

Assist T•II CANN With Ryan White Care Act Reauthorization

T•II CANN will be working on behalf of both service-providers funded under Title II and people living with HIV/AIDS who are dependent on Title II funded programs. To be as responsive as possible to the needs and concerns of our community, we need the following:

1. We want to keep you informed! If you are not yet on our fax-board or e-mail lists, please send us your information so that you will be able to receive important information and alerts as Reauthorization of the CARE Act proceeds.
2. We need your input! If you are a Title II funded service provider or a PLWHIV who depends on ADAP or other Title II funded services, and you are interested in serving on our Reauthorization Advisory Committee, please contact us by e-mailing or faxing your name, address, phone number, fax number, and e-mail address to grose@T2cann.org or weaids@aol.com; fax: 202/588-8868.
3. The T•II CANN Board is always interested in new board members. If you are a provider, or consumer, of Title II funded services and are interested in serving on our Board of Directors over the next three years (which will include Ryan White Reauthorization in Congress) contact Bill Arnold or Gary Rose at T•II CANN (202) 588-1775. The Board meets in person twice a year and more often by conference call. Board members are reimbursed for T•II CANN related expenses.

Thanks for your help!

The Ryan White Care Act Title II Community AIDS National Network, Inc. (T•II CANN) is a non-profit organization focused on CARE Act issues. We are dedicated to initiating and supporting activities that develop and that ensure access to care for all people infected or affected by HIV. For more information on membership and its benefits, please fax contact information to T•II CANN at (202) 588-8868. ■

Work Incentive Act for People with Disabilities

By Thomas P. McCormack
Consultant to T•II CANN

The Ticket to Work and Work Incentives Improvement Act of 1999 passed Congress and signed by President Clinton on December 17, 1999 has numerous, complex provisions affecting SSDI, SSI, Medicare, Medicaid, return-to-work, and vocational rehabilitation services for disabled persons.

The Act offers states a set of interrelated options for enhancing Medicaid coverage for disabled persons who work. It limits, but does not fully eliminate, the threat of being found "no longer disabled" for those patients in remission who are ready to return to work or are already actually working. AIDS agencies and even businesses can now get federal funding for return-to-work, benefits counseling, and vocational rehabilitation services. Previously, clients could only get these services from state vocational rehabilitation departments.

States which chose to give Medicaid to middle-income, working disabled persons under the 1997 Balanced Budget Act¹ can now raise their income and asset eligibility levels. They can also cover "ex-disabled" working persons, those with still-serious impairments who "flunk" Social Security Continuing Disability Reviews (CDRs) while working. In addition many, but not all, states can get demonstration grants to give Medicaid to "pre-disabled" working persons, those with serious impairments that would advance to full disability without Medicaid treatment.

Beginning October 1, 2000, the bill also gives 4.5 years of additional

premium-free Part A Medicare coverage (after the 9 month Trial Work Period and 36 month Extended Period of Eligibility, during which Part A is ALREADY free under current law) for those who have returned to work. Thereafter, just as before, those who are still disabled can continue their Medicare coverage indefinitely.²

The bill also mitigates, but doesn't completely end, the threat of CDRs ending medical as well as cash benefits for those found to have "medically improved" enough to no longer be "disabled." Working, in itself, can't be used as evidence of medical improvement; those actually working can't be given "routine" CDRs and those who do not pass CDRs due to working can apply to have benefits reinstated for up to 6 months while Social Security decides if they are no longer disabled. Medical improvements can still bring an end to SSDI, SSI, Medicare, and Medicaid, except in the above-mentioned narrow instances. Finally, the bill allows disabled SSDI and SSI recipients to receive their vocational rehabilitation, related counseling and job-readiness services from qualified private sector and nonprofit providers, as well as state vocational rehabilitation agencies. Numerous technical strings are attached, of course, but this should prove to be a new source for funding portions of the case management/benefits advocacy budgets of many AIDS service organizations.

Because bill provisions are very complex, and each section is to be

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MESSAGE FROM THE BOARD

Oh Well, Life In The Real World



Well, the year 2000 is upon us with all the hype and expectation for the new millennium.

But as we look forward to the next century we bring with us the experiences of the previous. Because of my own journey as a radio journalist, I recall many of those experiences through the words that people say, and oft recall the moment through a turn of phrase or verbal expression. Even some of the most over used cliches may end up hitched to a significant experience.

For example, how many times have you heard someone say, "Oh, well, — that's life in the real

world?" While I cannot even begin to remember all the times I have heard this remark, one particular instance stands out. About two years ago, I had the opportunity to visit with Walter Payton, a legend for his prowess on the football field and as a gentleman in his life off the gridiron. At the time, we were speaking about the illness from which he suffered and ultimately died. As we talked about the illness and the slim prospects for a liver transplant, he commented in a haunting sort of way, that's life in the real world.

Since that time we spent together, his illness progressed and, without a needed transplant, he passed away. His life and death left a mark on the nation in both the capacity to care, and the impact such a personality can have on audiences

in the U.S. And yet, the nameless, faceless masses continue to struggle with diseases such as his, and such as HIV/AIDS. Yet those masses have names and faces — for many are friends, acquaintances, and neighbors of yours and mine. Care, compassion, effective access to treatment, a nation that believes in all — let this be life in the real world in the days, months, and years that will be the millennium before us. For we truly are building off the shoulders of giants.

Herbert Perry, LPA/EA
Chair and CFO of T•II CANN

Editor's Note: Herb has served on numerous community AIDS related boards.

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If you have anything of interest to share with the Title II community, please send it to:

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Visit T•II CANN's website at www.t2cann.org.
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Work Incentive

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effective on different dates in the coming years, no one should rely on a brief summary for major decisions. A more detailed bill summary is available, as is a longer explanation, by emailing tomxix@ix.netcom.com.

Footnotes

¹Alaska, California, Iowa, Massachusetts, Minnesota, Nebraska, Oregon, South Carolina, Vermont, and Wisconsin already cover middle-income working disabled persons who are not yet on, or have gone off-SSDI. All other states can do so as well if they so choose.

²Once SSDI checks stop, Medicare Part B can be continued by paying the \$45.50 monthly premium oneself. Those who can't afford this can get the welfare office to do so for them by applying at the welfare office for the SLIM/QI program if their earnings are under \$1939 monthly. Once "free" Part A

Medicare ends (after 45 months back at work presently and after 99 months back at work beginning October 1, 2000) the Part A premium [either \$166 or \$301 monthly] must be paid; those who can't afford that can apply to have the QWDI program to do so with monthly earnings under \$2832. ■

To receive a copy of
**"Returning to
Work and
Keeping Medicare
and Medicaid"**

please contact Thomas

McCormack at

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Ensuring Access to Treatment for Persons Living with HIV Through the AIDS Drug Assistance Program (ADAP)

By: Rich Fortenberry, T•II CANN

“...in accordance with guidelines issued by the Secretary of DHHS...”

About the Author: Rich Fortenberry is in his 12th year of living with HIV and is a former registered nurse. Rich recently joined the Board of Directors of T•II CANN. He will primarily be working with rural, underserved, and minority community-based organizations, providing technical assistance in a variety of areas. These will include developing infrastructure, organizational and collaborative services, and support in applications for funding. Rich will also be working with the NORA work group on reauthorization of the Ryan White CARE Act. Prior to coming to Washington, Rich founded and developed the financing of Heartland CARES, Inc. in Western Kentucky. Successful grant applications included Ryan White Title III, HOPWA, and HUD Continuum of Care programs, as well as the CDC/CPG HIV Prevention program in the region.

The AIDS Drug Assistance Program (ADAP) is the sole means of access to treatment for a growing number of persons living with HIV disease. This group includes persons who do not have health insurance covering prescriptions. The proportion of newly diagnosed and treated persons who must rely on ADAP is increasing. In the future, clients will begin to enter care earlier in the course of progression from early HIV infection to AIDS. This population group is generally not qualified for a disability determination and, even when they do qualify, their disability benefit exceeds the upper income limits of eligibility for supplemental security insurance (SSI). Many HIV positive

persons with social security disability insurance (SSDI) benefits well below the Federal poverty level do not qualify for Medicaid and prescription coverage.

The Ryan White CARE Act, as reauthorized in 1996, includes fairly clear and unambiguous language that requires the states to ensure they provide access to treatment (i.e., ADAP) “...in accordance with guidelines issued by the Secretary of DHHS...” (See box titled “ADAP Authorizing Legislation.”)

The reference guidelines are “issued by the Secretary of DHHS” of the U.S. Department of Health and Human Services through various agencies within the U.S. Public Health Service. These include the DHHS Panel on Clinical Practices for Treatment of HIV Infection, as well as the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

The DHHS Guidelines for the Use of Antiretroviral Agents in HIV-

Infected Adults and Adolescents states:

“...in order to achieve the maximal flexibility in tailoring therapy to each patient over the duration of his or her infection, it is imperative that drug formularies allow for all FDA-approved nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors, and protease inhibitors as treatment option.” (December 1, 1998:20; June 17, 1998:22)

The medications listed in a Minimal ADAP Formulary (contact the editor of *The Voice* at PotoInc@aol.com or fax 973-579-3622 for the list) includes the drug recommendations of current guidelines for antiretroviral therapy, guidelines for the prevention and treatment of opportunistic infections, and co-infection with HIV and tuberculosis. While T•II CANN doesn't support dictating a “minimum formulary” for any ADAP, the treatments included in the Guidelines would likely be considered a good standard of care list to have available by most informed specialists treating HIV disease. ■

ADAP Authorizing Legislation

Contained within the Ryan White CARE Act as Amended in 1996.

Excerpted from *The U.S. Public Health Service Act — 42 U.S.C. 300 et. Seq. Title XXVII, Part B: [Pub. Law 104-146]*

Section 2616. PROVISION OF TREATMENTS.

“(a) IN GENERAL. — A State shall use a portion of the amounts provided under a grant awarded under this part to establish a program under section 2612(a)(5) to provide therapeutics to treat HIV disease or prevent the serious deterioration of health arising from HIV disease in eligible individuals, including

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You Do Have To Be Disabled To Get Medicaid, Right? Wrong!

By: Thomas P. McCormack
Consultant to T•II CANN

How many times have we read in news articles, opinion pieces, and AIDS advocacy groups' pronouncements something like this about Medicaid: "It's fine, but you have to be disabled to be eligible for it. If you're "only" HIV-positive you can't qualify. The rules should be changed to cover persons who aren't disabled (yet)."

A couple of years ago Vice President Gore even made what turned out to be an ill-considered promise to an assembly of AIDS activists: He'd have that Medicaid rule requiring one to be disabled "waived!" Unfortunately, the same Administration didn't give him or anybody else the authority to do that, unless there were no new costs. Now, the latest activity is a bill introduced in Congress with the support of House Minority Leader Richard Gephardt to "waive" "the Medicaid disability rule"(sic).

But to say that only those with full-blown AIDS and who have been found disabled by the Social Security Administration (SSA) can get Medicaid isn't totally accurate. In all states, Medicaid now covers poor persons who are: over age 65; under age 18; pregnant; blind; members of families with children (including-in almost all states-the father if he's at home); and those found disabled by SSA. In reality, Medicaid covers six different kinds of low-income persons and the disabled are only one of those six.

It is true that many persons do qualify for Medicaid in the "disabled" category-but many others get it through the other five category routes. SSA generally accepts full-blown AIDS as disabling if it actually prevents substantial work, but it also accepts persons who are "only" HIV positive as disabled if their medical conditions prevent work



too. Most of the first AIDS patients were childless, sighted gay men in the prime of life, whose route to Medicaid-indeed, whose only possible route to Medicaid-was as disabled. And so the limited perception that only those full blown AIDS patients, found disabled by SSA, could get Medicaid.

Medicaid, however, has been awarded to thousands of other poor persons who are HIV positive because they were under 18; over 65; blind; pregnant; or members of families raising minor children. Almost all of the larger, better funded states use their own money, without federal help, to give medical assistance to poor persons who don't fit in any of the six federal Medicaid categories. Most notably, this would include not-yet-disabled, childless adults in the prime of life.

In fact, since AIDS emerged in the early 1980s, federal Medicaid has been broadened to cover persons who are not fully disabled in several ways.

1. States can pay COBRA premiums (to keep health insurance from one's former job in force for 18 or even 29 months after leaving work) with federal Medicaid money for anyone-even those who aren't disabled or members of the other five Medicaid categories — with countable income under the national poverty level (\$707 monthly for the unemployed, \$1,458 for those working). But only a few states have implemented this little-known, little-understood option.

2. States may receive waivers under federal law to cover needy, "pre-disabled" persons who are not in any Medicaid category in their Medicaid programs, but only if they can show that federal costs won't be increased. These programs are accomplished under 1115 and 1915(b) of the Social Security Act. Many states are operating waivers under this authority, but these waivers as of yet do not specifically include people living with HIV who fall outside the other categories listed above.

3. States, under the 1997 Balanced Budget Act (BBA), can offer Medicaid with federal support, at small premiums, to working persons with medically disabling conditions (who SSA can't consider "disabled" because they're actually working) with incomes up to about \$43,000 a year. By early 2000, Alaska, California, Iowa, Massachusetts, Minnesota, Nebraska, Oregon, South Carolina, Vermont, and Wisconsin will have opted to do this.

4. One little-noticed result of the 1996 welfare reform law was that states got the right to define what constitutes a family for Medicaid coverage purposes. Under the old

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measures for the prevention and treatment of opportunistic infections.

(b) ELIGIBLE INDIVIDUAL. — To be eligible to receive assistance from a State under this section an individual shall—

- (1) have a medical diagnosis of HIV disease; and
- (2) be a low-income individual, as defined by the State.

(c) STATE DUTIES. — In carrying out this section the State shall—

- (1) determine, in accordance with guidelines issued by the Secretary of DHHS¹ which treatments are eligible to be included under the program established under this section;
- (2) provide assistance for the purchase of treatments determined to be eligible under paragraph (1)², and the provision of such ancillary devices which are essential to administer such treatments;

- (3) provide outreach to individuals with HIV disease, as appropriate to the families of such individuals;
- (4) facilitate access to treatments for such individuals³; and
- (5) document the progress made in making the therapeutics described in subsection (a) available to individuals eligible for assistance under this section

(d) DUTIES OF THE SECRETARY. — In carrying out this section, the Secretary shall review the current status of State drug reimbursement programs established under section 2616(2) and **assess the barriers to the expanded availability of treatments** described in subsection (a). The Secretary shall also examine the extent to which States coordinate with other grantees⁴ under this title to reduce barriers to the expanded availability of the treatments described in subsection (a).” [NOTE: “title” references the entire CARE Act]

Notes referencing underlined provisions:

- 1 “Guidelines issued by the Secretary of DHHS...”Are enumerated by the attached document, “Guidelines for the use of Antiretroviral Agents in the Treatment of HIV Infection in Adults and Adolescents” and various other guidelines issued by CDC and NIH
- 2 The purpose of the AIDS Drug Assistance Program (ADAP) is stated here; specifically, the duty of the State [Commonwealth] to provide assistance in accessing prescribed medications
- 3 This provision furthers the duty of the state to “...facilitate access to treatments...”
- 4 With respect to “other grantees under this title...” any other programs, defined in the context of SCSN to include, categorically, Title I, III, IV, Dental AETC, and SPNS grantees

Medicaid

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AFDC welfare system, families with fathers at home could only be eligible if he’d been laid off after long employment or if he met state “incapacity” rules (temporary disability less strict than SSA’s). Now, under the reformed TANF welfare system, most states have dropped these limits and cover all poor families with children-no matter what the father’s status. And states can set Medicaid income levels for such families much higher than before.

5. Under the state Child Health Insurance Program (CHIP) created by the 1997 BBA, children under age 19 with family incomes under 200% of poverty [yearly, \$22,400 for family of two, \$27,700 for

three, \$33,400 for four, \$39,000 for five] are eligible for Medicaid or similar CHIP health insurance even if they aren’t disabled. The law even gives states the right, in some cases, to give this coverage to the children’s parents-whether or not they’re disabled. Vice President Gore has called for making the parental coverage standard in this program, and for increasing the income level as well.

But the Ticket to Work and Work Incentives Improvement Act, which Congress passed and the President signed on December 17, 1999, now offers states even more options:

6. On a demonstration project basis, many states can also give Medicaid, under the same income rules, to working, “pre-disabled” persons who are at risk of

becoming fully disabled without early Medicaid treatment, using the same rules as for the fully disabled workers. They could even get extra federal money for doing so, too. Although this demonstration project was authorized, appropriations are needed to launch this.

7. And states which cover the working, fully disabled can also include those workers who have recovered from their disabilities but still have a potentially serious condition like HIV. Here, too, extra federal money can help states do this. However, the working disabled Medicaid provisions don’t go into effect until October 1, 2000 and HCFA has yet to establish all the criteria for this waiver.

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8. States can set the income and asset eligibility levels for workers who are disabled, formerly disabled or potentially disabled even higher than the already-generous 1997 law allows if they charge reasonable (but still very, very small) premiums to those who can afford them.

States need to take the working disabled coverage option-and then go on to take the sub-options of covering those at risk of becoming disabled and those who've recovered but still have serious underlying conditions. Both the

“pre-disabled” and the “ex-disabled” could then get Medicaid with incomes up to about \$43,000 yearly — or even higher.

Without this, “waiving” the disability rule alone won't do much good. The fact is that non disabled persons are likely to be employed, even if at menial jobs. Someone earning as little as the minimum wage gets an income of about \$950 monthly. That's far, far above the Medicaid level for a non-disabled person, which averages about \$350 in even the most generous states. And it's even above the levels for those who are disabled — \$512 in most states, \$676 in the most generous state (California).

So “waiving” the disability rule won't do much alone. Thoughtful advocacy will be required at the state level to enact the Medicaid coverage choices which states already have-including those enacted into law in 1999.

Thomas McCormack wrote the *AIDS Benefits Handbook* (Yale University Press) and handled Medicaid eligibility policy at the federal Department of Health and Human Services. He has done benefits advocacy for several AIDS and disability groups and now serves as policy consultant for T•III CANN. These opinions are his own, and not those of any organization. You can email him at tomxix@ix.netcom.com. ■



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