs for the medical home care concept. These are excellent starting points to obtain needed data about the cost of care for these children with special health care needs/disabilities.

With the managed care environment moving toward capitated approaches in some markets across the United States, providers have to consider how to make payment adjustments for the health status of youth with special health care needs/disabilities. Most capitated payment systems do not include risk adjustment; therefore, children and adults with com-

plex medical conditions are especially susceptible to unfavorable risk selection because they are more expensive than a comparative healthy population. Thus, providers need the knowledge and skills to negotiate risk-adjusted payments, consider reinsurance policies to protect themselves from losses, and consider carve-outs when the plan has not established risk adjusters.²⁴

CALL TO ACTION

With most children with special health care needs/disabilities surviving into adulthood, solutions are urgently needed so they can have optimal health and, through early intervention, be active participants in adult society.

Health Insurance

Gathering Data

Understanding the health care issues for young adults with special health care needs/disabilities requires comprehensive data. This information should come from a careful study of the “leavers” of the child health insurance system using large data sets and focusing on the young adult age group separate from the 18- to 64-year-old group. These studies should outline the numbers affected, the cost to provide the appropriate care, and the consequences of the lack of health insurance to the young adult and to the safety net health care system as a whole. In conjunction with longitudinal studies, case studies exemplifying the problems young adults with special health care needs/disabilities face would be helpful. This would bring a personal side to the problem for the legislators. Examples for this approach are the studies now being conducted around the leavers of the welfare system.

Research

The current plan to improve health coverage for the uninsured appears to be an incremental approach. Studies are needed to model private and public system expansion solutions that would include an outline of the number of uninsured young adults who would obtain coverage from the plan, the cost of the program and the methodology needed to make it function, and pros and cons to each approach including issues of crowd out. Suggestions proposed by Fishman,³ such as changing the unemployability standard of SSI for Medicaid eligibility, should be considered. This would assist young adults with functional disabilities whose disability status keeps them from participating in employer-sponsored insurance.³ Similarly, studies should be undertaken to assess the readiness of adolescents with special health needs to be independent and purchase their own health insurance if they are redetermined off SSI and Medicaid at the age of 18 years. In addition, an evaluation of whether the age of 18 years is the best time to redetermine eligibility for SSI should be undertaken. New models need to be constructed to incorporate those with serious chronic illnesses so they can participate in large insurance pools and make the cost of health insurance affordable.

Several legislative proposals have suggested increasing the age for Medicaid eligibility for youth with special health care needs/disabilities to 25 years of age or mandating private coverage under parental insurance until 25 years of age. Studies should be completed to find out by what age young adults with and without disabilities finally obtain jobs with the availability of affordable health insurance. This may not occur until long after completing postsecondary education and could be later than 25 years of age.

The barriers to employer-based health coverage for young adults with special health care needs should be studied. Elements that should be outlined include the relationship between insurance status and employer characteristics, like size, and work status (full- or part-time) and health status of young adults with special health care needs/disabilities.

Assessing State Plans

Studies should be undertaken to clarify why current pathways to increase coverage are not being used by the states. Studies should be completed of the available state programs that could be disseminated throughout the United States, such as increasing the income eligibility to Medicaid, increasing Medicaid buy-in programs, increasing the number of waivers offered to low-income adults without children, and increasing the number of state Ticket To Work programs. With the downturn in the economy and the CMS allowing state waivers to decrease the benefits covered under Medicaid, studies should document if youth with special health care needs/disabilities are losing needed and possibly life-prolonging benefits.

Provide Technical Assistance

Health care providers should work closely with the new technical assistance centers authorized under the ticket to work legislation and approved by CMS (formerly known as the Health Care Financing Administration). They are assisting states to build systems that support competitive employment for people with disabilities. These centers should focus on transition issues for young adults with special health care needs/disabilities, and pediatric health care providers should be involved with these centers as they work with states to define disability and medically improved categories within the context of the Ticket To Work legislation. One of the goals of this collaboration would be to define “disability” and “medically improved” so that more young adults with special health care needs/disabilities could work and obtain better health coverage.

Advocacy

Grass-roots advocacy groups for young adults with special health care needs should be brought together to keep the issues and suggested solutions in the limelight for the legislators and their staff as they consider their legislative agendas in future congressional sessions. Past successful examples of coalition building are those advocates for the Ticket To Work and the Family Opportunity Act.

Payment Issues

Needed Data

Fundamental to improving reimbursement is the availability of reliable cost data. Pilot projects could jump-start exploring experimental approaches to develop models that assess the cost of transition services and build risk-adjusted payment plans.

Developing New Models

Geriatric models of coordinated community care should be investigated, such as social health maintenance organizations, Program of All-Inclusive Care for the Elderly, and Community Medical Alliance models²⁵ to see what lessons could be transferred to a younger age group. Similarly, health outcome and cost data could be gathered on disease-specific transition models, such as the cystic fibrosis, hemophilia, and Ryan White programs.

Studies are needed to develop the case for the efficacy of the team approach to care of young adults with special health care need/disabilities. The Partnership for Solutions is starting to undertake this effort (see next section).

Improve Benefits

With cost data elucidated, risk-adjusted contract approaches need to be expanded so appropriate reimbursement can be obtained and more young adults with special health care needs/disabilities can have access to services.

Pediatric health care providers should continue to form coalitions to work with private payers and employers to improve benefit packages. An example of this approach is the work that The Partnership for Solutions, A Robert Wood Johnson Foundation grant-funded project, is doing with Fortune 500 companies to establish a case for businesses to become involved with assisting in providing services, such as transportation and respite care, nutrition services, and medical social services.

CONCLUSION

Youth with special health care needs/disabilities want to become independent members of society, attaining the education, jobs, careers, social interactions, recreation, and health and well-being that all youth seek. Yet, when youth with disabilities between 19 and 23 years of age in the United States, they often lose health insurance, which in many cases, has been the foundation that assisted their survival and is necessary for them to be healthy and ready to participate in adult society. New policies and solutions to make health insurance available and affordable to young adults with disabilities and assist providers to meet their health care needs need to be put in place and evaluated, and effective strategies need to be widely implemented so that American society does not continue to lose the talent pool of these young adults.

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