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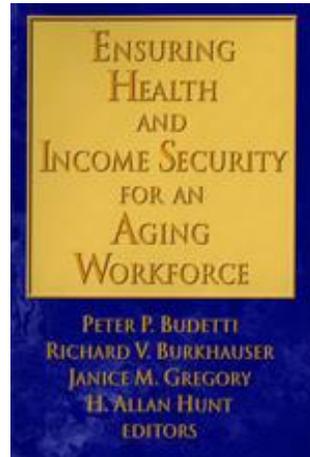
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## Commentary [on Chronic Illness and Disability]

Vicki Gottlich  
*Center for Medicare Advocacy*

Patricia Nemore  
*Center for Medicare Advocacy*



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# Commentary

Vicki Gottlich  
*Center for Medicare Advocacy*

Patricia Nemore  
*Center for Medicare Advocacy*

**Ms. Gottlich:**

Since my boss is sitting in the back of the room, I have to say that I also just joined the Center for Medicare Advocacy. With Alfred Chiplin, who is an Academy Member, and Toby Edelman, who also used to be at the National Senior Citizens Law Center, we're establishing the Healthcare Rights Project.

Trish and I have decided that we're the tokens in this conference. We're the token nonresearchers, nonacademics. We're advocates and attorneys, and our comments are going to be based on our clients, who are really the real people whom Michele Singletary talked about.

I'm going to be talking about employer-sponsored insurance and Medicare. Trish is going to be talking about Medicaid. I can talk real fast because I'm from New York.

In terms of employer-sponsored insurance, I wanted to raise three issues that are crucial for people with chronic illness and people with disabilities. They are the voluntariness of the program, the cost of the program, and the lack of recourse available to participants and beneficiaries in employer-sponsored health insurance plans.

We've heard a lot today that the health insurance system is voluntary. You can look at the numbers of people who are covered under employer-sponsored health insurance as a glass half full or a glass half empty. I think of it as a glass half empty. I think that there are a lot of people who work for employers that offer health insurance who are either not covered by their plan or who can't afford to participate in the plan.

But when we talk about voluntariness of the employer-sponsored system, it's more than the voluntary nature of offering a plan. It's the voluntary design of the plan. Some of the benefit plans are really good, as Wally Maher said this morning, and some of the plans are really

awful. And I've had clients say to me I'm not going to enroll in this plan because it costs too much and I get nothing out of it. It doesn't help me for the kinds of things that I need.

The other issue with voluntariness is the ability of the employer to change the health plan whenever the employer wants to with very little input from the employee community. We as lawyers are familiar with the case, the *McGann* case and the *Owens* case in which employers decided to terminate coverage for AIDS-related illnesses after beneficiaries filed claims for AIDS-related illnesses.

Employers are also terminating retiree health plans, increasing co-payments and deductibles in retiree health plans as a result of new accounting standards. And if you look at the statistics, the number of people covered by retiree health plans has decreased in the past 10 years. That leads us to cost. We've already heard about the cost of COBRA health care continuation insurance. You need to remember that COBRA offers a special benefit for people who have been found eligible for Social Security disability, and those individuals can purchase an extension of COBRA from months 19 through 29 until they become eligible Medicare. The kicker there is that the premium is 150 percent of the cost, and that's often unaffordable for a lot of people who really need health insurance.

The other issue of cost is the increase in the cost of premiums, deductibles, and co-pay. People who used to be able to afford to purchase or buy into or be covered by their employer plans can no longer be covered by those plans because of the costs.

The third issue that I've done a lot of work on is recourse, and I'm going to give you examples. I cannot tell you the number of clients I have seen who are people with chronic illness, who had been covered under a plan, a health plan with very good benefits, who are suddenly told that they are no longer eligible for those particular benefits or covered for the services that they need. There's not been a change in the health plan. There's not been a change in their health status. There's no cap on the benefit. It's just that there is some twitch by the employer; maybe they'll claim that something that was skilled services is no longer skilled services. That's very frequent.

And the recourse of the individual is to file an appeal. While under ERISA you can take legitimately 360 days to complete the appeals process. There is no expedited review as there is under Medicare managed

care or under Medicaid. So for clients who are poor, they can't afford to continue paying for the service out of pocket. Their choice is to forgo the service, to change their lifestyle; I've had individuals who could have been cared for at home and end up going to a nursing home or going on Medicaid. I've seen too many people who should be getting benefits under their employer-sponsored plan switch to Medicaid. It means the employer is off the hook, but we as taxpayers are paying for the benefit.

Medicare does better for people with disabilities. Of the 39 million Medicare beneficiaries, 5 million are younger people who are eligible because they receive Social Security disability benefits. Karen did a good job of explaining why Medicare provides such a good benefit for people with disabilities. It's a stable benefit. Once you're eligible for Medicare, you're eligible Medicare and the population that we're talking about generally does not go off Social Security disability benefits, so they don't lose their access to Medicare. But Medicare also has some problems for people with chronic conditions. The first one is the Medicare coverage package. We hear a lot about the issue of prescription drugs, and I work on that issue as well as a lot of people in this room, but another bigger issue is the lack of coverage for chronic care. There are home health benefits. There are limited long-term care benefits. They are not sufficient. There's going to be a roundtable discussion tomorrow morning. I encourage people to go hear that discussion, because it's really an important issue for people with disabilities.

The other issue is one that the Alzheimer's Association has been working on, which is that routine services that are provided under Medicare are pursuant to local medical review policies, not provided to people with certain disabilities. So the Alzheimer's Association has started to look at several of the local medical review policies and discovered that things like MRIs, routine blood work to determine whether or not you have dementia or maybe have a vitamin deficiency, or some rehabilitative therapies are not available to somebody with a diagnosis of Alzheimer's disease, or dementia, or sometimes multiple sclerosis, or Lou Gehrig's disease—to certain kinds of chronic illnesses.

The problem with the local medical review policies is that they're not made up by HCFA. There is no national review of these policies. And, in fact, if you go through the administrative process and you get

to the administrative law judge, the ALJ is not bound by these policies; but they are the first barrier and very few people appeal.

Another issue that affects people with disabilities is the issue of medigap coverage. As most of you know, people who are on traditional Medicare often will buy a medigap policy to supplement their Medicare coverage. The Medicare statute guarantees that medigap policies will be issued to people who become eligible for Medicare, based on age. So if you're 65 and you become eligible for Medicare, there's a window in which you are guaranteed to be issued a medigap policy regardless of your health condition or your health status. There's no such guarantee for people with disabilities. The Department of Health and Human Services tried to get that included in the Balanced Budget Act of 1997. It was not passed. It's a very important issue for people with disabilities. The other thing that is interesting is that in a lot of states there are no medigap policies available for people with disabilities or else the policies that are available are low-rated policies.

I'm going to conclude with one anecdote. When I was in Tennessee, the State Health Insurance Counseling Program told me they'd received a phone call from a man who was on Medicare because of disability. He had previously worked in the State Insurance Office, so he was very familiar with the insurance policies. He tried to get a medigap policy. The only policy that was available to him was very costly and it was rated D. So he said, I as an insurance commissioner am not going to pay a lot of money for a policy that is a worthless policy. It's a very important issue.

**Ms. Nemore:**

Last week, Vicki and I attended the Families USA Health Action 2000 conference, which, as you might expect, was a little bit different in tone from this conference, and we heard in the opening plenary the exhortations of Michael Moore, the film maker who produced "Roger and Me" and "The Big One," basically exhorting us to take to the streets with cameras in hand to document the failings of our health care system. And so it's an interesting shift for me to come to your conference and hear the presentations of researchers who I would hope are providing the research base for us to move into public policy stances that are consistent with the name of the National Academy for Social

Insurance. I feel like we haven't heard a lot about the concept of social insurance today, and I hope that that topic will continue to emerge in the remaining hours of the conference today and tomorrow.

Vicki and I are on the panel as presenting a consumer perspective on the issues of health care for people with chronic disabilities; neither Vicki nor I are consumers of Medicare or Medicaid, and I think it's really important for us all to be aware of that. We are advocates for those people, but we are not consumers of those programs. And I suspect if you had consumers of those programs presenting a perspective, they would be a lot less polite than I think this forum warrants us to be.

That said, I would like to remind us of some things about the Medicaid program and what its role is in coverage of people with chronic disabilities, people with disabilities, and generally with the more needy segments of our society.

The Medicaid program is a needs-based program, so in order to get benefits you have to have low income and resources. It is a program based on both categorical and financial eligibility. You have to fit into a category. You have to be a child who needs care or the parent of a child who needs care under the old AFDC segment, or you have to be a person in the SSI segment who is aged, blind, or disabled. Generally, most of Medicaid requires that you fit into one of those two categories, and you have to meet the financial income and resource tests.

A good thing about Medicaid is that it does focus resources on the people most in need and on people with very high medical expenses. Another good thing about Medicaid is that it has a core package of services that are required to be provided by all states. There is also in Medicaid a whole range of services that are not required to be provided by states, that are optional, and I'll get a little bit more into that in a minute. That can be a serious problem for people. It's one of the less salient features of the program in terms of meeting people's whole needs.

It's an entitlement program. If you fit into the categories and you fit the financial eligibility, you are entitled to Medicaid. That makes it different from CHIP; the new CHIP program for children is not an entitlement, and that makes a big difference. There are issues about how we expand public coverage and which direction to go.

A really important aspect of Medicaid that we often hear compared with the private health insurance sector is due process rights under

Medicaid. The review system in Medicaid is really very good. It doesn't always work as well as it's supposed to, but what's on paper is a constitutional guarantee of due process, due to the *Goldberg v. Kelly* case from 1969 that says people in brutal need have a constitutional right to due process. and there is a fair hearing process and review process that's really better than what we who have private sector insurance have, and it's really better than Medicare. So that's a very good aspect of it. And there is a huge body of case law that fleshes out what people's rights are in Medicaid, which has some very, very strong positive elements of what it means to be entitled to a core package of services.

What does Medicaid do for people with disabilities? The easiest route in is receipt of SSI disability. Generally, until our recent move into trying to help people back into the labor force, that meant that you were not working. So in order to get the SSI coverage, you were a disabled person who was unable to work.

The one category of Medicaid coverage that is an exception to the "unable to work" norm is called the qualified severely impaired individual category. This is for people who were on SSI, were not working, have gone back into the workforce, and but for their earnings they would still be entitled to SSI. So it allows you to disregard all your earnings and still get Medicaid coverage. That's required for the states to include in their program.

One of the things that is important to remember about Medicaid is that there are a lot of categories, and that's a significant drawback to the policy. That is something that makes Medicare as a public program far more attractive. You get Medicare because you're 65 or you get Medicare because you're disabled, period. You don't have to fit into one of 27 different categories.

There are a couple of required Medicaid categories of SSI-related people who might be disabled people who are entitled to Medicare. There are also 16 options that states can choose, and that's where some of the new work incentives pieces from the last couple of years, have come in. There is a buy-in: states can choose to have a buy-in program for people with incomes up to 250 percent of poverty. They can choose, out of the work incentive package that was passed in this past session of the Congress, to cover people between the ages of 16 and 65, and the state can set the income and resource levels. That's a very significant change from normal Medicaid, because even if you fit into the

working disabled category where your earnings are disregarded, SSI has resource limitations which are very, very strict, and a lot of people can't meet those. So under this new option, states can expand, eliminate, do what they want with respect to resources. There is another category for states to choose to cover people who have gone back into the workforce and are actually found no longer disabled, but who still have a severe medical condition, and the state can choose to cover those people as well without the income and resource limits.

Again, the problems are that these are state options. States have to choose them in order for them to be of any value to people.

The Medicaid program requires states to cover a core package of services, which includes in-patient, out-patient, lab, x-ray, doctors' visits, and a couple of other important things that aren't necessarily particularly relevant for people with disabilities. The things that are most necessary probably for a lot of people with disabilities are all state options: drugs, prosthetic devices, durable medical equipment, physical therapy, other kinds of rehab, private duty nursing, and personal care.

All states provide drug coverage. Most states provide most of those other services and supplies, but they are state options. A state can choose to pull out of those services without any legal ramifications. It can obviously have serious political ramifications and obviously do terrible harm to people who need the services, but they can opt out of providing those.

There are a number of people with disabilities who get coverage under both Medicare and Medicaid, and they don't intersect necessarily very well. Medicaid actually has better home health provisions, which can be very important and beneficial to people with disabilities.

One of the pieces of the work incentives legislation that was passed this past year was to provide grants for the states to develop an infrastructure to help people going back to work who are disabled. One of the requirements for a state to get that grant is that it makes personal care services available to people in the workforce. This is a tremendously important benefit and could be very valuable to people.

That is a brief overview of what Medicaid offers. Medicaid is so complex, and the access to the program—through the process of applying and showing how much income you have and how many resources you have and providing all that verification—is an enormous barrier to people. We've heard over and over again, "I don't want the govern-

ment messing in my business.” “I don’t want to have to show that.” That’s a huge difference between Medicare and Medicaid. To get Medicare, you just show you’re disabled or over 65, and you’re entitled to Medicare based on your earnings. And that is one of the most serious drawbacks of the Medicaid program.