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Mandatory or Optional? The Truth About Medicaid

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MANDATORY OR OPTIONAL? THE TRUTH ABOUT MEDICAID

TUESDAY, JUNE 28, 2005

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The committee met, pursuant to notice, at 3 p.m., in room G50, Dirksen Senate Office Building, Hon. Gordon H. Smith (chairman of the committee) presiding.

Present: Senators Smith and Carper.

OPENING STATEMENT OF CHAIRMAN GORDON H. SMITH

The CHAIRMAN. Ladies and gentlemen, welcome to this hearing on the Aging Committee. Our topic is "Mandatory or Optional? The Truth About Medicaid."

We are glad you are all here, and I am especially pleased to welcome our distinguished panel of witnesses, who I am certain will share with the committee a great deal of information that will help us make decisions as Congress moves forward with development and consideration of a reconciliation package later this year.

Medicaid is a vital safety net program for 54 million elderly, disabled, chronically ill and poor Americans who rely upon it for their health care. The purpose of this hearing is to learn about a fundamental aspect of the program, use of mandatory and optional populations and benefits.

To some these categories simply mean that those who are considered mandatory populations should receive care through Medicaid, and that those who are optional probably have other alternatives and do not really need Medicaid's help.

Well, by the end of this hearing I believe we will all learn that it is not necessarily the case. In fact, if we allow optional beneficiaries to lose Medicaid coverage, they will simply join the ranks of millions of uninsured Americans and end up costing taxpayers far more in the long run. We also may learn today that there are whole groups of Americans without health care coverage, and no matter how poor or sick they may be, they cannot receive care through Medicaid.

Exploration of these issues is very important as we move forward to try to determine, one, how to meet the $10 billion reconciliation instruction given to the Finance Committee, and two, how to improve and reform this vital program.

As we consider proposals intended to respond to the budget reconciliation instruction and deliberate ways to improve the overall

Medicaid program, we must proceed with very real caution and heightened sensitivity.

It is my experience, both as a State Senator in Oregon, and as president in the Oregon Senate, and now as a member of the U.S. Senate, that much good can be accomplished when we work together and remain focused on the people this program helps. Unfortunately, because of its complexity and the severity of many beneficiaries' health status, much damage can also be done if Medicaid is not approached in the right way.

That is why I continue to advocate for bringing all stakeholders to the table, because only when all voices have been heard can a solution be discovered that will be able to garner majority support from the U.S. Senate.

Using the Aging Committee, I plan to hold a series of hearings over the next year and a half to provide a forum to share ideas, concerns and hopefully craft proposals that will result in a higher quality, more efficient, more sustainable Medicaid program. The focus of these hearings will be divided between the short-term challenge of meeting the reconciliation instruction and the long-term challenge of improving the program.

So I look forward to working with my colleagues as we delve into Medicaid and welcome input from all Medicaid stakeholders. After all, every voice must be heard because all have an important and unique perspective to bringing to the table the right kind of solutions and reforms.

We hope to have more of my colleagues here. There are a tremendous amount of things going on on the floor and other meetings that were called and canceled, so hopefully more will find their way to join us soon.

We have two panels today. The first will be Ms. Diane Rowland, who is the executive vice president of the Henry J. Kaiser Foundation in Washington, DC.

Diane, why do you not take the hot seat, and share with us what you would have us know.

STATEMENT OF DIANE ROWLAND, Sc.D., EXECUTIVE VICE PRESIDENT, THE HENRY J. KAISER FAMILY FOUNDATION

Ms. ROWLAND. Thank you, Mr. Chairman. I am delighted to be here and very pleased that you are holding this hearing as well as the series you have planned on Medicaid.

Medicaid is today our largest health care program, and as you know, the only real source of long-term care assistance in the Nation. It assists 54 million Americans, including 8 million with severe disabilities and 5 million who are low-income elderly. The elderly and disabled are not the face of Medicaid. It is often the children that the program covers. Yet they account for 70 percent of all spending on the program. So really, Medicaid has very much become a program for the elderly and disabled, even though the majority of its beneficiaries are children.

Much of the spending in the program is driven by long-term care. Medicaid now covers half of all long-term spending in the Nation, and 60 percent of nursing home residents depend on Medicaid for assistance with the substantial cost of long-term care. Financing these roles, however, as you've noted, has become an increasing challenge for both the Federal and State Governments.

The structure of Medicaid provides for joint financing between the Federal Government and the States. There are certain requirements put on the States in terms of who they must cover and what services they must provide in order to receive matching funds from the Federal Government for the services they cover. The matching rate varies from 50 to 77 percent depending on the per capita income of the State so that the Federal Government assists those States that are poorer at a greater level.

On average today 57 percent of all spending on Medicaid to covered by the Federal Government, so there is a large Federal stake in what happens to the State programs under Medicaid.

In terms of what is required for Medicaid coverage, States are required to cover all children under the poverty level, pregnant women and children who are under age 6 in families with incomes under 133 percent of the poverty level, and the aged and disabled who are recipients of cash assistance through the Supplemental Security Income Program. Those are the so-called mandatory populations for Medicaid.

What is optional in Medicaid coverage is that states can cover individuals with higher incomes who meet these categories, and especially a group we call the medically needy. The medically needy are individuals who meet the categories for Medicaid assistance under the mandatory rules, but have somewhat higher incomes, whose medical expenses allow them to spend down below the Medicaid eligibility levels and obtain Medicaid. Nursing home care is one of the most frequently utilized services for people who spend down to Medicaid eligibility.

Twenty-nine percent of all people covered by Medicaid today are covered at the option of the State and not required by federal law; expenditures for populations and services covered at state option account for almost 60 percent of overall program spending. About 48 percent of all elderly people covered by the Medicaid program are covered as optional groups, compared to only 22 percent of children. So it really is in the services the program provides to people who are elderly and those with disabilities where the term "optional eligibility" becomes most appropriate, mostly because nearly half spend down.

On the benefit side federal law requires States to cover physician services, basic hospital care, laboratory services and some nursing home services, but leaves many of the other benefits, including prescription drugs, home and community based services, personal care services, and a lot of what is needed for someone with long-term care needs as optional benefits.

It is hard to imagine if you were putting together a benefit package today that you would leave some of these services optional and put others into the mandatory category. This point was just so aptly demonstrated by Congress in making prescription drugs a part of the Medicare benefit package.

Medicaid's evolution as a long-term care provider has largely grown through the optional services. Benefits offered today at State option account for about 30 percent of all Medicaid spending.

So overall when we look at the picture of mandatory versus optional populations and spending, we see that 61 percent of all Medicaid spending is either for optional services for people who are covered as mandatory populations or for optional and mandatory services for the optional population.

But are they really optional? Is any of this really at State option? As the laws are changed to move toward broadening Medicaid coverage beyond its origin as the source of coverage for the welfare population, often those additions were made optional for the States so that new requirements would not be imposed on States unable to afford their State matching share.

Increasingly, the Congress moved to make children more of a mandatory population, but the elderly and the disabled were left more at State option, in part, I believe because of the substantial cost that those individuals can impose, given their greater health care needs and use of long-term care.

About 85 percent of all Medicaid spending on long-term care is optional. So when we think of long-term care services as the dominant role that Medicaid plays for people who are elderly or with disabilities, we are really talking there about a set of services that is largely considered optional. However, if you talk to any of the individuals needing these services, they are anything but optional, they are in fact essential benefits.

One can clearly make the case that if you were revisiting Medicaid and trying to design it anew today, you would probably never make many of the optional benefits optional, nor limit the populations covered to the income levels that Medicaid covers as mandatory. You would clearly redesign it to provide a broader range of protection for all low-income individuals and a more stable benefit package for those in need.

The question has always been one of resources and the options were put in place to try not to impose additional resource requirements on States that were resource poor. The question today of resources continues. States now want increased flexibility but without additional resources that increased flexibility is very likely to lead to penny-wise and pound-foolish solutions.

Cost-sharing for poor families on Medicaid is one of the flexibility options that States have asked for. We know that you can collect some money from low-income individuals, but if they are living on $750 a month it may be pretty difficult to pay 5 or 10 dollars per prescription. We know that cost-sharing leads to barriers to primary care, and I think it is pound foolish because in the end we will see many of these individuals end up sicker and needing hospital care, sicker in the emergency room, and in the end will have to pay more for the cost of their care because we delayed the early primary and preventive care that can make a difference.

Similarly, some States have begun to look at imposing enrollment premiums even for the lowest-income individuals, people living at less than 8 or 9 thousand dollars a year. Your own State of Oregon actually tried the premium route and discovered that enrollment in the program declined by over 50,000 people largely as a result of their inability or unwillingness to pay the premium. That was about half of the enrollees covered who were subject to premiums. So we know that premiums may sound good and seem like a way to save some additional funds, but may in the end result in growing our uninsured population instead of providing additional revenues to the Medicaid program.

The CHAIRMAN. What was the amount of the premium Oregon charged?

Ms. ROWLAND. It ranged from $6 to $20 a month, depending on the income. It was on a sliding scale. Sounds modest, but what we find is that our ability to understand what it takes to live on $750 a month for a family of 3 may mean that what seems like very nominal cost-sharing or premium amounts to us may in fact not be within the budget of the families we are talking about.

The CHAIRMAN. How would that compare to copays or an upfront portion for a particular service?

Ms. ROWLAND. The copays might range from 3 to 5 or 10 dollars. They have been limited under the Medicaid program to date, but one of the areas of flexibility States have requested is to raise the copays.

In the Utah experience there was an expansion of coverage to additional low income people with an annual enrollment fee of about $50 a year, hospital services and many mental health services were not covered and substantial copayments well imposed on covered services.

So we are seeing costs for beneficiaries imposed within the program. It may be worthwhile looking at how costs have affected some of the higher income children who cost-sharing is allowed under the SCHIP program. In Medicaid we are primarily talking about adults who in some states are covered at 28 or 29 percent of the poverty level and do not really able to have much in the way of financial resources to pay for their care.

Instead of cutting benefits, I believe, the real solution to making Medicaid sustainable is actually to make it less necessary. If we had universal health coverage or if we had some broader form of long-term care assistance, the future sustainability of Medicaid would not be in question. But now in the absence of these broader solutions, I think as you have stated so well in your opening statement, we really do need to take care to make sure that any changes to Medicaid do not shred the only safety net out there for millions of our sickest and frailest citizens. I believe we should be looking at ways to better coordinate care under Medicaid and to better organize services through Disease Management and other programs that help the chronically ill to get the care they need and not fall through the cracks and get sicker before we treat them.

There are also ways I think we can really move to improve the delivery of long-term care services, with more home and community based services. We need to be building on these experiences.

You also mentioned the uninsured and the fact that some individuals, no matter how poor, never qualify for Medicaid, and that is the case for adults without dependent children who do not meet the disability definition. We should really be looking at ways to secure coverage for our lowest income population and not through Medicaid shred the safety net Medicaid provides. I am glad you are holding this hearing to begin to explore these issues.

Thank you, and I would welcome any questions.

The CHAIRMAN. Can you talk a little bit more about the creation of mandatory and optional, and would you just discard those definitions or would mandatory become more of the preventive kind of medicine and optional, I guess, cosmetic surgery?

Ms. ROWLAND. Clearly, Medicaid, when it was enacted in 1965, was a follow-up program to what was then known as the Kerr-Mills Act, which was assistance to States to provide care for the aged. When it was enacted it was seen as a program that could help people who were on welfare. So at the time the Aid to Families with Dependent Children Program, and by 1972 with the Federalization of Cash Assistance with the Supplemental Security Income Program for the Aged, Blind and Disabled, Medicaid really became the provider of medical services for the cash assistance population.

One historical thing of interest is that in 1972 when the Aged, Blind and Disabled became a Federal cash assistance program under Supplemental Security Income, there was concern that not all States would be willing to provide full Medicaid coverage to all of the SSI Federal entitlement people. States were thus given the option of not providing coverage and using their old rules for the aged and disabled that were in place in 1972. A few States still follow those rules.

So I think that the implementation of disability coverage under Medicaid really provided the first "if we are going to expand coverage to a population, not all States may be able to step up to the plate and cover that full population, so we will give them options."

Therefore, if you really look at the history of the program, optional populations were always those that had a worthiness to be covered by Medicaid. No one doubted that they were too well off, but coverage was optional because Congress did not want to impose requirements on States that may not have had adequate resources to provide coverage. Over time, some groups especially children, became a popular part of the program. Today many children are mandated for coverage because of the progression of a year at a time covering all children under poverty. That has not been the case for adults, so adults have remained largely covered at the option of the State.

The CHAIRMAN. Obviously, I was being facetious when I mentioned cosmetic surgery as an optional procedure, but can you name something that is an optional procedure now that really ought to be a mandatory procedure?

Ms. ROWLAND. Well, I certainly think that prescription drug coverage, which is an optional benefit, but available now in all the States, would be part of any benefit package today. Clearly a lot of the other services, such as prosthetic devices, and durable medical equipment, are optional services that you would think would be required for a program that covers people with severe disabilities. I think most of the other services that tend to be in the optional category like dental services and vision care may be optional if you were talking about a benefit package for working Americans, but when you are talking about the benefits needed by some of the lowest income and poorest Americans, you may want to include those as mandatory rather than optional services.

Where the real options are that I would consider part of a mandatory program are around the long-term care benefits, where intermediate care facilities for the mentally retarded, home and community based care and other services are not part of the mandated benefits, only nursing homes.

The CHAIRMAN. How about mental health? Can you speak to that as an optional service?

Ms. ROWLAND. Mental health I think is one of the area obviously that has emerged as a place where prescription drug coverage is essential. While mental health services in terms of physician visits are covered under the mandatory section of the program, prescription drugs are optional so clearly one of the main treatment options is an “optional” benefit.

In fact, I just heard that the State of Florida is planning to impose some prior authorization requirements on use of psychotropic drugs. I think one of the areas where mental health really needs to be addressed is that if the services needed for treatment are optional, then providing people with access to the provider, but no access to the agents that they need to maintain their status is really counter productive.

It is also an area where we found that many States, as they look to slim down or restructure their benefit packages have left mental health services out. Specifically when Utah was doing its primary care benefit package, it did not include mental health services.

The CHAIRMAN. At all?

Ms. ROWLAND. Not at all. You know, it included the basic physician services with copays and four prescription drugs per month with copays, but mental health specialist services and hospital care were excluded from the benefit package.

I think one of the dangers we have today is that when we talk about the Medicaid benefit package being too comprehensive, many of the services that are optional today are being considered for elimination. The slimmer the benefit package, the less able this program will be to meet the diverse health needs of the population it serves.

The CHAIRMAN. When you cut out the mental health component, have you ever quantified in the research that you do what it means to other costs that are borne by the State in terms of county jails, in terms of State hospitals, emergency rooms?

Ms. ROWLAND. We have not done any studies that would relate to the other societal costs for cutting out mental health services from Medicaid specifically. We do know from some of the work on the uninsured population, the societal costs for people without health insurance coverage who do not get the health care they need contributes to problems among children in school, to people not engaging productively in the labor force, and to more preventable hospitalizations, because if people were under treatment they would not need to be hospitalized for care.

There are definite costs to not providing coverage that we see from our analysis of the uninsured. I think we know from States that have been looking at cutting back on some of the prescription drug coverage for people with mental illness, that there is obviously going to be a rise in costs in other areas, probably hospitalization, but also I think as you are pointing out, to the prison system, and to society in general.

The CHAIRMAN. In your testimony you spoke of the Oregon experience, my State, and some of the cost-sharing or cost-shifting that has gone on under the Oregon health plan. Can you speak to the Oregon experience as you see it and what the Congress might learn from mistakes that may have been made there?

Ms. ROWLAND. Well, I think we see from Oregon a State that tried to do as much as possible to provide adequate and broad coverage to its low-income population. It was willing to take some risks and challenges in how it tried to set up its tiering of benefits. It had broad use of managed care and also has been a State that led the way in terms of community based care as an alternative to nursing home care.

Yet I think that when budgets get tight and revenues from the Federal Government are not there to help support States through some of the economic downturns they face, you see that as you trim on benefits you have people who go without the care they need. We see a higher rate of hospitalization for conditions that are avoidable if they are subject to early preventive care. Especially around use of cost sharing we see people deferring care that should be available at the beginning, and we see providers saying that they are seeing it imposing greater administrative burdens on them for trying to collect the cost sharing. This really results in providers actually getting less payment for the services they provide since under Medicaid law they cannot require the beneficiary to pay the cost sharing before rendering services. As a result I think in some States we have seen some providers unwilling to continue to participate in the program, thereby further compromising access for the low income population.

The CHAIRMAN. If premiums are not the answer or maybe counterproductive to the right answer, what could be reasonably required in terms of to induce responsibility, avoid abuse, without hurting peoples' access to using Medicaid but not abusing Medicaid?

Ms. ROWLAND. I think that cost sharing is probably more difficult than premiums, so let me just differentiate between the two.

The CHAIRMAN. They are very different, but what works and what does not?

Ms. ROWLAND. I think that premiums have their negative effect on overall participation, but they do not influence how someone uses the health care system, whereas cost sharing influences how somebody accesses the health system, when they access it and how much they use.

I think that one of the more effective ways to control utilization and work with patients is to have them enrolled in managed care plans that actually try to manage their care and give them incentives. I think it is counterproductive to have cost sharing for preventive services where you want people to have no barriers to use services. I think if you try to distinguish within the benefit package on the benefits that may be less necessary, perhaps that is one place where you could impose some of the cost sharing. But premiums I think work the best if you are trying to get participation in the program financially from individuals, but they do discourage enrollment.

If one is going to use premiums, one of the most important things is how you keep people established in the program. So if I used premiums I would combine them with longer term eligibility so that you do not have people dropping on and off.

The CHAIRMAN. As you see the Finance Committee wrestle with a $10 billion reconciliation, are there some obvious things that you would suggest to us to do so that we do not hurt the people we are trying to serve and improve the program? What would you have the Finance Committee do with that $10 billion?

Ms. ROWLAND. They always say that you should go where the money is if you are trying to save money, and I think one of the places that we see tremendous opportunity to improve care as well as potentially reduce costs is in better coordination between Medicare and Medicaid of the care of the dual eligible population.

About 18 percent of all Medicare beneficiaries are currently also getting assistance from Medicaid. They account for 42 percent of all Medicaid spending so. We need to look at better management, especially around some of their prescription drug needs, around their coordination of care between the Medicare benefits and Medicaid, around long-term care to achieve possible savings. This is the group for whom disease management and better care management may well result not only in some savings to both Medicaid and Medicare but also in improved quality of care.

I think around the children's services——

The CHAIRMAN. Can you quantify that? How much would that save? I mean, 5, 10?

Ms. ROWLAND. I think you could probably get to 5 or 10 over a couple of years.

The CHAIRMAN. We have 5 years to do it, so.

Ms. ROWLAND. Really 4, right?

The CHAIRMAN. Exactly, 4. We are burning up the first year here.

Ms. ROWLAND. I think that is one area. The other area is obviously where States have already been very aggressive in trying to get better prices for prescription drugs, to try to better control utilization of the prescription drugs. Possibly introducing some tiering so that some of the brand name drugs are not as available and have limited differential cost sharing could be used. Most of the current employee benefit plans have tiered cost sharing in the Medicaid program working with preferred drug lists and working with better pricing is a priority getting better prices is both important to make sure that the drugs that are needed are available but also as a way to save some money.

The CHAIRMAN. A lot of the information sharing on that is being done by a number of States. I believe even Oregon is doing that. Do you think we can glean from that the kind of information that will allow for tiering and for more effective use of——

Ms. ROWLAND. I think you can glean some from that. I think the other issue that you really are going to have to visit is what the implications on January 1, 2006, of pulling the dual eligibles drug coverage out of Medicaid and over to Medicare is going to mean for the State's ability to continue to get the kind of discounts and rebates that they have gotten in the past. They will obviously have a lower market share now.

Second, obviously, revisiting some of the issues in the clawback and the lack of a wraparound for some of the dual eligible beneficiaries where States are not eligible for federal matching funds—if they try to supplement the Medicare package. This is the area of concern to people with mental illness who really need some of the drugs that may not be well covered under the Medicare formulary. I think that is an area where helping the States to be able to still obtain Federal matching funds if they wrap around is an important item to consider. It would not save money, but it might really save lives.

The CHAIRMAN. Do you think policies on copays should wait to consider options for all program aspects, or can we look at drugs and not cause damage in other areas?

Ms. ROWLAND. Well, we have always looked at drugs a little differently, because as I said, they have been an optional benefit. Adults covered by Medicaid can be changed minimal copays imposed on prescription drugs.

One of the experiences though is that many States used to have a dollar or two dollar copay for prescription drugs. They decided in many ways that that was too expensive to administer, and so a lot of States dropped copays on drugs.

One of the most negative experiences with copays for prescription drugs was actually in the State of New Hampshire, where they imposed copays on individuals who often needed mental health drugs. They did not take their drugs and they ended up in nursing homes and hospitals, costing the State substantially more.

I think that the one thing to always remember with this population is what may seem like a prudent policy for individuals who are relatively healthy does not always apply to the Medicaid population where individuals not only have fewer resources than others in society, but also often have more co-morbidities and health care problems that require very delicate balancing to make sure they do not get out of kilter.

The CHAIRMAN. I think you have answered my questions. You have been very, very helpful, Ms. Rowland. You have added measurably I think to the Senate record, and I think your advice to us is be careful of the designations of mandatory and optional populations. I think I am understanding you to say that flexibility may ultimately save money short term, but cost money long term and will not ultimately save us money, and may throw people off coverage that really should be covered.

Ms. ROWLAND. That is right. One of my colleagues likes to say there is no such thing as an optional person, and I think that is something to remember as we move forward in this debate.

The CHAIRMAN. Anybody optional here? [Laughter.]

No. I think everyone here is mandatory. Thank you very, very much for your time and for sharing the experience of the Kaiser Family Foundation.

Ms. ROWLAND. If there is anything else we can provide we would be glad to work with you and look forward to working with you. Thank you.

The CHAIRMAN. We look forward to that as well. Thank you so very much.

[The prepared statement of Ms. Rowland follows:]

THE HENRY J. KAISER FAMILY FOUNDATION

THE KAISER COMMISSION ON
Medicaid and the Uninsured

Medicaid: Addressing the Future

Testimony by

Diane Rowland, Sc.D.

Executive Vice President
The Henry J. Kaiser Family Foundation

and

Executive Director
Kaiser Commission on Medicaid and the Uninsured

before the

Senate Special Committee on Aging

Dirksen Senate Office Building
Washington DC

June 28, 2005

Mr. Chairman and Members of the Committee -

I am pleased to be here today to participate in this hearing on the Medicaid program and its role for low-income Americans, especially our senior citizens. I am Diane Rowland, Executive Vice President of the Henry J. Kaiser Family Foundation and Executive Director of the Kaiser Commission on Medicaid and the Uninsured.

Medicaid is today our nation's health care safety net providing the glue to keep poor families and the elderly and people with disabilities from falling through the many cracks in our health care system. It provides health and long-term care coverage to over 53 million Americans, assisting many Americans with the most complex health care needs and the least resources to deal with these problems. It has become an especially important source of supplemental coverage, most notably for long-term care assistance and help with premiums and cost-sharing for 7 million of Medicare's sickest and poorest beneficiaries.

Medicaid's Multiple Roles

The Medicaid program takes on multiple roles in providing health and long-term care services to low-income families, the elderly, and people with disabilities. It is a health insurer, a supplement to fill Medicare's gaps, the nation's only program providing assistance to the aged and disabled with long-term care costs in the community and in nursing homes, and the primary financial support for our nation's safety net hospitals and clinics.

In these roles, Medicaid has a broad reach -- it is the source of health insurance coverage for 40 percent of poor Americans and one in four American children, finances health and long-term care coverage for about 20 percent of people with severe disabilities and 44 percent of people living with HIV/AIDS, supplements Medicare for 15 percent of Medicare beneficiaries, and helps pay for the care of 60 percent of nursing home residents. In meeting these health needs, Medicaid accounts for nearly one of every five dollars of health care spending, nearly one of every two dollars spent on long-term care, and over half of public mental health spending. Jointly financed by the federal and state governments, Medicaid is now the nation's largest health care program at an annual cost of over $300 billion. The federal government covers roughly 57 percent of all Medicaid spending, making Medicaid the largest source (43 percent) of federal support to the states.

Medicaid's most widely acknowledged role as a source of health coverage for 38 million low-income children and their parents helps to keep millions of low-income families from joining the nation's growing uninsured population. However, Medicaid's role as a health insurer for low-income families is neither its most unique nor its costliest role. It is Medicaid's assistance to the 8 million low-income people with disabilities and 5 million elderly people who need both medical and long-term care services that dominates Medicaid spending. Together, children and their parents account for three-quarters of Medicaid enrollees and 30 percent of spending, while the elderly and disabled account for a quarter of beneficiaries and 70 percent of spending (Figure 1). In 2003, per capita expenditures per child were $1,700 compared to $12,300 per disabled beneficiary and $12,800 per elderly Medicaid beneficiary. This spending reflects the higher utilization of acute care services and long-term care to meet the ongoing chronic care needs of the disabled and elderly (Figure 2).

For low-income Medicare beneficiaries, Medicaid coverage is particularly important. Although Medicare provides basic medical coverage, the required premiums and cost-sharing and gaps in benefits, most notably for long-term care coverage, leave many holes to be filled by Medicaid. The 7 million elderly and disabled individuals with both Medicare and Medicaid -- the "dual eligibles" -- are among Medicare's poorest and sickest beneficiaries (Figure 3). In addition to having low incomes, these dual eligibles are more likely than other Medicare beneficiaries to be in poor health, suffer from chronic diseases, and have limitations on their activities of daily living leading to long-term care needs. As a result, the dual eligible population accounts for 14 percent of Medicaid beneficiaries, but 42 percent of all Medicaid spending (Figure 4).

Although Medicaid is a substantial investment of federal and state dollars, it also provides an effective return on investment by improving access to care for our low-income population. Uninsured children and adults are less likely to obtain medical care and more likely to lack a usual source of care than those with Medicaid. Among the elderly and disabled with Medicare coverage, Medicaid coverage promotes access comparable to that of those with private supplemental insurance and notably better than that experienced by the population with only Medicare coverage.

Filling these multiple roles makes Medicaid both a complex and costly program. Medicaid is complex because it is not a single program, but an array of services and programs which are structured and operated somewhat differently in each of the 50 states and the District of Columbia. It is a costly program because health care, and especially long-term care, is expensive and Medicaid covers those with the most substantial health needs, including those with severe disabilities and chronic health problems requiring on-going care.

THE STRUCTURE OF MEDICAID

Medicaid is jointly financed by the federal and state governments with the federal government covering 57 percent of overall spending. The federal government matches state spending, providing 50 to 77 percent of spending, picking up a higher share in states with low per capita income (Figure 5). The structure of Medicaid provides states with federal matching funds for coverage of mandatory populations and services, but also enables states to obtain federal matching funds for a wide range of optional services and broader population coverage. This provides states with the flexibility to obtain federal matching payments to cover a broad range of services for their low-income residents and to adjust coverage to respond to emerging health problems, but also leads to variations in the scope of coverage across states.

States that elect to participate in Medicaid (currently all states do participate) are required to cover all children under the poverty level, pregnant women and children under six with incomes at or below 133 percent of the federal poverty level, and most elderly and disabled recipients of cash assistance under the Supplemental Security Income (SSI) cash assistance program. Because the federal statute requires states to cover these groups as a condition of participating in Medicaid, they are referred to as the "mandatory" eligibility groups (Figure 6). Similarly, because states are required to cover basic benefits including hospital, physician, laboratory, and nursing home services, the required services are referred to as "mandatory services".

These requirements are the minimum investment the federal government requires states to make in return for federal funds picking up 57% of overall spending. They set a national floor for coverage in all states, but states are not limited in their ability to draw additional federal matching funds to extend coverage beyond the minimum levels required.

Beyond the federal requirements, states have the option to extend coverage to children at higher incomes, their parents, and other low-income elderly and persons with disabilities in the community and in nursing homes and still receive federal matching funds for the cost of their coverage. These groups are referred to as "optional" populations because states are not required to cover them. All states extend coverage beyond the required populations and coverage varies widely across states. With regard to benefits, states also have the option to cover additional benefits above the required set for both "mandatory" and "optional" eligibility groups. Many of the "optional" benefits, such as prescription drug coverage and intermediate care facility services for the mentally retarded (ICF/MR) are integral to Medicaid coverage and offered in all states. For both "mandatory" and "optional" benefits, States have the discretion to limit the amount, duration, and scope of coverage.

The terms "mandatory" and "optional" refer to Medicaid's statutory design and link back to its roots in 1965 as the medical coverage program for the nation's welfare population. The populations historically eligible for cash assistance are "mandatory" under Medicaid law, while most populations not eligible for cash assistance were made eligible for Medicaid through new laws enacted over the program's 40-year history. As new groups were made eligible for coverage with federal matching funds, most were offered as an option -- rather than a mandate -- to states. These options provide states with the flexibility to adopt changes and expand eligibility with federal funding support, but do not imply a lesser standard of need or worthiness than coverage for mandatory groups and services.

Eligibility

The likelihood of qualifying for Medicaid on the basis of a "mandatory" or "optional" group varies substantially by group (Figure 7). Most children (79%) qualify on the basis of "mandatory" coverage, reflecting Congressional legislative changes that have raised the minimum income eligibility threshold above cash assistance levels -- most notably, requiring states to cover all children from families with incomes below poverty and young children and pregnant women up to 133 percent of poverty. In contrast, nearly half (48%) of the elderly qualify through "optional" eligibility groups, reflecting state decisions to extend coverage to nursing home residents and the medically needy population who have incomes above SSI eligibility levels.

Coverage of the medically needy is a major state option allowing individuals to obtain help from Medicaid after "spending down" income and resources due to health care expenses. This is particularly important to elderly individuals in nursing facilities and children and adults with disabilities who live in the community and incur high prescription drug, medical equipment, or other health care expenses.

Some examples of individuals covered at state option are provided below:

- An elderly nursing facility resident whose annual income ($7,184) is just above SSI standards (74% of poverty) but below 100% of poverty $9,570 in 2005).
- A 68 year-old widow with multiple conditions, such as fibrosis of the lungs, rheumatoid arthritis, and high blood pressure, whose income ($8,400) is too high to qualify for SSI (74% of poverty of $7,082 in 2005) but qualifies for Medicaid home and community-based services, allowing her to remain in the community.
- A 22-year-old woman with disabilities who earns less than $23,925/year (250% of poverty in 2005), whose employer does not offer coverage and needs Medicaid's coverage of physician services, personal care services, and prescription drugs.
- An 85 year-old with Alzheimer's disease with a monthly income of $1,472 (less than 300% of SSI) qualifies for nursing facility care. She is allowed to keep $30 a month for personal needs, and the remainder of her income goes to the nursing facility to cover her medical and support needs.
- A 50-year old man who has multiple sclerosis with recurring drug and physician costs that average $750/month "spends down" to Medicaid medically needy eligibility levels (median is 55% of poverty).

Benefits

States must provide physician services, hospital care, nursing facility care, and other "mandatory" services to beneficiaries covered at state option, but they can also provide an array of "optional" services to both mandatory and optional populations (Figures 8 and 9). Services offered at state option include prescription drugs and a broad range of disability-related services, such as, case management, rehabilitative services, personal care services, and home and community-based services. Many of these "optional" benefits provide important benefits for both Medicaid "mandatory" and "optional" beneficiaries and are particularly important for persons with disabilities and the elderly. Given the range of disabilities covered by Medicaid, many of the "optional" benefits are essential to appropriate care and management of people with disabilities on Medicaid. For the aged and disabled who rely on Medicaid to fill Medicare's gaps, "optional" benefits like prescription drugs, dental and vision care, and home and community based services are the most important gaps Medicaid fills.

Impact on Spending

Overall, individuals covered at state option account for 29 percent of Medicaid enrollees and 60 percent of all Medicaid expenditures for both "mandatory" and "optional" populations are "optional." The majority of "optional" spending (86%) pays for services to the elderly and disabled. Some of the sickest and poorest Medicaid beneficiaries are considered "optional" and many of the "optional" benefits provided under Medicaid, such as prescription drugs and rehabilitation services, often are integral to appropriate care and functioning for the population Medicaid serves.

As shown in Figure 10, "optional" populations account for about 42 percent of all Medicaid spending and of this spending, 70 percent is for "mandatory" services and 30 percent is for "optional" services. Spending is not evenly distributed among the "optional" populations. As shown in Figure 11, the elderly and disabled represent 29 percent of the "optional" populations covered but account for 83 percent of Medicaid spending on "optional" populations.

Although three fifths of total Medicaid spending is "optional", the share of spending that is "mandatory" or "optional" varies substantially across beneficiary groups (Figure 12). Only 20 percent of spending on children is "optional" while 84 percent of spending on the elderly is "optional." "Optional" spending is driven in large part by coverage of long-term care services for the elderly and persons with disabilities for nursing facility care, ICF/MR services, and home and community-based services. As a result of state decisions to cover these services, over half (57%) of total "optional" spending is for long-term care services (Figure 13). Eighty-five percent of Medicaid spending on long-term care is "optional" (Figure 14) and two thirds of that is for institutional care. While one in five optional long-term care dollars is for home and community-based waiver services and other home care, only 4 percent of total long-term care spending is for "mandatory" home health services and 11 percent for required institutional coverage.

Most optional spending is devoted to the frailest and most vulnerable Medicaid beneficiaries, including many elderly people. These populations rely on Medicaid for help with long-term care needs, including nursing home and community-based services. These services are not available through Medicare or private insurance and therefore, Medicaid's coverage provides an essential safety net; most frail elderly and disabled could not function without this help.

Providing more options in the community for the elderly and people with disabilities is a national priority and will be even more important as the population ages. Today, there is wide variation in the availability of home and community-based care across the states. While 11 states, including Oregon and Washington, spend more than half of their long-term care dollars in community settings, 16 states spend less than one-third of their long-term care dollars on non-institutional options.

State Flexibility

While the framework of Medicaid provides states with considerable flexibility over the design and scope of their Medicaid programs, states, under increasing fiscal pressure, are asking for additional flexibility to alter federal coverage rules without waivers. Giving states more flexibility to impost cost-sharing or scale back benefits that restrict coverage for working families could reduce program costs but also shift costs to the poor and their providers and add to administrative burdens for providers. Those on Medicaid are generally sicker with more chronic conditions and less income than the privately insured. Imposing additional financial requirements on families, most with incomes of less than $300 a week, is likely to result in delayed of foregone care leading to the negative health consequences we find among the uninsured. Given the extremely limited incomes of most Medicaid beneficiaries, nominal co-payments and cost-sharing are likely to lead to reduced access to early care and potentially more costly hospitalizations for untreated conditions. Imposing premiums on people with incomes below the poverty level may bring in limited revenue, but, as the Oregon experience shows, mostly reduces Medicaid costs by reducing enrollment and adding to the growing uninsured population. Tightening eligibility for long-term care in the community or nursing home to reduce Medicaid costs leaves an elderly couple of modest means facing nursing home costs averaging $70,000 a year with no help until destitute.

State flexibility without additional federal resources does not provide a painless solution to the fiscal pressures facing Medicaid. These short-term strategies will not achieve significant savings for states or facilitate Medicaid's ability to meet the health needs of the low-income population and adequately pay their providers nor will they help address the increasing long-term care needs of an aging population. Instead they will further increase the number of uninsured Americans and shift more costs to doctors and other health care providers who care for Medicaid patients. Long-term strategies that invest in Medicaid to promote better management of chronic illness, disease prevention, and coordination with Medicare to more effectively address the needs of the high costs enrollees who rely on both programs offer a better and more humane alternative for containing costs.

LOOKING AHEAD

Medicaid's role in providing health and long-term services to our nation's most vulnerable people and its widening safety net responsibilities have brought notable improvements in coverage of low-income families and assistance to the elderly and individuals with disabilities. As the primary source of financing and coverage for the low-income population, Medicaid has been a critical force in moderating the growth in America's uninsured population over the last three decades. Without Medicaid, millions of our nation's poorest children would be without health insurance.

Medicaid continues to provide coverage beyond that of private insurance or Medicare to the most vulnerable and frail in our society - acute and long-term care services for persons with chronic mental illness and retardation; medical and long-term care services and drug therapy for those with AIDS; assistance with Medicare's premiums and cost-sharing and prescription drug coverage for poor Medicare beneficiaries; and home-based and institutional care for those with severe physical and mental disabilities that require long-term care. In the absence of Medicaid, it is hard to envision how these enormous societal needs would be met.

Yet, one of the most daunting challenges facing Medicaid's future is how to meet the growing need for health and long-term care coverage within the constraints of federal and state financing. The fiscal situation in the states, coupled with the growing federal deficit, makes assuring adequate financing and meaningful coverage for low-income families, the elderly, and people with disabilities a growing challenge. Yet, it is a challenge that should be met with responsible proposals that assure that the most frail and vulnerable among us are protected and able to obtain the health and long-term services they need.

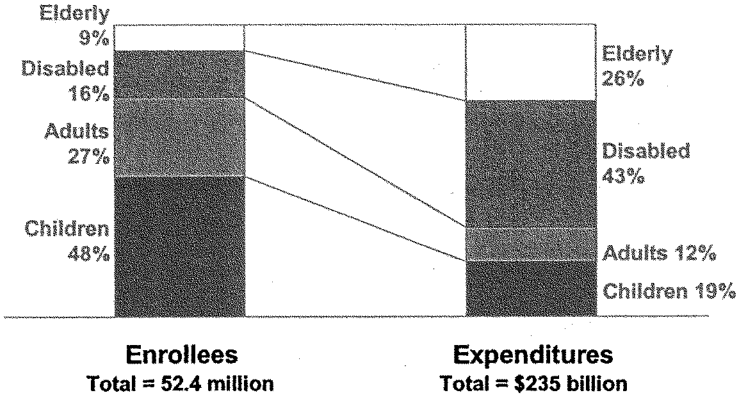
Underlying the debate over who pays for Medicaid is thus a more fundamental debate about we as a nation fill the gaps in our health care system to provide and finance care for the poorest and sickest among us (Figure 15). The solution to making Medicaid more sustainable is to make it less necessary. If we had universal health coverage and assistance with the high cost of long-term care, the future sustainability of Medicaid would not be a question. But, in the absence of broader solutions, policymakers need to find ways to maintain - not shred - the Medicaid safety net because without Medicaid millions more would be uninsured and many of our poorest and sickest citizens would be unable to obtain or afford the care they need.

There are no easy answers to reducing the cost of providing care to the over fifty million Americans who now depend on Medicaid for health and long-term care assistance - the poorest, oldest, frailest, and most disabled of our population. The high cost of caring for this population is reflective of their serious health problems, not excessive spending by the program. Program costs grow in response to downturns in the economy, rising health care costs, the needs of an aging population, and emerging public health crises and emergencies. Efforts at reform should be directed at finding ways to support and maintain the coverage the program offers while balancing the responsibilities for coverage and financing between the federal and state governments. Assuring that financing is adequate to meet the needs of America's most vulnerable and addressing our growing uninsured problem should be among our nation's highest priorities.

Thank you for this opportunity to share this information with the committee.

Figure 1

Medicaid Enrollees and Expenditures by Enrollment Group, 2003



Expenditure distribution based on CBO data that includes only federal spending on services and excludes DSH, supplemental provider payments, vaccines for children, administration, and the temporary FMAP increase. Total expenditures assume a state share of 43% of total program spending.
SOURCE: Kaiser Commission estimates based on CBO and OMB data, 2004.

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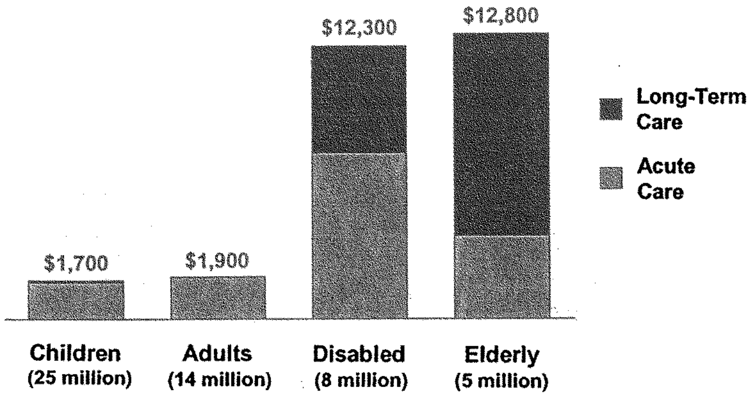
Figure 2

Medicaid Payments Per Enrollee by Acute and Long-Term Care, 2003



SOURCE: KCMU estimates based on CBO and Urban Institute data, 2004.

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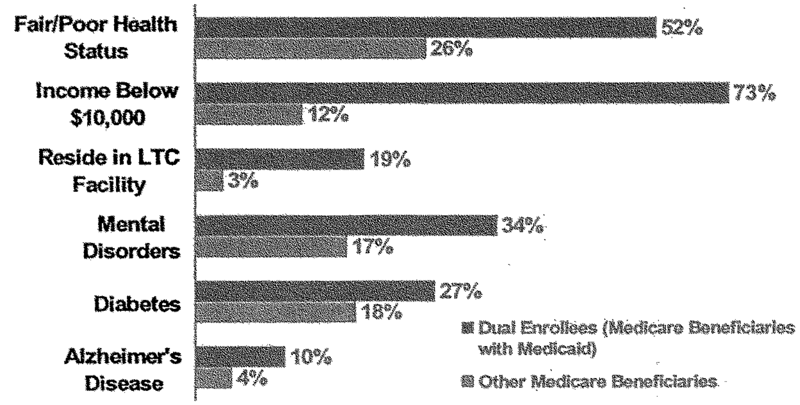
Figure 3

Dual Enrollees are Poorer and Sicker Than Other Medicare Beneficiaries



SOURCE: KFF estimates based on the Centers for Medicare and Medicaid Services Medicare Current Beneficiary Survey 2002 Access to Care File.

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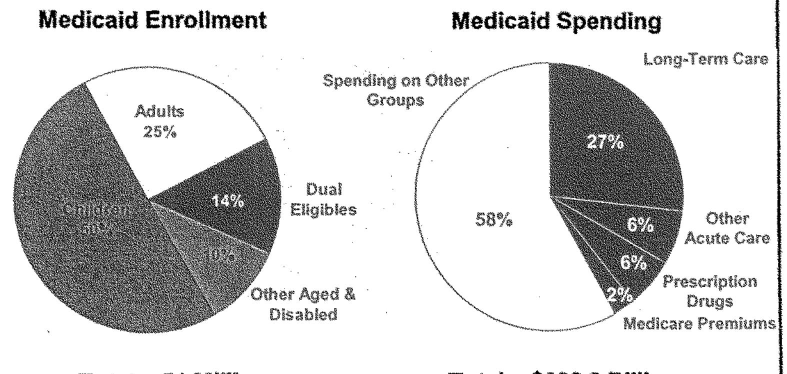
Figure 4

Medicaid Dual Eligibles: Enrollment and Spending



Total = 51 Million

Total = $232.8 Billion (42% on Duals)

SOURCE: KCMU estimates based on CMS data and Urban Institute analysis of data from MSIS.

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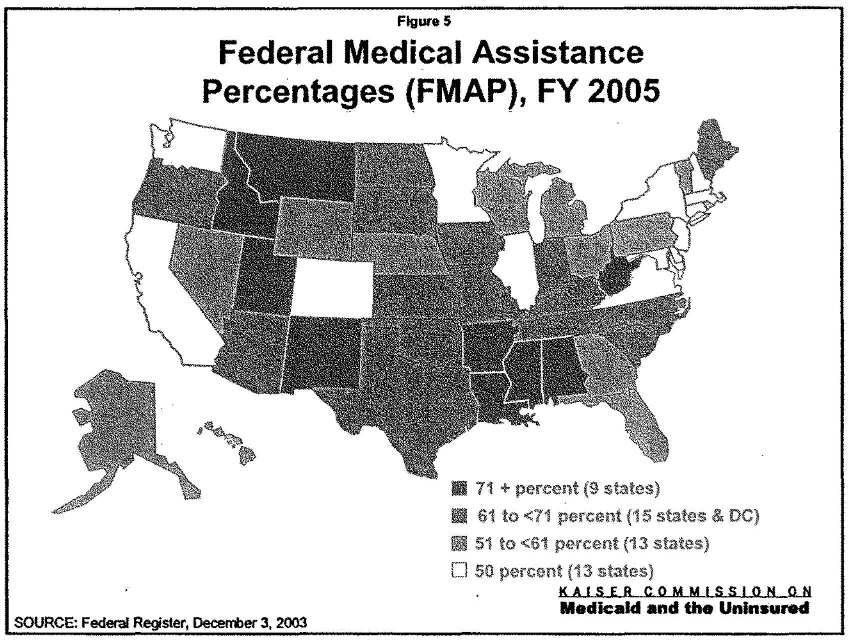

Figure 5

Federal Medical Assistance Percentages (FMAP), FY 2005

- ■ 71 + percent (9 states)
- ▩ 61 to <71 percent (15 states & DC)
- ▨ 51 to <61 percent (13 states)
- ☐ 50 percent (13 states)

SOURCE: Federal Register, December 3, 2003

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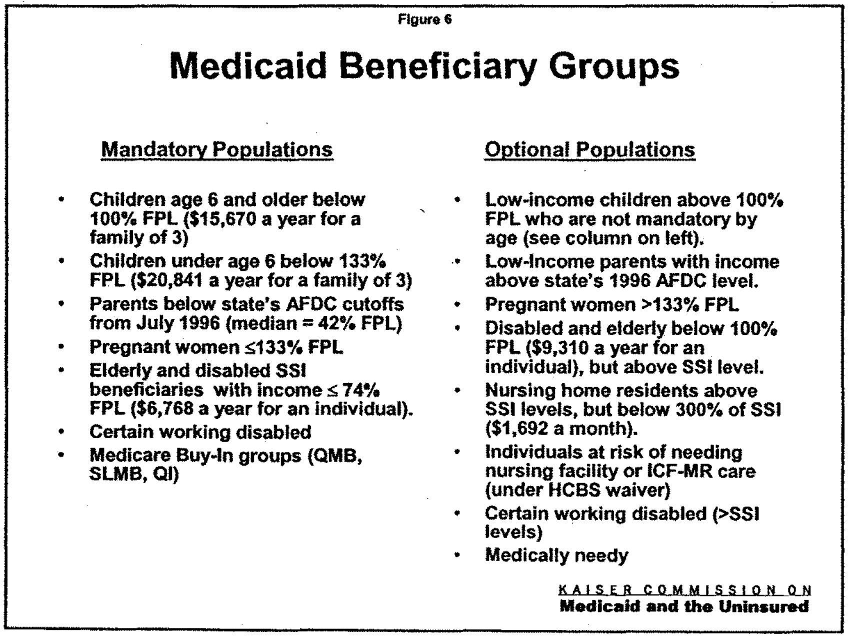

Figure 6

Medicaid Beneficiary Groups

Mandatory Populations

- Children age 6 and older below 100% FPL ($15,670 a year for a family of 3)
- Children under age 6 below 133% FPL ($20,841 a year for a family of 3)
- Parents below state's AFDC cutoffs from July 1996 (median = 42% FPL)
- Pregnant women ≤133% FPL
- Elderly and disabled SSI beneficiaries with income ≤ 74% FPL ($6,768 a year for an individual).
- Certain working disabled
- Medicare Buy-In groups (QMB, SLMB, QI)

Optional Populations

- Low-income children above 100% FPL who are not mandatory by age (see column on left).
- Low-income parents with income above state's 1996 AFDC level.
- Pregnant women >133% FPL
- Disabled and elderly below 100% FPL ($9,310 a year for an individual), but above SSI level.
- Nursing home residents above SSI levels, but below 300% of SSI ($1,692 a month).
- Individuals at risk of needing nursing facility or ICF-MR care (under HCBS waiver)
- Certain working disabled (>SSI levels)
- Medically needy

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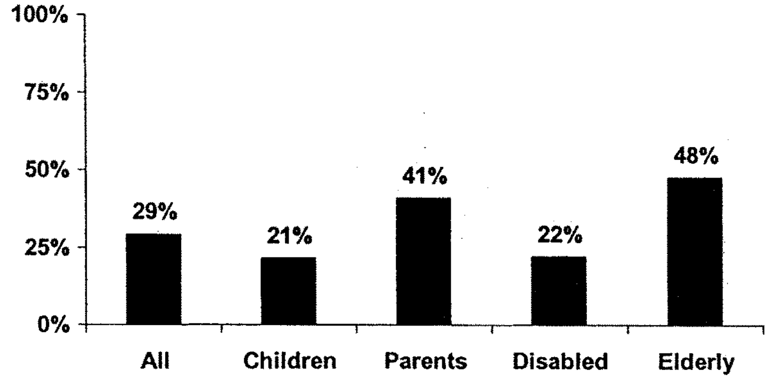
Figure 7

Percent of Medicaid Beneficiaries with Optional Eligibility, 2001



SOURCE: Urban Institute Estimates based on FFY data from MSIS 2001 and CMS 64 reports.

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Figure 8

Medicaid Acute Care Benefits

"Mandatory" Items and Services

- Physicians services
- Laboratory and x-ray services
- Inpatient hospital services
- Outpatient hospital services
- Early and periodic screening, diagnostic, and treatment (EPSDT) services for individuals under 21
- Family planning and supplies
- Federally-qualified health center (FQHC) services
- Rural health clinic services
- Nurse midwife services
- Certified pediatric and family nurse practitioner services

"Optional" Items and Services*

- Prescription drugs
- Medical care or remedial care furnished by other licensed practitioners
- Rehabilitation and other therapies
- Clinic services
- Dental services, dentures
- Prosthetic devices, eyeglasses, durable medical equipment
- Primary care case management
- TB-related services
- Other specialist medical or remedial care

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Figure 9

Medicaid Long-Term Care Benefits

"Mandatory" Items and Services	**"Optional" Items and Services***
Institutional Services	
- **Nursing facility (NF) services for individuals 21 or over**	- **Intermediate care facility services for the mentally retarded (ICF/MR)** - **Inpatient/nursing facility services for individuals 65 and over in an institution for mental diseases (IMD)** - **Inpatient psychiatric hospital services for individuals under age 21**
Home & Community-Based Services	
- **Home health care services (for individuals entitled to nursing facility care)**	- **Home- and community-based waiver services** - **Other home health care** - **Targeted case management** - **Respiratory care services for ventilator-dependent individuals** - **Personal care services** - **Hospice services** - **Services furnished under a PACE program**

*These benefits are treated as mandatory for children under 21 through EPSDT in this analysis, with the exception of Home and Community-based waiver services.

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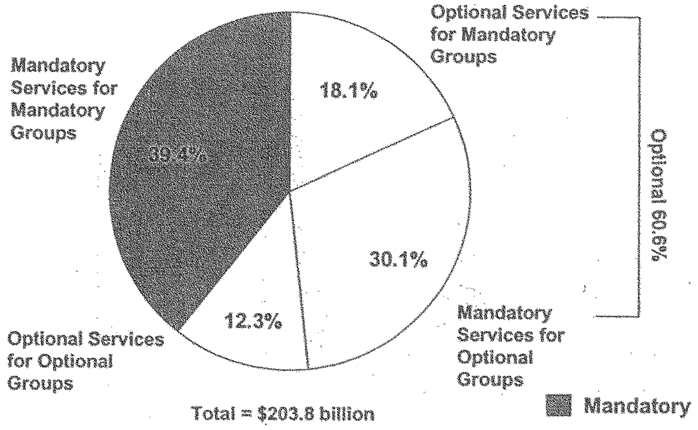
Figure 10

Medicaid Expenditures by Eligibility Group and Type of Service, 2001



NOTE: Total expenditures do not include disproportionate share hospital (DSH) payments, administrative costs, or accounting adjustments.

SOURCE: Urban Institute Estimates based on FFY data from MSIS 2001 and CMS 64 reports.

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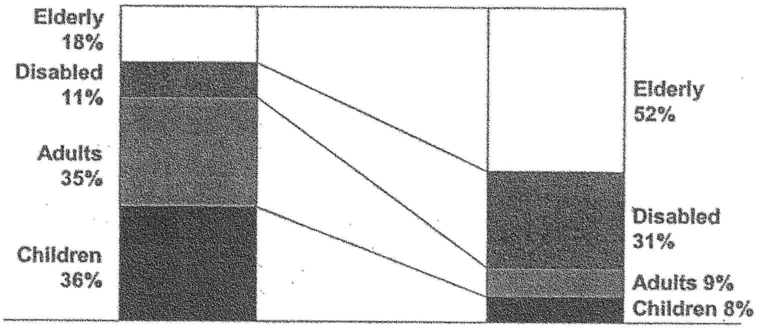
Figure 11

Medicaid Optional Enrollees and Their Expenditures, by Group, 2001



"Optional" Enrollees

Total = 13.8 million

Expenditures for "Optional" Enrollees

Total = $86.5 billion

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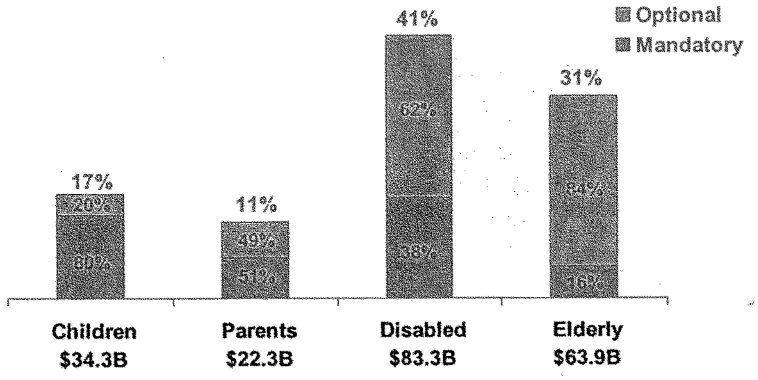
Figure 12

Medicaid Expenditures by Eligibility Category and Type of Service

Percent of Total Spending:



NOTE: Optional services for mandatory groups are counted as "optional" spending.
SOURCE: Urban Institute Estimates based on FFY data from MSIS 2001 and CMS 64 reports.

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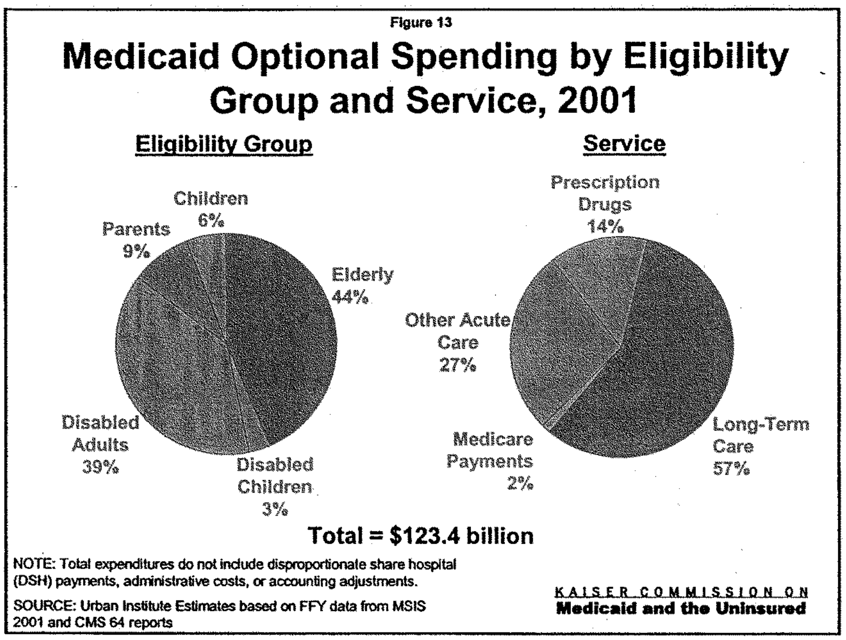

Figure 13

Medicaid Optional Spending by Eligibility Group and Service, 2001

Total = $123.4 billion

NOTE: Total expenditures do not include disproportionate share hospital (DSH) payments, administrative costs, or accounting adjustments.

SOURCE: Urban Institute Estimates based on FFY data from MSIS 2001 and CMS 64 reports

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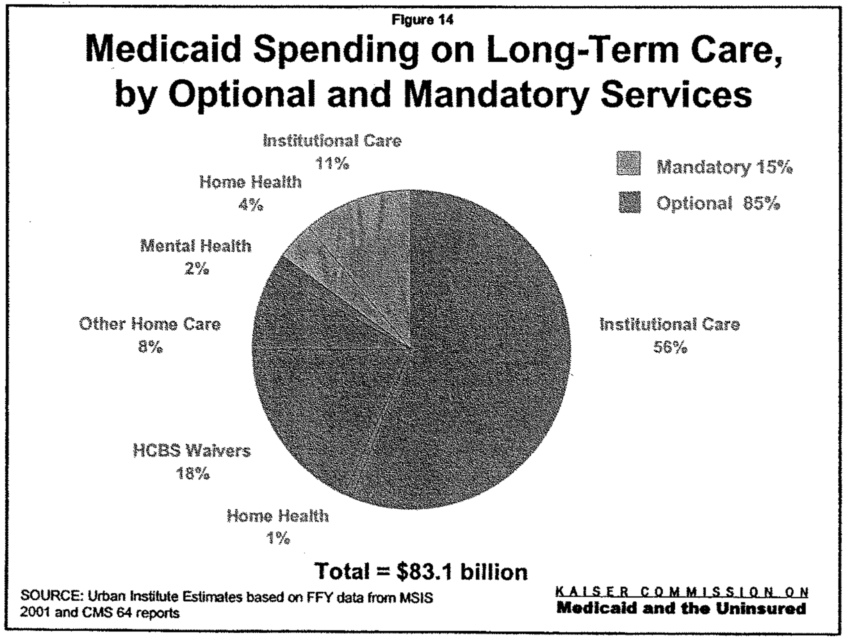

Figure 14

Medicaid Spending on Long-Term Care, by Optional and Mandatory Services

Total = $83.1 billion

SOURCE: Urban Institute Estimates based on FFY data from MSIS 2001 and CMS 64 reports

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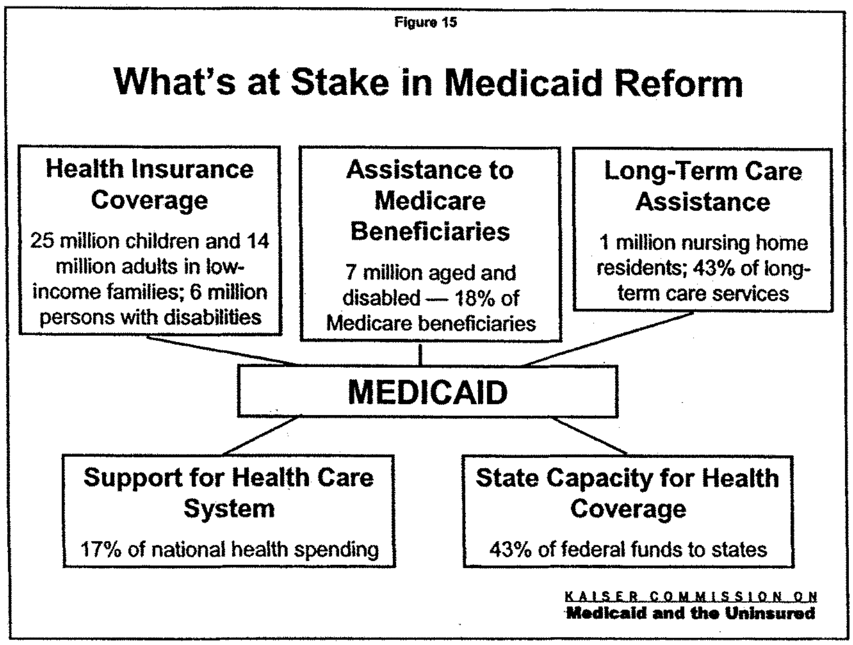

Figure 15

What's at Stake in Medicaid Reform

Health Insurance Coverage

25 million children and 14 million adults in low-income families; 6 million persons with disabilities

Assistance to Medicare Beneficiaries

7 million aged and disabled — 18% of Medicare beneficiaries

Long-Term Care Assistance

1 million nursing home residents; 43% of long-term care services

MEDICAID

Support for Health Care System

17% of national health spending

State Capacity for Health Coverage

43% of federal funds to states

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The CHAIRMAN. We will now call up our second panel. That panel will consist of Pamela S. Hyde, who is the secretary, New Mexico Department of Human Services at Santa Fe, NM—welcome, Pamela; Howard Bedlin, vice president for Public Policy and Advocacy, the National Council on the Aging here in Washington, DC; Jeffrey Crowley, project director, Health Policy Institute at Georgetown University here in the District; and Sister Karin Dufault, who is the chair of Board of Trustees, Catholic Health Association in Seattle, WA.

Why do we not go in the order announced? So, Pamela, you are first at bat.

PAMELA S. HYDE, J.D., SECRETARY, NEW MEXICO HUMAN SERVICES DEPARTMENT, SANTA FE, NM

Ms. HYDE. Thank you, Chairman Smith, distinguished members of the committee when they get here.

The CHAIRMAN. Yes. [Laughter.]

Ms. HYDE. My name is Pamela Hyde. I am secretary of the New Mexico Human Services Department. That is a department that is responsible in New Mexico for the Medicaid program. We also administer several other Federal and State programs.

I am grateful to the chairman and to the committee for holding these hearings, and I am especially grateful to you, Senator Smith, and to our Senator Bingaman, for your leadership in trying to find some compromise in this process and for trying to resist the massive cuts that were originally proposed to the program. So thank you.

The CHAIRMAN. You are welcome.

Ms. HYDE. I would like to make three points about the role of the Medicaid program in serving people with mental illness, and then make three recommendations.

First, Medicaid is a critical source of funding for the services upon which persons with mental illness rely. Reducing that funding will not make those service's needs go away. Individuals served through Medicaid are often severely disabled by mental illness or substance abuse, and without services designed to assure their ability to live and work in the community, they end up in other systems where services will significantly be more costly, such as inpatient settings, emergency rooms, or they will be inappropriately addressed, such as jails, prisons, juvenile justice settings and homeless shelters.

Medicaid now exceeds for the first time half of the public mental health expenditures nationwide. In New Mexico Medicaid accounts for over 60 percent of those public mental health expenditures. States need Federal assistance to increase their expenditures for mental health and substance abuse, not decrease them, by absorbing reductions in Federal funding or forcing States to reduce the single most important source of funding for behavioral health treatment in support of services.

Medicaid recipients of mental health services generally need ongoing services due to the severity and chronic nature of their disorders. However, some of the adults most in need of mental health and addictions services are not quite disabled enough to receive a disability designation. The irony is that in many States a member of a “mandatory population” with a less critical clinical need may be entitled to a mandatory mental health service, while an optional or even ineligible, high-need, high-risk adult or child cannot get an optional or a mandatory service such as assertive community treatment, multi-systemic therapy, or even medications.

Second point. Many of the populations and most of the services considered to be optional in the Medicaid program are simply not optional for people with mental illness. Mandatory services, as you know, include outpatient, inpatient, physician services. However, they do not include medication monitoring or prescription medications, which are critical, especially for people with severe mental illness.

They do not include clinical services of psychologists or social workers or personal assistance programs. Mandatory services do not include those community based services that are particularly helpful for the management of symptoms and life with mental illness.

They also do not include those most widely accepted evidence-based practice such as medication algorithms, assertive community treatment, family cycle education, therapeutic day care, respite care, multi-systemic therapy or even targeted case management. Even psychologists and social workers, as I indicated, are not mandatory in the Medicaid program.

These are all services that are not optional by any means for adults with serious mental illness or children with severe emotional disturbance. States are forced to reduce the cost of their Medicaid programs. They have no choice but to reduce those services that are considered optional by the Federal Government. Since some populations in need of behavioral health services in almost all the services needed by seriously mentally ill adults and severely emotionally disturbed children are optional, these artificial distinctions have a disproportionate impact on such individuals.

Third. Medicaid rules and regulations stifle creativity in the treatment of persons with mental illness and addictions, and prevent the utilization of evidence based practices for such individuals.

I have mentioned that some already, but some of the most appropriate supportive services for these individuals, such as a supported housing, supported employment, integrated treatment approaches for co-occurring disorders, respite care for adults, afterschool therapy, they are difficult if not impossible to get in the Medicaid program even through waivers. States find themselves in the awkward situation of being required to fund medically oriented services for populations that would best be served by a rehabilitative or supportive therapies approach.

The mandatory and optional categories just do not work well for people with behavioral health needs, and some CMS waivers, Oregon being an example, even allows mental health and substance abuse benefits to be excluded from some of the limited benefit package approaches being tried through waivers.

Because of the historical unwillingness of the Federal program to pay for institutional care for adults between 18 and 64, we have something called the IMD exclusion which makes it very difficult for States to make the case about financing of home and community based services in order to obtain these waivers for adults with mental illness.

I want to highlight just three recommendations in this short time, and would be glad to answer questions.

First, Medicaid reform cannot be disconnected from Medicare. Many adults with serious mental illness are duly eligible for both programs as are many children. Once Medicare Part D begins, many of these individuals are going to find themselves dealing with multiple formularies and having to receive some of their medications through Medicare, some through Medicaid, and some not through either. Medicare does not cover all the needs of persons with mental illness and in many ways is discriminatory about that benefit, especially not the Medicaid optional rehab services. So coordination of benefits is necessary and it is always difficult to do that coordination for the individual, for their families and their providers.

Additionally, dual-eligible individuals have to wait 2 years, as do all dual-eligibles, to become Medicare eligible. They may receive Medicaid services during that 2 years, then they must switch to those services that Medicare will cover and begin the coordination of benefits. The 2-year waiting period should be eliminated so that those dually eligible individuals can be covered by Medicare upon receipt of their disability determination. Better yet, Medicare should pick up all the medication costs for this population from the day they are determined to be disabled, and should assure that the formularies cover all the drugs they need, including the newest anti-psychotic medications that have less side effects and therefore higher compliance rates.

Congress should seriously consider having the Federal Government take over the whole care of persons who are dually eligible. I know that is controversial, but in fact, I believe that it would save a lot of administrative costs both at the provider level, at the State level and at the Federal level, trying to do this coordination of benefits.

Second. Make it simple to allow States to put evidence-based practices into their State plans or waiver programs. States have to wait long periods of time for approvals of State plan amendments and waiver requests even if they are changes other States have been doing for years. Mexico right now is waiting for approval for the addition of ACT teams. Almost every other State already has these in their State plan, it should not be a big thing to do.

Anything another State has been allowed to do, especially if it helps to implement an evidence-based or promising practice for adults or children with behavioral health needs, should be allowed on a fast-track approach. CMS needs to work with States to come up with creative ways to deal with the IMD exclusion so that housing supports and supported employment can be available for persons with mental illness. These services are available through waivers for other disability categories.

Third. As Congress considers reforms, do not make those reforms different for optional and mandatory populations without considering what may not be optional in the lives of those with serious behavioral health needs, and frankly, avoid simply making current optional services mandatory or simply protecting current mandatory populations and services. The assumption is that States are going to behave inappropriately in order to gain more Federal money. In fact, we share common goals including increasing services as well as containing costs.

States do not want to be in a situation where they have to reduce services or eligibility that will hurt the most vulnerable individuals because the Federal Government wants to preserve services for so-called mandatory populations and reduce its own spending for so-called optional ones. We should work together to contain costs while providing critical services for those most in need.

Thank you. I would be glad to answer any questions.

[The prepared statement of Ms. Hyde follows:]

TESTIMONY OF

PAMELA S. HYDE, J.D.
SECRETARY, NEW MEXICO HUMAN SERVICES DEPARTMENT

SENATE SPECIAL COMMITTEE ON AGING
JUNE 28, 2005

Chairman Smith, Senator Kohl, and distinguished members of the Committee, my name is Pamela Hyde, and I am Secretary of the New Mexico Human Services Department (HSD). HSD is responsible for New Mexico's Medicaid program and also administers other federal and state programs such as TANF, Food Stamps, Child Support Enforcement, and LIHEAP. As Secretary, I work with my colleagues in other departments across the state on health insurance and service delivery issues for children, families, seniors, and persons with disabilities, including persons with behavioral health needs. In other times of my life, I served as Ohio's Mental Health Director, Seattle's Housing and Human Services Director, and the CEO of Maricopa County's (in Arizona) Regional Behavioral Health Authority or RBHA. Over the years, I have had the privilege of consulting with many jurisdictions about behavioral health and services for persons with disabilities, including the use of Medicaid as a fund source for such services. I was the consultant assisting the President's New Freedom Commission on Mental Health's Subcommittee on Medicaid until I was appointed by Governor Richardson as Secretary of HSD in New Mexico.

In this role, since 2003, I have had the privilege to lead our state's innovative approach to behavioral health services financing and service delivery. New Mexico's Interagency Behavioral Health Purchasing Collaborative brings together 15 agencies to jointly purchase services for persons with mental health and substance abuse service needs, using multiple fund sources (including Medicaid, federal block grants, state general funds, child welfare funding, and other state and local funds). This joint purchase will be through one vendor to create a single and consistent statewide behavioral health delivery system throughout New Mexico. We are in the process of transitioning to that vendor multiple types of funds from six of those state agencies beginning July 1, 2005.

With Congress and the Administration engaged in the process of considering reductions of billions of dollars in Medicaid, it is important to try to understand how this enormously complex program works, what services it provides, and who the people are that it serves. I am grateful to the Chairman and to this Committee for conducting this careful scrutiny and honored to have the opportunity to assist. I am especially grateful to Chairman Smith for his leadership in trying to find compromise in this process and for resisting massive federal budget cuts to this critical program. I am also grateful for New Mexico's Senate leaders – Senator Bingaman who is a champion for the Medicaid program and for the low-income people and children it serves; and Senator Domenici who has been a spokesperson for persons with mental illness and their families.

Today, I would like to make three points about the role of the Medicaid program in serving persons with mental illness and/or substance abuse/addictions, and make three recommendations.

First, Medicaid is a critical source of funding for the services upon which persons with mental illness and/or substance abuse/addictions rely, and reducing that funding will not make these needs go away. Rather, individuals served through Medicaid are often severely disabled by mental illness or substance abuse, and without services designed to assure their ability to live and work in the community, they end up in other systems where their services will be significantly more costly (for example, emergency rooms or inpatient facilities) or will be inappropriately addressed (for example, jails/prisons or homeless shelters). The costs to society, to these other systems, and to the individuals themselves and their families are significantly higher than serving them appropriately through the Medicaid program where state and federal governments share the cost of community-based rehabilitative and supportive services that allow them to live and succeed in jobs, schools and communities.

According to data published in 2002 by the US Department of Health and Human Services, 16 percent of adult Medicaid beneficiaries and 8 percent of children use mental health services. Medicaid recipients of mental health services are generally adults or children with psychiatric disabilities who need on-going services due to the severity and chronic nature of their disorders. About 1.2 million adults receive Supplemental Security Income (SSI) and therefore Medicaid benefits due to a psychiatric disability; 260,000 children receive SSI and Medicaid due to a psychiatric disability. However, some of the adults most in need of mental health and addiction services are not quite disabled enough to receive a disability designation.

In most states, for example in New Mexico, if adults do not have children or are not disabled enough to be on SSI/SSDI, they are not eligible for Medicaid. As a result, they rely on paltry amounts of state general fund dollars from the General Assistance program for their food, housing and health care. Many states have eliminated similar programs so that such individuals have nowhere to turn. The irony is that in many states, a member of a "mandatory" population (for example, a low income TANF family) with a less critical clinical need may be entitled to a "mandatory" service such as a physician visit while an "optional" high need, high risk adult or child cannot get an "optional" service such as ACT, MST or medications.

According to federal SAMHSA and CMS officials, Medicaid programs spend nine to 17 percent of their overall expenditures on mental health and addiction services. In the early part of this decade, Medicaid became the single biggest source of funding for public mental health services administered by states (not including in-prison services for inmates of correctional facilities), accounting for over 50 percent of public mental health expenditures and more than a third of the mental health expenditures managed by state mental health agencies. In New Mexico, Medicaid accounts for over 60 percent of those expenditures and will account for almost 75 percent of the expenditures purchased through the Interagency Behavioral Health Purchasing Collaborative.

According to one study,[1] states spend four percent of its substance abuse expenditures for the treatment and prevention of substance abuse and addiction and ninety-six percent of its expenditures for the impacts on families, children, and other systems of not treating those substance abuse needs. States need federal assistance to increase their expenditures on mental health and substance abuse services, not decrease them by reducing federal funding or forcing states to reduce the single most important source of funding for behavioral health treatment and supportive services.

Second, many of the populations, and most of the services considered to be optional in the Medicaid program are simply not optional for persons with mental illness and/or addictions. Persons with mental illness are treated differently – one could say even in a discriminatory manner – compared to persons with other disabilities or medical needs in the Medicaid and Medicare programs.

"Optional" but critical services for persons with mental illness are available to states largely through what is called the Rehabilitation or Rehab Option. Mandatory services include outpatient, inpatient and physician services. However, they do NOT include medication monitoring or prescription medications, clinical services of psychologists and social workers, or personal assistance services. Mandatory services do NOT include those community based services that are particularly helpful for the management of symptoms and life with mental illness. They also do NOT include those now widely accepted evidence-based practices such as assertive community treatment (ACT), family psychoeducation (FPE), multi-systemic therapy (MST) or targeted case management (TCM). These are all services that are not optional by any means for adults with serious mental illness or children with severe emotional disturbances.

As states are forced to reduce the costs or the growth in costs of their Medicaid programs, they have no choice but to reduce access to services for those populations that are considered optional or to reduce optional services. Since some populations in need of behavioral health services and almost all the services needed by seriously mentally ill adults and severely emotionally disturbed children are optional, these artificial distinctions have a disproportionate impact on such individuals.

In waiver processes, CMS sometimes allows states to exclude optional mental health benefits from limited benefit package approaches to controlling Medicaid costs. Coupled with the disparate treatment of mental illness and substance abuse in the Medicare program, persons with mental illness are often treated differently and unfairly. Their physical health costs increase; their costs to other state/federal programs grow.

Third, Medicaid rules and regulations stifle creativity in the treatment of persons with mental illness and addictions, and prevent the utilization of evidence-based practices for such individuals. Some of the most appropriate supportive services for adults and children with mental illness or emotional disturbances such as supported

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[1] National Center on Addiction and Substance Abuse at Columbia University. (2001). Shoveling up: the impact of substance abuse on state budgets. New York, NY: Author, 13.

employment or housing arrangements for adults, integrated treatment approaches for persons with co-occurring disorders, and after school therapeutic programs for children are difficult if not impossible to obtain approval for – even through waivers as they are for other disabled populations. Because the Medicaid program for mentally ill individuals is medically rather than rehabilitatively oriented and because of the historical unwillingness of the federal program to pay for institutional care for adults with mental illness that had previously been paid for by states, a so-called IMD (Institutions for Mental Disease) exclusion is enforced for adults between the ages of 18 and 64. The IMD exclusion prevents states from making the case they are required to make about the financing of home and community based services in order to obtain waivers to fund these appropriate supportive services for adults with mental illness. Such waiver services are available for persons with developmental disabilities and other disabling conditions.

Again, states find themselves in the awkward situation of being required to fund medically oriented services for populations that would best be served by a rehabilitative or supportive therapies approach. The mandatory and optional categories do not work well for persons with behavioral health needs.

There are a number of recommendations that were made by the consultants who finished the background paper for the Medicaid Subcommittee of the President's New Freedom Commission on Mental Health. However, I want to highlight only three recommendations as you consider Medicaid reform and how it will impact persons with behavioral health needs.

First, Medicaid reform cannot be disconnected from Medicare. Many adults with serious mental illness are dually eligible for both programs. Until the Medicare Part D program begins, these adults receive their prescription drug services from Medicaid, and some of their physician or inpatient services through Medicare. Once Medicare Part D begins, many of these individuals will find themselves dealing with multiple formularies and having to receive some of their medications through Medicare, some through Medicaid, and some not through either (that is, they will have to self-pay for medications Medicare will not cover and that a state elects not to continue covering). Medicare does not cover all of the needs of persons with mental illness, especially not the Medicaid optional rehabilitative services, so coordination of benefits is necessary and is always difficult for the individual, their families and their providers.

Additionally, dually eligible individuals have to wait two years to become Medicare eligible. They may receive Medicaid services during that two years, then they must switch to those services that Medicare will cover once the waiting period is through.

At the least, the two year waiting period should be eliminated so that these dually eligible individuals can be covered by Medicare upon receipt of their disability determination. Better yet, Medicare should pick up all the medication costs for this population from the day they are determined to be disabled, and should assure that the formularies cover all the drugs they need, including the newest anti-psychotic medications that have less side effects and therefore higher compliance rates.

Best, Congress should seriously consider having the federal government take over the whole care of persons who are dually eligible, perhaps starting with those who are eligible due to mental illness and/or substance abuse. The savings to systems, to providers, and to states in not having to deal with coordination of benefits and the associated administrative burdens would be enormous. The simplification of process and better coordination of care for such individuals would be equally significant.

Second, make it simple to allow states to put evidence-based practices into their state plans or into waiver programs. States have to wait long periods of time for approvals of state plan amendments and waiver requests even if they are changes other states have been doing for years. New Mexico is waiting for approval of the addition of ACT teams to its state plan. Anything another state has been allowed to do, especially if it helps to implement an evidence-based practice for adults or children with behavioral health needs should be allowed on a fast track approach through forms and technical assistance from CMS regional offices charged with helping states do so. Rehab Option services should not only be allowed but be encouraged for all states. And, CMS needs to work with states to come up with creative ways to deal with the IMD exclusion so that housing supports and supported employment can be available to persons with mental illness and addictions just as they are for DD and other populations taking part in home and community based services waivers.

Third, as Congress considers reforms, do not make those reforms different for optional and mandatory populations or services without considering what may not be optional in the lives of those with serious behavioral health needs. Every state is now seeking to constrain the growth in health care costs. To the extent Medicaid is experiencing that growth because of increased pharmaceutical costs and increased eligibility of older and higher cost individuals, states are seeking the same kind of ability to control these rising costs as the federal government. CMS should work with states to find ways to do so without hurting those most reliant on the Medicaid and Medicare programs. The attitude seems to be that the federal government wants to control its costs and leave the states to figure the rest out on their own. The assumption is that states are going to behave inappropriately in order to gain more of the federal government's money instead of realizing that we are in this together; it's a partnership; and we share common goals

Congress has given CMS more funding to implement Medicare Part D, and put auditors into every state regularly and constantly. The Administration has proposed funding for the federal government to do additional outreach to get more eligible people enrolled, especially children. States want to do all these things, too. However, no one has given the states more money to implement all the administrative changes that are being put on their plates to implement Part D. No one has given me more staff to answer all the questions and produce all the reports demanded of us by the CMS auditors. No one has given me any money to do the additional outreach we'd like to do but cannot afford because we do not have the state match to serve additional people who might enroll.

If we get more people on the program (and we'd like to do so) I will simply have to do additional cost containment strategies to stay within my Medicaid budget. This in a state with high uninsurance rates, high poverty, and significant mental illness and substance abuse needs. This in a state that has been penalized from the beginning of the SCHIP program because we took a step before the federal government did to increase eligibility for children. That means we lose SCHIP dollars every year when other states get to use them for the very same population.

States are not the enemy. We have less flexibility than the federal government does. We do not want to be in the situation where we have to reduce services or eligibility that will hurt the most vulnerable individuals with mental illness because the federal government wants to preserve services to "mandatory populations" and reduce its own spending on so-called "optional" ones. The states and the federal government have a common goal to contain costs while providing critical services to those most in need. We should work together to do so. Thank You.

The CHAIRMAN. Thank you very much, Pamela. You mentioned in your testimony that some States have obtained waivers in order to exclude mental health from the optional category. How many States have done that?

Ms. HYDE. Mr. Chairman, I am sorry, I do not have the number of the States that have done that, but Oregon is certainly an example. When they did a limited plan, one of the things that were excluded were mental health and substance abuse services. New Mexico has a limited benefit plan that we are about to implement, but we did include mental health and substance abuse services, but that was an option. Had we chosen not to do so to save more money, we could have done that. But the point here is those are considered optional, they are not considered critical to the health of our Nation.

The CHAIRMAN. Has New Mexico quantified the other costs that are borne by the State when this option is pursued? I mean what has New Mexico done? Have you cut back on the mental health?

Ms. HYDE. Mr. Chairman, at the moment, no, and I think I need to say I have a fairly strong behavioral health background, so as the person in charge of this program I would probably lay my body down before we did that.

But having said that, we are actually—the only way we can increase services, because we have lost Federal money—we have lost FMAP because our economy got slightly better. We have lost the extra FMAP that the Federal Government provided, and we have lost huge proportions of it, more than other States, more than every other State except Texas even though we are an extremely poor State.

Having said that, the only way we are able at this point to increase services—and frankly, mental health is one of the sets we are trying to increase—is through better matching of existing State dollars. So we have something called the Interagency Behavioral Health Purchasing Collaborative. It is a unique approach. We are trying to look at every dollar and every State agency that is legitimately considered matchable, and use that to increase, for example, ACT teams we are trying to put into our State plan. We are trying to add intensive outpatient therapy and maybe next we will be looking at multi-systemic therapy which is now only done as an enhanced service at MCOs' options. In other words, our managed care organizations can do it just because they think it is a good thing to do, but it is nothing that we require in our State plan at this point.

The CHAIRMAN. As someone with your professional background, I assume you can attest to the fact that physical health and mental health are not exclusive, that both are legitimate fields?

Ms. HYDE. Mr. Chairman, absolutely, and in fact, what we know, that a lot of times people with severe mental illnesses or children with severe emotional disturbances also have higher physical health implications. So the cost to any health care program for untreated mental health services could be high, higher accidents, higher health and heart disease, higher high blood pressure, other high physical health needs go together with these issues.

The CHAIRMAN. Thank you very much, Pamela.

We have been joined by my colleague, Senator Tom Carper, former Governor of Delaware.

Senator CARPER. A graduate of Ohio State University. [Laughter.]

The CHAIRMAN. Yes.

Senator CARPER. I see that Pamela Hyde spent some time in, was it Columbus?

Ms. HYDE. Senator, yes, I did.

Senator CARPER. What did you do there?

Ms. HYDE. Actually, I worked for Governor Richard Celeste as his mental health director in his cabinet there, among other things.

Senator CARPER. When did you leave Ohio?

Ms. HYDE. I left Ohio, Senator, about 1990.

Senator CARPER. I think that was the year that George Voinovich was elected Governor.

Ms. HYDE. Mr. Chairman, that is correct.

Senator CARPER. All right, good enough. [Laughter.]

The CHAIRMAN. You have an opening statement, right?

Senator CARPER. I have no statement, but I am anxious—not anxious. I am looking forward to being able to ask a couple of questions when the time comes, but thanks very much. To our witnesses, whether you are from Ohio or not, you are welcome.

The CHAIRMAN. Or Delaware.

Senator CARPER. When I was at Ohio State I used to think Delaware was a little town just 30 miles north of Columbus. Later on after I graduated from Ohio State, I found out it was a whole State, and they were looking for a Governor, so I showed up and applied. [Laughter.]

Ms. HYDE. Mr. Chairman, Senator, I lived in Delaware for not too long. Delaware, Ohio, of course. [Laughter.]

Senator CARPER. Someday I will tell you a great story about going back for my high school reunion and running into a guy, and I had a State trooper with me. I was trying to get to a high school reunion, and just north of Columbus looking for this place, and I ran into this guy in a convenience store, and I had to get to this high school reunion just before 7 o'clock in the evening before they took the picture, the class reunion picture.

We went into this convenience store just about halfway between Columbus and Delaware, Ohio. This guy was coming out and I said I am trying to find my class reunion and told him where it was. He said, "Well, just go down this road, take a turn, go there and there." He said, "By the way, where are you from?" I said, "Well, I am from Delaware." he said, "Well, what do you do there?" I said, "Well, I am their Governor." he said, "I work in Delaware every day." He was thinking Delaware, Ohio, I am thinking the State. So here was a guy did not know we had a State either. [Laughter.]

The CHAIRMAN. All right. Our next witness, Howard Bedlin. You know where Delaware is?

Mr. BEDLIN. I go to the beach there all the time.

Senator CARPER. God bless you.

Good for the economy. [Laughter.]

STATEMENT OF HOWARD BEDLIN, VICE PRESIDENT, PUBLIC POLICY AND ADVOCACY, NATIONAL COUNCIL ON THE AGING, WASHINGTON, DC

Mr. BEDLIN. Thank you, Mr. Chairman, Senator Carper. I am Howard Bedlin, vice president for Public Policy and Advocacy with the National Council on the Aging.

Over 5 million seniors receive some form of assistance from Medicaid. A typical senior on Medicaid is a very poor, chronically ill widow in her 80's. In our view, the distinctions between mandatory and optional populations and services are not helpful in evaluating how to reform the program. Optional beneficiaries are among our Nation's most needy and vulnerable. They are not less worthy. Many optional services are essential, they are not less valuable.

Over the past 6 years both the Administration and the National Governors Association have recommended treating these populations and services quite differently, essentially by eliminating minimum Federal consumer protections. But would Federal nursing home quality standards for optional groups be eliminated? Could a State charge 50 percent coinsurance for home care to a senior at the poverty line, or could a State mandate children to supplement their mothers' nursing home payments? I hope not.

With the Federal Government paying 57 percent of Medicaid costs, imposing minimum standards is not unreasonable. Seniors may have the most to lose if Medicaid reform results in the elimination of Federal protections for optional populations and services since over 84 percent of Medicaid spending on the elderly is optional.

It is very difficult too for a senior to qualify for mandatory Medicaid services. In general they must need nursing home care. They have to have a monthly income below only $590—that is a little over $7,000 a year—and have non-housing assets below $2,000, which is not adjusted for inflation and has not been updated for over 20 years.

The primary senior Medicaid question we need to address is who will pay for long-term care? The States do not want to pay for it. The Federal Government does not want to pay for it, and seniors and their families simply cannot afford it.

Our long-term care crisis is growing worse. Overburdened caregivers are sacrificing their own health. Seniors have few choices to stay in their own homes, and after working hard throughout their lives, millions of seniors are forced to bankrupt themselves before getting help from Medicaid, which pays about 43 percent of our Nation's long-term care costs, more than any other source.

While Medicaid nursing home coverage is mandatory, only 16 percent of Medicaid's long-term care dollars for seniors are spent on home and community services, primarily through the Home and Community Based Waiver Program and the Personal Care Program, both of which are optional, but should be mandatory. Both fall far short of meeting consumers' and families' needs and suffer from enormous State variations. Even Medicaid protection against spousal impoverishment is institutionally biased since it is mandatory for nursing home care, optional for home and community based waivers, and non-existent for personal care.

Congress needs to take action this year to improve access to home and community services. NCOA recently released a report estimating that over 13 million households of those over age 62 are candidates for using a reverse mortgage to pay for home care, and the private sector funding could increase for such households that have an impaired member by $953 billion. Congress should permit States to use Medicaid dollars to reduce up-front reverse mortgage costs, and allow seniors who take them out to protect some assets from a State recovery.

Additional Medicaid reforms to promote independence and choice and reduce per capita costs are included in our written statement. For example, States should be able to provide home and community care through a State plan amendment rather than a burdensome waiver. Another important Medicaid category of service for seniors and people with disabilities is the Medicare savings programs which pay for Medicare premiums and cost sharing. These include the so-called QMB and SLMB programs. In addition, the QI–1 program also pays Medicare premiums for low-income beneficiaries, but it is a 100 percent Federal capped allocation and it is scheduled to expire this October 1.

While these programs are mandatory, there is no requirement that the Federal and State Governments find and enroll those who are eligible. Very few actually receive the benefits they are entitled to. QMB take-up rates are only 33 percent, while SLMB take-up rates are an abysmal 13 percent. That is about 1 out of 8 of those who are entitled to it actually get it.

Important lessons can be learned from a study issued just last week by the NCOA-chaired Access to Benefits Coalition which analyzed the best practices on outreach and enrollment.

Congress needs to strengthen the Medicare savings programs by simplifying and consolidating them, improving outreach and enrollment, indexing the asset test to inflation, and extending the QI–1 program for 5 years at a minimum.

In conclusion, our Nation's moral compass should be guided by how we treat our poorest and most vulnerable citizens, and frankly, Mr. Chairman, in terms of how we are caring for America's most frail mothers, grandmothers and great-grandmothers, we are doing a lousy job. With the aging of the baby-boom generation, there is a great need and opportunity for a national dialog and debate about how to best address our Nation's long-term care crisis. America needs a comprehensive national strategy that includes a strong public sector safety net and foundation of support, supplemented by a variety of high-quality private sector funding mechanisms.

NCOA looks forward to working with you, Mr. Chairman, and members of this committee and Members of Congress to address these challenges in a way that protects the most vulnerable, provides quality services, spends dollars as efficiently as possible, and promotes choice, independence and dignity. Thank you.

[The prepared statement of Mr. Bedlin follows:]

THE NATIONAL
COUNCIL ON
THE AGING

Testimony of the

National Council on the Aging

Before the
U.S. Senate Special Committee on Aging

on

Medicaid and America's Seniors

June 28, 2005

Howard Bedlin
Vice President, Public Policy and Advocacy
National Council on the Aging

300 D Street, SW | Suite 801 | Washington, DC 20024 | PH: 202-479-1200 | F: 202-479-0735 | www.ncoa.org

Thank you for this opportunity to testify on the Medicaid program and its importance to America's seniors. I am Howard Bedlin, Vice President for Public Policy and Advocacy for the National Council on the Aging (NCOA), the nation's first organization formed to represent America's seniors and those who serve them. Founded in 1950, NCOA is a national network of organizations and individuals dedicated to improving the health and independence of older persons and increasing their continuing contributions to communities, society and future generations.

Over 5 million of the oldest, lowest income, most vulnerable seniors in our nation receive some form of assistance from the Medicaid program. This assistance provides an essential safety net that meets critical health and long-term care needs not covered under Medicare.

In 2001, Medicaid spent an estimated $64 billion on the elderly. Approximately 9% of Medicaid enrollees are elderly, while about 26% of Medicaid dollars are spent on seniors. On average, Medicaid spends over $13,000 per year per elder enrollee, more than any of the other three categories of eligible groups (people with disabilities, children, and pregnant women and families). This is largely because Medicaid is the nation's primary payer for long-term care, including nursing home care that cost the program an average of over $124 per day in 2002, or over $50,000 per year in 2005. Medicaid also pays for some home and community services to help maintain independence and provide relief to family caregivers – the primary providers of long-term care in the country.

Another major Medicaid category of service for seniors is the Medicare Savings Programs, which pay for Medicare premiums and cost sharing. These include:

- The Qualified Medicare Beneficiary (QMB) program, which pays for Part B premiums and Parts A and B deductibles and coinsurance for beneficiaries with incomes below 100% of the Federal Poverty Level (FPL - $9,570 for singles; $12,830 for couples), and non-housing assets below $4,000 for singles and $6,000 for couples (twice the standard under the Supplemental Security Income (SSI) program); and
- The Specified Low-Income Medicare Beneficiary (SLMB) program, which pays for Part B premiums for beneficiaries with incomes between 100% and 120% of FPL, and assets levels similar to QMBs.

A third major category of services for seniors under Medicaid had been prescription drug coverage. This, however, will effectively end on January 1 when the new Medicare prescription drug benefit becomes available. States may continue to cover some drugs and receive a federal match for those Medicare will not cover, such as benzodiazepines, barbiturates, medications for weight gain or loss, and over-the-counter products. Unfortunately, states will not be able to receive a federal Medicaid match for helping low-income beneficiaries pay their cost sharing which – again unfortunately – for many will rise more rapidly than the general rate of inflation (at the rate of Medicare Part D cost increases).

State Medicaid programs also cover a number of other important services for seniors, such as dental services and dentures, respiratory care, prosthetic devices, orthotics, durable medical equipment, hearing aids, optometrist services and eyeglasses, podiatry and chiropractic care.

Seniors who also rely on Medicaid are known as "dual eligibles," or eligible for both Medicare and Medicaid. This group also includes younger persons with disabilities who have met the two-year waiting period criteria for Medicare eligibility. We appreciate the attention this Committee has already paid to dual eligibles by holding a hearing earlier this year on dual eligibles and the new Medicare prescription drug benefit, as these individuals face difficult and unique transition issues, and challenges in our health and long-term care systems in general. It is significant to note that over half of dual eligibles (52%) are in fair or poor health – more than twice the rate of other Medicare beneficiaries (24%) – and about one-third of dual eligibles have significant limitations in Activities of Daily Living (ADLs), compared with 14% of other Medicare beneficiaries.

Most of the seniors on Medicaid are women. The average woman over age 65 lives six years longer than the average man. As a result, she is often widowed and living alone. According to the Older Women's League (OWL), older women have average annual incomes of $15,615 compared with over $29,171 for men, with correspondingly lower assets. Not surprisingly, over 70% of adults ages 19 and older on Medicaid are women. The reality is, the typical senior on Medicaid is a very poor, chronically ill widow.

Mandatory and Optional Populations and Services

A primary focus of today's hearing is the traditional distinctions in the Medicaid program between mandatory and optional populations and mandatory and optional services.
In our view, these categories are not helpful in evaluating how to reform the Medicaid program. Many optional beneficiaries are among our nation's most needy and vulnerable. They are not less worthy. Many optional services are essential. They are not less valuable.

Unfortunately, a number of Medicaid reform proposals over the past five years have recommended treating these populations and services very differently, to the potential detriment of the elderly. Essentially, these proposals have suggested that minimum federal consumer protections should be eliminated for optional populations and services. In 2001, the National Governors Association (NGA) under Policy HR-32 suggested that for mandatory populations and services: "The federal government has essentially already defined this core group by establishing minimum standards below which no state is permitted to go. Therefore, for all of the populations covered under the federal minimum standards, states would guarantee both eligibility as well as the federal minimum requirements with respect to benefits." These guarantees and standards would not have been assured for optional benefits and optional populations. We were pleased, however, that the June 15, 2005 NGA *Medicaid Reform Preliminary Report* stated that the traditional distinction between mandatory and optional populations "are arbitrary distinctions when it comes to the need for health care services." We agree.

In its January 2003 budget proposal for FY 2004, the Administration proposed that states be given "carte blanche" flexibility to determine eligibility, services, cost sharing, and consumer protections for optional populations and services. The proposal also suggested that federal Medicaid contributions be capped. The Leadership Council of Aging Organizations, a broad coalition of over 50 national senior organizations, responded by stating: "The proposal would create incentives for states to underserve high cost enrollees, such as older Americans in need of long-term care. Persons needing the most expensive care, who are most likely to cause states to exceed their spending cap, would be at greatest risk of being targeted for potentially harmful cost containment strategies, such as limiting access or services."

The coalition also expressed serious concerns about undermining critical consumer protections for optional populations and services, asking:

- Would essential federal nursing home quality standards for optional groups be eliminated?
- Could a state choose to charge 50% coinsurance for home and community services to a frail senior with income at the poverty line?
- For an optional beneficiary, could a state choose to eliminate current spousal impoverishment protections?
- Could a state require families of optional Medicaid nursing home residents to supplement the payment to the nursing home?

These concerns illustrate the problems inherent in Medicaid reforms that might eliminate federal standards protections for optional populations and services, as well as the stake that seniors and their families have in this debate. With the federal government paying an estimated 57% of Medicaid expenditures, it is not unreasonable that certain minimum federal standards be met in return. While greater flexibility is desirable in some areas, we need to remember that the program is complex, the populations served are vulnerable, states are under budget pressures to cut the program, and significantly greater flexibility in certain areas could lead to discrimination against needy populations or harmful reductions in quality of care. It is also important to note that states already have a great deal of flexibility in administering the Medicaid program. As the June 2005 Kaiser Family Foundation report discussed in today's first panel concluded: "The legal distinction of services by mandatory and optional classes imposed by federal statute may not provide a useful roadmap for Medicaid restructuring."

Seniors may well have the most to lose if Medicaid "reform" results in the elimination of federal protections for optional populations and services. Fully **84.4% of Medicaid spending on the elderly is optional** – far more than for any other eligible category group. In addition, 48% of the elderly qualify for Medicaid through optional eligibility groups, again greater than for any other category.

It is also important to remember just how difficult it is for a senior to qualify for Medicaid in the mandatory category. Excluding MSP recipients, most of these individuals must need nursing home care, have income below the SSI level (only 74% of FPL, or annual income of only $7,082 for singles and $9,494 for couples) and non-housing assets below $2,000 for singles and $3,000 for couples. Surprisingly, the **asset limits are not adjusted annually for inflation and have not been updated in over 20 years.**

An important optional eligible group can access Medicaid in 35 states through the medically needy program. The program was designed for those with income somewhat above the eligibility levels, but who incur significant health costs. People can "spend down" by incurring medical expenses that reduce their income below the state's eligibility level. This option is particularly important for elderly nursing home residents. Fifteen percent of elderly Medicaid enrollees are medically needy, a higher percentage than for any other group. In 2000, $10.9 billion of the $23.8 billion spent on the medically needy were elderly enrollees (46%).

Medicaid and Long-Term Care

The primary issue America must address regarding seniors needing Medicaid is simply: Who will pay for long-term care? Long-term care is expensive and those who need it most – persons over 85 years of age – are the fastest growing segment of our population. The future is scary. The states do not want to pay for it. The federal government does not want to pay for it. And seniors and their families cannot afford it.

Our nation faces a long-term care crisis that is rapidly growing worse. After working hard throughout their lives, millions of seniors are forced to bankrupt themselves before receiving help. Overburdened caregivers are sacrificing their mental, physical, and economic health. America's so-called long-term care "system" is characterized by limited choices, fragmentation, confusion and institutional biases. And the lifeblood of our nation's long-term care system is the Medicaid program.

Medicaid pays for an estimated 43% of our nation's long-term care costs – more than any other source. In 2001, 57% of total Medicaid spending for optional populations and services was for long-term care. Of the $83 billion Medicaid spent that year for long-term care, fully 85% of the amount was for optional populations and services ($70.7 billion). An estimated 60% percent of nursing home residents are on Medicaid and about 46% of nursing home revenues are derived from the program.

Our nation spends far more Medicaid long-term care dollars on institutional care than for home and community services, despite consumers' and families' strong preferences for the latter and the generally lower per capita costs for these services. Medicaid spends about 70% its long-term care dollars on institutional care. The nursing home bias for seniors on Medicaid is even more alarming. According to the Urban Institute, **only 16% of Medicaid's long-term care expenditures for the elderly are spent on home and community services.** The time for empty rhetoric on this problem is over. Congress needs to take action on Medicaid's institutional bias this year.

NCOA is very concerned about the prospect that the federal and state governments may attempt to shift even more of the burden for the cost of long-term care on to those in need and their families. Congress is proposing to cut Medicaid by $10 billion over the next 5 years. The NGA *Medicaid Reform Preliminary Report* stated: "Medicaid can no longer be the financing mechanism for the nation's long-term care costs and other costs for the dual eligibles." A recent survey by the Kaiser Family Foundation found that 17 states have targeted long-term care for Medicaid cuts. A February 2005 *Business Week* article on Medicaid stated: "Seniors and the disabled are pushing the program to the breaking point" and "policymakers in Washington and in state capitals increasingly have their eye on the looming cost of caring for the elderly and disabled."

Improving Access to Medicaid Home and Community Services

Rather than cutting benefits for low-income seniors and people with disabilities who need long-term care, more must be done to address the institutional bias in Medicaid. The two primary programs for accessing home and community services are the Home and Community-Based

Services (HCBS) waiver program and the Personal Care program. Both programs are optional and provide a broad range of services including important relief to family caregivers through respite and adult day services. Ideally, the programs should be mandatory. Congress in 1981, under section 1915(c) of the Social Security Act, authorized states to waive certain federal requirements and provide home and community services to those who would otherwise qualify for institutional care under Medicaid. All states have HCBS waiver programs. In 2002, an estimated 74% of HCBS waiver dollars spent were for Mentally Retarded/ Developmentally Disabled (MR/DD) enrollees. States have also had the option to offer personal care services under their state plan since the mid-1970s. In 2000, 27 states covered these services. In 2002, Medicaid spent $16.4 billion on HCBS waiver services and $5.6 billion on personal care.

Unfortunately, Medicaid home and community services – so critical to maintaining independence, dignity and choice for millions of frail seniors and persons with disabilities - fall far short of meeting the needs of these population and their families. A 2000 report from the University of California, San Francisco estimated that more than half the states had waiting lists for HCBS services. The Kaiser Family Foundation found that Texas, for example, has almost 75,000 people on its waiting list, with an average wait time of 2 years.

There is also great variation among states in the level of coverage for home and community services provided. An Urban Institute study found that Medicaid long-term care spending in 1998 in the highest spending states was about four times greater than in the lowest spending states. A 2003 Government Accountability Office report found that differences in state policies have tremendous consequences for those who need long-term care. Two of the best state home and community service programs in the nation are in Oregon and Wisconsin. We are hopeful that the Chairman and Ranking Member of the Committee will hold future hearings on how others can learn from and replicate the successful programs in your states.

Another example of Medicaid's institutional bias is the fact that under current federal Medicaid law, protections that keep the spouses of Medicaid enrollees from also becoming impoverished are mandatory for nursing facility services, optional for HCBS waiver programs, and appear to be prohibited under the Personal Care program. In general, Medicaid will cover a beneficiary's nursing home care and permit the spouse who does not need benefits to keep one-half of the couple's countable assets, up to a ceiling. The monthly income allowance ranged from $1,492 to $2,267, with asset allowances ranging from $18,132 to $90,660, in 2003. An estimated fifteen states do not provide spousal impoverishment protection for HCBS waiver programs. It makes no sense for federal law to prohibit a state from providing spousal protections for personal care. Providing spousal protections for home and community services will alleviate a huge financial and emotional burden for many married couples. It should be noted that a much higher percentage of Medicaid home and community service recipients are married than nursing home residents. The failure to provide spousal protections can bankrupt a healthy spouse or split families apart, providing incentives for divorce, lawsuits and other serious conflicts. We need a more family-friendly policy. States should be given the flexibility to provide spousal impoverishment protections under the personal care services program. In addition, incentives should be created for states to provide spousal protections under both the personal care and HCBS waiver programs.

We are pleased, however, that state Medicaid programs increasingly are making consumer directed services available, such as cash and counseling. But much more can and should be done. Consumer directed programs offer maximum choice and control for people to select, manage, and dismiss their workers. Consumers can decide which services to use, which workers to hire, and what time of day they will come and leave. They can decide whether to hire family members and whether to spend the available funds on things other than services. Evaluations from the initial three cash and counseling demonstration projects in Arkansas, New Jersey and Florida have provided significant and meaningful results in finding that consumers experienced improved quality of life and satisfaction with their care.

NCOA testified in April before the House Energy and Commerce Committee on encouraging seniors to use the equity in their homes to stay at home through increased use of reverse mortgages. In January, NCOA released a report entitled: *Use Your Home to Stay at Home: The Role of Reverse Mortgages to Pay for Long-Term Care at Home.* Based on our analysis of the 2000 Health and Retirement Study, NCOA estimates that almost half of households age 62 and older - 13.2 million - are candidates for using a reverse mortgage to pay for long-term care at home (defined as being able to receive a minimum of $20,000 from this loan). The amount of funds that could become available if these older homeowners liquidated a portion of their home equity is substantial. By calculating the amount of funds that could be available from reverse mortgages for individual households, we estimate that these loans could increase private sector funding for in-home services and supports in total by $953 billion.

Payments from a reverse mortgage can help reduce dependence on Medicaid and reduce the risk of institutionalization. Increased use of this financial option for long-term care could result in savings to Medicaid ranging from about $3.3 to almost $5 billion annually in 2010, depending on market penetration rates increasing from 4 percent to 25 percent of older homeowners.

Congress and the states have an important role to play in encouraging the appropriate use of reverse mortgages. Within the context of Medicaid reform, the federal government can give states a variety of tools to use to promote reverse mortgages, including:

- Permitting states to use Medicaid dollars to reduce up front reverse mortgage costs;
- Permitting states to allow seniors to protect a certain amount of assets from estate recovery if they take out a reverse mortgage;
- Clarifying the priority of liens to enable spouses of nursing home residents to take out reverse mortgages; and
- Clarifying that proceeds from reverse mortgages will be treated as loans and not income for purposes of determining Medicaid and other means-tested program eligibility.

There are a wide variety of other Medicaid long-term care reforms that would promote greater independence, dignity and choice, while reducing per capita costs. For example, NCOA supports:

- The President's "Money Follows the Person" rebalancing proposal (S. 528). Under the proposal, for persons transitioning out of institutions, the federal government would cover the entire first year of costs for Medicaid home and community-based waiver services in select states;
- Permitting states to provide Medicaid home and community-based services (HCBS) under a state plan amendment, rather than having to go through an often burdensome waiver process;
- Giving states more flexibility by eliminating the current requirement that Medicaid HCBS coverage be linked with a need for nursing home level of care;

- Recognizing under the Medicaid eligibility asset test that persons in need of HCBS must pay for housing, food, clothing, utilities, and transportation, while nursing home residents do not incur these costs;
- Permitting states to include savings from Medicare and other federal programs in their Medicaid HCBS waiver budget neutrality calculations;
- Reducing barriers for states to provide consumers with greater opportunities to choose consumer directed models of Medicaid home and community services; and
- Permitting Medicaid recipients in need of long-term care to receive community attendant services as an alternative to institutional care (S. 401).

A final note of interest on Medicaid long-term care optional vs. mandatory services: few realize that home ***health*** services are a mandatory Medicaid benefit for individuals entitled to nursing facility services under state Medicaid plans. Services must be medically necessary and ordered by a physician as part of a plan of care. In 2001, Medicaid payments for home health services totaled $3.5 billion for more than 1 million beneficiaries. Beneficiary eligibility does not depend on the need for institutional care. According to a 2000 report from George Washington University:

> "Misperceptions [about the Medicaid home health benefit] are common, however, that additional Federal requirements do further restrict who may receive home health services... [M]any assume that individuals must be *eligible* for nursing facility care in order to receive home health services (i.e., that they must meet a state's nursing facility level-of-care criteria). This misunderstanding has most likely arisen because people have misinterpreted the word *entitled* to nursing facility care to mean *eligible* for nursing facility care. The Federal requirement specifies only the minimum coverage group and does not require that the individual meet a nursing facility level of care (i.e., be eligible)." [*Understanding Medicaid Home and Community Services: A Primer*, George Washington University, Center for Health Policy Research, October 2000]

We know of no evaluation of how the Medicaid home health benefit is actually working in the states. It may be desirable for the Government Accountability Office to evaluate the Medicaid Home Health program.

The Medicare Savings Programs (MSPs)

As stated earlier, the MSPs provide critical protections against out-of-pocket costs for the lowest income Medicare beneficiaries. Medicaid pays for this protection under the QMB and SLMB programs. We agree with the NGA and many others that, ideally, these programs should be a federal Medicare responsibility.

It is important to understand that a third MSP is the Qualified Individual (QI-1) program. It is similar to the SLMB program in that it pays for Part B premiums, but for beneficiaries with incomes between 120% and 135% of FPL, with similar SLMB asset levels. However, the program is not under Medicaid and is not even permanent. The QI-1 program was established under the 1997 Balanced Budget Act and is 100% federally funded, up to a capped allocation to the states. It was initially created for a 5-year period, and has been extended for one year each time it was scheduled to expire. NCOA is pleased that the Administration has again supported extending the program for a year, but we strongly believe the program should be permanent and combined in some fashion with the SLMB program. At a minimum, we urge Congress this year to extend the QI-1 program for at least five years. We are particularly grateful to Senator Bingaman for his continued efforts to protect and extend the program.

Although MSP programs are mandatory, there is no requirement that the federal and state governments make the efforts necessary to find and enroll beneficiaries in these programs. According to CBO, **QMB take-up rates are only 33%, while SLMB take-up rates are an abysmal 13%.** In addition, according to a 2003 report for CMS by the Research Triangle Institute, QMB and SLMB enrollment rates vary significantly by state – from 26% to 88%. *Far more* needs to be done to find and enroll these vulnerable beneficiaries in MSP programs, whose value has been demonstrated in improving access to care. This also applies to Medicaid itself where, even after 40 years, enrollment among eligible seniors is only 60%. It is NCOA's fervent hope that outreach and enrollment efforts to provide extra help to low-income beneficiaries under the new Medicare prescription drug benefit will create opportunities to improve MSP and Medicaid take-up rates as well.

A number of relevant lessons have been learned and should be applied from a recent *State Solutions* demonstration, directed by the Rutgers Center for State Health Policy. Additional important lessons can be learned from the first nationwide study, issued last week by the NCOA-chaired Access to Benefits Coalition, of best practices on local and national outreach and enrollment strategies: ***Pathways to Success: Meeting the Challenge of Enrolling Medicare Beneficiaries with Limited Incomes***. NCOA also supports the creation of a National Center on Senior Benefits Outreach and Enrollment in the Older Americans Act to help focus our attention and efforts, and address these serious shortfalls.

NCOA urges Congress to review and take action to strengthen the Medicare Savings Programs in order to: (1) simplify and consolidate the programs; (2) improve outreach and enrollment efforts; (3) index the asset test to account for inflation; (4) increase federal contributions; and (5) improve the levels of protection consistent with those under the Medicare Part D prescription drug benefit.

Finally, few realize that coinsurance under the QMB program is paid to providers at the Medicaid reimbursement rate, not the Medicare rate. In almost every instance, the Medicaid payment rate to providers is lower than the Medicare rate. This is particularly true of skilled nursing facility care. We continue to wonder whether these lower QMB cost sharing payments are contributing to provider access problems for QMBs.

Conclusion

Our nation's moral compass should be guided by how we treat our poorest and most vulnerable citizens. Medicaid is the essential health care safety net for over 5 million frail seniors. The vast majority of dollars spent on seniors under Medicaid are for services and populations that are technically identified as optional. These distinctions are not helpful in reviewing alternatives for reforming the program.

As Congress looks to reform Medicaid it is important to understand what is driving Medicaid cost increases and how these relate to the broader challenges facing our nation's health care system in general. For example, Medicaid has been more successful than the private sector in controlling health care spending per person. From 2000-2003, per capita Medicaid acute care spending increased 6.9% vs. a 12.6% average increase in monthly premiums for employer sponsored insurance, even though Medicaid serves a sicker population. Medicaid spending growth has predominantly been driven by enrollment growth. The aged and disabled accounted for only 10%

of the 8.4 million increase in Medicaid enrollment from 2000 to 2003. Much of the spending growth reflects a shift from private to public spending, not additional health care dollars spent overall.

Decision-makers must deal with the fact that Medicaid is the primary source of payment for long-term care and that these services are expensive. NCOA fears that the growing number of seniors who become impoverished and rely on Medicaid may cause major cuts in Medicaid services and coverage for younger people who lack basic health insurance. With the aging of the baby boom generation, there is a great need and opportunity for a national dialogue and debate about how to best address our nation's growing long-term care crisis. America needs a comprehensive national strategy and a universal long-term care program that includes a strong public sector safety net and foundation of support, supplemented by a variety of high quality private sector funding mechanisms. Additional federal revenues should be on the table, as should the appropriate roles of Medicare, Social Security, and the Older Americans Act. We should also look to other countries for the lessons that can be learned from their long-term care program experiences. NCOA is also hopeful that the December White House Conference on Aging will jumpstart this important national dialogue by underscoring the importance of these challenges, reflecting on the best use of public and private resources, and beginning to develop the outline of a plan for our nation in dealing with the growing long-term care crisis.

NCOA looks forward to working with members of Congress and others to address these Medicaid and long-term care challenges in a manner that protects the most vulnerable, provides quality services, spends dollars as efficiently as possible, and promotes choice, independence and dignity.

The CHAIRMAN. Howard, as we look for ways to save $10 billion over 5 years without reducing coverage to the people that should be on Medicaid, are there any things in your view that we ought to be considering? I mean how would you counsel us on that?

Mr. BEDLIN. Well, other than questioning whether we really should be saving $10 billion—we will leave that aside for the moment——

The CHAIRMAN. But I mean are there some programmatic things that we ought to be doing differently that would save the money so we can serve more people?

Mr. BEDLIN. Well, the two that I mentioned in my statement, for example, are looking at reverse mortgages, No. 1. We asked the Lewin Group to analyze how much savings could potentially be realized if we made those more available and a greater number of seniors who have an impairment, that have an ADL dependency, many of whom are very good candidates for a reverse mortgage actually took one out, and I think the study found that there could be savings of 3 to 5 billion. It is not I think over the next 5 years, but it is something that we think should be very seriously looked at this year. We could certainly share those estimates with you to give you a sense of what would need to be done to achieve those level of savings.

The CHAIRMAN. For the benefit of the committee, describe these reverse mortgages and how they would work in answering the question of long-term care.

Mr. BEDLIN. A reverse mortgage is essentially a loan that would allow a homeowner to convert home equity into cash while living at home for as long as they want. The borrower could continue to live in their home. They can receive payments as a lump sum or a line of credit or a monthly payment, and then the loan comes due when the last borrower moves out, dies or sells the home. They would never owe more than the value of the house, and we believe that many people could use their home to stay at home, and that they could delay the need to spend down onto Medicaid, and we think that it makes a lot of sense for a whole host of reasons, and could save some money as well.

The CHAIRMAN. Where is it being done now?

Mr. BEDLIN. The FHA makes so-called HECM loans available, and there are not a great many that have been sold. I think consumers need to learn more about them. There is a great deal that could be done in terms of public education. The up-front costs in some instances are prohibitive, and we think that there are ways that those could be reduced to make them more available.

We did a pretty comprehensive report this past January that we are happy to share with the committee. We had the author, who is an expert, Barbara Stucki, testify a couple months ago before the House Energy and Commerce Committee, and detail some specifics about the potential as well as what Congress could do to promote these. So that is one thing we think could save money.

Second, we do believe that making home and community services more available could reduce per capita costs. We would love to see the Congressional Budget Office take a broader view of the potential cost savings, not only in Medicaid but in Medicare and other programs as well. We do think that making home and community services more available could delay institutionalization. It could reduce cost, could improve quality of life, and through some pretty straightforward changes to Federal law, the institutional bias could be reduced somewhat, and we think that those could reduce Medicaid spending as well.

The CHAIRMAN. Because it would be far less expensive to leave them in their homes than putting them in these other institutions, that is your point.

Mr. BEDLIN. That is certainly our view, and if you look at Oregon, for example, which has, I would argue, one of the Nation's best home and community base care programs, and Wisconsin, Senator Kohl's State, those two States have done a wonderful job. I think there are important lessons that could be learned from those States, and I think that they spend their long-term care dollars much more efficiently and wisely than many other States.

The CHAIRMAN. That is a very good suggestion and certainly one that I am hoping that we will produce to answer the question of long-term care and who pays for it, and obviously I think while my State and others have done some things wrong, we certainly have done some things right, and that is one of them, and I appreciate you pointing it out. But I did not hear you promoting new premiums or higher copays. Would you speak to that as how effective or ineffective you think that would be?

Mr. BEDLIN. Well, I certainly have very serious concerns about higher cost sharing on populations that have such low income and assets. I think there are a number of studies, one recently by the Center on Budget Policy and Priorities, that found that higher cost sharing would keep the people in need from using the services that they really require to be well. So I think in the long run, while it could reduce utilization, you probably would find more people in emergency rooms because they would delay or neglect their health care needs.

So I think we really need to be extremely cautious about shifting even more costs onto the poorest Americans because I think at the end of the day it will not serve them well.

The CHAIRMAN. Thank you, Howard.

Senator Carper, do you have a question for this witness?

Senator CARPER. Yes, I do.

Mr. Bedlin, I want to come back and talk just a little bit about home and community-based services if we could. I think you mentioned that these are primarily optional services, and I would ask a couple of questions. What else can we do to increase the availability of these home and community services? A corollary to that is, maybe just talk a little about the cost of those services, and are they cheaper in your view than the cost of institutionalization?

Mr. BEDLIN. Thank you. Our written statement includes a number of specific recommendations. For example, there is a piece of the legislation that the administration has recommended that was introduced I believe by Senator Harkin, I believe, Senator Smith, you are a cosponsor, S. 528, Money Follows the Person proposal, which we think makes a great deal of sense for people transitioning out of institutions. The Federal Government would cover 100 percent of the first year of Medicaid home and community-based waiver costs. We very much support that and would like to see that enacted into law this year.

I mentioned earlier a State plan amendment rather than having to go through a waiver, would give States more flexibility. We also think that under current Medicaid law, in order to receive a waiver service, an individual needs to meet a nursing home level of care requirement. In other words, if a State has a three activities of daily living impairment requirement to get nursing home care, an individual getting home and community-based waivers also needs to have a three ADL impairment level. We think States should have more flexibility to distinguish between those two. So it might be three ADLs for nursing home care, but two ADLs for home and community services.

I mentioned spousal impoverishment protections, mandatory for nursing home care, optional for home and community-based waivers, non-existent for personal care. That could be addressed.

There is also a great deal that is going on in States on consumer directed care. Cash and counseling demonstrations in Arkansas, New Jersey and Florida have had very positive results. There are some things that could be done at the Federal level to make those more available, and I think a lot of people would be very interested in those kinds of alternatives.

In terms of savings, the concern has always been that people are going to come out of the woodwork because they want home and community services, and generally are not rushing to get into nursing homes. So the question is whether or not the savings that I think are probable on a per capita basis, whether or not those might be offset by more and more people utilizing the service. So that is really I think the issue that we need to look very closely at.

I know that in Wisconsin they have run I think some very good numbers showing that overall that there would be net savings. I do think that if you look at it on a case-by-case basis certainly you would find that home and community services are much less expensive. You know, for nursing home care, Medicaid on average is paying over $50,000 a year. It is much less than that for home and community services, and I do think that if you target the home and community-based care effectively, you can definitely realize cost savings in the long run and I think have a much more family friendly policy for folks that are caring for not only seniors but younger people with disabilities as well.

Senator CARPER. Thanks very much for responding to that.

Mr. Chairman, I am going to have to slip out and go meet with a former Governor of Ohio in just a moment. Can I ask another quick question of Ms. Hyde?

The CHAIRMAN. Sure.

Senator CARPER. Who is your Governor now?

Ms. HYDE. Mr. Chairman, Senator Carper, in New Mexico, where I am from, it is Governor Richardson.

Senator CARPER. Bill Richardson?

Ms. HYDE. You bet.

Senator CARPER. You know he was a member of the class of 1982 elected to the U.S. House of Representatives with Mike DeWine, Tom Ridge, John McCain, John Spratt, Marcy Kaptur also from

Ohio. There are a whole lot of people, and yours truly. When you see him, tell him that an old classmate says hello. Give him my best.

Ms. HYDE. I will do that, thank you.

Senator CARPER. I am going to try to come back before the panel finishes. Thank you.

The CHAIRMAN. Thank you, Senator.

Jeff Crowley.

STATEMENT OF JEFFREY S. CROWLEY, PROJECT DIRECTOR, HEALTH POLICY INSTITUTE, GEORGETOWN UNIVERSITY, WASHINGTON, DC

Mr. CROWLEY. Mr. Chairman, Senator Carper, good afternoon. I am Jeffrey Crowley, a project director at the Georgetown University Health Policy Institute. Thank you for inviting me to provide a disability perspective to the current Medicaid policy discussion.

An estimate 9.2 million non-elderly people with disabilities depend on Medicaid, and an unknown percentage of the 5.4 million seniors on Medicaid also have disabilities. For these individuals, Medicaid is generally the only place they can turn to have the full range of their needs met for health and long-term services.

Medicaid is the largest source of funding for developmental disability services, largest source of health coverage for people with HIV/AIDS, largest source of funding for State and local spending on mental health services, and it provides critical support for people across the spectrum of disability, including persons who are blind, individuals with traumatic brain injuries, spinal cord injuries, epilepsy and multiple sclerosis.

Much recent discussion has taken place over the difference between mandatory and optional beneficiaries. For people with disabilities the mandatory/optional distinction has no connection whatsoever to the level of disability or the need for health and long-term services. Some parties have characterized optional beneficiaries as higher-income individuals with less serious need for Medicaid assistance. Virtually all Medicaid beneficiaries with disabilities have extremely low incomes and all have met the same standard for serious long-term disability.

Seventy-eight percent of Medicaid beneficiaries with disabilities are mandatorily eligible. States, however, have several options to extend coverage beyond Federal minimums. These include the Poverty Level Option, which is particularly important for States that wish to extend coverage to many SSDI recipients; the Medically Needy Option, which permits States to cover individuals who spend down to coverage by subtracting medical expenses from their incomes.

There is no relation however, between the income standard for mandatory Medicaid and the Medically Needy income limit. Therefore, individuals may start out with income above Medicaid standards, but their effective income after their medical expenses are counted, leaves them often extremely poor. In one State individuals must spend down to $100 per month.

The CHAIRMAN. Where is that?

Mr. CROWLEY. That is in Louisiana, and also Arkansas has a Medically Needy income limit of $108 per month.

Although these and other options respond to differing needs of certain groups within the disability community, they share important commonalities. All the populations covered by the optional categories meet the same standard of need as mandatory populations, and the vast majority of individuals receiving Medicaid coverage through these options have very low incomes.

Although all mandatory services are critical, the EPSDT benefit is a mandatory service that is unique to Medicaid and is especially important to people with disabilities. The EPSDT benefit ensures that children on Medicaid are screened on a regular basis, and if a disability or health condition is diagnosed, the State covers the treatment. The rationale for this essential protection is that by intervening early, the harmful effects of disability can be minimized, and in some cases lifelong disability can be prevented.

Medicaid optional services sometimes have been characterized as discretionary services. The list of optional services, however, I think are more appropriately characterized as indispensable disability services because they are not frequently needed by people who are otherwise healthy. Moreover, many people end up on Medicaid because they have tried and failed to obtain these services elsewhere in the private market or in Medicare.

Critical optional services include prescription drugs, physical therapy and related services. The personal care option is also particularly important for extending access to community living services.

Optional services are mandatory for meeting the needs of people with disabilities, therefore, a State should not be permitted to not cover them or eliminate them every time there is an economic downturn.

The savings required by the budget resolution should not be achieved at the expense of Medicaid beneficiaries. I encourage you to focus on prescription drug reforms to achieve savings. Additionally, 42 percent of Medicaid spending is for services for low-income Medicare beneficiaries, the dual-eligibles. Even minor program adjustments to reduce the Medicare cost shift could relieve significant pressure off Medicaid.

Congress could, for example, end or phaseout the Medicare waiting period. Net savings could be achieved, however, through reductions in or elimination of the $10 billion in funding provided under the Medicare Modernization Act for the regional PPO stabilization fund.

Many other policy proposals to achieve Medicaid savings I believe are misguided and are a direct threat to people with disabilities. It would be very dangerous for the Congress to grant any new benefits package flexibility. New flexibility for States could only lead to new discrimination for people with disabilities. People with disabilities already have experience with States' ability to tailor benefits to specific populations through the Home and Community-based Services Waiver Program. What we have seen there is that which populations can access services and which cannot is not rationale.

Several policymakers have proposed relying more heavily on the private market. Unfortunately, people with disabilities often end up on Medicaid because the private market has failed them. Individuals with disabilities are already subject to cost sharing in Medicaid. In fact, when Medicaid does impose cost sharing, people with disabilities and chronic conditions, the people that use the most services, tend to bear the highest burden.

The best and perhaps only way to make long-term progress is not to look to Medicaid alone for policy solutions. The challenges facing Medicaid are a result of broad failures with our health system and long-term care system. Until broader reforms are implemented, however, we must continue to shore up Medicaid so that it can continue its successes at serving people with disabilities and others.

Thank you for the opportunity to appear before you today.

[The prepared statement of Mr. Crowley follows:]

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GEORGETOWN UNIVERSITY

Health Policy Institute

Statement of Jeffrey S. Crowley
Project Director, Health Policy Institute
Georgetown University

Before the Special Committee on Aging
United States Senate

June 28, 2005

2233 Wisconsin Avenue, NW Suite525 Washington DC 20007
202-687-0880 202-687-3110 facsimile
http://HPI.georgetown.edu

Mr. Chairman, Senator Kohl, and Members of the Committee,

Good afternoon. I am Jeffrey Crowley, a Project Director at the Health Policy Institute at Georgetown University. Thank you for inviting me to provide a disability perspective to the Medicaid policy discussion over distinctions between mandatory and optional eligibility groups and services. The majority of my work involves examining Medicaid and Medicare policy issues as they impact people with disabilities. Previously, I worked in HIV/AIDS policy as the Deputy Executive Director for Programs at the National Association of People with AIDS (NAPWA), and HIV policy issues continue to be an emphasis within my cross-disability work. I am grateful for the opportunity to provide my views on the impact on people with disabilities of various short and long-term Medicaid policy proposals.

Medicaid works for people with disabilities. Because of Medicaid, millions of children, adults, and seniors with disabilities are able to lead healthy and full lives. Notwithstanding these facts, Medicaid is imperfect and does not meet the needs of all beneficiaries with disabilities. As a nation, we have made great strides in valuing all of our citizens, including individuals with disabilities, yet Medicaid policies can sometimes hold people back by not providing them access to the health and long-term services they need if they wish to remain in their own home and remain fully engaged in their own communities. Nonetheless, the tools for building on Medicaid's success—and expanding access to community services—already exist within Medicaid, and the need to address this significant shortcoming of Medicaid does not lie in weakening the current structure of the program or taking financial resources out of the program.

As the policy debate over the future of Medicaid has unfolded, it has sometimes been frustrating to listen to common assertions about Medicaid. It has been said that Medicaid is broken, its spending is out-of-control, it is unsustainable, and that it is hurting rather than helping the individuals it is intended to serve. While the nation's health system faces many serious challenges, Medicaid is being set up as a scapegoat, and is inappropriately being blamed for a whole host of deficiencies with our broader health system. This is being done to justify radical, harmful change. I would like to help dispel some of these notions of Medicaid's failures by telling you about Medicaid's significant successes at serving people with disabilities.

Medicaid's Role for People with Disabilities

An estimated 9.2 million non-elderly individuals with significant disabilities rely on Medicaid, and an unknown percentage of the 5.4 million seniors on Medicaid also have significant disabilities.[1] For these individuals, Medicaid is generally the only place they can turn to have the full range of their needs met for both health and long-term services and supports.

Medicaid is the largest source of funding for developmental disability services, providing essential support to individuals and families of persons with mental retardation, cerebral palsy and other conditions; it is the largest source of health coverage for people with HIV/AIDS, greatly eclipsing both Medicare and the Ryan White CARE Act as a source of financing for life-saving HIV/AIDS health services; it is the largest source of state and local spending on mental health, providing essential support for community-based mental health services. Medicaid is a critical source of support for people across the spectrum of disability, including individuals who are blind, persons with traumatic brain injury, individuals with spinal cord injuries, individuals with epilepsy, multiple sclerosis, and various forms of serious mental illness including bipolar disorder, depression, and schizophrenia.[2]

Notwithstanding Medicaid's critical role, it does not cover all Americans with disabilities. Only an estimated 20% of non-elderly people with chronic disabilities are covered by Medicaid.[3] Individuals covered by Medicaid are the subset of the disability population whose disability is so severe that they met a strict standard for disability established by Congress and administered by the Social Security Administration and who have very low-incomes, and meet other financial and residency requirements.

Medicaid Eligibility for People with Disabilities

Much recent discussion has taken place over the difference between mandatory and optional Medicaid beneficiaries. With regard to people with disabilities, the mandatory/optional distinction has no connection whatsoever to the level of disability or the need for health and long-term services. Some parties have characterized optional Medicaid beneficiaries as higher income individuals with less serious need for Medicaid assistance. Virtually all Medicaid beneficiaries with disabilities have extremely low incomes and all have met the same standard for serious, long-term disability.

The majority (78%) of Medicaid beneficiaries with disabilities are mandatorily eligible.[4] These are individuals who are determined by the Social Security Administration to be disabled, and on the basis of their low-incomes and limited resources, they receive Supplemental Security Income (SSI).[5] In 2005, SSI provides an income supplement up to $579/month, ensuring that individuals with disabilities have income of at least 74% of the federal poverty level.[6] Because this income support is so low, many states provide state supplementary payments.[7]

There are several optional eligibility categories that states can use to extend Medicaid coverage to people with disabilities. I would like to highlight just a few of the primary options available to states:

Poverty Level Option: As of October 2001, 18 states plus the District of Columbia had taken up the poverty level option which permits states to extend Medicaid coverage to people with disabilities up to the poverty level.[8] This option is particularly important to many Social Security Disability Insurance (SSDI) recipients. These are individuals who paid into the Social Security system when they were employed, and after they became disabled for five months, they began receiving SSDI. Unlike SSI which supplements income up to 74% of poverty, SSDI payments are calculated from past payroll deductions to Social Security. Higher income workers receive higher SSDI payments if they become disabled. In May 2005, the average SSDI payment for a disabled worker was $897. This amounts to 112% of the federal poverty level. Therefore, the average SSDI recipient, although, quite poor, has income in excess of mandatory Medicaid standards. The poverty level option gives states the opportunity to extend coverage to some of these individuals.

Medically Needy Option: As of 2002, 35 states plus the District of Columbia operated medically needy programs.[9] This option permits states to extend coverage to individuals with extensive needs for health and long-term services who do not qualify for Medicaid as recipients of SSI. Frequently, these are low-income individuals with incomes slightly higher than the mandatory income standard, as well as individuals who may start out with significantly more income, but qualify when their incurred medical expenses are deducted from their income. The opportunity to spend down is particularly important to elderly individuals residing in nursing facilities and children and adults with disabilities who live in the community and incur high prescription drug, medical equipment, or other health care and long-term services expenses.

States have broad flexibility in operating their medically needy programs.[10] Although there is a general rule that once a state decides to make a Medicaid service available, it must make the service available to all beneficiaries when the service is medically necessary, this requirement does not apply to the medically needy. States are permitted to provide a more limited package of benefits to medically needy individuals. States also have broad flexibility in setting the medically needy income limit. Individuals with income above the highest income standard for categorically needy coverage, in states with medically needy programs, qualify for coverage when they incur medical expenses so that their income minus medical expenses is below the medically needy income limit. There is no relation, however between the income standard for mandatory Medicaid (which guarantees income of 74% of the poverty level) and the medically needy income limit. In fact, medically needy income limits are quite low. In 2001, the median medically needy income limit was 55% of the poverty level.[11] Therefore, individuals may start out with income above other Medicaid standards or above the poverty level, but their effective income, after medical expenses are deducted, can be significantly lower than mandatorily eligible beneficiaries with disabilities—and in some states can be exceedingly low.[12]

Katie Beckett Option: Twenty states have taken advantage of the Katie Beckett option (also called the TEFRA option), which is a state option created in 1982 that permits states to extend Medicaid coverage to children with significant disabilities who qualify for an institutional level of care, but whose family income would make them ineligible for Medicaid.[13] It permits states to not count parental income when determining financial eligibility for Medicaid. These are children whose need for services and supports is greater than most families can afford, and in the absence of this coverage option, parents may have to consider relinquishing custody of their children in order for them to receive Medicaid assistance in an institution.

Work Incentives Options: As of October 2004, 31 states have taken advantage of Medicaid work incentives options.[14] Over the past decade, the Congress and other policy makers have become increasingly sensitized to the barriers of obtaining health insurance coverage for people with disabilities. In many cases, Medicaid beneficiaries with disabilities would like to enter or re-enter the workforce, but have been afraid to do so because of the loss of Medicaid coverage. Even if employment comes with health insurance coverage, this coverage is often inadequate to meet the needs of people with disabilities. Through the Balanced Budget Act of 1997 (BBA)[15] and the Ticket to Work and Work Incentives Improvement Act of 1999 (Ticket to Work)[16], Congress created new state options for individuals with disabilities to retain Medicaid coverage while working. The BBA and Ticket to Work, taken together, give states the option to provide Medicaid coverage to working people with disabilities up to 450% of the federal poverty level and to use less restrictive income and resource methodologies when determining eligibility.[17] It is important to note, however, that enrollment in these programs has been limited and they do not account for a significant share of the Medicaid population of people with disabilities. Moreover, when the Government Accountability Office (GAO) looked at states early experience with these programs in 2003, a detailed review of four states found that the majority of participants in these programs had low very incomes with most earning less than $800 per month.[18]

Home and Community-Based Services Waivers: All states plus the District of Columbia, with the exception of Arizona, have at least one home and community-based services waiver.[19] Waivers are very different from the state plan options described above in that states do not need to comply with certain Medicaid rules. While these waiver programs have led to improvements in the delivery and availability of community living services, there are significant shortcomings with waivers—states can use them to extend access to some people with disabilities, but not others based on the type of disability or where individuals reside. Moreover, unlike state plan services, states are permitted to limit access to services. Waiting lists for home- and community-based waiver services can be quite long. For example, Texas has nearly 75,000 people on its waiting list for community living services and the average wait time is one-and-a-half years to receive services.[20]

These waiver programs, like state plan options, are one more way that states have broad flexibility to extend Medicaid eligibility to people with disabilities. Under the section 1915(c) waiver authority, states have the option of providing community-based long-term services and supports to individuals with disabilities at risk for institutionalization. States seeking these waivers have the option to make the eligibility requirements for these programs comparable to those for institutional services, including the 300% rule which permits states to provide institutional services to individuals whose income is below 300% of the current SSI payment level. This option is particularly important to state efforts to extend Medicaid coverage to beneficiaries in the Title II disability programs, including disabled adult children (DACs) who qualify for a Title II benefit and Medicare on the basis of a parent's work history and who have limited independent financial resources.

Although these options respond to differing and sometimes highly specific needs of certain groups within the disability community, they share several important commonalities. States were given these options to respond to important national health policy goals. All of the populations covered by these optional categories meet the same standard of need for Medicaid services as mandatory populations, and the vast majority of individuals receiving Medicaid coverage through these options have very low incomes. It is possible to live in a state with none of these options so that people with disabilities with income of $600 per month or less have no way to receive Medicaid assistance, no matter how extensive their need for health and long-term services. While state flexibility is an important goal, and state experimentation in Medicaid has led to program innovations, the time for experimentation has passed. An urgent challenge facing the Congress is to ramp up mandatory eligibility for these critical eligibility groups. In the context of strengthening and improving Medicaid, Congress may wish to consider a phased-in conversion of these and other "optional" eligibility categories to mandatory coverage, such as requiring coverage of all people with disabilities living in poverty to have access to Medicaid, and ensuring that individuals with disabilities residing in all states have the option to spenddown to Medicaid coverage.

Aldora Vinson, Medicaid Beneficiary

Aldora Vinson is 81 years old and lives alone in Thaxton, Mississippi. Her monthly income is $597. She suffers from severe diabetes, arthritis, hypertension, and pain. Her medications for these conditions would cost her $1,177 per month if Medicaid did not pay for them. Medicaid also pays for several other services she requires, including home health treatment, eyeglasses, and medical supplies. In 2004, Ms. Vinson's Medicaid eligibility was threatened when the state decided to eliminate coverage for her and 48,000 other "optional" seniors and people with disabilities. Subsequent action by the state's legislature protected her Medicaid coverage.

Medicaid Services Needed by People with Disabilities

All of the mandatory Medicaid services, including physician, hospital, and diagnostic services, are critically important to individuals with disabilities—and essentially anyone who seeks out health care. There is one mandatory benefit, however, this is unique to the Medicaid program and which is especially important to people with disabilities.

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Services: The EPSDT benefit ensures that children on Medicaid are screened on a regular basis and if a disability or health condition is diagnosed, the state must cover the treatment, even if the state doesn't provide the same services to adults in Medicaid. The rationale for this essential protection is that by intervening early, the harmful effects of disability can be minimized, and in some cases lifelong disability can be prevented. The EPSDT benefit also serves as an important tool in assisting children and young adults under age 21 to live in the community.

As the Congress considers changes to the Medicaid program, I strongly encourage you to defend the EPSDT benefit and the principle that children must be regularly screened and treated for health conditions when they arise in order to minimize and prevent disability. This is an essential investment in future generations. As the Congress considers future improvements, you may wish to provide new resources and impose new requirements on states to provide for continued access to community living services when individuals with disabilities become adults and "age out" of the EPSDT benefit. This is especially urgent in light of the fact that one in five young adults with disabilities (aged 19-29) is uninsured.[21]

Nick DuPree, Medicaid Beneficiary

Nick DuPree is a 23 year old resident of Alabama who drew national attention to the community-based services Medicaid provides to children and young adults through the EPSDT benefit. For several years, he led a national campaign to address the problem of young adults who lose access to critical EPSDT benefits when they turn 21.

Nick has a form of muscular dystrophy, and as a result of a botched surgery, he developed an infection that led to significant impairment. He has required the use of a ventilator for the past eleven years. For the past thirteen years, Nick has received Medicaid home- and community-based services—because his family's private coverage did not provide for in home care. Nick is one of thousands of people with disabilities who relied on Medicaid EPSDT services in order to live at home. In his case, he also relied on EPSDT services to support him in attending college. Despite the enormously positive improvement in Nick's life made possible by the EPSDT benefit, Alabama was ready to cut him off and put him in a nursing home when he turned 21. Because of the widespread attention brought to his plight, his state established a small scale waiver to permit Nick and a limited number of other young adults to continue receiving community living services. Throughout the country, states routinely reduce or eliminate critical services when young adults with disabilities turn 21.

Optional Medicaid Services are Essential Disability Services

In the recent policy discussion, Medicaid optional services sometimes have been characterized as discretionary services. The list of optional services are more appropriately characterized as indispensable disability services because they are frequently services not often needed by otherwise healthy individuals, but which play a critical role in meeting the health and long-term services needs of people with disabilities. Quoting a prominent disability advocate, Robert Williams, "there is nothing optional about our need to eat or to go to the bathroom." Moreover, many people end up in Medicaid after trying, but failing to obtain these services from the private market or Medicare.

Selected Medicaid Optional Services

Acute Care

- Prescribed drugs
- Medical care or remedial care furnished by licensed practitioners under state law
- Diagnostic, screening, preventive, and rehabilitative services
- Clinic services
- Dental services, dentures
- Physical therapy and related services
- Prosthetic devices
- Eyeglasses
- TB-related services
- Primary care case management services
- Other specified medical and remedial care

Long-Term Services and Supports

- Intermediate care facility for people with mental retardation (ICF/MR) services
- Inpatient and nursing facility services for people 65 or over in an institution for mental diseases (IMD)
- Inpatient psychiatric hospital services for children
- Home health care services
- Case Management services
- Respiratory care services for ventilator-dependent individuals
- Personal care services
- Private duty nursing services
- Hospice care

Source: Kaiser Commission on Medicaid and the Uninsured, "The Medicaid Resource Book", July 2002.

Every Medicaid optional service is essential to some individuals with disabilities. However, there are a few services for whom the need and dependence on these services is so critical, they are important to highlight:

Prescription Drugs: All states plus the District of Columbia provide coverage for prescription drugs, a service that is often a cornerstone of treatment for many individuals. It is hard to imagine how anybody could consider prescription drugs discretionary when one considers their role in modern medicine, evidenced by the dramatic decline in HIV/AIDS mortality brought about by the development of highly active antiretroviral therapies in the mid-1990s.[22] Prescription drugs also are an essential service that enables individuals with serious mental illness to live in the community and lead fulfilling and engaged lives. Recent advances in the pharmaceutical management of epilepsy have led to a standard of care where significant numbers of people with epilepsy able to become seizure free. As we look to the future, pharmaceuticals are expected to play an even greater role in improving lives and potentially reducing other Medicaid costs, for a broad range of health conditions.

While states have broad discretion in managing the Medicaid pharmacy benefit, states have been largely responsible in providing broad access to pharmaceuticals, in part because they are cost-effective. In absence of drug therapies, individuals with disabilities incur greater levels of hospitalization or disease progression. Many exciting things are happening at the state level with regard to managing the Medicaid pharmacy benefit and using clinical evidence to drive decision-making over when formulary restrictions and other cost-saving measures are appropriate. Greater reliance on evidence-based medicine, if done properly, holds the potential to produce significant savings for states and improve access to appropriate therapies. At the same time, there is increasing concern that some states, out of a desire to control pharmacy costs, are limiting access to prescription drugs in ways that are harmful to Medicaid beneficiaries. Mississippi and Tennessee are two states that are imposing "hard limits" of providing only 2 brand name drugs per month. Several other states have limits as low as three or four drugs per month, although the majority of these states impose "soft" limits and make drugs available above the cap through prior authorization.[23] Many, if not most, of the drugs used to treat disabilities are not available in generic forms. Moreover, the effective HIV treatment regimens that I referenced for their success at keeping people alive all require three to five brand name drugs. Across the spectrum of disability, many conditions require multiple drugs, and many individuals with disabilities receive treatment for multiple co-morbid conditions. It is not uncommon for people with disabilities to take 10 or more prescription drugs. Given that Medicaid beneficiaries with disabilities must sustain themselves with such limited incomes, often less than $600 per month, and that Medicaid beneficiaries with disabilities generally have no other source of coverage for prescription drugs, hard limits on the number of prescription drugs individuals can receive are counter-productive and inadequate to meeting the needs of people with disabilities. Again, when the Congress considers longer-term improvements to Medicaid, I urge you to consider strengthening federal standards for the adequacy of the Medicaid pharmacy benefit.

Physical Therapy and Related Services: As of January 2003, thirty states plus the District of Columbia provided physical therapy services and twenty-five states provided occupational therapy services.[24] Physical therapy and related services are illustrative of many optional services which may not appear as critical services, except to people with disabilities who rely on them. These services are not commonly used by Medicaid beneficiaries who do not have disabilities. Therapy services, such as physical therapy, occupational therapy, and speech and language therapy are critical to supporting individuals in minimizing the burden of disability and maximizing independence. For example, access to speech and language therapy services may mean that individuals with certain neurological conditions are able to communicate with others. Physical therapy services help people with conditions such as cerebral palsy to maintain control over their muscles—a defining symptom of their type of disability. Occupational therapy services help people with disabilities learn skills for performing activities of every day life and address psychological, social and environmental factors that impede independent functioning. Because persons with disabilities may be more susceptible to certain types of injuries, rehabilitation services are also critical in helping individuals to recover quickly—and to regain and maximize their ability to function in ways that may have been already impaired, due to disability.[25]

Personal Care and Rehabilitation Services: As of January 2003, twenty-eight states plus the District of Columbia provided personal care services and forty-three states provided rehabilitation services.[26] Personal care is a critical mechanism for providing long-term services and supports to individuals with disabilities so that they can live in and participate in life in the community. Many states also cover psychosocial rehabilitation services which, when combined with personal care and targeted case management services, can meet a wide range of service and support needs of persons with mental illness.

Optional services are mandatory for people with disabilities. I began this statement by saying that Medicaid works for people with disabilities. It works precisely because individuals are able to rely on Medicaid, in many states, for a range of optional, disability services that they cannot obtain elsewhere. There is nothing about these services that would justify permitting restrictive limitations. Indeed, efforts to restrict access to these services through arbitrary coverage limits is counter productive. When the level of service provided is insufficient based on what is medically necessary for the individual, real people are subjected to significant and long-lasting harm, and this will likely lead to increased Medicaid costs. Since the mandatory/optional service distinction is an historical artifact that does not distinguish between essential and discretionary services, Congress should consider longer-term reforms that create a more rational basis for permitting states to control costs, yet which do not depend on denying coverage for critical services. Since optional services are essential disability services, states should not be permitted to severely restrict them or eliminate them every time there is an economic downturn.

Current Policy Debate

I understand that this hearing, and much of the Congress' current interest in Medicaid is being driven by reconciliation instructions that call for the Finance Committee to find program savings of ten billion dollars over the next five years—and some level of savings is expected to come from Medicaid. Medicaid is already an underfunded and undervalued workhorse that is sustaining much of the rest of our health system. To the extent that savings come from Medicaid, I would urge each of you to ensure that such savings are as small as possible.

Prescription Drug Reforms

Many Members of Congress have defended budget savings targets for Medicaid by citing a "consensus" that significant Medicaid savings could be achieved by enacting prescription drug reforms, including a move to reliance on average sales price (ASP), and away from average wholesale price (AWP) for purposes of calculating Medicaid prescription drug rebates. While it will be incumbent upon the Congress to ensure that pharmacists are adequately reimbursed for dispensing prescription drugs to Medicaid beneficiaries, this is an area where the Congress should focus its efforts in identifying savings.

Also, when considering longer-term program improvements, this is an area where important changes can be made by building on the successes of certain states to use evidence-based medicine to manage the prescription drug benefit in a way that does not impede access to critical drugs for people with disabilities and others.

Responding to the Medicare Cost Shift

When Medicare was created, it excluded two important benefits—prescription drugs and long-term care. Attempts have been made over the years to expand Medicare's role in financing long-term, with limited success.[27] In the meantime, the share of nursing home costs paid for by Medicaid has doubled, from 22 percent in 1970 to a projected 52 percent in 2005.[28] Policy makers have focused almost exclusively on the prescription drug gap rather than the long-term care gap in Medicare, despite the fact that the cost of nursing home care for seniors is twice that of prescription drugs – representing a major cost to states and people in need.[29] An estimated 42% of Medicaid spending is for services for low-income Medicare beneficiaries (individuals receiving both Medicare and Medicaid are known as dual eligibles).[30] Even after the implementation of Medicare prescription drug coverage in January 2006, Medicaid will still be responsible for financing the costs of long-term care for low-income dual eligibles. Congress should look to the Medicare program to relieve some of the financing pressure on Medicaid. In fact, the burden on Medicaid programs for providing services to Medicare beneficiaries is so great that even minor program adjustments could relieve significant pressure off Medicaid. For example, Congress could:

- end or phase-out the Medicare waiting period in which individuals must wait twenty-nine months from when the Social Security Administration determines them to be disabled to receive Medicare. For low-income Medicare beneficiaries, Medicaid steps in to serve as the primary payer until Medicare coverage begins. One possible approach to addressing the problem is the *Ending the Medicare Disability Waiting Act of 2005* (S. 1217);
- require the Centers for Medicare and Medicaid Services (CMS) to amend the manner in which it implements the Medicare "in the home" requirement with respect to power wheelchairs and scooters. This policy denies Medicare coverage of power mobility devices when they are not needed exclusively in the home. Thus, an individual with multiple sclerosis, for example, who is able to navigate their home by leaning against the walls would be denied Medicare coverage for a power wheelchair, even though this is needed for individuals to leave their homes independently, such as to go to the store, visit their physician, or attend religious services. This policy is a burden on Medicaid because, for dual eligibles, Medicaid often ends up paying for these devices, even though it is a Medicare covered service;
- shift responsibility to Medicare for paying Medicare cost-sharing for dual eligibles. Medicaid, not Medicare, is currently responsible for assisting low-income Medicare beneficiaries with paying the Part B premium ($78.20/month in 2005) and cost-sharing for services under Medicare Parts A and B;
- relieve some of the burden on Medicaid for providing long-term services and supports by expanding Medicare's coverage of long-term services.

While the current reconciliation process requires savings to the federal government and would not simply permit a substitution of Medicare spending in place of Medicaid spending, Congress has the opportunity to enact program improvements to Medicaid by shifting more of the financing burden for services for low-income Medicare beneficiaries onto the Medicare program. Net savings could be achieved through reductions in or elimination of the $10 billion in funding provided under the Medicare Modernization Act (MMA) for the regional preferred provider organization (PPO) stabilization fund. Such a move has been endorsed by the Medicare Payment Advisory Commission (MedPAC).[31] I understand that many Members of Congress are reluctant to consider changes to the MMA before the law's main provisions become operational. Given the immense harm that could come to low-income Medicaid beneficiaries if the bulk of the reconciliation spending reductions is directed at Medicaid, however, this stabilization fund for private plans is simply indefensible. Moreover, while the reluctance to make policy changes within Medicare is understandable, it is unavoidable given the need to address the impending crisis caused by the absence of any transition period when more than 6.4 million low-income people with disabilities and seniors have their drug coverage transitioned from Medicaid to Medicare. Staff at the Centers for Medicare and Medicaid Services (CMS) is working very hard to ensure a smooth transition to Medicare drug coverage for dual eligibles. However, given that the most vulnerable segment of the Medicare population is being moved into the Part D prescription drug program first, with not a single day of overlapping drug coverage by Medicaid and Medicare, it strains plausibility to believe that this transition can be perfectly seamless. There is an urgent need for Congress, prior to January 1, 2006, to establish a short-term, one-time transition period so that individuals can continue to rely on Medicaid if they are unable to access appropriate drug coverage through Medicare, for the first six months of 2006.

Many other policy proposals to cut Medicaid benefits or eligibility, including many positions supported by the nation's governors, are misguided and are a direct threat to people with disabilities.

Benefits Package Flexibility

The nation's governors and other have advocated for new freedom to tailor benefits packages and give differing benefits to different groups of Medicaid beneficiaries. They have argued that they do not seek to deny any benefit when it is truly necessary, but they do not wish to provide benefits to individuals who do not need them. Nevertheless, it would be very dangerous for the Congress to grant any new benefits package flexibility. New flexibility for states could only lead to new discrimination for people with disabilities.

Historically, the comparability requirement, the provision of the Medicaid law that says that benefits must be comparable among groups of Medicaid beneficiaries has been an important principle and consumer protection. For example, because of the comparability requirement, individuals with HIV/AIDS in the 1980s were able to defend their right to receive AZT (the only FDA-approved antiretroviral medication at the time) when states sought to deny coverage on the basis of the drug's cost. A decade later, the comparability principle having been reinforced to states, meant that when highly active antiretroviral therapy regimens were approved, Medicaid programs provided access to these costly drug therapies without significant disruptions. Today, all parties agree that access to these medications are a good investment for states—and are a profound success.

Moreover, people with disabilities already have experience with states' ability to tailor benefits to specific populations through the home- and community-based services waiver program. What we have seen there is that which populations can access services and which cannot, in a given state, is not rational. And this can lead groups of people with disabilities to be pitted against each other fighting over inadequate resources. Moreover, despite the success of these waiver programs, they have not been expanded to meet all of the need. Giving new flexibility with regard to the benefits package would not improve Medicaid, and would not address the underlying problem of the need for more resources to meet the unmet need. Rather, it would open up Medicaid to political considerations—and would inevitably lead to winners and losers within the disability community based on sometimes unfounded perceptions of who is "truly needy". It would move decision-making over who gets Medicaid services they need away from qualified health professionals to program administrators.

Greater Reliance on the Private Market

Recently, several policy makers, including several Governors, have proposed transforming Medicaid by relying more heavily on the private market to deliver services. Unfortunately, the reality for Medicaid beneficiaries with disabilities is that they rely on Medicaid because the private market has failed them. Private insurance has a long track record of denying coverage for people with disabilities and private insurance benefit packages are designed for healthy working populations. As such, they are wholly inadequate for low-income individuals with disabilities whose eligibility for Medicaid is dependent on being so severely disabled that they are unable to work at a substantial level. In particular, private health insurance does not cover long-term care services and supports.

Moreover, some policy makers have advocated for a greater reliance on private long-term care insurance. While the establishment of a viable private long-term care insurance system may be beneficial for the nation, the existing private long-term care insurance market is inadequate. Coverage that is commonly available is not likely to be adequate to meet the future needs for long-term services and supports; and it is widely believed to not be a cost-effective retirement planning vehicle for most people. Moreover, private long-term care insurance is not an option for people with disabilities, who will be turned down for medically underwritten policies.

Promoting Personal Responsibility Through Increased Cost-Sharing

Several policy makers have made claims that Medicaid would be strengthened if individual beneficiaries were asked to show more personal responsibility for their care and support. Many persons have complained about so-called "first dollar" coverage for Medicaid beneficiaries.

Individuals with disabilities are already subject to cost-sharing in Medicaid. In fact, when Medicaid imposes cost-sharing, people with disabilities and chronic conditions—people who access the most services—tend to bear the highest burden.[32] A recent analysis found that, on average, Medicaid beneficiaries with disabilities receiving SSI (income of 74% of the poverty level) paid $441 in out-of-pocket medical expenses in 2002.[33] Therefore, it is not a question of whether people with disabilities should be charged cost-sharing (since they already bear a significant share of their health care costs in relation to their income). Rather, the policy discussion must focus on determining what level of cost-sharing is appropriate given their very low-incomes and extensive needs.

Additionally, Medicaid does not cover all of the health and long-term services needs of people with disabilities who must often spend extensive personal resources on transportation to multiple doctors' offices and to visit other services providers. For persons who receive long-term services, even in the best cases, the level of services provided by Medicaid is inadequate. This means that Medicaid beneficiaries sometimes pay out-of-pocket to supplement what Medicaid provides, or they rely on family members or friends as informal caregivers. There is no documented widespread evidence that Medicaid beneficiaries with disabilities are abusing the system or are refusing to pay cost-sharing when they are able.

Increased Consumer Direction of Services

Consumer direction, which gives individuals with disabilities greater control over the long-term services they receive, is an important policy innovation that is strongly supported by people with disabilities. A key element of consumer direction is the ability to hire, fire, train, and supervise personal assistance attendants, as well as the opportunity to directly purchase services. Consumer direction, however, is not an appropriate tool for reducing Medicaid spending. Based on the Cash and Counseling Demonstration programs in four states that tested the individual budget (*i.e. voucher*) concept for consumer direction, the Bush Administration developed the Independence Plus Initiative to encourage states to seek waivers that incorporate principles of consumer direction.[34]

Recently, however, some Governors and others have seized on consumer direction initiatives as a "magic bullet" for reducing Medicaid costs. The Cash and Counseling Demonstrations were not intended to save money for states, and they did not yield significant cost-savings for states.[35] Individual budgets and other forms of consumer direction of services may achieve some savings in certain contexts. However, consumer direction should never be used to produce large savings for Medicaid by denying individuals adequate funding to purchase the services they are directing—and consumer direction should not be used to justify the elimination of other vital community living services. Further, different approaches to consumer direction have been used by states that do not rely on individual budgets, but these successful models have not been sufficiently highlighted. As the Congress seeks to identify short-term program savings to meet the Finance Committee's reconciliation instructions, I encourage you to resist any entreaties to rely on consumer direction to produce Medicaid savings.

Limiting Enforcement of the Medicaid Act

One of the most troubling proposals offered in the context of achieving program savings relates to efforts to limit the use of consent decrees. Consent decrees are voluntary agreements entered into by state and local governments and other parties that can be an important alternative to lengthy trials and complex protracted litigation. They have been especially important in remedying systemic problems. Proposals have been offered that would impose grossly unfair burdens on people with disabilities and others protected by the Medicaid Act and other federal laws. This type of policy change has the potential to harm both the interests of Medicaid beneficiaries and states, and I encourage the Congress not to consider such changes as a means of achieving a budget reconciliation target.

Consent Decrees and People with Disabilities: Examples from Connecticut

Connecticut currently has three agencies which are operating under federal consent decrees for at least a portion of their responsibilities. The Department of Mental Retardation (DMR) is operating Southbury Training School under a federal magistrate pursuant to a consent decree, and has just signed a consent decree (recently approved by the Legislature) to an action brought by the Arc of Connecticut on the DMR's waiting list and the Medicaid requirement for reasonable promptness in providing services to eligible participants. The Department of Children & Families is operating under a consent decree concerning child protective services and children in its custody. The Department of Education (DOE) is operating pursuant to the P.J. *v.* State of Connecticut consent decree which requires the DOE to take steps to increase the number of students with intellectual disabilities who participate in classes and in extracurricular activities with their peers who do not have disabilities. In each of these cases, the consent decrees resulted from many years of adversarial hearings and negotiations. All require a sustained compliance over many years to achieve the goals agreed upon. Many policies put in place by one administration or one legislature go forward through time, spanning many administrations and new legislatures.

Longer Term Solutions are Needed

After the Congress finishes its work to respond to the short-term issue of meeting the Finance Committee's reconciliation instructions, I hope that the Congress will engage in a process to consider longer term improvements to Medicaid. Strengthening Medicaid cannot be predicated on simply giving states new tools to avoid covering people with disabilities who are eligible for Medicaid and who need Medicaid's assistance. Strengthening Medicaid also cannot be predicated on giving states new tools for giving people less than they need. As the only place to turn for millions of low-income people with disabilities, the only meaningful solutions are those that shore up financing for Medicaid and which ensure that Medicaid does a better job at purchasing services or meeting the diverse needs of its beneficiaries.

The best and perhaps the only way to make progress, is not to look to Medicaid alone for policy solutions. The challenges facing Medicaid are the result of broader failures within our health and long-term care systems. By identifying broad national solutions to respond to the growing cost of health and long-term services we can strengthen Medicaid. By taking serious and meaningful steps to control prescription drug prices, across all payers, we can strengthen Medicaid. By developing trusted, national systems for evaluating new medical technology (so that decisions about who gets new drugs, new devices, and other technology is driven by careful decision-making—and not simply denying the latest technology to low-income Medicaid beneficiaries) we can strengthen Medicaid. By seriously looking at the issues facing the country in financing and planning for future long-term services needs, we can potentially take a lot of pressure off Medicaid—and lead to greater retirement and economic security for millions of Americans. By doing so, we can strengthen Medicaid.

Ending Medicaid's Institutional Bias

While Medicaid plays an essential role in providing long-term services, this is an area where Medicaid must do better. People with disabilities are looking to the Congress to urgently address barriers that prevent millions of Medicaid beneficiaries from receiving community-based long-term services. Medicaid law requires states to provide nursing home care, but permits without requiring states to provide the same level and types of services in the community. This is called the "institutional bias". Hundreds of thousands of people with disabilities would like to receive long-term services and supports that enable them to live in their own home, but are forced to be segregated in an institution as their only option for receiving this assistance.

Michael Dubois, Medicaid Beneficiary

Michael Dubois is a 35 year old resident of Gainesville, Florida with quadriplegia following a spinal cord injury in 1983 as a result of a diving accident. He receives Supplemental Security Income (SSI), Medicaid and Medicare. Since his injury at age 16, he has resided in several nursing homes because his elderly parents are unable to care for him. Medicaid pays for the nursing home where he currently resides in Gainesville, Florida. Mr. Dubois applied for the state's brain or spinal cord injury home- and community-based services waiver in August 2000 that would permit him to live in the community. Because of limits on participation in the waiver program, Mr. Dubois remains institutionalized.

The disability community's preferred solution is for the Congress to swiftly enact the Medicaid Community Attendant Services and Supports Act (MiCASSA, S. 401). This legislation would mandate home and community based services for those individuals with disabilities who are in or are eligible for care in institutional settings. Some policy makers have raised concerns with the MiCASSA model out of concern for the potential cost. While the solution to the challenge of providing expanded access to community-based services will require new resources, the disability community is also supportive of several other initiatives that would make incremental progress toward enacting MiCASSA. This includes strongly supporting the Money Follows the Person Act (S. 528), an important first step that would provide for a competitive demonstration for states to receive expanded funding for one-year for each person that a state moves out of a nursing home or other institution into the community. The disability community also strongly supports the Family Opportunity Act (S. 183, also called the Dylan Lee James Act), which would provide states with the option to provide critical support for families with children with serious disabilities. Additionally, there are other incremental steps that the Congress can take to expand access to community-based long-term services. The federal government could assist states in rebalancing their long-term care programs through providing an enhanced match for personal care and rehabilitation services. These approaches could be phased-in over time.

Conclusion

Thank you for the opportunity to provide a disability perspective on a broad range of current Medicaid policy issues. The Aging Committee has historically played a key role in helping Members of the Senate to appreciate the complex issues impacting Medicaid beneficiaries with disabilities. As you continue your deliberations this year, please permit me to provide any assistance to the Committee that would be helpful in understanding the impact of various policy options on people with disabilities of all ages that depend on Medicaid.

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[1] Congressional Budget Office (CBO) March 2005 Baseline estimate of Medicaid enrollment for 2005.

[2] For additional background information on Medicaid's role for people with disabilities, see: Jeffrey S. Crowley and Risa Elias, *Medicaid's Role for People with Disabilities*, Kaiser Commission on Medicaid and the Uninsured, August 2003.

[3] Jeffrey S. Crowley and Risa Elias, *Medicaid's Role for People with Disabilities*, Kaiser Commission on Medicaid and the Uninsured, August 2003.

[4] *Medicaid: An Overview of Spending on "Mandatory" vs. "Optional" Populations and Services*, Kaiser Commission on Medicaid and the Uninsured, June 2005.

[5] Eleven states are so-called 209(b) states, which take advantage of a provision in federal law that permits them to have more restrictive eligibility requirements than SSI standards for establishing mandatory eligibility for Medicaid for people with disabilities and seniors, as long as the state standards are no more restrictive than the state standards that were in effect in 1972 when the SSI program was established. Individuals in these states with excess incomes must be permitted to "spenddown" to Medicaid eligibility by incurring medical expenses, which when deducted from their income, makes them eligible for Medicaid. These states are Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia.

[6] *Social Security: Understanding the Benefits, 2005*, Social Security Administration.

[7] As of October 2001, 21 states reported providing this supplementary coverage to people with disabilities and an additional 3 states provided this coverage only to persons who are blind. Source: *Aged, Blind, and Disabled State Summaries*, National Association of State Medicaid Directors, 2002.

[8] *Aged, Blind, and Disabled State Summaries*, National Association of State Medicaid Directors, 2002.

[9] *MSIS State Summary FY2002 (Table 3: FY2002 Medicaid Eligibles by Maintenance Assistance Status)*, Centers for Medicare and Medicaid Services.

[10] Jeffrey S. Crowley, *Medicaid Medically Needy Programs: An Important Source of Medicaid Coverage*, Kaiser Commission on Medicaid and the Uninsured, January 2003.

[11] Jeffrey S. Crowley, *Medicaid Medically Needy Programs: An Important Source of Medicaid Coverage*, Kaiser Commission on Medicaid and the Uninsured, January 2003.

[12] For example, as of 2001, Louisiana's medically needy income limit was $100/month and it was last changed in 1985 and Arkansas' limit was $108/month and it was last changed in 1988. This is the maximum amount of income the states permit medically needy individuals to keep for all non-health related expenses including rent, food, and other expenses.

[13] Bazelon Center for Mental Health Law, http://www.bazelon.org/issues/children/publications/TEFRA/fact3.htm.

[14] White, J., Black, W., and Ireys, H., *Explaining enrollment trends and participant characteristics of the Medicaid Buy-in program, 2002-2003*, Mathematica Policy Research, 2005.

[15] Public Law 105-33.

[16] Public Law 106-170.

[17] Andy Schneider and Risa Ellberger, *Medicaid-Related Provisions in the Ticket to Work and Work Incentives Improvement Act of 1999*, Kaiser Commission on Medicaid and the Uninsured, April 2000.

[18] *Medicaid and Ticket to Work: States' Early Efforts to Cover Working Individuals with Disabilities*, Government Accountability Office, June 2003 (GAO-03-587).

[19] *Overview of State Home and Community-based Services (HCBS) Waivers*, Centers for Medicare and Medicaid Services, http://www.cms.hhs.gov/medicaid/1915c/mrddadult.pdf.

[20] Harrington, C. *Medicaid Long Term Care: Home and Community Based Services*. Presented at the Unmet Needs in Personal Assistance Services: Prevalence, Consequences, Costs and Policy Options hosted by Disability Statistics Center at UCSF.

[21] Cooper, B., *Young adults with a disability: Between a rock and a hard place*, Washington, DC: National Health Policy forum: 2001.

[22] For example, in 1997, AIDS-related deaths in the U.S. declined by more than 40 percent compared to the prior year, largely due to highly active antiretroviral therapies. Source: *The Global HIV/AIDS Epidemic: A Timeline of Key Milestones*, Henry J. Kaiser Family Foundation, see http://www.kff.org/hivaids/timeline/index.cfm.

[23] Unpublished data. Jeffrey S. Crowley, Kaiser Commission on Medicaid and the Uninsured/Georgetown Health Policy Institute 2005 survey of state Medicaid pharmacy policies.

[24] Medicaid benefits page, Kaiser Commission on Medicaid and the Uninsured website, see http://www.kff.org/medicaidbenefits/index.cfm.

[25] Jeffrey S. Crowley and Risa Elias, *Medicaid's Role for People with Disabilities*, Kaiser Commission on Medicaid and the Uninsured, August 2003.

[26] Medicaid benefits page, Kaiser Commission on Medicaid and the Uninsured website, see http://www.kff.org/medicaidbenefits/index.cfm.

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[27] Helbing, C. and Cornelius E.S., 1992. "Skilled Nursing Facilities – Medicare and Medicaid Statistical Supplement," *Health Care Financing Review.*

[28] National Health Accounts, projected prescription drug expenditures for 2004. http://www.cms.hhs.gov/statistics/nhe/projections-2003/t11.asp..

[29] National Health Accounts, Personal Health Care Estimates by Age Group, Fall 2004.

[30] *Medicaid: Issues in Restructuring Federal Financing*, Kaiser Commission on Medicaid and the Uninsured, January 2005.

[31] *Report to Congress: Issues in a Modernized Medicare Program*, Medicare Payment Advisory Commission, June 2005. See recommendation 3a. on page 58.

[32] Stuart, B. and Zacker, C., "Who Bears the Burden of Medicaid Drug Copayment Policies?", *Health Affairs*, 18(2):201-12, 1999.

[33] Ku, L. and Broaddus, M., *Out-of-Pocket Medicaid Expenses for Medicaid Beneficiaries are Substantial and Growing*, Center on Budget and Policy Priorities, May 2005.

[34] Jeffrey S. Crowley, *An Overview of the Independence Plus Initiative to Promote Consumer-Direction of Services in Medicaid*, Kaiser Commission on Medicaid and the Uninsured, November 2003.

[35] See "Lessons about Program Costs (8 b.) (page 43), "While improvement in access to care may be an important program goal under Cash and Counseling, overall costs may increase if access to care is improved, even if cost per month per recipient is constrained," *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report*, Mathematica Policy Research, June 2003.

The CHAIRMAN. Jeff, I wonder if you could comment for me on a recently issued proposal by the Governors suggesting that Medicaid should provide flexibility like SCHIP provides. What does that do?

Mr. CROWLEY. What that would do is provide a benefits package that is inadequate for people with disabilities. The SCHIP package has been modeled on the private sector standards which are based on serving health populations, and we have Medicaid as a safety net, and so people often move from the private market onto Medicaid so that they are very different populations.

The CHAIRMAN. You have made very clear in your testimony that services currently classified as optional really are not optional for the disabled population, so they ought to be in the mandatory category.

Mr. CROWLEY. That is correct. I often hear people talk about the cost of services and wanting to tailor services, but I think that people do not use services unless they need them. So if there is a problem with Medicaid beneficiaries getting services when they are not medically necessary, I think that calls for a policy response, but we have not seen any evidence of that. So when these services are made available, people only get them when they do truly need them.

The CHAIRMAN. We have heard a lot in Congress on the whole issue of asset transfers to be paper poor so you can get Medicaid. What is the experience of the disabled population in terms of asset transfers? Is this a real problem or is this more imaginary with the disabled?

Mr. CROWLEY. I think for people with disabilities, that does not really affect them because many of them have not accumulated assets. I would say—and this is not an area I have a lot of expertise in—is that there are special protections in the Medicaid law right now that allow parents and other family members to set up special trusts for their children with disabilities, adult children, so that after their deaths their children can continue to have additional support to supplement Medicaid, and I would just want to make sure that if changes are made in the asset transfer policy we continue to protect those special exemptions.

The CHAIRMAN. In the savings area you mentioned the drug benefit and States' ability to negotiate, and making sure that those kinds of medicines that the disabled tend to use most frequently are on their formulary.

Mr. CROWLEY. I mentioned——

The CHAIRMAN. Describe again the savings you would envision.

Mr. CROWLEY. With respect to prescription drugs.

The CHAIRMAN. Right.

Mr. CROWLEY. I think we could look to a number of areas. One issue that has been proposed is just to address the Federal rebate. Some States do get supplemental rebates, but not all States are able to obtain them. I think there is some concern that States' ability to obtain those supplemental rebates would be diminished with the implementation of the Medicare drug law, but I also think there is room to just increase the Federal rebate.

I also think there are ways to use evidence-based medicine, and I heard you earlier state that your State has been a leader in that, to achieve real savings. Some of the discussion about cost sharing has been what level of sort of cost sharing measures are appropriate given the low incomes of many Medicaid beneficiaries?

One thing I have noticed is that Missouri, they believe that they save a lot of money on mental health drugs, and their approach is not to really push the consumer, but they do a retrospective review. If they see that physicians are prescribing mental health drugs that they think are inappropriate for clinical standards, they send them a letter. It starts out with a letter just from the Department of Mental Health, but they escalate it, and they eventually get up to where it is one of two or three top psychiatrists in the State that intervenes personally. So they are not punishing individuals. They are not saying doctors cannot prescribe drugs. But they are really applying peer pressure.

The CHAIRMAN. They are looking for outcomes.

Mr. CROWLEY. Right. It has not hurt access, it has improved access to care, but it is also saving the State money. So I think we could look at other ways to use evidence.

The CHAIRMAN. So just monitor the process better than we are.

Mr. CROWLEY. That is correct.

The CHAIRMAN. Missouri is a State that has done that effectively?

Mr. CROWLEY. Missouri has done that with respect to mental health drugs. A number of States have very effective evidence-based medicine programs.

The CHAIRMAN. How about New Mexico, Pamela, on mental health?

Ms. HYDE. Chairman Smith, we are just implementing what we call a preferred drug list in New Mexico, and we are just beginning that with all of our medications. We have essentially exempted out the door the psychiatric medications from, “try other drugs first” or the “you must do a generic first,” because of all the issues about psychiatric drugs. However, the organization that is managing that for us happens to be headed by a physician whose son is mentally ill, so we have a very sympathetic doctor running that program, who does work with psychiatrists around their prescribing practices.

I think that Mr. Crowley is correct, that dealing with it on a peer basis is much better than some sort of arbitrary, kind of, “you cannot prescribe this medication unless you have tried 3 others first.” That generally is really bad for people with mental illness.

The CHAIRMAN. In terms of all the controversy around some of these psychiatric drugs right now, does the State of New Mexico feel any exposure if it gets more involved in the prescribing? Maybe you have a thought about that, Jeff. Are States being enjoined in some of the lawsuits that are being filed on these issues?

Ms. HYDE. Mr. Smith, New Mexico is not yet, and we are not too worried about it at the moment, because in fact, as I said, the way we are implementing this is we are actually treating psychiatric drugs differently. We are letting psychiatrists prescribe without any kind of up front authorization. It is more of a, as Mr. Crowley said, a retrospective review using peer involvement about it. It is not quite as formal as being described in Missouri, but we certainly recognize that you cannot treat anti-psychotics the same way you treat drugs for gastrointestinal disorders or other kinds of things of that nature.

Mr. CROWLEY. Could I also add, I do not think it is fear of lawsuits that is holding States back, and in some States, quite frankly, it is the pressure from the pharmaceutical manufacturers, and I think that might be a roll for Congress to step in and establish some standards.

I can also say, however, in States like Kansas, Washington States, they have managed to overcome this, and now I think they have a process that even the pharmaceutical manufacturers believe works effectively, but that was a big stumbling block initially.

The CHAIRMAN. Very good. Thank you.

Sister Dufault.

STATEMENT OF SISTER KARIN DUFAULT, SP, RN, Ph.D., CHAIRPERSON, BOARD OF TRUSTEES, CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES, SEATTLE, WA

Sister DUFAULT. Good afternoon, Mr. Chairman. I am Sister Karin Dufault, a member of the Sisters of Providence religious community and vice president Mission Leadership for the Providence Health System.

I am pleased to be here with you today as the chairperson of the Catholic Health Association to address your committee.

The Catholic health ministry provides care and services to Medicaid patients throughout the continuum of care. Our concern for Medicaid patients is rooted not only in our experience as service providers but as faith-based organizations and people committed to the common good and called to offer special protection for the poor and vulnerable.

As policymakers strive to make improvements in the Medicaid program, we believe that it is important to keep in mind the primary oath of medicine, first do no harm. There is too much at stake if we get this wrong.

CHA does believe that it is time for a serious and careful discussion about the Medicaid program and how best to modernize it. Mr. Chairman, we appreciate your efforts to do just that, to establish a bipartisan Medicaid commission to examine modernization of the program absent Medicaid budget cuts.

We also believe that the process should not be driven by cost saving target and that modernization be developed and implemented with primary consideration of the impact on patients and a goal of ensuring coverage, access and quality.

CHA supports providing States with flexibility to operate their Medicaid programs more efficiently, but we remain concerned about how that is done. Specifically, two components of increase flexibility, cost sharing and benefit package design have not achieved the desired goals of more appropriate utilization, reduced program costs and significantly increased the numbers of persons covered.

Our hospitals in Oregon have witnessed and experienced firsthand the results of increased Medicaid patient cost sharing. In 2003, under the Medicaid waiver, Oregon established a new Medicaid premium policy under which poor adults pay a $6 to $20 dollar monthly premium based on income. Oregon also implemented a new lockout period for non-payment of premiums and removed the ability of low-income and homeless beneficiaries to obtain waivers. What we saw is that patients who were unable to afford required cost sharing delayed needed medical services until the condition reached an urgent level.

Following the changes, the 7 Providence hospitals in Oregon experienced a 25 percent increase in uninsured patient activity in the emergency rooms, while hospital uncompensated care costs doubled over a 2-year period.

We cannot stress enough the importance of coverage provided through State optional categories. While categories of beneficiaries and services may be deemed optional, these categories do not seem like an option for the beneficiaries we serve.

I would like to provide you with one example out of many that we could provide that illustrates this point. Sally George, we will call her, age 70, a double amputee who suffers from Crohn's disease, was living in low-income housing when her health deteriorated. With the help of Medicaid she was able to move into Providence ElderPlace in Portland, OR. This innovative PACE program serves frail elderly in a community-based setting that is less expensive than traditional nursing facilities.

Sally, a caretaker herself, who looked after her own mother until her death at age 97, is grateful for the services she receives and the independence that she enjoys at ElderPlace. She feels fortunate that the doctor is in house, as well as the nurses, physical therapists and other caregivers. Sally hopes that the Medicaid funding for this optional program will continue to be there for her, even though she works hard to be as self-sufficient as possible.

Medicaid is a primary source of revenue for America's safety net institutions including many Catholic hospitals which serve a disproportionate share of low-income, uninsured and under-insured in their communities every day. In order to ensure continued access to services, attention must be paid to Medicaid payment rates for all providers. When Medicaid payment rates fail to keep pace with the cost of providing care, access to care for Medicaid patients is affected and the quality of care could be jeopardized.

We currently have some 45 million uninsured persons in our Nation. They rely on America's hospitals for their health care needs, and creating barriers to Medicaid will simply worsen an already terrible situation. Making the continuum of health care services and facilities more effective for patients and for the system itself requires that we focus most of our attention on helping people maintain health and independence while treating their chronic illness in the most appropriate setting.

Home and community-based services are proving to be cost effective means for keeping frail and disabled persons as independent as possible and avoiding or delaying the need for costly institutional care. However, it is important to realize that to be effective, a broad range of supportive services must be available. We strongly support policies that coordinate Federal and State supported health and housing services and move our Nation toward a more rationale and comprehensive long-term health care policy.

Medicaid represents a measure of how we as a society and the wealthiest Nation in the world treat the poorest and most vulnerable among us. The cumulative effect of Medicaid program reductions and cuts in other essential services for low-income individuals and families could be devastating.

Mr. Chairman, as Congress considers Medicaid reform, we urge you to make decisions that will preserve and strengthen this vital program while protecting those with the greatest need and the fewest resources.

Thank you for the opportunity to speak before you.

[The prepared statement of Sister Dufault follows:]

Testimony

Sister Karin Dufault, SP, RN, PhD
Chairperson, Board of Trustees
Catholic Health Association of the United States

The Special Committee on Aging hearing
"Mandatory or Optional? The Truth About Medicaid"

June 28, 2005

As the Senate Special Committee on Aging convenes to explore Medicaid reform, I am pleased to provide testimony on behalf of the Catholic Health Association of the United States (CHA). CHA is the national leadership organization representing the Catholic health care ministry. With over 2,000 members, CHA is the nation's largest group of not-for-profit health care sponsors, systems, facilities, health plans, and related organizations. CHA's members provide care to at least one in every six Americans in the health care system, either in an acute care or long-term care setting, in communities across the country. We have been caring for the nation's most vulnerable and disenfranchised individuals for more than 275 years and remain committed to accessible and affordable health care for all.

CHA does believe the time has arrived for a serious, careful discussion about the modernization of the Medicaid program. We also believe, however, that it is important that the process not be driven by cost-savings targets, and that modernizations be developed and implemented with primary consideration of the impact on beneficiaries and a goal of ensuring coverage, access, and quality.

The Catholic health care community provides care and services to Medicaid beneficiaries throughout the continuum of care. Our hospitals deliver babies, take care of premature infants in some of the nation's most advanced neonatal intensive care units, and care for adults and children who are sick or injured. Our clinics in schools and elsewhere in the community keep children well and manage chronic conditions such as asthma and diabetes. Our long-term care facilities provide assisted living and nursing home care for frail and chronically ill elders, and our home care and hospice programs serve persons of all ages who are recovering from or living with serious and disabling illness or are in the end stages of life.

We also know, both from direct experience and through our partners in Catholic Charities agencies and diocesan service programs, that many Medicaid beneficiaries also depend on other federal and state programs. These low-income individuals and families are facing cuts or challenges not only in their health care benefits but also in other essential services including housing and social service programs. The cumulative effect of program reductions on these individuals and families could be devastating. We urge Congress to take a broad look at the overall welfare of those in this country with the greatest needs and the least resources, and offer solutions that will address their needs.

We know from first hand experience that Medicaid is vital to the health and well-being of persons in this country who are materially poor. As policy makers from states and the federal government strive to make improvements in the Medicaid program, we believe it is important to keep in mind the primary oath of medicine: *first do no harm*. There is too much at stake if we get it wrong. The well being of persons who need Medicaid and the entire health care system is in the balance.

Our concern for Medicaid beneficiaries is rooted not only in our experience as service providers but as faith-based organizations committed to the common good and compelled by biblical mandate to offer special protections for poor and vulnerable persons. We consider access to adequate health care to be a basic human right, necessary for the development and maintenance of life and for the ability of human beings to realize the fullness of their dignity and fully contribute to society. Justice requires us to protect and promote the fundamental rights of people with special attention to meeting the basic needs of the poor and underserved, including the need for safe and affordable health care.

As a member of the Sisters of Providence religious community and Vice President of Mission Leadership for Providence Health System, I would like to tell you about my experience in care for vulnerable Medicaid beneficiaries. Providence Health System is a not-for-profit organization extending across a four-state area – from Alaska through Washington, Oregon, and into Southern California. Providence Health System operates 17 acute care hospitals (181,800 admissions), 20 long-term care facilities (1,741 beds), two PACE programs, and 20 low-income supportive housing and assisted living facilities (1,050 units). We operate comprehensive home care, hospice and palliative care services, primary care clinics, and educational facilities. Providence also sponsors health plans covering more than 850,000 members and other eligible enrollees in Oregon and Southwest Washington. In 2004, almost 34,000 people were employed by Providence Health System.

CHA supports providing states with flexibility to operate their Medicaid programs more efficiently. However, two components of increased flexibility—cost sharing and benefit package design—have not achieved the desired goals of more appropriate utilization, reduced program costs, or significantly increasing the number of persons covered.

Financial Implications of Cost Sharing

Our hospitals in Oregon have experienced first hand the results of increased Medicaid beneficiary cost sharing similar to proposals currently being discussed in Congress. In 2003, under a Medicaid waiver, Oregon established a new Medicaid premium payment policy under which poor adults pay a $6-$20 monthly premium based on income. Oregon also tightened premium payment policies by implementing a new lock-out period for non-payment and removing the ability of low-income and homeless beneficiaries to obtain waivers. Under the new lock-out rule, one missed payment results in disenrollment from the program for a period of six months. Previously, if a beneficiary missed a payment, they could pay the overdue premium and immediately reapply to the program. The state also required co-payments for various areas of care.

Following these state changes, the seven Providence hospitals in Oregon have experienced a steady increase in the percentage of uninsured patient activity in the emergency departments, from 16% in 2003, to 18% in 2004, to 20% to date in 2005. There is a continued dramatic increase in emergency room utilization for ambulatory sensitive conditions (conditions that could be treated appropriately in an outpatient setting) and a behavioral health crisis due to lack of medications. Our uncompensated care overall doubled over a two year period, costing $17,388,179 in 2002 and increasing to $34,994,443 in 2004.

Increases in cost sharing not only impose barriers for beneficiaries needing Medicaid coverage and services but also shift costs to hospitals and other safety net providers already absorbing Medicaid funding shortfalls. In the vast majority of states and for most services, Medicaid does not reimburse providers at a rate that meets their costs, which is only worsened when beneficiaries are unable to afford co-pays.

CHA is very concerned about proposals to increase the cost sharing requirements on Medicaid beneficiaries. Our experience has shown that imposing mandatory cost sharing has severely reduced Medicaid coverage and limited the beneficiary's financial ability to access care. When this occurs the impact on patients and safety net providers alike is dramatic.

Optional Beneficiaries and Optional Services

We cannot stress enough the importance of coverage provided through state-optional categories. While categories of beneficiaries and services may be deemed "optional," the health care coverage and services provided are critical to many individuals and families.

Sally George, aged 70 (whose name has been changed for privacy), a double amputee who suffers from Crohn's disease, was living in low-income housing when her health deteriorated. With the help of Medicaid, she was able to move into Providence ElderPlace in Portland, OR. This innovative program serves frail elderly in a community-based setting that is less expensive than traditional nursing facilities. Sally, a caretaker herself who looked after her own mother until her death at age 97, is grateful for the services she receives and the independence she enjoys at ElderPlace. As she told us at Providence, "Medicaid is so important. Without it, we wouldn't have any of this." Sally is dually eligible for Medicare and Medicaid and receives services through the state-option PACE program at ElderPlace.

Fifteen-year-old Taiviet Nguyen (whose name has been changed for privacy) suffers from a rare from of cancer. Taiviet is too sick to go to school, and his family is occupied with running the family business. With the help of Medicaid, Taiviet is being cared for at home by a team of hospice caregivers. While the value of treating a 15 year-old boy at his home rather than in an emergency room never can be measured in dollars alone, the fact is that Taiviet's home care is less costly than the care he would receive in a hospital. Hospice services are a state-option offered under Washington's Medicaid program.

L.C., a 54-year-old woman in Thurston County, WA, suffers from gastro paresis. This condition causes her stomach not to contract as often as it should and is symptomized by discomfort, nausea, vomiting, and uncontrolled weight loss. L.C. receives home care and Total Parenteral Nutrition (TPN) from Providence Senior and Community Services, a program reimbursed by the State of Washington as a state-option benefit under Medicaid. If Washington State had to scale back or eliminate this benefit due to federal Medicaid cuts, L.C. would not receive the home care she needs and would end up being hospitalized. Providence clinicians estimate her life expectancy would be two to four months without receiving TPN and nurse monitoring. This state option is critical for L.C.'s continued health.

These are some examples of "optional" beneficiaries or "optional services" under Medicaid. For the Medicaid beneficiaries we serve, optional categories certainly do not seem like an option, nor does meeting their health care needs. Reducing Medicaid access or services only increases the likelihood of hospitalization, the cost of uncompensated care borne by hospitals and providers, and ultimately affects employers through increases in insurance premiums due to the higher cost of health care. It becomes an endless cycle that will not be solved by simply cutting Medicaid expenditures. Changes to the Medicaid program must be considered in a broader context of modernizing the program and recognizing the erosive impact of the ever-growing number of uninsured on the health care system.

Mr. Chairman, we applaud your efforts to establish a Medicaid Commission to examine modernization of the program absent Medicaid budget cuts. We agree that an independent bipartisan review of the program needs to be undertaken and we are willing to work with you and the Members of this Committee in that regard. In the meantime, we believe there are a few things that can be done to improve the Medicaid program. Through our experience, the Medicaid program needs to place more emphasis on prevention, care management of chronic conditions, and on home and community-based care.

Securing the Safety Net

Health care services are not consumer goods. We do not know when, if, or how someone will get sick. We cannot predict illness, nor can we anticipate exactly which services an individual will need. Insurance policies exist for this very purpose—to protect someone or something from the unexpected. Without insurance, low-income people are far more likely to delay or even avoid needed care. They are often in poorer health and have a higher rate of illness than the general population. Several factors contribute to this phenomenon, including the inability of low-income people to obtain regular checkups or have access to appropriate nutritional options. Compounding these problems, low-income populations are unable to afford the high cost of health care and insurance. This is where Medicaid steps in. It is ultimately more cost effective for individuals to have coverage and receive preventative and early care when needed. The more costly alternative is for people who could not afford or obtain treatment to reach a point where their only option for acute illness is a hospital emergency room. We currently have some 45 million uninsured persons who may come to the nation's emergency rooms because they have nowhere else to turn for care. They rely on America's hospitals to address their health care needs. Creating barriers to beneficiary access to Medicaid, or scaling back on optional beneficiaries or services, will simply worsen an already bad situation.

Providence Health System in Oregon Responds

The total amount of charity care (uncompensated care) Providence provides to the uninsured and others who cannot pay for their health care continues to rise.

Year	Total Cost of Charity Care	Total Community Benefit*
2001	$10,657,671	$ 58,793,216
2002	$17,388,179	71,042,023
2003	$26,934,018	76,177,057
2004	$34,994,443	94,502,058

*Community benefits are health care and other services underwritten by Providence Health System, such as mission clinics, unpaid costs of Medicaid, education and research. Does not include Medicare shortfall.

Medicaid is a primary source of revenue for America's safety net institutions, including many Catholic hospitals, which serve a disproportionate share of the low-income uninsured and underinsured in their communities every day. In order to ensure continued access to services, attention must be paid to Medicaid payment rates for all providers. When Medicaid payment rates fail to keep pace with the cost of providing care, access to care for Medicaid beneficiaries is affected and the quality of care in departments serving large numbers of beneficiaries, such as obstetrics and trauma, could be jeopardized. Provider reimbursement under Medicaid must be sufficient to foster access to care and to promote quality.

Through its commitment to matching federal funds, Medicaid provides a safety net not only for beneficiaries and providers but for the states as well. The fundamental structure of the Medicaid program as an entitlement must be preserved and strengthened. American communities have long been committed to meeting the basic health care and long-term services needs of low-income Americans through a system of shared federal and state responsibility. We believe this shared responsibility should continue.

Measures to Improve Long-term Care

As people in our communities live longer, the Catholic health ministry is committed to providing a compassionate continuum of care that addresses the physical, social, psychological, and spiritual needs of persons. Making this continuum effective for patients—and for the system itself—requires that we focus more attention on helping people maintain health and independence while treating chronic illnesses in the most appropriate setting. The essential challenge for policy makers and providers alike is to design a system aligned to encourage the highest possible quality along the entire continuum of care.

We strongly support the growing movement of encouraging the delivery of services in the setting that is the least costly and most preferable to older and disabled persons - their homes. Home and community-based services are proving to be cost-effective means for keeping frail and disabled persons as independent as possible and avoiding or delaying the need for costly institutional care. However, it is important to realize that to be effective a broad range of supportive services must be available. This includes home health and homemaker services, adult day care, caregiver support, and case management. In addition, supportive housing must be available and affordable for these vulnerable persons to be able to remain in their communities. We strongly support policies that coordinate federal and state-supported health and housing services and allow older and disabled persons to be discharged from, postpone or avoid nursing home care.

CHA believes that innovations like Programs for All-inclusive Care for the Elderly (PACE) and other programs aimed at keeping frail, disabled and chronically ill persons at home through creative and flexible uses of Medicare and Medicaid funds should be an even greater part of a modernized Medicaid program. As such, we support S. 1067, the CORE (Community Options for Rural Elders) Act, to facilitate the development of PACE programs in rural areas.

CHA also believes that there needs to be a more rational mechanism for financing and structuring a long-term care system. We need to create alternatives for financing LTC services through such methods as public-private partnerships and tax credits to assist and encourage the purchase of long-term care. But for now, the bottom line is that the need for long-term care services is growing every year and Medicaid nursing home care is consuming 34 percent of all Medicaid costs and serving 60 percent of all nursing home patients. As the baby boom begins to retire over the next 10 years, sustaining or increasing such percentages will present formidable challenges to the Medicaid program.

Conclusion

Congress faces a daunting challenge to ensure that the Medicaid program continues to be both financially viable and responsive to the most needy in our communities. CHA agrees that Medicaid needs a comprehensive review and modernization. However, we believe it is important that such changes are developed and implemented with primary consideration of the impact on beneficiaries and with a goal of ensuring the provision of necessary care, optimizing coverage, enhancing quality and recognizing how changes in Medicaid will impact the entire health care system. This is less likely to be the result of a reform process driven by cost-savings targets.

We also know, from both direct experience and through our partners, that Medicaid beneficiaries are facing cuts or challenges in other essential services for low-income families. The cumulative effect of program reductions on these individuals and families could be devastating. We hope that Congress takes a broad look at the overall welfare of those in this country with the greatest needs and the least resources.

Members of CHA remain concerned about the potential Medicaid funding reductions included in the Congressional budget resolution. We do not believe cutting Medicaid spending is really a means of containing health care costs. It simply shifts the costs to other parts of a health care system already struggling to provide care to underinsured and uninsured persons and to those individuals who are least able to afford it. No program is without flaw, and we are very willing to work with you to identify ways to improve Medicaid while protecting the health and well-being of the people it serves.

Medicaid represents a measure of how we, as a just society and the wealthiest nation in the world, treat the poorest and most vulnerable among us. In the absence of accessible and affordable health care for all, Medicaid is a critical and important part of our nation's safety net. CHA urges Congress at this critical juncture to make decisions that will preserve and strengthen this vital program.

The CHAIRMAN. Thank you, Sister. I wonder if you can share with the committee and the audience, when you saw your emergency room utilization go up 25 percent and the ranks of the uninsured go up, how did you deal with that as a system, as Providence Health System? Did you have to eat it on your bottom line, or were you in a position where you would ultimately have to pass that on to other paying patients?

Sister DUFAULT. Well, it certainly did affect our bottom line. We did eat the cost. Our commitment to serving the uninsured and the under insured continues to be there. However, in order to sustain our ministry, and again, looking at that in the long run, how long——

The CHAIRMAN. You cannot eat it forever.

Sister DUFAULT [continuing.] Can we continue to do that and still continue to invest in our facilities and services? This is an issue in terms of recapitalizing our institutions and adding additional services. That is very important for us to consider.

So we certainly recognize our responsibility, but we do see it as a shared responsibility with our State and with our Nation.

The CHAIRMAN. So you would probably agree with me then that ultimately your ministry does not call on you to go bankrupt, and eventually you have to find a way to invest in the future and keep your books in balance as part of your ministry. So ultimately paying patients will have to bear these increased costs.

Sister DUFAULT. That is correct. There is a cost shifting that does occur. We know that when we have talked about the Medicare program as well, that there does have to be some bearing of the burden. However, I would say that this is becoming more and more difficult to do, especially as we negotiate with our managed care insurance companies.

Again, how long this shifting? The shifting is becoming more and more difficult to do.

The CHAIRMAN. So your comment then on copays and premiums, your experience is that those are counterproductive.

Sister DUFAULT. I think that we have been able to demonstrate in Oregon that it is counterproductive, that people are going off of Medicaid because of it or during this period, if they miss a payment and they are off of Medicaid for supposedly a 6-month period, they are unable to get back on because of the limits, in terms of the number of Medicaid eligibles that are allowed in the State. So again, what we saw was the uninsured continued to go up, and that is a serious problem. It is aggravating, on the other side, the increase of the uninsured population for our Nation.

The CHAIRMAN. The reason I am asking these questions, I would like the audience, and obviously, the larger public that may be viewing this, to understand that we are paying these costs already, and perhaps not very efficiently. But rightly or wrongly, the public generally, and I think many Members of Congress believe that there needs to be some sort of incentive not to abuse the system while you use the system. Are there things that you have found in Providence in Oregon or elsewhere that are good checks against abuse, but permit use?

Sister DUFAULT. Well, I think that one of the areas that has been mentioned by others is that we do have a health plan in Oregon, the Providence Health Plan, and we do have Medicaid recipients who are a part of that plan. We have been able to demonstrate that we have been able to manage the costs of the beneficiaries' care in a much more efficient manner than previously when they were not in a managed care program. I think that one of the other factors is that for those who go off and then use the emergency room, they are either using the emergency room for care that should have been provided in a primary care setting, or their situation is grave at the time that they are receiving care.

So again, the costs—and if that goes in the uncompensated care category, the charity care category, that cost goes up. So either that is passed on to others, the whole goal of providing the right care at the right time is not being done, increasing the overall cost to the system as a whole.

So what we advise is that the recipients receive the right care in the right place and be incentivized to be able to do that. The copays just add another incentive for not going there until things get a little worse.

So I hope that that addresses the question that you asked.

The CHAIRMAN. It very much does. On balance do you think Oregon has learned some good things that have been helpful to Providence?

Sister DUFAULT. Oregon has learned many good things, and I guess this is one of the other pieces that the committee may want to consider, is that the waivers, the demonstration projects that have been going on throughout this country need to be mined for what has worked and what has not worked. That will offer some opportunities for those things that have really worked to be a part of the program rather than a part of a waiver.

The CHAIRMAN. There are some savings in there as well that allow the right kind of coverage at the right time that it is needed.

Sister DUFAULT. Correct.

The CHAIRMAN. But I mean we ultimately, just like anywhere else, we have to do a better job of balancing our books here, and the more information experientially that you can give us to how to provide the outcome, serve the people that need it, qualify for it, with the best outcomes, that is really what we are looking for.

Sister DUFAULT. One of the areas that I mentioned was in terms of the PACE project, which is now being spread in many of the States. I think that we have been able to show how we have avoided hospitalizations by virtue of that program, reducing the costs, or being able to help people maintain a quality of life and reduce their need for acute care by virtue of the close supervision that they are being provided through such settings as the PACE program.

The CHAIRMAN. You have talked about some of the things Oregon has done well. What are the mistakes Oregon has made?

Sister DUFAULT. I think that one of the mistakes has been what we have spoken about in terms of the premium and also the copay. Incentivizing people to go off of Medicaid and be on the uninsured list is one of the areas. I think that has been a really big-mistake creating barriers. Then reducing what some of the "optional" category of services in order to have more people covered has also been counterproductive in many ways because it has just increased the need for some of the acute services.

The CHAIRMAN. What other States are you in? I know you are in Washington State.

Sister DUFAULT. Alaska, Washington, Oregon and California.

The CHAIRMAN. Are there things those States have done that you think could be good national models?

Sister DUFAULT. We have been able to replicate the PACE program in Washington based on our experience in Oregon, and again were able to get the waivers by virtue of what we demonstrated in Oregon. We have not replicated it in our other States, though it is being seriously considered. That is one of the principal areas where Providence Health System, I think, has assisted our Medicaid population.

The CHAIRMAN. Those States would need to apply for the same waivers that Oregon has under the current system?

Sister DUFAULT. Actually, it is one of the optional services now. It was not at the time that we initiated it. We did ask for waiver when we initiated it in Washington, and have multiple sites related to the PACE program.

The CHAIRMAN. You have answered my questions, been very helpful.

Any of you, hearing the others, have any closing comments you would like to make? You do not have to, but you are welcome to. Pamela.

Ms. HYDE. Senator Smith, you asked a couple questions of other folks that you did not ask of me, and I would like to tell you what we are doing in New Mexico. One was about the copay issue, or I should say cost sharing because there is two different kinds. Oregon has of course done a premium approach. We are in the process of requesting authorization to do an enrollment fee approach. If I personally had my own druthers, I would not do it, but the legislature said we should, and there is sort of pressure to do cost sharing. The theory of individuals should participate in their own care, I think philosophically is understandable. It is frankly going to cost us more to implement this than it is to save anything out of it.

We do have cost sharing already in our SCHIP program, so that is for the higher income children. For our working disabled program, we have increased those cost sharing, and by that I mean the copays. Other than that we do not have any kind of a premium or enrollment fee at this point.

The CHAIRMAN. What would the enrollment fee be?

Ms. HYDE. The enrollment fee we are proposing to be, I think it is $25 per month per family, and the point being here you could have 4 people in your family and if you did it per person that really would be prohibitive. I thoroughly anticipate—and I know it is in some of the other materials—that frankly, what will happen is probably what happened in Oregon, which is nonprofits and others will probably try to come up with money to help people enroll. I think that is just shifting costs to the charity population or the charity providers.

The other thing that is a little odd about this situation with cost sharing is we are not at this point allowed to require it except through waiver. Oregon is one of those that have done that. Utah has been able to do it through sort of a State plan definition. But what that does is it essentially means that if a person does not have the 2 bucks or the 5 bucks or whatever, then the provider eats it because they really cannot turn away that individual. So we do have to balance this issue for providers and others.

In our State the cost-sharing proposal is not going to impose any cost sharing at lower income levels for middle income, if you will, slightly over 100 percent of FPL. We are going to have this enrollment fee plus a modest amount for prescription drugs and physician services, but a higher amount for emergency room, $25 for an emergency room visit, the theory being to try to get people to go to physicians rather than waiting until they are sicker.

I do not know if this is going to work. I just want to echo this whole issue of cost sharing as a difficult one. I certainly philosophically understand the idea of personal responsibility. As a person responsible for the Medicaid program, I do not have any choice on some of these matters, but it is not a simple one as it seems on its face.

The CHAIRMAN. I think that is right. I think we would all acknowledge a need for personal responsibility. I mean all the paying patients that Providence has obviously exercise that, and there is not an unreasonable request that everybody pay something. But I guess what I am searching for is what is the level at which it is counterproductive, that on the one hand satisfies the demand of the tax-paying public, but the tax-paying public does not want these things so unproductive that they get these shifts in other billings that they get in the mail from their insurance companies.

I do not know that we have that answer, but obviously, whether it is called an enrollment fee or a premium or whatever we want to call it, I am really searching for what is the right level, what is the effective thing and the fair thing for the patient, the needy and the taxpayer?

Ms. HYDE. Senator Smith, one of the things that I think—again, it is not simple—but for those, let us take medications for example. One could say $2 is not enough to ask. If you are somebody who makes enough money to pay taxes, $2 probably seems like not much to ask. If you are a person on multiple medications, especially if those medications are not much fun to take, and you just soon not be taking them anyway, as is the case with some conditions, then this is just one more reason not to go get your medications.

So it may be an area where giving States a little more flexibility in the context of some guidance might be useful, rather than going all the way to where Oregon went, which I think was to try to impose a private sector model of cost sharing that I think really is not appropriate in these populations.

The CHAIRMAN. Another part of the question—and as a State administrator you would really be in a position to tell us this—I mean what does collecting the fee cost us in Government? I mean the Administration costs could be fairly astronomical to pick up a couple bucks.

Ms. HYDE. Senator Smith, when we look at the amount that it is going to cost us to implement these really relatively modest cost-sharing proposals—because our premium is not going to be a monthly premium, it is going to be a one-time enrollment fee, so an annual enrollment fee to try to make it less onerous on us and the families. Even at that, the overall savings is pretty much offset by the cost that it is going to cost us to do. Which means essentially we are doing it for the benefit of the tax-paying public who feels that it is important that people participate.

We have not analyzed—I do not know how we can until we do it—what the implications will be for people who either do not sign up or for people who fall off and cannot pay the money to get back on or for people who do not take their medications because of it. We have not implemented yet, so we do not know what that is.

Now again, we already have cost sharing at the higher income levels, and for the working disabled they are more than happy to pay $2 or $3 a prescription. That is different for somebody who is making 33 percent of the Federal poverty level, or maybe on SSI and has a major schizophrenia or manic-depressive illness or whatever.

The CHAIRMAN. I would be really interested to stay in touch with you, Pamela, to find out what your experience is. I hope you have a way to track it and can monitor it, because I think the whole country is looking to the laboratory, the 50 States, to help us find the right level, the right formula. HHS gives out 2,000 waivers a year.

Well, there have got to be some nuggets in there somewhere that we can learn from and include in not this $10 billion we are talking about, but ultimately whatever long-term reforms that we pursue in Medicaid, we really do need the States to share with us the kind of information you are likely to develop.

Sister, as you have ideas too, please do not be hesitate to share them with us.

Sister DUFAULT. Senator, I do not know if Oregon has done an analysis with regard to the recipients who went off of Medicaid with the premium, but I think that that would be something to really ask, because again, we do have—I mean we know that people went off. We do not know how much each of them were charged and what their income level was, because, you know, it is by income level. So that would be something that maybe the State could provide that data.

The CHAIRMAN. We will ask.

Howard or Jeff, do you have any closing comments?

Mr. BEDLIN. I just want to reiterate a point that did not come up in the Q&A but I think is very important, and that is that there are so many low-income families, children, people with disabilities, seniors, who are eligible for help under Medicaid and other programs that just are not getting it. I mentioned the QMB and SLMB programs, but if you look at the elderly who are eligible for Medicaid, only 60 percent of them actually get it. There are 40 percent of the seniors out there who could get Medicaid and are not getting it.

So I think at the same time that we are worrying about hitting a $10 billion savings figure and trying to figure out ways to shift more costs onto these populations, I think we also need to look at the bigger picture and try to get the neediest Americans the help that they are entitled to.

The CHAIRMAN. Why do the 40 percent not do it in your opinion?

Mr. BEDLIN. Lots of reason, and there is some analysis out there. It is burdensome in terms of forms that are very complicated to fill out. There is a stigma attached to many of these programs. Many are not available in languages other than English. There are real burdens in terms of finding these individuals. It is true for food stamps. Only 30 percent of the seniors after 40 years that are eligible for food stamps are getting it.

There is a lot that needs to be done, and I am concerned that while we are talking about trying to impose more costs onto these populations we are not getting them the help that they are eligible for, and that is one of the reasons why this is so unaffordable, that they are not even getting the assistance from a whole host of Federal programs because we are not committing the resources that are ultimately needed to find these people and enroll them in these low-income means tested programs, and I think that is a big problem that people are not focusing sufficient attention on.

The CHAIRMAN. Jeff, do you have a closing comment?

Mr. CROWLEY. Yes. Senator, you have spoken a lot about cost sharing, and I guess I just want to share my fears, as the Congress considers that, in that you may seek to eliminate this current protection that says services must be provided even when individuals cannot pay the cost sharing. I only have anecdotal data, but I have talked to many Medicaid beneficiaries that tell me they are embarrassed when they cannot pay $2 in cost sharing. It is not that they are willfully just gaming the system.

I am just really concerned that that will produce bad health outcomes, increase hospitalizations and other things if people just cannot get the services they need.

The last point I would make is that I know you are trying to get to what is a fair level of cost sharing, and while cost sharing is not charged in every State, what is fair may not be additional cost sharing. A study that was recently published by the Center on Budget and Policy Priorities found that the average cost sharing for SSI beneficiaries in Medicaid was $441 a year. So I think many Members of Congress will be surprised that individuals are already paying that level of cost sharing.

The CHAIRMAN. Ladies and gentlemen, we thank you. This panel has been very helpful in illuminating a very complex problem, and certainly has not made the Congress' challenge any easier, but you certainly have made us more informed. So you have added measurably to the Senate record, and you shared your time and your talent, and for that we thank you.

We are adjourned.

[Whereupon, at 4:45 p.m., the committee was adjourned.]

APPENDIX

PREPARED STATEMENT OF SENATOR JAMES JEFFORDS

Thank you Mr. chairman. I want to commend you and Senator Kohl for holding this important hearing today. While it is important that we understand the structure of the Medicaid program—it is even more important that we know who the people are who depend on Medicaid for their healthcare.

This is all the more true as the Congress begins to debate what, if any, changes need to be made to the Medicaid program.

Mr. Chairman, I also want to note for the record your contributions to this effort and to say that I was pleased to join you and Senator Bingaman in calling for a bipartisan Commission to review the Medicaid program.

I envisioned an effort similar to the commission on the Medicare program. That is, a commission whose members would include a range of stakeholders and who would have the opportunity to vote on its recommendations. Unfortunately, that did not happen and it remains to be seen whether the Administration's effort will contribute much to the Medicaid debate.

I also want to join you in welcoming our witnesses at today's hearing. Their testimony promises to shed light on who is served by the Medicaid program.

As we listen to them though, I would urge that we be careful not to stereotype or categorize those served by the Medicaid program.

All too often, we fall into the "jargon-trap" in Washington and suddenly people stop being viewed as people. Instead they become program "mandatories" or "optionals" or "dual eligibles". The worst is when Medicaid beneficiaries are called "bennies".

So I would just urge, that as we all listen to today's testimony, we remember that we are talking about "people". Their healthcare is not an option.

Let me also say that I am very concerned that we not let an artificially-set budget number—in this case $10 billion dollars—drive the policy making process.

Instead, our focus should be on determining if there is a better way to manage the Medicaid program and how we can help the States better provide services to people who depend on Medicaid.

In closing, I again want to commend Senator Smith and Senator Kohl because I believe this hearing is moving us in that direction.

QUESTIONS FROM SENATOR JEFFORDS FOR DIANE ROWLAND

Question. Ms. Rowland, I want to thank you for your statement and also commend you and the Kaiser Family Foundation for your ongoing work on Medicaid and providing health coverage for the uninsured.

Your statement closed by noting that there are no "easy answers" to covering the 50 million Americans who depend on Medicaid. You also note that policymakers, absent broader solutions like universal health care, need to maintain the "safety net."

The Kaiser Commission on Medicaid and the Uninsured has delved deeply into this issue and there are other efforts underway by several think tanks.

Can you share with us the current thinking among health policy experts on approaches that can assist us in maintaining the safety net?

Answer. Medicaid's performance as a safety-net in the recent economic downturn offers important insights into how Medicaid's eligibility and financing structures work to assure the program's safety-net role. By guaranteeing coverage to all who meet its eligibility standards and guaranteeing federal matching funds to states for their Medicaid spending as needed, Medicaid was able to offset the decline in job-based coverage among children from 2000–2003, and it kept the increase of 5 million uninsured adults from being even greater. Medicaid can respond to economic downturns and other health problems as a safety-net because it directs coverage and resources in accordance with need.

The pressure the recession generated on state Medicaid spending highlighted the importance of a greater federal role in financing Medicaid during economic downturns. An increased federal role is appropriate in light of the much more limited fiscal capacity of the states, the large share of Medicaid spending attributable to Medicare beneficiaries, and the national scale of the demographic and economic trends that drive Medicaid spending. Notably, the temporary federal fiscal relief granted to states in September 2003 enabled many to stave off or hold the line on an array of Medicaid cuts while addressing their budget shortfalls due to declining revenues.

Finally, as broad a safety-net as Medicaid provides, 45 million Americans—15 million of them living below poverty—remain uninsured. Under federal law, adults without children, no matter how poor, are excluded from Medicaid because they not meet the "categorical requirements" for federal matching funds under Medicaid. Federal financing to support Medicaid coverage for all Americans living in poverty would patch this weak place in our nation's safety-net health insurance program.

In sum, maintaining the existing financing structure—in which dollars follow services provided to individuals and federal matching funds follow state spending—is critical to Medicaid's role as our nation's health safety-net, able to respond when and where health needs increase. Increased federal support during economic downturns and recessions, when the demands on the program tend to rise sharply, would strengthen Medicaid's safety-net role.

Question. In listening to your statement I began to realize that we are not talking about a single Medicaid program. What we really are facing is at least 50 different Medicaid programs, each with its unique coverage policy and funding mechanism.

I know for example, that Vermont operates one of the most effective Medicaid programs and significantly, Vermont ranks very high health-related outcome measures. But Vermont, like other states, is also facing budget constraints that are forcing a reevaluation of its program.

Should there be some reassessment of what benefits should constitute a minimum national benefit package?

What in your opinion constitute the key elements that a state Medicaid program should have?

Answer. In the context of efforts to control Medicaid spending, some have questioned whether Medicaid's comprehensive benefits are necessary and proposed, instead, a limited basic benefit package with additional benefits for people with special needs.

In reassessing Medicaid's benefit package, it is important to bear in mind the people Medicaid serves and what their needs are. Medicaid's beneficiaries include infants and children, pregnant women, adults and children with disabilities, those with chronic physical and mental illnesses, seniors, people with HIV/AIDS, and many others, whose very low income and limited resources permit them to qualify for Medicaid. To address the diverse and extensive needs of these individuals, Medicaid covers a broad set of both acute and long-term care services, with no or nominal cost-sharing.

Despite the breadth of Medicaid's benefits and limits on cost-sharing, researchers have found that, when health status differences are taken into account, Medicaid beneficiaries do not use services at a higher rate than the low-income privately insured. Other research shows that Medicaid spending is highly concentrated in a small proportion of beneficiaries with intense health needs and utilization. These findings indicate that Medicaid's broad benefit package has not led to wide use of all covered services, but, rather, has facilitated access based on health needs. A comprehensive benefit package is necessary to ensure that Medicaid beneficiaries can obtain the care they need. To ensure that they obtain only the care they need is the role of states and managed care organizations, applying an array of utilization and disease management strategies.

Question. Congressional consideration of Medicare reform included several years of debate—and the debate itself was preceded by a national commission charged with making recommendations to strengthen Medicare.

The recent Medicare Modernization Act included many of these recommendations—not all of which were agreed to by everyone.

But one of the outcomes was the inclusion of new health promotion and disease prevention benefits. Some experts believe that these benefits will save money in the long run by preventing people from getting more serious diseases.

Short of EPSDT, are there any comparable efforts underway to bring modern health promotion into the Medicaid program?

Answer. As distinct from Medicare, Medicaid has always covered preventive care. Furthermore, to promote access to care, children and pregnant women are exempt from cost-sharing under Medicaid, and cost-sharing for others must be nominal.

EPSDT, the Medicaid benefit package for children, integrates early intervention, health promotion and disease prevention with more traditional coverage of treatment for disease and disability. Federal Medicaid law authorizes states to cover screening and preventive services, as well as case management, for adults too. Many states provide some coverage for immunizations, preventive services, health education, screening mammography, and other such benefits.

The wide and pioneering adoption of managed care in Medicaid as a care delivery model represents a broader kind of health promotion/disease prevention effort in the program. In its most successful form, managed care can improve access to appropriate care and effectively manage it for Medicaid beneficiaries, whom the fee-for-service system often does not serve adequately. Disease and care management strategies, which also have promise for improving the quality of care, are also being adopted by some states in their Medicaid programs.

QUESTIONS FROM SENATOR JEFFORDS FOR PAMELA HYDE

Question. Thank you for your statement Ms. Hyde. I agree with your assessment about the special challenges people with mental illness face in accessing health care services through the Medicaid program. I'm coming to the conclusion that the Medicaid program's exclusion of funding for Institutions for Mental Disease discriminates against people fighting mental disease. For example, in Vermont the Brattleboro Retreat has operated for many years under a waiver program that is now being withdrawn by CMS. Are there not instances where the best and most cost-effective treatment can be provided in these hospitals.

Answer. It is true that at times, the best care for an individual person for a short period of time is in a hospital setting, and some of the state-operated hospitals in the country are now among the best. The exclusion of IMDs is a historical artifact of the federal government not wanting to be responsible financially for services that were traditionally paid for by state governments. However, in the case of persons with developmental disabilities, the federal government does allow home and community based services, even when the institutional services from which individuals in such programs are diverted are state-funded and operated. It is also true that most states have now moved significant numbers of individuals from state facilities or large private facilities into more community based settings. Today, the IMD exclusion operates in some cases to prevent states from moving institutional funding for services for adults 18–64 into community settings that have a residential component, and operates to prevent states from providing some of the services that adults with mental illness need, such as supported employment and supportive housing settings. These same services are available for persons of all ages with individuals with developmental disabilities, using federal funds. In this sense, the IMD exclusion is in fact discriminatory.

The solution, however, may not be a full scale removal of the IMD exclusion, since we do not want to encourage the re-institutionalization of adults with serious mental illness (SMI). Rather, the solution, I believe, rests in CMS allowing states to include in their state plans the same services for adults with SMI that they allow for DD individuals, including residential supports and supported employment, as well as some of the flexible services and items that are being allowed by CMS for DD individuals under self-directed waiver approaches where a set amount of funds are provided for each individual to spend for the services and things they need to live successfully in the community. Another aspect of the solution may be to allow states to receive federal funds (FMAP) for community-based programs (including residential treatment and supports in small home-like facilities, just as DD individuals enjoy) for SMI adults that would otherwise be in larger institutional settings, so long as the state continues to provide the same level of state support that was provided for such individuals in the past or so long as the state reduces the number of individuals in large institutional settings. There must be creative ways to support adults with SMI to be successful in the community just as there has been with DD adults.

It's time we understood that the keys to success for Medicaid-eligible adults with SMI include housing and employment, things that are currently not fundable using federal funds.

Some people advocate for allowing federal funding for the acute care (less than 21 or less than 30 days) provided by state facilities, just as they would for acute care in private hospital settings. This might be a compromise, but with limited dollars, I personally would rather see federal funds more easily used to support smalled home-like environments and rehabilitation and supported employment and/or supported education approaches that are more geared to assisting adults with SMI to find their own recovery path.

The committee should note that the recent Bush Administration Medicaid reform proposals for which legislative language was just released include narrowing of the definitions of case management and rehabilitative services that will have a devastating affect on many states an on adults and children with serious mental and emotional illnesses. This is NOT the way to save money in the Medicaid program. It is in fact, a step backwards. It may in fact result in more adults and children institutionalized and is absolutely in opposition to the recommendations of the President Bush's President's New Freedom Commission on Mental Illness report.

I urge Congress to resist these attempts to limit federal funding for persons with mental illness throughout our country.

QUESTIONS FROM SENATOR JEFFORDS FOR JEFFREY CROWLEY

Question. Mr. Crowley, Medicaid plays an important role for schools in covering the cost of "related services" that are required by a child's Individual Education Plan (IEP) under IDEA.

Over the past few years, CMS has conducted a series of audits of school-based Medicaid claims. Vermont has been the subject of one of these audits. CMS and the state disagree on the findings of the audit, and CMS has been slow to respond to the issues raised by Vermont.

I have some real concerns about the timing and conduct of these audits. I am concerned that we might be discouraging schools from providing services to which our children are constitutionally and legally entitled.

Can you discuss the need for school-based Medicaid and the effect of these audits?

Answer. The civil rights law, the Individuals with Disabilities Education Act (IDEA), entitles children with disabilities to a free, appropriate public education in conformity with an individualized education program (IEP). An IEP is developed for eligible individuals with disabilities that describe the range of services and supports needed to assist individuals in benefiting from and maximizing their educational opportunities. The types of services provided under an IEP include services such as speech pathology and audiology services, and psychological and occupational therapies. While IDEA confers rights to individuals and obligations on the part of school systems, it is not directly tied to a specific program or an automatic funding source. For years, the Federal government has failed to provide anywhere near the level of funding promised in the IDEA statute. States' ability to appropriately rely on Medicaid funds for Medicaid services provided to Medicaid-eligible children pursuant to an IEP helps defray some of the state and local costs of implementing IDEA. This, in turn, helps assure that children receive all of the services they have been found to need in order to meet their full potential.

The sources of funding available to fund services under IEPs have been a contentious issue in the past. Some time ago, the Health Care Financing Administration (HCFA, the predecessor to the Centers for Medicare and Medicaid Services, CMS) attempted to limit the availability of Medicaid funding for services under IEPs. In 1988, the Congress addressed the issue in enacting the Medicare Catastrophic Coverage Act of 1988 (Public Law 100–360) in which it clarified that Medicaid coverage is available for Medicaid services provided to Medicaid-eligible children under an IEP. Under current law, the Social Security Act at section 1903(c) reads,

> "Nothing in this title shall be construed as prohibiting or restricting, or authorizing the Secretary to prohibit or restrict, payment under subsection (a) for medical assistance for covered services furnished to a child with a disability because such services are included in the child's individualized education program established pursuant to part B of the Individuals with Disabilities Education Act or furnished to an infant or toddler with a disability because such services are included in the child's individualized family service plan adopted pursuant to part H of such Act."

Nonetheless, federal officials have, from time to time, suggested that costs for school-based services are being inappropriately shifted to Medicaid. In response to these concerns, the HHS Office of the Inspector General (OIG) has carried out a number of reviews over the years, including a recent audit of Vermont's Medicaid school-based health services. The results of this audit were made public in January 2005. While I am not in a position to comment on the validity of the specific audit findings, I believe it is important to ensure that the rules governing these issues are clear, consistent, and implemented in an even-handed manner across all HHS regions. I also believe that, working within both the Medicaid and IDEA statues, the Federal government should take every opportunity to provide services to low-income children with disabilities. This has not always been the case.

While CMS and federal officials have important responsibilities to ensure that all federal Medicaid payments are appropriate and reimburse states for only allowable Medicaid services, without transparent rules and fair administration, supervisory unions in Vermont may be unable to provide optimal school-based services to children with disabilities. Moreover, there are significant concerns by representatives of children with disabilities in Vermont that federal officials are attempting to restrict Medicaid reimbursement in a manner that is expressly prohibited by the Social Security Act, and that audits are being used as a tool to create uncertainty that reimbursement will be allowable, thus leading states and school systems to preemptively restrict the school-based services it provides to children with disabilities. Indeed, my understanding is that Vermont has been a leader among states in using schools to meet the needs of children, and when appropriate, to receive Medicaid reimbursement for the cost of providing some of these services to Medicaid beneficiaries. There is a strong concern that this audit has had a chilling effect and has led supervisory unions to limit the services they provide under IEPs because they are unsure they will be able to receive Medicaid reimbursement for these services. The Congress could not have been clearer in its intent that it wants Medicaid to support the goals of IDEA; these narrow interpretations of the law are inconsistent with that intent.

Question. Vermont has been trying for two years now to gain approval from CMS of its Early and Periodic, Screening, Diagnostic, and Treatment (EPSDT) program.

The uncertainty that surrounds the administration of this program has led 25% of the Supervisory Unions in Vermont to withdraw from the program. They did not want to get caught in an audit if Vermont's plan was disallowed two years after its submission.

I fear the lack of response from CMS has hurt Vermont schools any may have denied children access to care.

What can be done to provide some certainty to the states so that they can focus on providing care to our neediest children?

Answer. The Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT) benefit is a mandatory Medicaid benefit that provides critical protection to children who receive Medicaid. EPSDT ensures that all children are screened on a regular basis, and when a disability or health condition is diagnosed, it ensures that Medicaid covers the treatment, even if a state does not provide the same service to its adult beneficiaries. EPSDT services can do much to help children maintain the ability to function as independently as possible, as well as improve their abilities, prevent secondary conditions, and reduce the incidence of increased disability. Access to these critical services can help families avoid institutionalization and keep their children at home. A critical outcome of EPSDT is that it allows children with disabilities to attend public schools in their neighborhoods or communities. According to the National Mental Health Association, a recent national survey found that mental illness begins very early in life, with 50% of lifetime cases starting by age 14. The problems caused by early onset of these and other illnesses is compounded by the fact that treatment is often delayed for ten or more years increasing the risk of school failure, teenage childbearing, unstable employment, early marriage, marital instability and violence. The early screening and diagnosis provided by the EPSDT benefit in Medicaid is critical to detecting and treating mental illnesses and a variety of disabilities and other conditions that can strike so early in life.

In Vermont, it is a common practice to use school nurses to conduct outreach and refer for treatment children covered by Medicaid who are eligible for services under EPSDT. Since not all of a school nurse's time should be billed to Medicaid, school systems have been instructed by CMS to rely on time studies to determine the percentage of time that school nurses are involved in such activities. Under this approach, a time study is conducted to determine the amount of time that school nurses (or other personnel) expend on outreach, find Medicaid providers, and facilitate enrollment in services. Schools then seek reimbursement from Medicaid based on the percentage of time that can be attributed to providing a Medicaid based on the percentage of time that can be attributed to providing a Medicaid beneficiary with EPSDT services, as determined by the time study.

Over the past ten years, the manner in which states can seek Medicaid reimbursement for school based services has been subject to controversy. During much of this time, there was no national policy on this issue and CMS regions had differing rules regarding permissible services and permissible reimbursement standards. In May 2003, CMS issued the *Medicaid School-Based Administrative Claiming Guide,* establishing a national standard for Medicaid payment for school-based services. The guide cites OMB Circular A–87 to state that "substitute systems" for allocating salaries and wages to federal awards are permitted in Medicaid. These sampling systems (including time studies), however, are subject to approval by the funding agency.

While I do not have the knowledge or expertise to respond to the specific issues affecting Vermont, it appears that the delay relates to federal approval for a time study as a substitute system for allocating salaries and wages to Medicaid. I have learned many Vermont stakeholders share the concern raised by Senator Jeffords that the lack of approval by CMS has led to considerable uncertainty and the end result is that children with disabilities may not be receiving all of the services they need; and for which Medicaid reimbursement should be available. Given the urgency of ensuring that children on Medicaid have access to the full range of school-based services that they need, consistent with EPSDT, federal policy makers should be required to provide a timely review of state submission of substitute sampling systems, and if the state proposal is deficient in some way, to provide technical support to the state so that it may construct a suitable system. Given the long history with this issue, it may be necessary for the Congress to press CMS to clarify permissible practices for states in seeking Medicaid reimbursement for providing Medicaid services in school settings to Medicaid-eligible children. As a first step, I encourage the Aging Committee to request from CMS all outstanding requests for substitute sampling systems used to bill for school-based services, including all approved and rejected sampling systems along with the date of action by CMS.

THE
CATHOLIC HEALTH
ASSOCIATION
OF THE UNITED STATES

CHA.

August 12, 2005

The Honorable Senator James Jeffords
Senate Special Committee on Aging
Washington, D.C. 20510

Dear Senator Jeffords,

Thank you for your excellent follow-up question to my testimony before the June 28, Senate Special Committee on Aging. As you stated in your question, there has been a lot of focus on methods to ensure appropriate utilization of health care by Medicaid beneficiaries—specifically, the effectiveness of beneficiary cost sharing in achieving appropriate utilization. Our experience in Oregon, as well as other studies, has shown that increases in beneficiary premiums and co-pays actually limit access to appropriate care. The unintended effects of this include elevated levels of illness, which are more expensive to treat, usually create a more urgent need for care, and result in increased visits to the emergency room.

My testimony highlighted the specific experience of our Catholic hospitals when Oregon's Medicaid program increased enrollee premiums and co-pays. Oregon's policy change resulted in a significant number of beneficiaries dropping Medicaid coverage, thereby becoming uninsured because of their inability to afford the cost sharing requirements. Consequently, the seven Oregon hospitals that are part of the Providence Health System experienced a 25 percent increase in uninsured patient activity in the emergency room over a two year period. While the State of Oregon did reduce Medicaid utilization and its program costs, the care needs and costs were in large measure shifted to the state's hospitals in the form of uncompensated care provided in the emergency department. Increases in cost sharing not only impose barriers for beneficiaries needing Medicaid coverage and services but also shift costs to hospitals and other safety net providers already absorbing Medicaid funding shortfalls. When this occurs, the impact on patients and safety net providers alike is dramatic.

This phenomenon is also described in a July 2005 study published by The Commonwealth Fund, which concludes that "even modest increases in premiums and cost-sharing may cause many to leave public coverage, especially those with the fewest financial resources. Because the most economically vulnerable individuals will disproportionately be the ones who leave, increasing premiums and cost-sharing risks creates a highly unstable, newly uninsured population with significant dependence on safety net providers and charity care in hospital EDs."[1]

WASHINGTON OFFICE
1875 Eye Street, NW
Suite 1000
Washington, DC 20006-5409
Phone 202-296-3993
Fax 202-296-3997
www.chausa.org

Access and Utilization for Medicaid Enrollees:
Based on the Oregon research and other studies, it is clear that low-income people are particularly cost-sensitive when it comes to health care services, and that access to care is often untenable for many Medicaid enrollees. Compounding this problem, many Medicaid beneficiaries cannot find a physician willing to accept Medicaid when they seek one out for needed care. Surveys in Washington State, Oregon, and California in recent years have shown that an increasing number of private physicians do not accept patients covered by Medicaid. In fact, according to the Washington State Medical Assistance Administration, only 33 percent of private physicians in Washington in 2002 accepted Medicaid – a percentage that has likely decreased in the last three years. [ii]

As a result of their inability to find a physician who will accept Medicaid, or the long wait due to overburdened community clinics, under-utilization of health care services is a greater problem than over-utilization for Medicaid enrollees. The exception to this is care received in the hospital emergency department, which results from lack of access to Medicaid providers in the community.

Given this dynamic, it is important for states to both ensure there are adequate numbers of physicians willing to accept Medicaid patients, as well as design delivery systems that ensure timely access to needed medical services on a regular basis.

Promising delivery models:
In the Pacific Northwest, we have had a long and successful history of managed care for private insurance, as well as Medicaid and Medicare, through a variety of delivery models ranging from staff-model HMOs to more open networks.

This embrace of managed care has allowed Providence Health System to successfully establish and operate five Program of All-Inclusive Care for the Elderly (PACE) sites in Oregon and Washington. PACE is a capitated program that combines Medicare and Medicaid payment to provide care management for frail elderly persons.

PACE brings together a multi-disciplinary team of professionals to assess the medical and social needs of the individual and arrange for the appropriate care and services to help the person maintain their health status and lifestyle. In our experience, by organizing around the patient's specific needs we are able in many cases to avoid both emergency room utilization and hospital admission as well as their associated costs.

Social Health Maintenance Organizations (S/HMOs) are another model that has been successful serving Medicare beneficiaries in Oregon, particularly dual eligible beneficiaries. The S/HMO, like PACE, receives a capitated payment but operates more like a staff-model HMO in providing both health coverage and a network of providers. In addition to offering the standard Medicare benefits, S/HMOs also provide case management, personal care aides, medical transportation, adult day health care and respite care.

Through programs such as PACE, S/HMOs and other models, Oregon has been able to reduce its nursing home utilization substantially in recent decades. As you are aware, nursing home care is one of the leading cost drivers for the Medicaid program nationally.

Whatcom County Pursuing Perfection Project – A community collaborative in Washington State led by a local Catholic hospital, St. Joseph Medical Center (PeaceHealth), community physicians, health plans and a host of other community participants, this project received a grant from the Robert Wood Johnson Foundation to develop a patient-centered, community-wide chronic care management system that will deliver recommended care 100 percent of the time. The Whatcom project's focus is on managing chronic conditions, specifically patients with diabetes and congestive heart failure. In its two years of operation, the Whatcom partnership has cared for about 130 patients. So far, improvements in outcomes due to transformed care management include: high patient satisfaction; avoiding $82,000 in costs for unnecessary ER and hospitalization; and cost avoidance from prevented or corrected medication errors valued at $285,785.[iii] While it is still small and local in scope, the Whatcom Pursuing Perfection Project offers considerable potential for transforming care delivery for the chronically ill and generating program savings for Medicaid.

In addition to the programs cited, there are a number of chronic disease management demonstrations created through the Medicare Modernization Act of 2003 that hold promise for both Medicare and Medicaid enrollees. The key characteristic of these and other chronic illness management programs is that they ensure access to care and are oriented toward the individual patient and management of his or her medical, social, and life-function needs. Chronic illness makes up 75 percent of our national health care costs, yet individuals with chronic illness make up less than 20 percent of the population receiving health care services.

We also would urge Congress as it deliberates on reforms to the Medicaid program to make home and community-based services a state option under Medicaid, including self-directed services based on the degree of a person's disability. Currently, states are able to offer home and community-based services only through a 1915(c) home and community-based care waiver. Under the waiver's budget neutrality terms, states cannot generate new spending under the waiver and must develop offsetting benefit reductions. By making it a state option and removing the budget neutrality terms, states could expand and further experiment with effective care management and case management programs, thereby ultimately better serving the needs of enrollees and reducing their long-term care costs.

Thank you for giving me the opportunity to further discuss this very important issue, and I look forward to working with you on Medicaid reform this year and in the future. If you have any additional questions, please call me at (206) 464-8840 or send me an e-mail at Karin.Dufault@providence.org.

Sincerely,

S Karin Dufault

Sr. Karin Dufault, SP, RN, PhD
Chairperson, CHA Board of Trustees

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[i] Bill J. Wright, Matthew J. Carlson, Jeanene Smith and Tina Edlund, "Impact of Changes to Premiums, Cost-Sharing, and Benefits on Adult Medicaid Beneficiaries: Results From an Ongoing Study of the Oregon Health Plan," Commonwealth Fund Pub. No. 848, July 2005.

[ii] "Low Income Patients Left Waiting For Care," Seattle Post-Intelligencer, Jan. 26, 2004.

[iii] Value of cost avoidance from prevented or corrected medication errors based upon Alaris Center cost estimate of $4,685 per medication error; costs for unnecessary ER and hospitalization based on average charge per service in Whatcom County.

ACAP

Association for Community Affiliated Plans

2001 L Street, NW, 2nd Floor · Washington, DC 20036 · ph: 202.331.4601 · fax: 202.296.3526

Statement for the Senate Special Committee on Aging
Mandatory or Optional? The Truth About Medicaid
June 28, 2005

The Association for Community Affiliated Plans (ACAP) is pleased to submit this statement for the record to the Senate Special Committee on Aging on the topic of the hearing entitled *Mandatory or Optional? The Truth About Medicaid.* ACAP represents 19 Medicaid-focused managed care plans that serve over two million Medicaid beneficiaries in states across the country. The mission of our organization is to improve the health of vulnerable populations through the support of Medicaid-focused community-affiliated health plans committed to these populations and the providers who serve them.

ACAP plans have long experience in helping states organize their Medicaid programs and controlling the costs of services. Our plans have expertise in providing quality care for children and families. Several states currently have or are in the process of exploring expansions of Medicaid managed care because plans such as ours are uniquely positioned to build on their experience to address the complex and challenging health care problems experienced by elderly and disabled Medicaid enrollees. Our plans also bring a value-added benefit in terms of the economic impact for the communities in which they are located; ACAP plans directly employ, on average, over two hundred people with several of our plans employing more than six hundred people.

Medicaid managed care plans have been found to save State and Federal governments from between 2 and 19% over unmanaged fee-for-service Medicaid. Medicaid managed care has generated significant savings for government payers for all populations, but particularly for Supplemental Security Income (SSI) and SSI-related populations. In addition, Medicaid managed care yields significant savings in pharmacy costs and decreased utilization of more costly inpatient services. In fact, most states incorporate some level of managed care in their Medicaid programs and many are expanding managed care to new geographic regions, populations and services.

For Medicaid beneficiaries, enrollment in Medicaid managed care plans means improved quality of, access to, and continuity of care. ACAP plans and similar Medicaid-focused plans improve the quality of care delivered to Medicaid beneficiaries by producing more quality improvement initiatives and measurement programs than either primary care case-management programs (PCCM) or traditional fee-for-service Medicaid.

The decisions made by the Congress will have a lasting impact on the Medicaid program. ACAP believes that any reform to this program should be thoughtfully considered and that policies changing Medicaid should be driven by the long-term needs of the program, and not only to meet budgetary limitations. Tens of millions of Americans rely on Medicaid to receive health care services and budget-driven policy can mean cuts in needed benefits and some beneficiaries losing the coverage they need.

ACAP supports a deliberative process to examine the issues in the Medicaid program. We are prepared to work with federal and state policymakers to offer proven, common-sense solutions to improving the quality of health care while keeping costs down.

ACAP Mission: To improve the health of vulnerable populations through the support of Medicaid-focused community affiliated health plans committed to these populations and the providers who serve them.

ACAP

Association for Community Affiliated Plans

2001 L Street, NW, 2nd Floor · Washington, DC 20036 · ph: 202.331.4601 · fax: 202.296.3526

On the Medicaid Drug Rebate

Created by the Omnibus Budget Reconciliation Act (OBRA) of 1990, the Medicaid Drug Rebate Program requires a drug manufacturer to have a rebate agreement with the Secretary of the Department of Health and Human Services for States to receive federal funding for outpatient drugs dispensed to Medicaid patients. At the time the law was enacted, managed care organizations were excluded from access to the drug rebate program. In 1990, only 2.8 million people were enrolled in Medicaid managed care and so the savings lost by the carve-out were relatively small. Today, *12 million people are enrolled in capitated managed care plans.*

Under the drug rebate, States receive between 18 and 20% discount on brand name drug prices and between 10 and 11% for generic drug prices. At the time the rebate was enacted, many of the plans in Medicaid were large commercial plans who believed that they could get better discounts than the federal rebate. Today, Medicaid-focused plans are the fastest growing sector in Medicaid managed care. According to a study by the Lewin Group, Medicaid-focused MCOs typically only receive about a 6% discount on brand name drugs and no discount on generics. **Because many MCOs (particularly smaller Medicaid-focused MCOs) do not have the capacity to negotiate deeper discounts with drug companies, Medicaid is overpaying for prescription drugs for enrollees in Medicaid health plans.**

The Lewin Group estimates that this proposal could save the federal and state governments and plans up to $2 billion over 10 years. This legislation has been endorsed by organizations representing both state government and the managed care industry, including the National Association of State Medicaid Directors, the Association for Community Affiliated Plans, Medicaid Health Plans of America, the National Association of Community Health Centers, and now, the National Governors Association.

As Congress is forced to make tough choices to control the costs of the Medicaid program, this proposal offers a "no-harm" option to control costs and ensure that there is not a prima facie pharmacy cost disadvantage to states using managed care as a cost effective alternative to Medicaid fee-for-service. We urge Congress to implement it as part of any Medicaid reform proposal that moves forward.

ACAP Mission: To improve the health of vulnerable populations through the support of Medicaid-focused community affiliated health plans committed to these populations and the providers who serve them.

Testimony Submitted on Behalf of the American Congress of Community Supports and Employment Services (ACCSES) and Disability Service Providers of America (DSPA)

The United States Senate
Special Committee On Aging
"Mandatory or Optional? The Truth About Medicaid"
June, 28 2005

American Congress of Community Supports and Employment Services

DSPA
Disability Service Providers of America

Marc Kilmer, Executive Director/CEO
1875 Eye St., NW, 11th Floor
Washington, DC 20006
Phone: (202) 466-3355
Fax: (202) 466-7571
www.accses.org

John D. Kemp, CEO
1875 Eye St., NW, 12th Floor
Washington, DC 20006
Phone: (202) 429-6810
Fax: (202) 429-6813
www.dspofamerica.org

This testimony is being submitted on behalf of the American Congress of Community Supports and Employment Services (ACCSES) and the Disability Service Providers of America (DSPA). ACCSES and DSPA are national, nonprofit organizations of community rehabilitation providers committed to maximizing employment opportunities and independent living for individuals with mental and physical disabilities.

Medicaid plays a vital role in the professional life of the disability service provider as well as in the personal lives of the people we serve. Over the past several months, policy changes to Medicaid have appeared more and more imminent and ACCSES and DSPA recognize that there is room for improvement in the overall Medicaid funded system. Our members would like to take this opportunity to outline several principles and suggestions which we hope you will adopt during this important debate.

Importance of Medicaid for Individuals and their Families

The Medicaid program is the primary government program that serves the medical needs of people with disabilities. With services provided by Medicaid, many people with disabilities have the support necessary to hold jobs, live independently, and become taxpayers. Without the support provided by Medicaid, these individuals would lose their jobs and would still be in of need medical services. Cuts would simply shift people with disabilities into more expensive government programs or take them off the tax rolls, will generating no savings in overall government spending.

It is also important to consider the importance of Medicaid on families of people with disabilities. For example, without the supports provided by Medicaid for a person with a disability, a family member will often have to stay at home and care for this person. This is devastating on low-income families. With Medicaid services providing a measure of independence for a person with a disability, there is no need for a family member to forgo a job to care for that person.

Due to examples such as these, we urge you to consider the positive impact of the Medicaid program on the individuals and families it serves as you discuss reductions in Medicaid spending. We also urge you to consider the financial ramifications that could result from cutting services to people who use Medicaid to provide support services that allow them to work and live independently.

Maintaining the Entitlement to Medicaid

Despite questions about its efficiency, Medicaid is an extremely successful public program. By providing health care coverage and disability services to over 52 million low-income people, the program allows individuals to obtain critical medications and devices, physician services, mental health care services, and home-health care services. Over the past several years Medicaid costs have increased as a result of rising enrollment and increased utilization of these services. While many see such spending increases as a cause for great concern, our members would argue that such escalation reflects the effective and responsive nature of the program. As health care costs continue to grow rapidly and the economy continues to wane in some areas of the country, more individuals are being forced to access safety-net programs, such as Medicaid, in order to obtain acute and long-term care services they cannot afford or access through the private market.

Much of Medicaid's success can be attributed to the program's unique federal-state financing partnership. The financing of Medicaid allows states to effectively respond to changes in demographics, emergencies, and economic downturns. Additionally, the guaranteed federal contribution encourages states to expand services to individuals, such as those with physical and cognitive disabilities, who are not required to be covered under the Medicaid statute. However, over the past several years, there has been increasing support for removing the entitlement of Medicaid in exchange for capped federal funding.

DSPA and ACCSES remain very much opposed to capping or block-granting the federal government's Medicaid contribution. Such attempts to control federal Medicaid spending would only succeed in denying Medicaid services to some of these states' most needy individuals. Additionally, caps would place an increased burden on already financially strapped states, creating a disincentive to provide comprehensive and vital services.

"Optional" Services and Populations

Recipient populations are considered eligible for Medicaid coverage as either "mandatory" or "optional." For example, people with disabilities who qualify for Supplemental Security Income (SSI) (having a monthly income below $579 for 2005 or about 75% of the Federal Poverty Line) are considered a mandatory population under Medicaid, however, many states provide coverage to people with disabilities up to and above the federal poverty line as optional populations.

The Federal government also mandates that states provide certain services to Medicaid recipients. These services include physician services, inpatient hospital services, nursing home care, and homes health services (including durable medical equipment) for those eligible for nursing home care. States may also choose to provide a number of optional services to Medicaid recipients including prescription drug coverage, emergency hospital services, diagnostic services, personal care services, rehabilitative services, case management services, durable medical equipment and intermediate care facility services for the mentally retarded (ICF/MR). Optional services and populations allow states an important form of flexibility. Just as the federal financing guarantee allows states to navigate different economic, demographic and emergency situations, Medicaid "options" allow individual states the ability to effectively serve their neediest populations.

Unfortunately, during the past several months there has been a great deal of discussion involving optional populations and services, including implicit suggestions by the Bush Administration that such services and populations are targets for potential cuts. The members of ACCSES and DSPA believe that it is extremely important to clarify that the term "optional" is a misnomer. Particularly for low-income individuals with disabilities, Medicaid services can be a matter of life or death; independence or institutionalization. What the Medicaid program refers to as "optional" services are often vital disability-related services. It is difficult to argue that a low-income 30 year-old male with severe schizophrenia can do without his daily medications or a 50 year-old female with cerebral palsy making $15,000 per year can afford her home-health services and wheelchair on her own. Yet, if "optional" populations and services were to face cuts, state would be forced to deny Medicaid coverage to some of the country's neediest individuals.

Removing the Institutional Bias/ Promoting Home and Community Based Services

Historically, people with disabilities have been regarded as incapable of participating in most activities of daily life and thus best served in institutions such as nursing homes or other restrictive environments. However, today we recognize such thinking as archaic and know that many people with disabilities are capable of working, going to school, and fully participating in their communities, often with the assistance of accredited or licensed community service providers, home care providers, job coaches or perhaps personal assistance services. There is strong desire by people with disabilities to live independently in their homes but, unfortunately, Medicaid has not changed to completely reflect this way of thinking.

An institutional bias exists in the Medicaid program as nursing home care remains a mandatory service under Medicaid, while home and community based services (HCBS) are most commonly offered under a "waiver" program. In 2002, 70 percent of Medicaid funding for long-term supports and services was spent on institutional care, whereas only 30 percent of such funding was spent on home and community based supports and services or non-institutional care.

Additionally, Medicaid has not made a commitment to attract highly qualified community providers by offering a competitive rate of reimbursement for their services. This provider shortage will be further discussed later in this testimony but is a major factor in the institutional bias that plagues the Medicaid program.

In 1999, the U.S. Supreme Court ruling in *Olmstead v. L.C.* found that unnecessary institutionalization is prohibited by federal law. The court stated that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment" (*Olmstead v. L.C.*, 521 U.S. 581, 119 S.St.2176). The Olmstead decision has served as a vehicle for change and many states have taken steps toward implementing this important ruling. But much work remains to be done.

The 1915 (c) waiver authority is currently allowing many states to offer home and community based services through the Medicaid program. Under the waiver authority, states are allowed to provide services not usually covered by the Medicaid program if these services are required to keep a person from being institutionalized. Case management, day training, homemaker, home health aide, personal care, adult day health, habilitation, and respite care are included as options under this waiver authority.

Our members support and encourage states to continue to use the 1915 (c) waivers to offer such services. However, we also support the passage of legislation such as the "Medicaid Community-Based Attendant Services and Supports Act (MiCASSA)" and the "Money Follows the Person Act." Such legislation would make it a requirement, rather than an "option," to offer home and community based services to those individuals that desire home care rather than institutional living.

"MiCASSA" would require that Medicaid offer individuals who are eligible for nursing home care or ICF/MRs the choice as to where their services would be provided – in an institutional setting or in the community and administrated by community service providers. The "Money Follows the Person Act" would create a demonstration project under the Medicaid program where Medicaid dollars would follow a person with a disability from an institution into the community setting.

Long-term care in the home setting is not only attractive in terms of modernizing the program, but is also a way to rein in long-term care spending. For some populations, home and community based services reduce per capita spending on individuals in need of long term care who would otherwise be institutionalized. Additionally, those being provided care in the home setting are able to maintain a greater level of independence and community integration. Such individuals are more likely to remain healthy and some are even able to return to work or school.

As the disability community continues to appeal for long-term care options in their homes and communities, the members of DSPA and ACCSES support permanent changes in the Medicaid system that would reflect this positive shift in demand.

Strengthening the Role of the Provider

Over the past few years, there has been increased attention on the workforce issues faced by private providers and their inability to attract and retain qualified, direct-support staff. It has become increasingly clear that one of the causes of this problem is directly related to insufficient Medicaid payments for wages and other benefits.

Many of the community rehabilitation providers, such as those represented by DSPA and ACCSES, rely heavily on Medicaid reimbursement. However, Medicaid reimbursement has not kept pace with the costs of providing services as well as the demand for such services. In fact, Medicaid usually offers the lowest reimbursement in the system (lower than Medicare or private insurers). In 2000, the median earnings of personal and home care aides were only $7.50 per hour.

The impact of such low reimbursement precipitates many of the other workforce related problems in the Medicaid long-term care system. For example, the wage crisis is a key factor in the high staff turnover rates among private providers. Because of low-wages, many well-trained individuals cannot afford to stay in the industry. In turn, the quality of long-term care services is compromised and the continuum of care is often interrupted. Additionally, provider organizations are regularly faced with considerable recruitment and training costs.

In March of this year, Representatives Lee Terry (R-NE) and Lois Capps (D-CA) introduced the *Direct Support Professionals Fairness and Security Act of 2005* (H.R. 1264). H.R. 1264 would amend the Medicaid statute to provide funds to states to enable them to include additional federal funding to providers to increase the wages paid to direct support professionals who support certain individuals with disabilities through targeted state Medicaid services. The members of DSPA and ACCSES would like to express their support for this important piece of legislation and urge adoption of it in the reconciliation process.

Medicaid reimbursement rates fail to reflect the vital role that providers play in Medicaid's long-term care system. Providers, such as the members of ACCSES and DSPA, are often a locus of knowledge when it comes to the utilization of services for individuals with disabilities as well as the administrative hurdles inherent in the Medicaid program. We are aware that administrative costs are being targeted as a way to reduce Medicaid spending and the members of our organizations would welcome such discussions. We believe that the provider is central to the efficiency of long-term care delivery and encourage Members of Congress to include disability service providers in the conversations on administrative costs and delivery of services.

Policy Improvement Should Drive Medicaid Reform

The members of DSPA and ACCSES recognize that changes to the Medicaid program are imminent in the coming years and are supportive of meaningful changes that will improve the quality and efficiency of services. However, our members are concerned that current policy discussions are being driven by numerical budget objectives.

Medicaid's fiscal problems are not unique to the program, but rather reflective of a larger problem – ever-increasing health care costs. In fact, Medicaid costs are increasing at a lower rate than health care costs as a whole, and lower than the costs of health care insurance purchased by employers and individuals. As the overall cost of health care increases Medicaid expenditures, the inability of many employers to offer comprehensive health care to their employees swells Medicaid enrollment. People with disabilities receive Medicaid not because they want to, but because the private system has failed them. As this Committee and the full Senate discuss changes to the Medicaid system, we encourage you to consider that the increasing costs in Medicaid are simply a side-effect of a greater problem in need of Congressional attention. Cuts to the Medicaid program will in no way solve the real crisis that our health care system currently faces; million of uninsured and steep annual increases in the cost of health care.

Many are supportive of Medicaid cuts under the assumption that they represent minor reductions in the growth rate of the Medicaid program and are necessary in order to curtail federal spending on domestic programs. These cuts may represent small numbers relative to a multi-trillion dollar budget, but to the recipients who will feel their impact, the loss of Medicaid coverage is in no way minor.

Furthermore, restraining Medicaid spending does not reduce the number of low-income individuals and people with disabilities who need services. For individuals with disabilities, health care coverage is a daily necessity used to maintain one's health and independence. Therefore, cuts to the Medicaid program will likely increase the number of individuals with acute care needs as their daily continuum of care is interrupted. Should such cuts be implemented, we will undoubtedly witness increases in utilization of community clinics, emergency room visits, greater dependence on other federal programs as people are unable to return to work, and even a return to institutionalization for many individuals with disabilities.

Conclusion

The members of ACCSES and DSPA oppose any changes to the Medicaid program that will threaten the availability of services to Medicaid recipients, especially those with disabilities. However, we do support meaningful changes to the Medicaid program that will result in improvements in the delivery of services, reductions in administrative obstacles, and improved efficiency in the program. We hope that you will include members of the Medicaid community, both consumers and providers, in the coming discussions on changes to the Medicaid program.

We thank you for this opportunity to submit testimony and encourage you to contact us with any questions you may have.

NCCNHR National Citizens' Coalition for Nursing Home Reform

Barbara J. Hengstebeck, President
Alice H. Hedt, Executive Director

1828 L Street, NW, Suite 801, Washington, D.C. 20036
202.332-2275; Fax 202.332-2949; www.nursinghomeaction.org

Statement for the Record of the National Citizens' Coalition for Nursing Home Reform for the hearing of the U.S. Senate Special Committee on Aging *Mandatory or Optional? The Truth about Medicaid*

June 28, 2005

The National Citizens' Coalition for Nursing Home Reform would like to thank the Committee for holding a hearing on one of the least-understood issues in Medicaid budget reconciliation: the difference (or lack of difference) between mandatory and optional beneficiaries. Eighty-five to 90 percent of nursing home residents who receive Medicaid are optional beneficiaries because their incomes are more than $579 a month, resulting in the startling fact that *more than half of all Americans who live in nursing homes are optional Medicaid beneficiaries.* Even so, when Medicaid cuts are sought, optional beneficiaries are often singled out – even though they are impoverished by the cost of long-term care and medically equivalent to other nursing home residents. They are at risk of losing a benefit that provides not only their nursing care but also their housing and assistance with routine daily living activities.

Medicaid is the essential safety net for frail elderly and disabled Americans whose assets are depleted and whose incomes are too low to cover nursing home costs that typically range from $4,500 to $6,000 a month. Two-thirds of the nation's 1.6 million nursing home residents receive Medicaid assistance, and the percentages are considerably higher in low-income rural communities and inner-cities. In addition to depleting almost all of their assets, Medicaid beneficiaries in most states are allowed to keep less than $50 of their own income each month to pay for personal necessities, such as clothing, that are not provided as part of their nursing home care.

It may be difficult to believe that states would cut optional beneficiaries from Medicaid without implementing alternatives for those who have no other source of payment. However, recent state actions show that fears that this could happen on a widespread basis are well-founded:

- In 2004, Georgia eliminated its adult medically needy program for nursing home residents. As a result, 1,700 elderly, frail and disabled residents lost their Medicaid benefit, even though they had almost no assets, too little income to pay for a nursing home, and in many cases, no family to help them. These people were saved from ejection from their residences by the determined effort of the long-term care ombudsman program and legal services agencies to enroll all of them in Qualified Income Trusts, a mechanism under which any income that exceeds the state cap is transferred into a trust and paid to the nursing home, with Medicaid making up the difference.

- In Kentucky, more than 2,500 people lost Medicaid coverage for nursing home care or were denied benefits to pay for nursing home services when the state changed its rules determining the level of care required to qualify for Medicaid. These residents' ability to receive nursing home care was saved by a lawsuit that ended with a consent decree in which the state agreed to change its regulations to comply with federal rules that protected their eligibility.

Ruth Morgan is a local Kentucky ombudsman who knew 46 of the Medicaid beneficiaries who were told they did not qualify for Medicaid under new state rules. She tells the stories of several of them:

> One of them was Vada Kerr. Ms. Kerr was 90+ years old and a double-leg amputee. She had multiple health problems, but she was a fighter and valued her independence. She insisted on transferring herself from her electric wheelchair to the commode and bed alone despite the recommendation from her physician that she be assisted. Ms. Kerr had no living family other than a nephew and his wife, both of whom were also disabled. She did not own a home, and would have had nowhere to go. Placement [in a personal care home without nursing services] would have been totally inappropriate for her. Her niece contacted the ombudsman, and we assisted her in filing an appeal. We then put her in touch with the attorney who filed the class action suit against the state. Ms. Kerr was the named client in that action. Unfortunately, she did not live to see the outcome. Her niece thinks she grieved herself to death.
>
> I remember one other 90+ lady who had been a school teacher all of her life. She lived at the facility for several years. She also had no family and had sold her home to pay for her care. She had adjusted to facility life quite well and thought of the facility as her home. She planned to live there till she died. She told me how awful she felt when she learned that the state of Kentucky no longer considered her to be their problem. When I told her that she had won her appeal, she cried and said, "Oh, thank you. I worried every day and decided that if I lost, I would just as soon be dead."
>
> One of our residents was extremely distraught about being moved out of her nursing home of seven years to a personal care facility where she did not get the help she felt she needed. The family is convinced that she threw herself out of her wheelchair intentionally. She suffered a fractured hip and was moved to skilled care. The family believes this was her goal. She died before the regulations were changed.

Nursing home residents in Kentucky and other states will be at much greater risk of dangerous and inappropriate discharges if Congress passes proposed legislation that would make it easier for states to return to court to overturn consent decrees in which they agreed to comply with Medicaid requirements. Litigation to establish or enforce consent decrees protected thousands of nursing home residents from eviction in the past year alone when states stripped them of their Medicaid eligibility.

If Congress does not reject consent decree legislation or safeguard optional beneficiaries' eligibility and entitlement to the same care that mandatory beneficiaries receive, NCCNHR believes many nursing home residents will be indefinitely hospitalized, where Medicare will cover their care, or will end up in other settings that are inappropriate, inadequate, and even dangerous.

NCCNHR is a nonprofit membership organization founded in 1975 by Elma L. Holder to protect the rights, safety, and dignity of America's long-term care residents.

NCCNHR is deeply concerned that at a time when the population of elderly Americans is set to explode, the debate about the future of Medicaid may be driven solely by efforts to cut costs and without careful regard for how our country will treat our "Greatest Generation" in the final days and years of their lives. At this time in our history, the government should initiate a strong and thoughtful *bipartisan* process to determine how to pay for long-term care in the future, to enable those who need financial assistance to choose from an array of appropriate services, and to ensure that all Medicaid-reimbursed long-term care is of high quality.

National
Mental
Health
Association

Headquarters: 2001 North Beauregard Street, 12th Floor, Alexandria, VA 22311-1732• Phone (703) 684-7722 • Fax (703) 684-5968
Government Affairs Office: 413 East Capitol St. SE, Washington, DC 20003-9997 • Fax (202) 675-8389 • www.nmha.org
Cynthia Wainscott, **Chair of the Board** • Michael M. Faenza, **President and CEO**

Senate Special Committee on Aging
Hearing on Medicaid Optional Beneficiaries and Services
Statement of Michael M. Faenza, MSSW, President and CEO
National Mental Health Association
June 28, 2004

Mr. Chairman and Members of the Committee:

The Medicaid program provides a lifeline of support for millions of low-income Americans who need mental health care. It is currently the single largest source of funding for mental health services in this country, comprising over half of mental health spending administered at the state and local levels. Medicaid covers critical mental health services ranging from inpatient hospital care to psychologist and psychiatrist services, rehabilitation, and prescription drug coverage. Importantly, many of these Medicaid services and benefits enable individuals to remain in their homes and communities instead of costly institutions.

In light of the fundamental importance of Medicaid to the mental health of millions of low-income people, the National Mental Health Association and our over 340 affiliates nationwide are alarmed by proposals to cut $10 billion in federal funding from this critical program. **We urge Members of Congress to find other ways to produce the savings called for in the fiscal year 2006 budget resolution.**

Limiting Coverage for "Optional" Beneficiaries

We are particularly concerned by proposals to cap funding and reduce coverage for so-called "optional" categories of beneficiaries as well as "optional" services.

"Optional" beneficiaries – those covered at state option –include low-income individuals with disabilities, children, parents, pregnant women, and senior citizens whose very lives often depend on the medical services they receive through Medicaid. They number almost 14 million individuals including 5 million children, 4.8 million parents, 2.4 million elderly, and 1.4 million adults with disabilities, and .2 million children with disabilities comprising 29 percent of those covered by the program. Many of them have mental health disorders and most have incomes at or below the poverty level. So-called "optional" beneficiaries include individuals with disabilities whose incomes are below 100% of poverty but above the limit for Supplemental Security Income (SSI) and individuals with such severe medical needs that once medical costs are deducted from their income they are eligible for Medicaid. "Savings" at the expense of these vulnerable people will simply exacerbate the already shocking numbers of those with mental illness among the homeless, our prison population, and the tens of thousands who take their lives every year.

Reducing Coverage of "Optional" Services

Virtually all community-based mental health services for children and adults with serious mental disorders are financed through optional Medicaid services. Under recent proposals, states could erode these benefits or impose limitations or cost-sharing requirements that effectively curtail access to these services. Traditionally, states have selected from among the following optional services in providing care for individuals with mental health disorders.

- Clinic Services
  Many services provided by community mental health centers are reimbursed under this option.

- Other Practitioner Services
  These services include treatment by state licensed psychologists, psychiatric social workers, occupational therapists and other mental health professionals.

- Prescription Drugs
  This is a critical benefit as the role of prescription drugs in mental health treatment has greatly increased.

- Targeted Case Management
  The targeted case management category enables states to provide intensive care coordination for many children and adults with mental health disorders. TCM is critically important to coordinating service delivery and ensuring continuity and integration of services that studies have shown is a vital aspect of successful treatment for serious mental illness.

- Psychiatric Rehabilitation
  These services may include individual and group therapies, psychosocial services, and physical, occupational, and speech therapies.

- Psychiatric Inpatient Hospital and Nursing Facility Services (for age 65 and older)
  States may opt to finance psychiatric inpatient hospital and nursing facility services for Medicaid recipients over age 65. (Federal law prohibits Medicaid reimbursement for persons *under* age 65 and *over* age 21 who reside in mental health facilities with more than 16 beds.)

- Inpatient Psychiatric Services for those up to 22 years old
  States use this option to finance residential treatment for children with serious mental and emotional disturbances.

- Community Residential Programs (less than 16 beds)
  States use this option to cover medical and other services for individuals with mental health disorders in group homes. (But, room and board cannot be covered by Medicaid).

Re-modeling Benefits after SCHIP

Recent proposals have also pointed to the State Children's Health Insurance Program (SCHIP) as a model for revising Medicaid benefits. But SCHIP or any benefit package modeled on private insurance coverage is not an appropriate substitute for the Medicaid population. SCHIP does not include benefits that are critical to many low-income children and adults with mental disorders. Using the private plan option under SCHIP, states have significantly restricted mental health benefits and appropriate treatment, typically limiting coverage of both inpatient care (to 30 days) and outpatient care (to 20 visits per year).[1] Moreover, SCHIP plans often do not include benefits such as intensive rehabilitation services, in-home care, and day treatment that are critical to many children with serious emotional problems. Without Medicaid coverage, these critical services will be inaccessible for most low-income children and adults.

Moreover, SCHIP plans do not include the vitally important Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit provided to children through Medicaid. EPSDT requires that treatment be furnished to children on Medicaid to correct or ameliorate physical and mental illness and conditions discovered by regularly scheduled screenings. Without this benefit, low-income families of children with mental health disorders would be unable to afford the psychiatric care their children need to progress in school and grow up to be healthy adults. The recent national survey sponsored by the National Institute of Mental Health (NIMH) found that unlike most disabling physical diseases, mental illness begins very early in life – 50% of lifetime cases of mental illness start by age 14 and 75% by age 24. The problems caused by early onset of these illnesses is compounded by the fact that treatment is often delayed for ten or more years increasing the risk of school failure, teenage childbearing, unstable employment, early marriage, marital instability and violence.[2] The early screening and diagnosis provided by the EPSDT benefit in Medicaid is critical to detecting and treating mental illnesses that can strike so early in life.

The medical care that Medicaid provides is far from "optional" for those low-income individuals who rely on this program. The NIMH recently reaffirmed that the rates of mental illness in this country continue to be extremely high, but most people do not receive the treatment they need. Individuals with mental health disorders receiving Medicaid coverage require access to a wide array of services, most of which are labeled as optional. The law already limits coverage to services that are medically necessary which gives states the flexibility they need to ensure only needed services are going to any one individual regardless of which eligibility category they fall into. We urge Congress not to diminish the level of benefits or restrict eligibility for such a critical source of coverage for mental health care. Already most people do not receive needed treatment resulting in job loss, school failure, homelessness, and even suicide. Further limiting medical services for individuals with mental illness will likely result in additional tragedy and increased cost as those denied needed treatment wind up in emergency rooms, homeless shelters, or jails.

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[1] General Accounting Office, *Medicaid and SCHIP: Comparisons of Outreach, Enrollment Practices and Benefits*, April 2000.

[2] Kessler, R., Berglund, P., Demler, O., Jin, R., Walters, E., *Lifetime Prevalence and Age-of-Onset Distributions of DSM-IV in the National Comorbidity Survey Replication*, Archives of General Psychiatry, June 6, 2005, pp. 593-602.