

CONSUMER DIRECTED SERVICES: IMPROVING MEDICAID BENEFICIARIES' ACCESS TO QUALITY CARE

HEARING BEFORE THE SUBCOMMITTEE ON HEALTH OF THE COMMITTEE ON ENERGY AND COMMERCE HOUSE OF REPRESENTATIVES ONE HUNDRED EIGHTH CONGRESS FIRST SESSION

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THURSDAY, JUNE 5, 2003

HOUSE OF REPRESENTATIVES,
COMMITTEE ON ENERGY AND COMMERCE,
SUBCOMMITTEE ON HEALTH
Washington, DC.

The subcommittee met, pursuant to notice, at 10:02 a.m., in room 2141, Rayburn House Office Building, Hon. Charlie Norwood (chairman) presiding.

Members present: Representatives Bilirakis, Deal, Whitfield, Norwood, Wilson, Buyer, Fletcher, Brown, Waxman, Stupak, Green, Capps, and Dingell (ex officio).

Also present: Representatives Stearns, Markey, and Allen.

Staff present: Chuck Clapton, majority counsel; Steve Tilton, health policy coordinator; Eugenia Edwards, legislative clerk; Patrick Morrissey, deputy staff director; Amy Hall, minority professional staff member; and Bridgett Taylor, minority professional staff member.

Mr. NORWOOD We now call this hearing to order. I would like to start by welcoming our witnesses and thanking them for joining us today. We do appreciate your time and effort to be here, all of you.

It is critical that we have an opportunity to learn from people with real-world experiences in the Cash and Counseling program. My understanding is that this program has been successful, but I believe it is vital that we hear directly from the experts as to what has worked and what has not. I am also hopeful that you might expand on how we could apply some of these principles in this program broadly to other areas of Medicaid, if that is possible, and, even better, expand the program to other States.

Once again, welcome all.

I want to remind the members that they have an opportunity of declining an opening statement; and if they do, that will increase their time from 5 to 8 minutes in questioning.

With that, I now yield to Ranking Member Sherrod Brown.

Mr. BROWN. Thank you, Mr. Chairman.

I want to thank our witnesses. Mr. Williams, especially, thank you for joining us.

Secretary White, nice to see you again. Sorry you are no longer in our State.

I want to thank the chairman and the committee for holding this important hearing. It is refreshing to be talking about ways to ac-

tually strengthen Medicaid and not dismantle it. It appears my colleagues on the other side of the aisle have had an epiphany. All my Republican colleagues on this committee voted to cut \$93 billion from the Medicaid program. Now at least we want to see—all of us want to see the program strengthened.

Medicaid is the largest health insurer in the Nation. Before Medicaid, virtually every low-income child and every low-income disabled American lacked coverage. One in five people with a specific chronic disability, 30 percent of children with chronic disabilities, 15 percent of working-age adults with chronic disabilities are covered by this program.

Over the last decade, the disabled have been the fastest growing eligibility category in Medicaid. It plays a critical role in providing coverage gaps for low-income disabled people. It is an essential part of our country's health care system, our long-term care system, and our economy. In Ohio alone, in my State, 36,000 health care professionals and 170 hospitals provide care to Medicaid beneficiaries.

I would add that of the 270 million people in our country, 90 million of them are served—their health care is provided by three government programs: Medicare, Medicaid, and SCHIP. To show how important these programs are—one out of three Americans—and that is why it is so important to continue to try to strengthen this program.

Five years ago Robert Wood Johnson Foundation in collaboration with the Federal Government began examining a new approach in access to quality health care. The program was coined Cash and Counseling, and was designed to empower the chronically ill and disabled, and to improve their quality of life. Through the Cash and Counseling program, Medicaid beneficiaries with disabilities can have a loved one or close friend provide personal care services like bathing and grooming or meal preparation while in their home. This novel approach cashes out the personal care services benefit in exchange for giving the beneficiary control over basic, often intimate, assistance, who provides the care, when they receive it, how it is delivered.

The preliminary evaluations of the Cash and Counseling program have been overwhelmingly positive. Robert Wood Johnson reported that satisfaction with the program was high; the paid caregivers are diligent in completing required tasks. Cash and Counseling could be a best practices program for disabled beneficiaries who need a little help to maintain a high quality of life. The program may have limits. Not everyone has a family member available or willing to deliver care. Not all family members have sufficient medical training to deliver more sophisticated health care. But the success of the program prompted the current administration to continue offering it under an Independence Plus waiver. For that, I applaud both the Clinton and Bush Administration.

In this program, it is possible to use the Cash and Counseling structure for medical services. It is difficult to see how an individual could or would want to hire their family member to be their pharmacist or cardiologist.

Another important consideration is the degree to which we are comfortable with intrastate and interstate disparities that logically occur when individuals are given a cash sum.

Realizing this program is in the infant stages of development, there are several policy issues to consider. The Medicaid program serves 37 million low-income and disabled Americans. It is a huge safety net. Part of its success is due to the Federal Government commitment to increase the safety net during times of economic hardship, times when 2.7 million jobs are lost in a matter of 2 years, times when the Federal surplus plummets into the red in a matter of 2 years, times like these in which we live.

That is why I am concerned with the Bush Administration's proposal to block-grant or more precisely block-loan Medicaid. It is nothing more than a loan tied to a Federal funding cap, which, in my mind, jeopardizes the future of this program. Capping Federal funding on Medicaid is tantamount to taking the umbrella from a person already standing in the rain. If Medicaid is truly headed toward fund capping, then it is unlikely that programs like Cash and Counseling would survive. It is nothing short of cruel to make a commitment to compensate a family member for providing services, personal services, only to cutoff that funding halfway through the year. That is no way to run a program. It is a realistic scenario if this block grant, block loan program from the Bush Administration is adopted.

Our hearing today highlights a program with potential for strengthening Medicaid while preserving its integrity. The stability of the States' health care system, the stability of the Nation's health care system depends on preserving and strengthening good public programs like Medicaid.

Mr. Chairman, I thank you for your time.

Mr. NORWOOD. I thank the gentleman.

I now recognize Dr. Fletcher from Kentucky for 5 minutes of opening statement.

Mr. FLETCHER. Thank you, Mr. Chairman. And I want to thank this committee and the chairman for holding this hearing. And my thanks to the witnesses as well. We look forward to your testimony about the exciting programs in Arkansas, New Jersey, and, most notably, Florida.

I think this is a significant step in the right direction for Medicaid programs, but, more importantly, it is a major advancement for Medicaid patients. The Cash and Counseling program applies common sense to a government program that has been lacking it for far too long, giving patients the power and ability to purchase services that they determine are appropriate services that work, and it has proven to work very well, I believe. The experience we have seen with Cash and Counseling debunks any misconceptions that people on Medicaid or their guardians are not capable of arranging for their own health care needs. In fact, they can do it, they want to do it, and they are more successful at it than under the old inflexible structure that unfortunately still exists in most States. How many other government programs have a satisfaction rate among participants close to 100 percent? This program dispels any myths that the Medicaid population somehow is not prepared to make wise decisions regarding their health care.

The reality is that, generally speaking, Medicaid does not optimize how it serves its patient. Additionally, the program's effectiveness continues to wane in many areas. A recent article by John Igelhart in the *New England Journal of Medicine* cited a study by MedPAC, the Medicare Payment Advisory Commission, that documented continued physician withdrawal from the Medicaid program. Over the previous 3 years, the number of physicians who accept all Medicaid patients dropped from 48.1 percent to 39.4 percent. This drop occurred despite large increases in Medicaid spending over the same timeframe.

Access to specialists is even worse and more concerning. In another study, researchers posing as Medicaid patients with fractured arms contacted 50 orthopedic specialists in California. A stunning 47, or 94 percent of them, refused to accept such a patient. Clearly, more is broken with Medicaid than many are willing to admit.

As a medical doctor who spent most of my adult career and professional career treating patients, I can personally attest to the access problems that plague America's otherwise excellent health care system. Our medical technology, our hospitals, our doctors, and our medical schools are second to none.

We must ensure that all Americans have access to our superb services. While a narrow experiment with only a few thousand patients, Cash and Counseling offers us a glimpse of the direction in which we must head to maximize that access. When patients, whether with Medicaid, Medicare, or private insurance, are afforded control over their health care dollars, the care they receive improves dramatically. It is my sincere hope that this approach can be expanded so that many more Medicaid patients can take advantage of it as well.

And, again, I want to thank you all for coming and testifying, and I yield back.

Mr. NORWOOD. I want to remind members that you can have a longer questioning period of 8 minutes if you forego your opening statement. It doesn't matter to me.

Mrs. Capps, would you like an opening statement?

Mrs. CAPPS. Yes, Mr. Chairman. Thank you very much. I thank you for holding this hearing, and I do look forward to hearing from our witnesses.

The Cash and Counseling demonstration projects appear to have proven to be very successful. It is exciting news to me. They have allowed many Medicaid beneficiaries to take control over their own lives, which is a worthwhile goal, and they have supported a continuum of care that we know is an important ingredient to making Medicare services work. Most health care providers can tell you that when a patient or, in this case, a beneficiary can get more effective personal attention, they can avoid many health care complications. This can lead to a higher quality of life and fewer expenses by the beneficiary. It is very cost-saving if it works well. The cost savings is to the taxpayer, because more extreme treatments down the road could perhaps be avoided or prevented. The Cash and Counseling demonstration projects support this idea.

We may be able to use this model to make many other improvements to Medicaid, Medicare, and health care delivery in general, but I believe we have to also understand this model's limits and

not get carried away and create a cash and medical care system. Cash and Counseling works because it is a set of services with predictable expenses and costs that can be provided by nonprofessional personnel. It works precisely because it does not deal with medical care, per se. It would be very hard, my colleague tried to imagine this, to ask a parent, a sibling, or a child to provide pharmacy services or to serve as a doctor. These examples are absurd, but they highlight the limits of the model.

I believe the demonstration project underscores a need which many fragile populations have, not all, but some parts of them, a need for case management, for a continuum of services, for a safety net to make sure that the community is able to be responsive to the individual's needs. And the particular demonstration project also works in this case I believe because they incorporate the direct involvement of the Robert Wood Johnson Foundation.

Robert Wood Johnson Foundation provides quality control and administrative support, elements that would be costly if this is converted into a national program or applied to medical services. I don't mean to say this as a deterrent, but I think we need to recognize, I hope we do, and that is why I look forward to hearing from you witnesses, to see exactly what the parameters are of the kind of services that you have experienced. I do want to make sure that we don't get too excited and overreach, but I also want us to recognize the very real successes that have been demonstrated in this project. And I yield back the balance of my time.

Mr. NORWOOD. With unanimous consent, I will recognize Bridgette's boss next for 5 minutes, Mr. Dingell.

Mr. DINGELL. Mr. Chairman, thank you. I thank you for holding today's hearing on consumer-directed personal care services and Medicaid. Increasing community-based care options for individuals living with disabilities is a critically important goal, and we must work with the States to achieve that purpose. Expanding access to personal attendant services and improving control over such services, the subject of this hearing, is an important element for committing options to work successfully.

Last month, along with a number of other members of this committee, I introduced H.R. 2000, the Strengthening of Our States Act. Amongst other provisions, the legislation encourages States to expand personal care services and supports under Medicaid, and helps the States expand community-based living options. It provides permanent enhanced Federal funding for States to provide personal attendant services and supports in Medicaid, and enhanced Federal funding for home and community-based waivers.

States do not have the budgetary means to serve all the individuals who choose community-based care, so they need to partnership with the Federal Government under the Medicaid program. For this reason I am particularly concerned with proposals I now see coming forward out of the administration on so-called Medicaid reform. The President would have us believe that severing or limiting State-Federal relationships under Medicaid and shifting the financial burden onto the States can help the families who depend on these programs. I believe the exact opposite will come to pass, particularly in the services we are discussing today. The assistance in funding for community-based and consumer-based services that are

there will wither, leaving individuals living with disabilities in a dire situation, and forcing many back into institutions or leaving them without any care at all.

One important point to consider is that the consumer-directed care program has been very successful; but there is no inherent reason that vouchers are required in order to give families more control over personal care services. States could be given incentives to improve consumer choice and control without capping funding for families so that families are guaranteed an adequate level of service which is not subject to future arbitrary budgetary cost-cutting measures.

In addition, even if people were given the ability to, quote, manage, close quote, their money for personal care services, this does not mean that people with disabilities should be given limited dollars to manage all their health care needs. As many will testify today, it is much easier to manage certain predictable daily tasks than it is to predict how to manage the amount of care an individual with disabilities will need when they are sick.

I look forward to the testimony of all the witnesses today on the successes of the Cash and Counseling program and how we might work here in Congress to encourage the expansion of this model so that it is not limited to only a few States and only a few populations. We want to ensure that all individuals living with disabilities can choose to receive the benefit of directing their own personal care services, but we also want to ensure that they have adequate protections so that they do not have to worry about whether the money will be there to take care of them from week to week.

Mr. Chairman, I thank you for your courtesy.

Mr. NORWOOD. Thank you very much, Mr. Dingell.

I now recognize Ms. Wilson from New Mexico for 5 minutes on an opening statement.

Mrs. WILSON. Thank you, Mr. Chairman. I wanted to thank you and also Chairman Bilirakis, who I think is feeling ill today and hasn't come in yet, for arranging this hearing. And thank him for giving me the charge as well as my colleague from Kentucky Mr. Whitfield, and Dr. Fletcher, and Mrs. Bono, and Nathan Deal to look at the Medicaid program over the summer and the fall in a task force to see if we can improve the health status of those who would depend upon it, and what changes need to be made to the Medicaid program to improve the satisfaction of those who depend upon it.

The first thing we wanted to do was to identify some things that States are doing. Medicaid is a program that is different in 51 States. We wanted to look at what States are doing that seem to make a difference and seem to make some common sense. And the Cash and Counseling and consumer-directed care is part of what we would like to see propagated across the country on a program that seems to work for a particular segment of the Medicaid-dependent population. Florida, Arkansas, and New Jersey have been able to experiment with what happens when individuals and families are allowed to determine what care they need most and how best to provide it.

It seems to make sense to me that satisfaction goes up when a program is personally tailored to the people who depend upon it

every day, and I am looking forward to hearing from the witnesses today on how this program has operated and affected your lives, what you have seen, and what you would recommend to us with respect to what we need to change in the Federal law to make it easier to do these kinds of things.

In the past several years, the Congress has focused intensely on the Medicare program, and in modernizing it and in adding a prescription drug benefit to it and so forth. Meanwhile, Medicaid has gone largely under the radar, and yet it has now passed Medicare in both dollars and enrollees as a Federal health care program. I think it is about time we started looking seriously at ways that we make this program better for the people who depend upon it, and I look forward to the testimony today in this first of what I think will be many hearings and meetings over the summer and the fall. And I yield back the balance of my time.

Mr. NORWOOD. Mr. Markey, we welcome you to our subcommittee, and understand that you would like an opening statement. You are now recognized.

Mr. MARKEY. I thank you very much, Mr. Chairman.

This is a very good program, obviously, and it is one that should be expanded upon in the future in order to help people who are trying to help themselves. All of these individuals and families are heroes, but heroes need help in situations like this. And much of what we are talking about here today is aimed at ensuring that families are able to do what is possible in order to ensure the best possible standard of life for their families.

This year the Federal Government is spending \$177 billion on Medicaid, which is a lot of money. By 2006, we will be spending \$197 billion on Medicaid, the Federal Government. And on the one hand, that is a big amount of money, but looking at it from a different perspective, it is really not, because the tax cuts from 2001 and 2003 combined in 2006 are going to be \$244 billion just for that 1 year. So that is a huge tax cut for 1 year, \$244 billion, if the entire Medicaid program is only \$197 billion.

So, in other words, you could easily finance the increase from \$177 billion to \$197 billion, the Federal share in 2006, which is 20 \$billion, out of the \$244 billion tax cut of the year 2006 alone. And I think, looking at it in that context as to whether or not we can afford to continue to expand Medicaid to ensure that families are given the help that they need shows that the money is there, that we could do it, that we do have a capacity to help these families. And a program like this that is so successful is a demonstration project, but it has demonstrated that success is something that we should continue to enhance and improve upon, because the more that we do for these families, the more that they can do for us and for our country.

And so I thank you, Mr. Chairman, for having this hearing, and I hope that by the end of the day that we will understand how important it is to spend the money to help these families.

Mr. NORWOOD. I recognized you out of order and hoped you would sing us a little song or had a poem. I am disappointed. But thank you for being here.

Mr. Whitfield from Kentucky, do you wish an opening statement?

Mr. WHITFIELD. Mr. Chairman, I will waive my opening statement.

Mr. NORWOOD. Mr. Stupak. I apologize.

Mr. STUPAK. I waive.

Mr. NORWOOD. You will waive and go for 8 minutes.

Mr. Green, would you wish an opening statement?

Mr. GREEN. Thank you, Mr. Chairman. I would like to place my full opening statement into the record. But, again, I appreciate you having the hearing, and I know meeting with my own constituents that individuals with disabilities, that they really would just like to be as close to home as they could, and anything we can do to help that, to keep them from being institutionalized, again, I appreciate you bringing up this, having this hearing so we can discuss it.

Mr. NORWOOD. Thank you very much, Mr. Green.

Is there anyone, any member, who has—Mr. Waxman wishes an opening statement. You are recognized for 5 minutes.

Mr. WAXMAN. Thank you very much, Mr. Chairman.

For a person with chronic illnesses or disabilities, personal care services could make the difference between dependence and independence, between living in an institution and living in a community.

Some people have the financial wherewithal to assure that, their own personal care. Some people have families who can provide these services on their own, and some people must turn to Medicaid. The first thing to be sure of today is that Medicaid itself can make these services available to those who need them.

State Medicaid budgets are in crisis, and this Congress and the Bush Administration have been unwilling to help States in a real way, so there are serious cuts in eligibility, in benefits and Medicaid programs around the country. Somehow the Congress and the President can find \$1 trillion of tax cuts, but they cannot find the money to make sure that Americans get basic health care. In fact, the Republicans in the House this year voted for \$100 billion in cuts in Medicaid, but no chairman is willing to have a hearing on the real needs of Medicaid and all its beneficiaries.

So let me move on to the more narrow topic of today's hearing. The second thing to be sure of today is that when these services are available from Medicaid, they are provided in a way that best meets the desires and needs of the person. For many people Cash and Counseling is clearly the preferable model for getting personal care services. People like choosing their own attendants, hiring their families and friends as caregivers for such intimate care, and doing their own training of attendants. It is not for everyone, and it is not necessarily easy to carry out, but for those who want to and can use it, this model should be available in Medicaid.

The final thing to be sure of today is that we are cautious about what we take away from this discussion. This cannot be done on the cheap. There has to be enough cash for Cash and Counseling to work. This model is not a cost-containment device. The virtues of this model cannot readily be transferred to a wide range of medical and health services. You can't hire your friends and family to be your pharmacist or your drug company. You don't need intimacy with your equipment suppliers. And the financing of any expansion

beyond personal care services would be complicated, risky, and wrong.

The demonstrations that have been done so far have involved a relatively simple assessment of basic services and hours and how much they cost. If anybody attempts to carry this to a broader range of medical and health services, in essence, a voucher program, it would put people at risk almost as severe as being completely uninsured. This is the stuff of actuaries and risk managers, and even they are predicting for the average need, not the individual need. We should not force people to risk their health on making a good guess of what they need.

We have the opportunity to provide good and flexible personal services with these models; indeed, many of us have supported legislation to provide States with increased resources to do so. And I urge my colleagues to consider joining in this legislation.

And, finally, I am grateful to our witnesses for coming today. I want to thank them for their testimony and their help, and I look forward to hearing from you.

Thank you, Mr. Chairman.

Mr. NORWOOD. Thank you.

[Additional statements submitted for the record follow:]

PREPARED STATEMENT OF HON. MICHAEL BILIRAKIS, CHAIRMAN, SUBCOMMITTEE ON HEALTH

I now call this hearing to order. I would like to start by welcoming our witnesses and thanking them for joining us today. I am particularly pleased to see my fellow Floridians today and I am very much looking forward to your testimony. It is critical that we have an opportunity to hear from people with real world experience in the "Cash and Counseling" program. My understanding is that this program has been successful, but I believe it is vital that we hear directly from the experts as to what has worked and what has not. I am also hopeful that you might expand on how we could apply some of the principles in this program broadly to other areas of Medicaid—and even better expand the program to other states.

The three Cash and Counseling demonstration programs currently supported by the Centers for Medicare and Medicaid Services (CMS) increase the health care options for some Medicaid beneficiaries. These programs provide the beneficiary with a cash allotment that can then be used to purchase health care services or other needed items. The structure of this program ensures that beneficiaries are able to meet all of their health care requirements while at the same time empowering the participants to make use of resources in a way that best meets their individual needs. This system makes certain that Medicaid is using its limited resources in the most efficient manner possible.

Medicaid beneficiaries participating in Florida's Cash and Counseling demonstration, have reported increased satisfaction with Medicaid services and that the overall quality of their care has improved. The Florida demonstration also found that the flexibility of the program delayed institutional and other high cost out-of-home placements by allowing its participants to more efficiently use the money that would have otherwise been spent directly by Medicaid.

I am certain that today's hearing will help us identify whether or not these demonstration programs can be used as models to expand and build on in other states. I understand that CMS recently approved Florida's request to expand its Cash and Counseling program statewide. I hope that other states follow Florida's lead and increase beneficiary access to this promising model. An expansion is warranted given that the Supreme Court's landmark *Olmstead* decision requires states to administer services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." I believe it is incumbent on other states to follow Florida's lead and ensure that the cash and counseling option is available to every Medicaid beneficiary for whom this type of model is appropriate.

I would again like to offer a warm welcome to all of our panelists and thank them for their time and effort in joining us today. I now recognize the Ranking Member, Mr. Brown, for an opening statement.

PREPARED STATEMENT OF HON. W.J. "BILLY" TAUZIN, CHAIRMAN, COMMITTEE ON
ENERGY AND COMMERCE

Thank you, Chairman Bilirakis, for holding this important hearing today. Thanks also to Mr. Mahoney, Mr. White, Mr. Reimers, Mr. Williams and Ms. Gittens for making the time to come testify before the Health Subcommittee about the innovative Consumer Directed Services available through the Medicaid program.

Of the 40 million Americans covered by Medicaid, about one-sixth or 6.9 million are non-elderly adults with disabilities. The Medicaid program plays an important role for these individuals. Through Medicaid, people with disabilities obtain access to medical and hospital care, as well as long-term care services.

Currently about 1.2 million Medicaid beneficiaries receive disability-related supportive services in their homes. Most receive them from government-selected home care agencies, whose professional staff arrange the services for the beneficiary. As a result, many Medicaid beneficiaries who have disabilities and receive supportive services from these agencies often report that they have little control over who provides their care, when they receive it, and how it is delivered. For many, this lack of control over basic assistance leads to dissatisfaction, unmet needs, and diminished quality of life.

Over the past few years, with the help of President Bush's New Freedom Initiative, some states have expanded opportunities for Medicaid beneficiaries. Significantly, some beneficiaries have been permitted to direct and manage their own services and control their budgets for their health care needs. Under this model, consumers are given a monthly allowance to purchase disability-related goods and services. This affords consumers the authority and tools to craft their own services plans, with the freedom to use both traditional and nontraditional providers. This freedom also empowers beneficiaries with the choice of hiring, firing, scheduling, training, and supervising their providers, rather than being at the mercy of a particular provider.

Consumer Directed Services also provides assistance to help beneficiaries plan and manage their responsibilities, and allows them to designate representatives (such as family members) to make decisions on their behalf. All of these features make the model adaptable to a wide variety of Medicaid beneficiaries including people with developmental disabilities, physical disabilities, and serious mental illness, as well as elderly individuals.

From all indications, we are examining a program that works. One recent evaluation, completed for the Robert Wood Johnson Foundation, revealed that Medicaid recipients with disabilities who direct their own supportive services were significantly more satisfied and appeared to get better care than those receiving services through traditional Medicaid providers. The study found that with self-direction, 82 percent of the recipients' satisfaction and quality of life were improved substantially and many indicated that their unmet needs for care were reduced. These compelling results further emphasize the importance of expanding Consumer Directed Service to more state Medicaid programs.

Due to their unique and often extensive health needs, Medicaid beneficiaries with disabilities use a great deal of medical services. On average, Medicaid spends nearly eight times more for a beneficiary with a disability than for a child who qualifies for Medicaid based on income. In a time when spending on Medicaid consumes between 15 and 20 percent of all state budgets, and Medicaid costs grew by over 13 percent last year, almost all states are now being forced to make painful cuts to their Medicaid programs. Given the harsh fiscal reality, it seems possible that Consumer Directed Services could result in a mutually beneficial situation for both the states and beneficiaries with disabilities. With a defined contribution for Consumer Directed Services, states would have a better ability to forecast their Medicaid expenditures, all the while giving beneficiaries with disabilities greater discretion when choosing their services, and better satisfaction. This could enable beneficiaries with disabilities to manage their care in ways that better meet their needs, without raising public costs.

Medicaid beneficiaries should expect to control what happens in their own lives. This includes having a direct say about the home and community services and some of their health care choices they receive through the Medicaid program. Chairman Bilirakis and I are very interested in learning more about how we can expand the use of Consumer Directed Services in the Medicaid program. We hope you will be able to provide a unique perspective on the innovative strategies being pursued to improve the critical services that Medicaid currently offers.

The Medicaid program is truly at a crossroads. If we are not willing to make some major changes in Medicaid and look at dynamic programs such as Consumer Directed Services, the long-term prospects for the program will not be bright. We have

serious challenges facing Medicaid today. Today, we are focusing on one initiative to put patients first and improve the quality of care received by Medicaid beneficiaries. Over the next few months, we will look at more innovative programs for beneficiaries as well as ways to address the long term financing issues facing the program. America's Medicaid beneficiaries deserve this and more.

Mr. NORWOOD. I would like to take a minute and introduce our guests to the committee, your panelists who many have come a long way. And we are all very grateful for your participating in this. We want you to enjoy this time. And, remember, we consider you the experts. So give us your presentation, and we are just going to have a very happy dialog here.

First, we want to welcome Dr. Kevin Mahoney, associate professor of Boston College. Thank you, sir, for coming a long way. We appreciate it.

And Ms. Patricia Gittens, who we are delighted you are here. Ms. Gittens brings to us real life experiences in this Cash and Counseling process, and we are most anxious to hear from you and grateful.

Mr. Secretary, Terry White, we are glad you are here from the Florida Department of Elder Affairs.

And Mr. Bob Williams, thank you, sir, for coming, codirector. Advancing Independence and Modernizing Medicare and Medicaid.

We are going to ask each of you in turn to present your statement. Try to stay within 5 minutes. I am not going to cut you off if it is 6, but try to keep it in that timeframe.

And with that, we will start with Dr. Mahoney. And if you will give us your testimony.

STATEMENTS OF KEVIN J. MAHONEY, ASSOCIATE PROFESSOR, BOSTON COLLEGE, GRADUATE SCHOOL OF SOCIAL WORK; PATRICIA GITTENS; TERRY F. WHITE, SECRETARY, FLORIDA DEPARTMENT OF ELDER AFFAIRS; AND BOB WILLIAMS, CO-DIRECTOR, ADVANCING INDEPENDENCE AND MODERNIZING MEDICARE AND MEDICAID

Mr. MAHONEY. Thank you very much, Mr. Chairman and members. I have the privilege of being the national program director for the Cash and Counseling demonstration, and we really appreciate this chance to appear before you today.

Today, in most States, whether you are elderly or a younger person with disabilities, if you are on Medicaid and you need help with such basic activities as bathing, dressing, getting to the bathroom, you have little, if any, choice about who helps you, when they come, or what they do. But for years people in the disability community have been saying, if I had more control over these basics, basic services, my life would be a lot better, and I could do it for the same amount of money, maybe even a little less.

The Cash and Counseling demonstration is at its heart a test of this very idea. It is a test where people are literally given a choice between traditional agency-delivered services, or managing an equivalent amount of money to meet their own personal assistant service needs. It is a large-scale test that has involved over 6,700 people in a three-State controlled experiment.

Janice Maddox is a perfect example of the desire of seniors to have more control over who enters their home and who provides intimate care. At 75, Ms. Maddox does not have the best health; she

has diabetes and glaucoma and is confined to a wheelchair possibly as a result of several strokes. But despite her physical frailty, Ms. Maddox possesses a tremendous asset, an extensive support network of friends and family who want to help her to continue to live independently.

For 5 years Mrs. Maddox received personal assistance services from aides sent to her by an agency that contracted with Medicaid. Then her daughter read about Arkansas' Cash and Counseling program in the newspaper. Mrs. Maddox enrolled, and her oldest daughter Johnetta Thurman became her representative to help her with the decisionmaking process. Mrs. Maddox's monthly allowance through Cash and Counseling pays her adult granddaughter to spend at least 2 hours a day, 7 days a week attending to Mrs. Maddox's needs. Her allowance is also used to pay for her grandson \$10 a week to do odd jobs around the house, and it also helps with such things as cost of over-the-counter medications and toiletries.

Mrs. Maddox's daughter, who lives in Chicago and travels frequently to Arkansas for her mother, believes the program has made an immense impact in improving the quality of her mother's life, which she says there is something about having family look after her. She doesn't get nearly as many allergic reactions or bed sores now. And I think that is because when it is your own you are looking after, you pay more attention.

The Cash and Counseling program has from day one been a unique partnership funded by the Robert Wood Johnson Foundation and ASPE, the Office of the Assistant Secretary for Planning and Evaluation. It operates under waivers and oversight from the Centers for Medicare and Medicaid Services.

As you will see in a few minutes, the quantitative evaluation—and this is a major controlled experiment, randomized control—is done by mathematical policy research, and we have had a qualitative evaluation that follows 25 people in each of these States up close and personal, and what did this really mean in their lives.

The three States, as you have heard, are Arkansas, New Jersey, and Florida. In Arkansas and New Jersey, this is an alternative to the Medicaid personal benefit. Florida, as you will hear, it is really an alternative to three different 1915(C) home and community-based service waivers. All three States cover the elderly and adults with disabilities. Florida is unique in also covering children with developmental disabilities.

If I could have your permission, I would show a few quick overheads. In these opening remarks, I would like to present the first results from the demonstration. They come from Arkansas, which was the first State to implement. They implemented within a month of getting their Federal waivers. And it focuses on the effects on quality of care.

I am going to flash through these because of the—let us see. No, nothing is happening. I will flash through these, and I will do it this way.

In the qualitative evaluation, we had the chance to look at impacts on satisfaction, on unmet need, health outcomes, and life satisfaction. You have copies of these, so I will go at it this way. As a key to reading these—and if you could flash through, or do you think I can? Okay. Wonderful.

These are the quality of care measures that we are looking at. It is still not going forward.

Mr. NORWOOD. Mr. Mahoney, we have all of these slides in each of our handouts; is that correct?

Mr. MAHONEY. That is correct.

Mr. NORWOOD. Your time is over. And I am going to recommend to the members of the committee, if they would, and maybe they already have, look through these slides in our handout that we have.

Mr. MAHONEY. If I could have 30 seconds, I could summarize it.

Mr. NORWOOD. Thirty seconds.

Mr. MAHONEY. Not unsurprisingly, the effects on reduce—the effects on satisfaction are the kind researchers rarely in their life will see. They are 20 percentage point difference more satisfied, major reductions in unmet need. Where people will be surprised at are the health outcomes. They are either the same, or you end up with fewer—statistically significantly fewer bed sores among the younger adults with disabilities, fewer contractures among the elderly. Even effects from modest benefits on overall life satisfaction.

The thing that I hope I get the chance to talk about with the committee later is, looking ahead, all three of these States in a bipartisan fashion are trying to make this program permanent. Florida—

Mr. NORWOOD. That is my first question to you, so you are going to get a chance.

Mr. MAHONEY. Florida has passed legislation, and the Robert Wood Johnson Foundation is looking at additional—a national program that could help other States.

Thank you.

[The prepared statement of Kevin J. Mahoney follows:]

PREPARED STATEMENT OF KEVIN J. MAHONEY, NATIONAL PROGRAM DIRECTOR, CASH AND COUNSELING DEMONSTRATION AND EVALUATION

Mr. Chairman and Members of the Committee, good morning. My name is Dr. Kevin J. Mahoney. I am the National Program Director for the Cash and Counseling Demonstration and Evaluation and a faculty member at the Boston College Graduate School of Social Work. Thank you for inviting me to testify this morning.

Today, in most states, whether you are an elderly individual or a younger person with disabilities, if you need Medicaid assistance to perform basic activities of daily living like bathing, dressing, toileting, transferring or eating you will rarely have much say over who helps you or when they come, never mind what they actually do. But, for years, people with disabilities have been saying, “If I had more control over my services, my quality of life would improve and I could meet my needs for the same amount of money or less.” The Cash and Counseling Demonstration (CCDE) is, at its heart, a policy-driven evaluation of this basic belief—a test where people are given a choice between traditional agency-delivered services or managing an equivalent amount of money to meet their ongoing personal assistance service (PAS) needs—a large scale test involving over 6,700 individuals from three states in a controlled experiment.

Janice Maddox is a perfect example of the desire of seniors to have more control over who enters their home and who provides intimate care.

At 75, Ms. Maddox does not have the best health. She has diabetes and glaucoma and is confined to a wheelchair, possibly as a result of several strokes. She needs help getting in and out of bed, dressing, bathing, meeting her dietary requirements, taking her medications, and keeping up with her housework.

But despite her physical frailty, Mrs. Maddox possesses a tremendous asset: an extensive support network of friends and family who want to help her continue to live independently. Her many children, grandchildren, great-grandchildren, siblings, and extended family, including neighbors, provide a continual stream of sound and motion for Mrs. Maddox, a widow, to watch bemusedly from her wheelchair.

For five years, Mrs. Maddox received personal assistance services from aides sent to her by an agency that contracted with Medicaid. Then her daughter read about Arkansas' Cash & Counseling program, in the newspaper. Mrs. Maddox enrolled, and her oldest daughter, Johnetta Thurman, became her representative decision maker.

Mrs. Maddox's monthly allowance through Cash & Counseling pays her adult granddaughter to spend at least two hours a day, seven days week, attending to Mrs. Maddox's needs. Her allowance is also used to pay her grandson \$10 a week to do odd jobs around the house and helps cover the cost of over-the-counter medications and toiletries.

Ms. Maddox's daughter, who lives in Chicago and travels frequently to Arkansas to make sure her mother's needs are being met, believes the program has made an immense impact in improving the quality of her mother's life. "There's just something about having family look after her. She doesn't get nearly as many allergic reactions or bed sores now, and I think that's because when it's your own you're looking after, you pay more attention."

The Cash and Counseling Demonstration and Evaluation (CCDE), funded by the Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services, is a test of one of the most unfettered forms of consumer direction—offering elders and younger persons with disabilities a cash allowance in place of agency-delivered services. It operates under a research and demonstration waiver granted by the Centers for Medicare and Medicaid Services (CMS). The purpose of this project is to determine whether cash allowances maximize consumer choice and promote program efficiencies.

In the states where the program is being implemented, i.e., Arkansas, Florida and New Jersey, consumers who meet project eligibility criteria and express interest in participating in CCDE are randomly assigned to participate in the program (managing a cash allowance to purchase services) or serve as a control group and receive services through the state's existing system. The evaluation compares outcomes for consumers receiving traditional service packages with those receiving cash allowances with respect to cost, quality, and satisfaction.

My presentation today summarizes findings about the effects of Cash and Counseling on well-being, unmet needs, health outcomes, and consumer satisfaction. It focuses on the first of the demonstration programs to be implemented, Arkansas's IndependentChoices. Mathematica Policy Research, Inc. conducted the evaluation.

DEMONSTRATION TESTS A NEW MODEL OF MEDICAID PERSONAL ASSISTANCE

Medicaid beneficiaries who have disabilities and receive supportive services from home care or case management agencies often report that they have little control over who provides their care, when they receive it, and how it is delivered. For some, this lack of control over basic, often intimate, assistance leads to dissatisfaction, unmet needs, and diminished quality of life. Many states are expanding opportunities for interested Medicaid beneficiaries to direct their disability-related supportive services by letting them control the budget for their approved care. This approach could enable beneficiaries to better meet their care needs, without increasing public costs. However, critics fear that such options jeopardize consumer health and safety.

In the Arkansas Cash and Counseling demonstration, called IndependentChoices, consumers had the opportunity to receive a monthly allowance, which they could use to hire their choice of caregivers (except spouses) and to buy other services or goods (such as assistive devices and home modifications) to meet their personal care needs. Allowances were equal to the number of hours of care consumers were expected to receive under the traditional Medicaid program, and averaged about \$320 per month. Consumers were required to develop written plans for managing the allowance and have them approved by counselors. In addition, virtually all consumers chose to have the program's fiscal agents write checks for their purchases and withhold payroll taxes for caregivers hired with the allowance. Consumers who were unable or unwilling to manage the allowance themselves could designate a representative, such as a family member, to do so for them.

DEMONSTRATION'S RANDOMIZED DESIGN AND COMPREHENSIVE SURVEY DATA YIELD DEFINITIVE RESULTS

Cash and Counseling was designed to provide definitive evidence about its effects on a variety of outcomes, including many that pertained to care quality. Enrollment into the Arkansas demonstration, which occurred between December 1998 and April 2001, and was open to interested Arkansans who were at least 18 years old and

who were eligible for personal care services under the state Medicaid plan. The 2,008 adults who volunteered for the demonstration completed a baseline telephone interview and then were randomly assigned to direct their own supportive services as IndependentChoices consumers (the treatment group) or to rely as usual on services from home care agencies (the control group).

Data on quality of care outcomes were collected nine months later, when all treatment and control group members (or their proxy respondents) were asked to complete a follow-up telephone interview. The 1,739 survey respondents answered factual questions about disability-related adverse events and health problems, and gave their opinions about (1) satisfaction with care, (2) unmet needs for assistance with daily activities, (3) quality of life, (4) general health status, (5) self-care, and (6) ability to perform daily activities without help from others. Demonstration evaluators then used statistical models to compare the treatment and control groups on these outcomes for non-elderly and elderly sample members, while controlling for a comprehensive set of characteristics that were measured during the baseline interviews.

CONSUMER SATISFACTION IMPROVED MARKEDLY, WITH NO ADVERSE HEALTH EFFECTS

The resulting analysis showed that the Arkansas Medicaid beneficiaries who had the opportunity to direct their personal care services themselves received better care than the control group, which relied on services from agencies. IndependentChoices significantly increased the proportion of consumers who were very satisfied with their care and their paid caregivers, and thinned the ranks of the dissatisfied. Specifically, IndependentChoices consumers were much more satisfied with the timing and reliability of their care, less likely to feel neglected or rudely treated by paid caregivers, and more satisfied with the way paid caregivers performed their tasks. The program also reduced some unmet needs for personal assistance services and substantially enhanced consumers' quality of life. Moreover, it produced these improvements without compromising consumer health or functioning. Both elderly and non-elderly adults had better experiences under IndependentChoices than under agency-directed services, though impacts on most outcomes were larger for the non-elderly.

FINDINGS ABOUT COSTS, CAREGIVER OUTCOMES, AND IMPLEMENTATION ARE ALSO NEEDED

Although the quality and consumer satisfaction results suggest that the Cash and Counseling model, as implemented under IndependentChoices, benefits users of personal care services, other issues must be examined before the model's desirability can be fully confirmed. Public costs could increase or decrease under IndependentChoices—a critical factor in times of state budget crises. In companion analyses, evaluators will examine how IndependentChoices may have affected the use and cost of personal care, acute care, and long-term care, as funded by Medicaid or Medicare. They also will examine program effects on consumers' informal and paid caregivers, and explore implementation lessons of interest to states. Evaluators will repeat these analyses for Florida and New Jersey and compare the results across all three states.

CASH & COUNSELING CONSUMER PROFILES

Often the best way to see the effects of a program is by looking at how it affects individuals.

Grace Wall: Aging with Independence

Grace Wall, of Zephyrhills, Fla., has always been independent. But at 83, with a host of health problems that include congestive heart failure, two hip replacements, loss of sight in one eye, and lung cancer, that independence is harder to maintain.

For six years, Mrs. Wall took care of her paralyzed husband before he died in 1991. Now she lives alone in a mobile home. She gets her health care through Medicaid, as well as various personal assistance services, such as help with shopping and housekeeping "things that she has difficulty doing on her own now."

Mrs. Wall used to get those services through a Medicaid contractor. But in September 2000, she enrolled in Consumer Directed Care (CDC), Florida's Cash & Counseling program. Mrs. Wall says that CDC has changed her life.

"I just feel better," she says. "This gets what I need to get done without much fuss."

Now Mrs. Wall can hire people she knows and trusts to help her. A good portion of her \$437 monthly budget goes toward buying medications and health care supplies. She also uses the money for transportation and to maintain her home.

At first, Mrs. Wall admits that she was daunted by the paperwork. But her CDC consultant has helped her through that and Mrs. Wall says the rewards have been well worth the effort.

Mrs. Wall says CDC has enabled her to do things she wouldn't otherwise have been able to do and made difficult tasks simpler for her. She also feels more secure with help that is close at hand and accountable to her. Agency workers, she notes, were not always there for her when she needed them. "Now I can rely on my worker, and I couldn't before. I can get help when I need it."

Tammy Svihla: Getting Help on Her Own Terms

Single motherhood is tough for a woman on a limited income, but Tammy Svihla, who has multiple sclerosis (MS), does it all from a wheelchair without complaining.

Not much ruffles this 36-year-old mother of three. She's conquered many problems, and she's not about to give in to MS.

She lives in a rented two-story house in High Bridge, N.J., with her two youngest children (her eldest lives nearby with his grandparents). Although she is a take-charge type of person, she needs help with some of the basics, like dressing, showering, getting up and down the stairs, cooking, cleaning, and shopping. Ms. Svihla says she gladly accepts help when it comes on her own terms. "I've had a string of personal care aides through here, and most of them never lasted very long," she says.

A former retail store manager, Ms. Svihla jumped at the chance to direct her own care through New Jersey's Personal Preference program. "I saw it as an opportunity to take control " to decide for myself who walks through my front door," she says. "That's very important when you have young children in the house."

Today, Ms. Svihla employs two reliable, handpicked helpers: a neighbor and an aide she found by posting flyers in her neighborhood. Ms. Svihla manages her monthly \$1,035 allowance herself, with minimal assistance from a bookkeeper provided by the program. About half of the money covers payroll and taxes, and the rest pays for personal care items and goods for her home, including incontinence pads, an air conditioner and fans, and touch lamps. She's also purchased some home office equipment to help her manage her paperwork better.

Personal Preference, it turns out, is exactly what Ms. Svihla needed. "This program just makes sense," she says. "Others should know about it."

LESSONS LEARNED

Consumers like Cash & Counseling. Across all three states, clients express high levels of satisfaction.

- In Arkansas, 96 percent of clients say they would recommend the program to others; 82 percent say the program has improved their lives, and 65 percent say the program has improved their lives a great deal.
- In New Jersey, 97 percent of clients say they would recommend the program to others seeking more control over their personal care.

However, Cash & Counseling is not for everyone. For some, the traditional service delivery system works well because they are unable or don't want to make decisions about their care and arrange their own services.

Many consumers hire family members or friends to be their personal caregivers. This may be a reason why satisfaction with the program is so high "consumers are hiring people they know and trust to work for them. During this period of worker shortages, the CCDE allowed consumers to tap a new work force.

- In New Jersey, 63 percent of clients used their monthly budgets to hire family members, while 20 percent hired friends, neighbors, or church members.
- In Arkansas, Cash & Counseling consumers were more satisfied with their relationships with their paid caregivers than were consumers receiving traditional services.

For those under age 65, the program decreased the hours of human assistance received, but increased the likelihood of purchasing equipment, assistive devices and home renovations.

Nearly all consumers use the program's financial planning and book-keeping services and find them helpful. These services can reduce clients' fears of being overwhelmed by paperwork.

- In Florida, 80 percent of Cash & Counseling clients used a program consultant to help develop their purchasing plans; of those, 90 percent found the assistance

useful. Ninety-eight percent of Florida clients said the program's bookkeeper was managing their financial responsibilities for them.

There have been no major instances of fraud or abuse. Consumers are managing their budgets responsibly and spending their money the way the program intends.

LOOKING AHEAD

The Cash and Counseling approach has been a bi-partisan effort in all of our states. Each of the three Cash and Counseling states is working to make consumer-directed care a *permanent* option for disabled and elderly Medicaid beneficiaries. In fact, Florida has already enacted legislation to that effect. At the federal level, the Centers for Medicare & Medicaid Services (CMS) have issued model waiver templates encouraging states to develop consumer-directed waiver program options. Simultaneously, New Jersey and Arkansas have asked CMS to clarify its policy to allow states to pay for a wide array of assistive devices and home renovations under Medicaid's personal care benefit "without having to rely on waivers."

Meanwhile, The Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation, the Centers for Medicare and Medicaid Services and the Administration on Aging are exploring the feasibility of expanding the Cash & Counseling demonstration to other states. As part of an "environmental assessment" financed by The Robert Wood Johnson Foundation, twenty-one states have indicated a desire to replicate this basic "consumer-directed individualized budget" model.

I appreciate your invitation to participate in this hearing and look forward to your questions and comments. For follow-up questions, I can be reached at Kevin.mahoney@bc.edu or by calling (617) 552-4039.

Mr. NORWOOD. Thank you, Dr. Mahoney. I appreciate it.

Ms. Gittens, you are now recognized for your testimony.

STATEMENT OF PATRICIA GITTENS

Ms. GITTENS. Thank you, Mr. Chairman.

My daughter Jewel Stephen is 15 years old. Jewel has a developmental delay and is a med-waiver client in the State of Florida.

When the Consumer-Directed Care Project was introduced, I was given the opportunity to enroll Jewel in the project. Now she is in the experimental group, and her direct care comes from her brother, her sister, her teacher's aide, and myself. I order her therapeutic equipment from a catalog. I purchase her personal care supplies wherever I can find the best bargain. She has had a ramp and a wheelchair-accessible bathroom added onto the house we live in. She has access to Hart-Line transportation, which provides wheelchair-accessible van pickup at the door of our home. We have been able to save considerably. The savings that we accumulate I use to purchase anything that will enhance Jewel's independence, safety, welfare, and health.

I am a very strong advocate of the Consumer-Directed Care Research Project. The project affords the consumer with a wider range of selection for providers. Since the providers do not need to be med-waiver-certified, the choice is broader. For direct care, the consumer can hire family and friends, and they are more familiar with the consumer. As a result, Jewel is much more comfortable. Jewel now receives care from her brother, her sister, and they understood her better, and she is much more comfortable having them around. In the past we have had to interview many strangers, and we have had to go over the initial orientation many times with different people of who Jewel is, what Jewel likes, what Jewel needs. But now she is around the people that know her best and love her the most.

The consumer and the family are now in control as opposed to the support coordinator, and we know what the providers are billing because the time sheets must be approved by the representative of the project. The representative in this case is my mother, and she handles all of the paperwork. Before, in the med-waiver program, the provider billed directly to the support coordinator, and there was some accountability lost because the provider may or may not have actually provided the service. The consumer was unaware of what was billed. Whenever I use the monies to spend, I have to account to her present consultant, who used to be her support coordinator. Once a month I give her all the receipts of all my expenses. When her supplies can be purchased at Walgreen's or Sam's Club rather than an elite group of med-waiver-certified companies, her chances for flexibility and savings increase.

The services approved through the med-waiver program were only for medically necessary services, but now it is much more broad, and Jewel's medical, physical, emotional needs are all met.

I do have some concerns about the project's execution. I have witnessed some anxiety in families who don't have any prior experience in anything of this sort. Because of the families' taking control, the support coordinators are encouraged to stay clear unless they are called on for help. However, I wonder if some families or consumers know the right questions to ask.

I would love to see a support group in existence. A support group is one of the perks that were mentioned in the enrollment stage, but I have not seen it come to fruition. I would also love to see ongoing training offered at certain intervals in order to refresh the memories of the consumer and the consumer's family.

There are two other services I would love to see added to the budget for the Consumer-Directed Care Research Project. They are therapy, and wheelchair-accessible vans.

Recently my daughter's speech and occupational therapist discontinued her service because, according to their report, she was not progressing significantly enough. I am very concerned about this, because her school report shows that she was progressing, and I know that lost therapy could mean lost mobility and lost skills. So if therapy was on the program, I or my mother, as the representative, could go into the community, interview with different therapists, and then hire them whether they are through Medicaid med-waiver or not.

Also, I am not able to take my daughter out as much as I would like to due to her size, my size, and the size of our car. She receives transportation services, which do help; however, the services are limited to certain times, certain days, and certain locations. And since she is 15, I believe she would love to get out more.

In conclusion, it is an honor for me to testify today. I am extremely grateful that my daughter did happen to be in the experimental group. Her being in this project has enhanced our family life tremendously, and I hope and pray that the project will become a way of life for all interested consumers in the United States of America.

Thank you, Mr. Chairman.

[The prepared statement of Patricia Gittens follows:]

PREPARED STATEMENT OF PATRICIA GITTENS

My experience with the Consumer Directed Care Research Project is both a personal and a professional one.

My daughter—Jewel Stephen—is 15 years old. Jewel has a development delay, has been diagnosed with agenesis of the corpus collosum, and is a Med-waiver client in the state of Florida.

My first experience with the med-waiver program was as a Support Coordinator. In this position, I was responsible for the managing of services for developmentally disabled adults. The services were made available by “providers”. Only med-waiver certified providers could offer these services. One’s being certified required the successful completion of a extensive application process.

When the Consumer Directed Care Project was introduced, I was given the opportunity to enroll my daughter. The enrollment process involved the completion of a basic application form and survey, which was completed by her support coordinator. Once the application was submitted, it was keyed into a computer system in Tallahassee. The computer randomly assigned half of all the applications into the control group and half of all the applications into the experimental group. In the control group, everything remains the same. The client still has a support coordinator and the client’s services are still made available by med-waiver certified providers.

In the experimental group, the client and/or the client’s family now gains control of the budget, the services provided, and who provides the service. My daughter, Jewel, was assigned to the experimental group.

Shortly thereafter, I was asked to serve as the Outreach and Enrollment employee for the Consumer Directed Care Research Project (“the Project”). My new position involved going to family homes in Hillsborough and Manatee Counties of Florida and conducting a presentation to explain the Project and answer any possible questions. If the family decided to enroll, I would complete the application packet for them and forward it to Tallahassee.

If the consumer was assigned to the experimental group, I would also review the purchasing plan that the family submitted. The purchasing plan is a budget proposal which itemizes the services needed and the projected cost of services. The main components of the purchasing plan are:

Directly Hired Workers (ie. Personal Care Attendants, Respite Workers, Homemakers, Companions); Therapeutic Equipment (ie. communication devices, eating utensils); Personal Care Supplies (ie. gloves, shampoo, incontinent products, lotion); Modification of Residence (ie. wheelchair ramps, wheelchair accessible bathrooms); Modification of Vehicles (ie. wheelchair lift); Community Services (ie. transportation, lawn care); Cash (ie. prepared meals); Savings; and, Emergency Back-up.

Jewel’s direct care comes from her brother, her sister, her teacher’s aide, and myself. I order her therapeutic equipment from a catalog. I purchase her personal care supplies wherever I can find the best bargain. She has had a ramp and a wheelchair accessible bathroom added onto the house we live in. She has access to Hart-Line transportation which provides wheelchair accessible van pickup at the door of our home. We have been able to save considerably. The savings are to be used for the purchase of anything that will enhance the welfare, independency, safety, and/or health of the consumer.

The management of the purchasing plan is the consumer’s responsibility. The consumer is not to ask the consultant (formerly known as the support coordinator) to do things she is responsible for. Information about roles and responsibilities can be gathered from the CDCRP consumer notebook. If there are still questions, the consumer is then encouraged to talk to the consultant.

The purchasing plan should be updated if the consumer:

- changes the hourly rate pay of one or more employees
- has a change in the monthly budget amount
- adds a new purchasing category
- changes the savings amount or planned savings purchases
- has a change in needs
- has a change in the emergency backup plan
- has an account balance more than 1½ times the monthly budget
- accumulates excess amounts of cash

The consumer can be flexible in the spending of the allotted funds—as long as she doesn’t spend more than the total available amount in the account balance. The consumer must keep track of unpaid amounts such as payroll and invoices. Also, all properly authorized employee timesheets must be submitted to Personal Attendant Accounting Services, Inc in Virginia (PAAS). PAAS retains the actual monies of each consumer’s budget. Bookkeeping services and quality reviews are conducted by PAAS. PAAS pays employees by mailing payroll checks to the project representa-

tive. The representative is a family member or friend the consumer chooses to handle all paperwork involved in the project. (Jewel's representative is my mother).

There are rare occasions when a consumer may be disenrolled from the project. Disenrollment from CDCRP is usually voluntary, but may occur by necessity. Disenrollment is usually due to loss of medicaid eligibility or death of the consumer.

I am a very strong advocate of the Consumer Directed Care Research Project. The project affords the consumer with a wider range of selection of providers. Since the providers do not need to be med-waiver certified, the scope of choice is broader. For direct care, the consumer can hire family and friends who are more familiar with the consumer. For professional services, the consumer can consider (and possibly interview) more agencies. As a result, the consumer is much more comfortable.

The consumer and the family are now in control as opposed to the support coordinator. The consumer knows what the providers are billing because the time sheets must be approved by the consumer. In the med-waiver program, the provider billed directly to the support coordinator. The accountability was lost, because the provider may or may not have actually provided the service. The consumer was unaware of what was billed.

When supplies can be purchased at Walgreens or Sam's Club, rather than an elite group of med-waiver certified companies, flexibility and the chance of savings increase.

The services approved through the med-waiver program are exclusively for "medical necessity" and the approval process is much more stringent than that for the project.

I do have some concerns about the project's execution. I have witnessed some anxiety in families who have no prior experience in anything of the sort. The support coordinators are encouraged to "stay clear" unless they are called on for help (for the most part). However, I wonder if some families or consumers know the right questions to ask. I would love to see a support group in existence. A support group is one of the perks that were mentioned in the outreach and enrollment stage, but, I have not seen it come to fruition.

I would also love to see ongoing training offered at certain intervals in order to refresh the memories of the consumer and the consumer's family.

My daughter happens to have an excellent consultant (formerly known as support coordinator). She is reliable and professional. I hope every other consumer in the project receives the same quality of consultant help.

There are two other services I would love to see added to the budget for the Consumer Directed Care Research Project. They are: therapy and wheelchair accessible vans. Recently, my daughter's speech and occupational therapists discontinued service because, according to their report, she "was not progressing significantly enough". I am very concerned about this because her school report shows that she was progressing and I know that lost therapy could mean lost mobility and lost skills for her. Also, I am not able to take my daughter out as much as I would like to—due to her size and the size of our car. She receives transportation services which help; however, the services are limited to certain times, certain days, and certain locations. Since she is 15, I believe she would love to get out more.

In conclusion, it is an honor for me to testify about the project. I am extremely grateful that my daughter happened to be in the experimental group. Her being in the project has enhanced our family life tremendously. I hope and pray that the project will become a way of life for all consumers in the United States of America. Thank you.

Mr. NORWOOD. Thank you very much.

Mr. Secretary, you are recognized now for your statement.

STATEMENT OF TERRY F. WHITE

Mr. WHITE. Good morning, Mr. Chairman and members of the committee. I want to thank you for your invitation and my opportunity to be here before you today to talk about Consumer-Directed Care.

The Florida Department of Elder Affairs has been pleased to join the Robert Wood Johnson Foundation, the U.S. Department of Health and Human Services, and Arkansas and New Jersey in the national Cash and Counseling demonstration project and evaluation.

The Florida program called Consumer-Directed Care was designed to provide consumers more flexibility, choice, and independence in determining and arranging their own care. I stand here today as a strong supporter of consumer direction, because I know it improves the quality of life by restoring self-reliance and dignity.

The Florida model challenges the traditional mindset of the last 38 years in terms of the creation of the Medicaid program with the understandings that only the care managers are the only folks that can direct care for their clients, and that the Medicaid service recipients are incapable of managing their own care effectively and responsibly.

Consumer-Directed Care puts into practice Governor Bush's commitment to increasing choices for frail elders and disabled Floridians by providing them the opportunity to be an active participant in their health care decisions.

Before discussing the Florida model, I would like to share with you the impact that this program has had on one of our clients, Lois Duffy. In her own words, quote: My existence has become a real life. Now, I purchase the food I want and need rather than just what I can think of sitting here alone, unquote.

Her worker Carlene has also benefited from the partnership, and in her words: Working for Lois has been a reward for both of us. For myself, I needed a part-time job with flexible hours; for Lois, it has given her a new lease on life.

Now, if you would, contrast Lois' experiences with that of other Medicaid waiver experiences who are at risk because they are not receiving the services that can help them maintain independence through the traditional Medicaid system.

The enrollment group for the Consumer-Directed Care Project includes frail elders, developmentally disabled children and adults, and physically disabled adults already participating in Medicaid waiver programs. Our department administers the project in collaboration with other State health and human service agencies. Allowable purchases include services and items such as personal care, homemaking, consumable medical and personal care supplies, adaptive devices, home repairs and maintenance, and errands and shopping assistance.

Florida implemented Consumer-Directed Care through our existing networks of case managers and support coordinators, who now become known as consultants to our Consumer-Directed Care clients. This represents a major paradigm shift from the traditional service delivery model. Instead of case managers coordinating the care, the consumer develops a plan based on their own individual needs.

To date, Florida has enrolled 2,820 participants in the Consumer-Directed Care model, including 814 elders. Based on a survey conducted by our Department, 94.4 percent of the respondents said that they were either satisfied or very satisfied with the project. There will be a formal evaluation in 2005.

Governor Bush and the Florida Legislature believed in this program so much that they created a statewide Consumer-Directed Care model in the 2002 legislative session, and we are currently working on that to implement that statewide. We have learned a

number of valuable lessons from participating in this project, and I would like to share those with you.

First, consumer direction can increase the quality of life and consumer satisfaction. Consumers potentially can receive more services with an increase in quality.

Second, consumer direction care can work for frail elders. Though it was utilized in the disability communities since the 1980's, it was more challenging to implement this within the older population in Florida. However, when the concept spread, it became very, very popular, and now we have folks really wanting to become involved in the system.

Third, concerns about potential fraud and abuse in consumer direction care are unfounded. Florida's Consumer-Directed Care Project, like that of Arkansas and New Jersey's, encounter no instances of fraud and abuse.

Fourth, one size does not fit all. Consumers must be willing and able to manage their own care or have a representative who can act on their behalf. It is true that some individuals require a more formalized approach.

Fifth and last, States that implement Consumer-Directed care programs should consider choice and quality issues. We have to be careful that we do not create an overabundance of options that could potentially lead to fiscal and operational challenges that could ultimately harm the consumer.

We have stretched the Medicaid program in an attempt to wrap it around the needs of today's population, yet there are still 47,000 Floridians who are potentially eligible for Consumer-Directed Care but have no option at this point. The Consumer-Directed Care model is, in fact, a model, and one we would like to grow for our elders and disabled. As you consider reforms for Medicaid, this is an excellent model that shows an example of State innovation.

While you are working in the direction of comprehensive Medicaid reform, I would like to highlight some policy recommendations from the Medicaid world which we must operate in, and that we base this on our experiences.

First, increase the flexibility in the delivery of home community-based care services. Florida would like to have the ability to administer the Consumer-Directed Care model without the limitations and burdens of a waiver. With the flexibility to develop our own programs, we could make a more efficient use of our limited resources and meet the needs of our most vulnerable citizens.

Second, consumer direction helps address worker shortage issues, especially in our rural areas, by adding family members and friends to the available pool of workers.

Third, consider broadening the definition of personal care under the Medicaid State plan services. We would like to join our partners in Cash and Counseling demonstration projects in requesting a broader definition of personal care that would include home modification and assistive technology.

In closing, I thank you again for the opportunity to be before you, and I would be happy to answer any questions later.

[The prepared statement of Terry F. White follows:]

PREPARED STATEMENT OF OF TERRY F. WHITE, SECRETARY, FLORIDA DEPARTMENT OF
ELDER AFFAIRS

Good morning, Mr. Chairman and Members of the Committee. Thank you for your invitation and for the opportunity to address the Committee on improving Medicaid beneficiary access to quality care through a consumer-directed model of services.

The Florida Department of Elder Affairs has been pleased to join the Robert Wood Johnson Foundation, the U.S. Department of Health and Human Services, and Arkansas and New Jersey, in the national Cash & Counseling Demonstration and Evaluation project. The Florida program, called "Consumer-Directed Care," was designed to provide consumers more flexibility, choice and independence in determining and arranging their own care.

I speak to you today not only as the Secretary of the Florida Department of Elder Affairs, but also as a former executive director of an Area Agency on Aging in southwest Florida. It was in my former role at the Area Agency on Aging that I was initially skeptical about Consumer-Directed Care, because I was concerned about the potential for fraud and abuse. Under the Consumer-Directed Care model, Medicaid recipients can hire family members and friends as paid workers. My apprehension was based on the concern that some family members or friends might take advantage of their loved ones, by accepting payment without actually providing the services for which the money was intended. After viewing the program firsthand for just a short period of time, however, my concerns were quickly allayed. I am pleased to tell you that I stand here today as a strong supporter of consumer direction, because it improves quality of life by restoring self-reliance and dignity. The Florida model challenges the traditional mindset, fostered over the 38 years since the creation of Medicaid, that the individuals charged with overseeing and coordinating care for Medicaid recipients know what is best for their clients, and that Medicaid Waiver service recipients are incapable of managing their own care effectively and responsibly. Consumer-Directed Care puts into practice Governor Bush's commitment to increasing choices for frail elder and disabled Floridians, by providing them with the opportunity to be active participants in their health care decisions.

Before discussing the implementation of the Florida model, the project's result and lessons learned, I would like to take a brief moment to share with you the impact Consumer-Directed Care has had in the life of one of our clients, Lois Duffy. In her own words, "How different is my life now? Setting up days and times for [my worker's] help is a cooperative effort and I am glad to say it has never been a problem. My existence has become a real life! Now I [go to the store to] purchase the food I want and need, rather than [requesting] just what I can think of [while] sitting at home alone. She also takes me to my average of four doctor's appointment per month. She comes in the office with me and afterwards, on the ride home, we discuss what we each understood the doctor to say; it's amazing how much recall she has and how very helpful to me it is to have her input." Her worker, Carlene, has also benefited from this partnership: "Working for Lois has been a reward for both of us. For myself, I needed a part-time job with flexible hours. Also, I needed to feel like I was needed. For Lois, it's given her a new lease on life. She is finally able to trust the person working in her home, she's able to have the hours she needs, and she's had the transportation to doctors that's been reliable. We never run out of things to talk about and have built a nice friendship in the process."

Contrast Lois' experience with that of many other Medicaid Waiver recipients, who tell us that they are unable to obtain the services they want when they want them, because of worker shortages or other problems with the traditional model of care. Many of these consumers sit at home alone, and they are at risk because they are not receiving the services that can help them remain independent, yet the traditional Medicaid system does not allow them to take advantage of support systems that are available right in their community.

IMPLEMENTATION

The enrollment group for the Consumer-Directed Care Project includes frail elders, developmentally disabled children and adults, and physically disabled adults who were already participating in either the 1915(C) Aged and Disabled Medicaid Waiver or the 1915(C) Developmental Disabilities Program Home and Community-Based Services Medicaid Waiver. In order to provide limited cash allowances to consumers and to allow responsible family members (such as spouses and parents) to be hired as paid workers, Florida was granted a 1115 Medicaid Waiver for this project from the Centers for Medicare and Medicaid Services. The 1115 Medicaid Waiver offers options that surpass the traditional 1915(C) Waiver, but it is more difficult to obtain, much more complicated to administer, and requires an extensive evaluation component. Though we support the objective evaluation of public pro-

grams, we feel we have enough data and information to support the expansion of consumer-directed options. The evaluation requirement under the 1115 Waiver poses an administrative burden and diverts resources that could be used to serve additional consumers.

The Florida Department of Elder Affairs, as the grantee organization, administers the project in collaboration with a statewide workgroup that includes other state health and human services agencies: the Agency for Health Care Administration, the Department of Children and Families Developmental Disabilities Program and Adult Services Program, and the Department of Health Brain and Spinal Cord Injury Program. The project was implemented in 19 of Florida's 67 counties for elders and physically disabled adults, and statewide for developmentally disabled children and adults. Consumers who were randomized into the treatment group benefit in the following ways:

- develop a purchasing plan and manage the funds assigned to them;
- receive support services from a consultant (case manager or support coordinator) and a fiscal intermediary/bookkeeper;
- decide which allowable services best meet their needs;
- hire and direct employees and independent contractors who may be family members or friends, and/or agency providers; and
- assess the quality of services received.

Allowable purchases include the following services and items: personal care; homemaking; consumable medical and personal care supplies; adaptive devices, wheelchair ramps, grab bars; home repairs and maintenance; errands/shopping assistance; and pest control/yard work.

To help ensure budget neutrality, which is required by the 1115 Medicaid Waiver, the consumer's budget is based on actual expenditure history, or it is determined through use of a discounted care plan. The discount rates, which were developed at the beginning of the project based on historical expenditures in the Medicaid program, range from 83% for physically disabled adults to 92% for developmental disabled adults and children. These percentages represent the actual amount of Medicaid dollars that clients were able to access under the traditional, case managed service delivery model. This means that consumers have been unable to access 8-17% of their approved Medicaid budgets, because of problems such as worker shortages. The consumer-directed model, therefore, offers increased protection for consumers who find that agency workers are not available.

Florida implemented Consumer-Directed Care through the existing networks of case managers and support coordinators. Under the project, these individuals are "consultants" who assist and empower consumers, and monitor expenditures and the potential for fraud and abuse. This represents a major paradigm shift from the traditional service delivery model, where case managers coordinate and direct the care, based on the results of assessments. Under consumer direction, the purchasing/care plans are developed by the consumer, and are frequently revised as conditions change. A viable backup plan is required to assure continuity of services in the event a worker or agency representative is terminated or otherwise unavailable.

PROJECT RESULTS

From April 2000 to September 2002, Florida enrolled 2,820 consumers in Consumer-Directed Care, including 1,004 adults; 1,002 children; and 814 elders. Approximately one-half of these individuals were assigned to the treatment group, and 917 consumers—420 children, 374 adults and 123 elders—are still managing budgets and receiving services under this program today.

Though the formal project evaluation conducted by Mathematica Policy Research, Inc. is not completed, early results show very high consumer satisfaction, increased access to needed services, and an overall improvement in quality of life for participants. The formal evaluation, which will be completed in 2005, will analyze three components: impact, cost and implementation. Other, less formal evaluations support these results: fully 94.4% of 251 respondents surveyed by the Department of Elder Affairs in April and May 2002 indicated that they were "satisfied" or "very satisfied" with the project.

Based in large part on feedback from existing consumers and advocacy groups, Governor Bush and the Florida Legislature created a new statewide Consumer-Directed Care program during the 2002 session. Governor Bush signed the bill into law on May 1, 2002. The new program will be administered by the Agency for Health Care Administration, Florida's Medicaid Agency, in collaboration with the other departments who have participated in the Cash and Counseling Demonstration. The Agency for Health Care Administration has received preliminary approval

from the Centers for Medicare and Medicaid Services on the waiver amendment that is needed to implement the new statewide program.

LESSONS LEARNED

Florida has learned a number of valuable lessons from participating in this project.

1. *Consumer direction can increase quality of life and consumer satisfaction.* In addition to offering more flexibility, choice and independence, Consumer-Directed Care improves quality of life and consumer satisfaction, because services are tailored to the unique and individual needs of the consumer. Under this approach, consumers can receive more services, with an increase in quality, for the same budget. By hiring workers directly, they do not have to pay agency overhead costs.

2. *Consumer direction can work for frail elders.* Though elements of consumer direction have been utilized in the disability community since the 1980s, many policy makers have questioned the applicability for a frail elder population. Though it was more challenging to implement Consumer-Directed Care among the elder population in Florida due to lack of available family supports, the concept became very popular once the initial group of consumers began to see the benefits of this approach. In addition, some case managers who were originally apprehensive about consumer direction became strong advocates once they began to see the positive impact on the clients they served.

3. *Concerns about the potential for fraud and abuse in consumer direction are unfounded.* Florida's Consumer-Directed Care project, like the Arkansas and New Jersey Cash & Counseling projects, encountered virtually no instances of fraud and abuse. Though the project provides consultants and a fiscal intermediary to support consumers, ultimately, it is the consumer or their representative who defines quality and monitors expenditures. In fact, consumers who encountered problems with workers who were family members did not hesitate to terminate employment if the family member did not perform satisfactorily.

4. *One size does not fit all.* Consumers who participate in Consumer-Directed care must be willing and able to manage their own care or have a representative who can act on their behalf. We realize that we cannot take a "one size fits all" approach to providing health care for Medicaid recipients. Consumers who find the management of finances challenging, or do not have built-in family or community supports, may require a more formalized approach to help them maintain their independence. The benefits of consumer direction—increased access to quality services; more control, flexibility and independence for consumers—lead us to believe that this model will help many of our most vulnerable citizens remain independent in the community for longer periods of time, while dramatically improving the quality of their lives.

5. *States that implement consumer-directed programs should consider choice and quality issues.* Though multiple options for consumer supports are preferred, there are issues involving economies of scale and quality that need to be considered in a consumer-directed program design. If there are an unlimited number of consultants, and each consultant has only a limited number of consumers to assist, some consultants may not be able to acquire the experience and develop the skills necessary to truly empower consumers. An overabundance of consultants could also lead to challenges in the areas of training and technical assistance. While multiple options for fiscal intermediaries may benefit the consumer, too many options may create a financial hardship for each company, ultimately harming the consumer.

POLICY RECOMMENDATIONS

We have stretched the Medicaid program in an attempt to wrap it around the needs of today's population. Yet, there are still 47,000 Floridians who are potentially eligible for consumer-directed care and who do not have this option. The consumer directed care model is in fact a model, and one we would like to grow for our elders and disabled. As you consider reforms to Medicaid, this model is an excellent example of the potential of state innovation.

While you are working in the direction of comprehensive Medicaid reform, I would like to highlight some policy recommendations for the Medicaid world we must operate in today. Based on experiences with Consumer-Directed Care, the Florida Department of Elder Affairs would ask you to consider the following:

1. *Increase flexibility in the delivery of Home and Community-Based Services.* In order to implement a fully consumer-driven model of care, states need flexibility to give small cash allowances and to allow responsible family members to be paid as workers. The current mechanism that provides this flexibility, the 1115 Medicaid Waiver, is much more labor intensive to administer than the 1915(C) Waiver.

Though the streamlined Independent Choice waivers produced by the Centers for Medicare and Medicaid Services have helped encourage states to adopt consumer-directed models, Florida would like to have the ability to administer consumer-directed service models *without* the limitations and burdens of a waiver. With the flexibility to develop our own program designs, we can make more efficient and effective use of our limited resources, while ensuring that the needs of Florida's most vulnerable citizens are met.

2. *Consumer direction helps address worker shortage issues.* This approach helps consumers, especially those in rural areas, obtain increased access to services. This is a major issue for Florida and for all states, and the problem will only worsen with the aging of the baby boomers.

3. *Consider broadening the definition of personal care under Medicaid State Plan Services.* Arkansas and New Jersey, our partners in the Cash & Counseling Demonstration and Evaluation, offered a consumer-directed approach to Medicaid State Plan personal care assistant (PCA) services. A broader definition of personal care would allow these states, as well as others, to provide increased supports for frail and disabled consumers. Presently, the federal definition of personal care refers to "human assistance." We join our colleagues in these other states in suggesting that this language be broadened to include home modifications, assistive technology, and other services and appliances that would enable and encourage individuals with disabilities to meet their personal care needs.

I want to thank you again for allowing me the opportunity to speak before the Committee today. I will be happy to respond to any questions you might have.

Mr. NORWOOD. Thank you, Mr. Secretary.

Mr. Williams, you are now recognized for your opening statement.

STATEMENT OF BOB WILLIAMS

Mr. WILLIAMS. I have abbreviated my prepared comments somewhat to cut to the chase, hopefully. What I think I have to offer you most today, however, comes not just from my knowledge of the Medicaid program, its strengths and ways it must be improved upon, but from the obvious fact that, like others testifying today, I rely a lot on help from others and technology like I am using now to live the life I have created for my family and myself.

I have always had the good fortune of being employed and having employer-based insurance coverage, so I have never been on Medicaid. But like the others here, and over 80 percent of the estimated 12 million Americans of every age who need this help, I have always gotten it from family, friends, and, for the last decade, mostly my wife Helen.

I will draw on these blends of perspectives to try to answer two key questions: What are the practical lessons we can and ought to learn and apply from the Cash and Counseling demonstration? And, equally importantly, what are some things that we cannot, and should not, assume or read into the findings of this demo?

Like most other successful experiments, the demo set out to provide an obvious answer to a common-sense question: Do people with disability want to have a great deal of control over the quiet, intimate forms of help and supports that make our lives possible? The answer to that question is, of course. Yes, we do. And it is important that, as policymakers, you understand the reasons why this is so.

The things that I and others need help with, eating, showering, dressing, cleaning one's backside, are all essential and very private, personal matters; the type of things, in short, that you want someone you know well, can rely upon, value, and trust implicitly, that you want to work with you, and not a complete stranger, regardless

of how competent or proficient such a person might be. That is one of the main reasons why people want the freedom to use a friend, someone in their family, or another individual of their own choosing to provide the assistance they need daily.

Two other reasons have to do with what I will call availability and proximity. Now that I have left government, for example, I work mostly from home. The major reason for this is that Helen also is home a lot of the time. Thus, while I do not require a great deal of help during the day, I know, when I do, that she will typically be close at hand. Similarly, if someone needs help preparing a meal or going shopping, it might make sense to hire a friend or neighbor to do it, or to have a meal or grocery brought to their front door by a local restaurant or something like the Giant Store's Peapod delivery service.

This is the potential strength and beauty of an individualized budget approach such as the one used in Cash and Counseling. It enables the person with the disability or the parents of the child with the disability to decide how to use limited Medicaid dollars in ways that best ensures their independence and basic well-being. But it is important to acknowledge that the approach is no panacea. It has its limitations and pitfalls that Congress, the administration, and the States, as well as the disability and aging communities, must actively work to avoid.

An approach like Cash and Counseling generally seems to work well for people when the following is true in their lives: First, the individual has family and friends who already are helping them out a good bit or could help them find others who could offer the needed assistance. That is, there is already a network of support they can tap both to recruit and pay people to provide services for them.

Second, the money allocated in the individualized budget must be adequate and be able to be adjusted whenever the needs of the person change. There should be clear nationwide standards for determining and readjusting such budgets. It would be wrong for Congress, in my view, to provide States complete license in this regard. I can comment on this further during your questioning, but one of my greatest fears about this approach is that, based on the continuing State budget crises, that absent basic Federal safeguards, that at least some States would take advantage of it not simply to encourage consumer choice while managing costs responsibly, but to cut costs in ways that are extremely harmful to the health and independence of children, adults, and older Americans with disabilities. You should not allow this to happen.

I said at the start that there were some things that we cannot and should not assume or read into the findings of this demo. I would like to briefly highlight what they are, if I might.

The first is the assumption that Cash and Counseling is somehow a silver bullet that will in itself dramatically increase access to Medicaid community living services in States that take it up. This approach can certainly be a critical piece for many needing access to these services and supports, but it is not the total solution, nor is it an approach that everyone can or wants to use. As we have heard, it works well for people who already have family and friends and can use the money to supplement the help they already receive, but it might not work so well for someone without a nat-

ural support network to turn to who wants to get out of a nursing home or avoid going in one altogether. For this reason, States that offer this option should do so on a purely voluntary basis and in a manner that does not disadvantage those who do not want to take it up.

Another assumption that seems to be being vented, that this demo's results may justify the so-called cashing out of the entire Medicaid benefit, including medical care and prescription drug coverage. I would say a couple of things on this. There is nothing in the demo's basic intent, design, or findings that would support such a policy leap. And, even more importantly, expecting people to know how to navigate, purchase, and manage their entire health and medical care is not only unrealistic, it would be setting many up to take a serious fall or worse.

My strong plea, therefore, is that, if this notion is put forward, Congress rejects it. Hence, if Congress authorizes other States to engage in similar activities, it should limit them to doing so with regard to personal care and similar services only, as the demonstration itself did.

The individualized budget approach embodied in Cash and Counseling is certainly one important way that States can offer people with disabilities of every age more choice and control over their lives and the services they need, but it is not the only one. Many States are using other methods to offer people the same choice and control. In the scheme of things, therefore, with the fate of Medicaid and the lives of those who rely on it very much up in the air, I frankly think that there are more pressing matters Congress needs to concern itself with.

There is much I object to about the President's larger Medicaid restructuring proposal which I will not go into now, but another budget proposal of President Bush that deserves the attention and wide bipartisan support in Congress is called the Money Follows the Person Initiative. Simply put, the initiative would fully reimburse States for 1 year of Medicaid home and community-based services for children, adults, and older Americans with disabilities who move from institutions into their own homes and communities. After the initial year, States will be responsible for matching payments at their usual Medicaid matching rate. It also would build upon existing States' success stories in Texas, Wisconsin, Michigan, and Washington.

Once again, I want to thank you for this opportunity to appear before you this morning, and even more so for your interest in these critical issues.

[The prepared statement of Bob Williams follows:]

PREPARED STATEMENT OF BOB WILLIAMS, CO-DIRECTOR, ADVANCING INDEPENDENCE

Good morning, Mr. Chairman and Members of the Committee. Thank you for asking me to testify on what we as a Nation can glean and apply from the Cash and Counseling demonstration. For the record, I am Bob Williams, the co director of Advancing Independence, a forum that promotes responsible changes to Medicare and Medicaid needed to enhance the health and independence of Americans with disabilities of all ages. Prior to this, I was an advisor to then HHS Secretary Donna Shalala. The Office on Disability, Aging and Long Term Care Policy in ASPE that I headed had a vital role in the design and funding of the demo, along with CMS, the participating States and the RWJ foundation. But, the hard work to launch the project was done well before I joined ASPE. So, the credit goes to others.

What I think I have to offer you most today, however, comes not just from my knowledge of the Medicaid program, its strengths and ways it must be improved upon. But from the obvious fact that like others testifying today, I rely a lot on help from others and technology like I am using now to live the life I've created for my family and myself. I've always had the good fortune of being employed and having employer based insurance coverage. So, I've never been on Medicaid. But, like the others here, and over 80% of the estimated 12 million Americans of every age who need this help, I've always gotten it from family, friends, and for the last decade, mostly my wife, Helen.

I will draw on these blends of perspectives to try to answer two key questions. What are the practical lessons we can, and ought to, learn and apply, from the Cash and Counseling demonstration? And, equally importantly: What are some things that we cannot, and should not, assume or read into the findings of this demo? Like most other successful experiments, the demo set out to provide an obvious answer to a common sense question. Do people with disabilities want to have a great deal of control over the quite intimate forms of help and supports that make our lives possible?

The answer to that question is, of course, yes we do; and, it's important that as policy makers you understand the reasons why this is so. The things that I and others need help with: eating, showering, dressing, cleaning one's back side, are all essential and very private, personal matters. The type of things, in short, that you want someone you know well, can rely upon, value and trust implicitly that you want to work with you. And, not a complete stranger, regardless of how competent or proficient such a person might be. That is one of the main reasons why people want the freedom to use a friend, someone in their family or another individual of their own choosing to provide the assistance they need daily. Two other reasons have to do with what I'll call, availability and proximity.

Now that I've left government, for example, I work mostly from home. A major reason for this is that Helen also is home a lot of the time. Thus, while I do not require a great deal of help during the day, I know when I do that she will typically be close at hand. Similarly, if someone needs help preparing a meal or going shopping, it might make sense to hire a friend or neighbor to do it. Or, to have a meal or grocery brought to their front door by a local restaurant or something like the Giant Stores' Peapod delivery service. This is the potential strength and beauty of an individualized budget approach such as the one used in Cash and Counseling. It enables the person with a disability or the parents of a child with a disability to decide how to use limited Medicaid dollars in ways that best ensures their independence and basic well being.

But, it's important to acknowledge that the approach is no panacea. It has its limitations and pitfalls that Congress, the Administration and the States as well as the disability and aging communities must actively work to avoid. An approach like Cash and Counseling generally seems to work well for people when the following is true in their lives. First, the individual has family and friends who already are helping them out a good bit or could help them find others who could offer the needed assistance. That is, there is already a network of support they can tap both to recruit and pay people to provide services for them. Second, the money allocated in the individualized budget must be adequate and be able to be adjusted whenever the needs of a person change. There should be clear nationwide standards for determining and readjusting such budgets. It would be wrong for Congress, in my view, to provide States complete license in this regard. I can comment on this further during your questioning, but one of my greatest fears about this approach is that, based on the continuing State budget crises, that absent basic federal safeguards that at least some States would take advantage of it. Not simply to encourage consumer choice while managing costs responsibly, but to cut costs in ways that are extremely harmful to the health and independence of children, adults and older Americans with disabilities. You should not allow this to happen.

I said at the start that there were some things that we cannot, and should not, assume or read into the findings of this demo. I'd like to briefly highlight what they are if I might. The first is the assumption that Cash and Counseling is somehow a silver bullet that will in itself dramatically increase access to Medicaid community living services in States that take it up. This approach can certainly be a critical piece for many needing access to these services and supports. But, it is not the total solution. Nor, is it an approach that everyone can or wants to use. As we have heard, it works well for people who already have family and friends, and can use the money to supplement the help they already receive. But, it might not work so well for someone without a natural support network to turn to who wants to get out of a nursing home or avoid going in one altogether. For this reason, States that

offer this option should do so on a purely voluntary basis and in a manner that does not disadvantage those who do not want to take it up.

Another assumption that seems to be being hinted at is that this demo's results may justify the so called, cashing out, of the entire Medicaid benefit, including medical care and prescription drug coverage. I'd say a couple of things on this. There is nothing in the demo's basic intent, design or findings that would support such a policy leap. And, even more importantly, expecting people to know how to navigate, purchase and manage their entire health and medical care is not only unrealistic, it would be setting many up to take a serious fall or worse. My strong plea, therefore, is that if this notion is put forward, Congress rejects it. Hence, if Congress authorizes other States to engage in similar activities it should limit them to doing so with regard to personal care and similar services only as the demonstration itself did.

The individualized budget approach embodied in Cash and Counseling is certainly one important way that States can offer people with disabilities of every age more choice and control over their lives and the services they need. But, it is not the only one. Many States are using other methods to offer people the same choice and control. In the scheme of things, therefore, with the fate of Medicaid and the lives of those who rely on it very much up in the air, I frankly think that there are more pressing matters Congress needs to concern itself with. There is much I object to about the President's larger Medicaid restructuring proposal, which I will not go into now. But, another budget proposal of President Bush that deserves the attention and wide bipartisan support in Congress is called the Money Follows the Person initiative. Simply put, the initiative would fully reimburse States for one year of Medicaid home and community-based services for children, adults and older Americans with disabilities who move from institutions into their own homes and communities. After the initial year, States will be responsible for matching payments at their usual Medicaid matching rate. It also would build upon existing state success stories in Texas, Wisconsin, Michigan and Washington.

Once again, I want to thank you for this opportunity to appear before you this morning, and even more so for your interest in these critical issues. I will be pleased to respond to questions or concerns you have during the questions and answer period.

Mrs. WILSON [presiding]. Thank you very much, Mr. Williams.

I would like to now shift into questions, and there is a couple of things that I would like to ask you to expand upon, if you could. Dr. Mahoney, you wanted to elaborate at the end of your statement. I think you were going to go into looking ahead and what needs to be done in order to make this permanent in some States, but also make it more likely that this model propagates across the country. And I wonder, I wanted to give you an opportunity to elaborate.

Mr. MAHONEY. Thank you very much. I will give a few examples.

What Florida did in passing, I understand unanimously, legislation that built in this consumer-directed option for the future I think could serve as one type of a model.

A second one, the States of New Jersey and Arkansas have written to CMS and asked, for instance, if the language for the Medicaid personal care benefit, which now is limited to hands-on human assistance, could be broadened to include the ability to—under the personal care benefit, purchase assisted devices, home renovations, things that meet that individual's personal care need. And we have examples from Cash and Counseling.

A third example that I am very pleased with is the Robert Wood Johnson Foundation in these last few months has authorized an environmental assessment where we have had teleconferences 48 States took part in, and the follow-up is we wanted to talk with States that were interested in replicating this model. And we have had individual calls with 21 States at this stage. So between the foundation and Health and Human Services, we really are looking

at the need for seed money and technical assistance for States to really replicate this individualized budget approach.

Mrs. WILSON. Secretary White, I had two questions for you. One was, are any of the Indian tribes involved in this experiment, or have you worked with IHS at all for any Medicaid-eligible tribal members?

And the second one, and I will do them back to back here and let you elaborate, is you said in your testimony that you were initially worried about the potential for fraud in consumer-directed care, but that those fears were not realized. What is it inherent in this program which makes it—which satisfied your fears or calmed your fears?

Mr. WHITE. The first question with respect to the Native Americans, not to my knowledge are there any of those individuals involved in this project as of yet. When it goes statewide, I am assuming that it will occur.

In response to your second question, I was an area Agency on Aging director in southwest Florida for almost 10 years, and I was concerned about the exploitation that might occur with the family member who—a child or a drug-dependent child or whatever taking advantage of Mom or Dad. In the Department's efforts in terms of educating all the network, the idea is that you empower the case manager, so to speak, to the point of you educating them very well in terms of determining whether or not this individual is eligible to be able to do this, and because of the training we were able to abort any of the issues with respect to fraud or exploitation.

Mrs. WILSON. Thank you.

Going down my list here, I think, Mr. Green, you were up for questions for 8 minutes, if you are ready to do so.

Mr. GREEN. Thank you, Madam Chairman.

Mr. WILLIAMS, I notice your wife's name is Helen, and my wife's name is also Helen. And after 30 plus years of marriage, I know that I rely on her to get by on a daily basis as much as you rely on your wife. If I were to become disabled, and there have been times, I guess, 4 years ago that she had to take of me after surgery, the need for care similar to the ones that you are discussing here today, and I know of no one else in the world who I would want to care for me other than my wife or my family, and I would like them, if necessary, to be compensated. So I can appreciate how liberating and comforting this benefit is to many disabled individuals who use it.

However, you point out in your testimony there are limitations to the types of services that family members can provide that expect people to know how to navigate, purchase and manage your entire health and medical care, would be setting many up to take a serious fall or even worse. Can you elaborate on that statement? And what kind of difficulties could individuals face if they are charged with managing all your or my health care as they are with personal care services?

Mr. WILLIAMS. Well, I think the two are like apples and oranges because no one ever knows, especially with a disability, when an unexpected health cost and illness will arise, and when they do, that is often the time I do not want to have to think about does this fit my individualized budget.

Mr. GREEN. Thank you.

You do mention your individualized budget. In one way States can give individuals with disabilities more choice and control over their lives and the services they need, but many States are using other methods to offer people the same choice and control. Could you describe some of the ways outside of the individualized budgets that States can give people more control or choice?

Mr. WILLIAMS. The term "consumer direction" means that an individual has a major say in the selection and direction of their own attendants and related services. One way to achieve this important end is through the use of individualized budgets such as in Cash and Counseling. But some States are ensuring the same choice and control by directing Medicaid community living providers to let the people with disabilities decide who they want to work for them. California, which was an early leader in this area, for example, has operated a large independent provider network for several decades. The way it works is that people with disabilities find people they want to use as attendants, and the State contracts directly with those individuals as independent Medicaid providers. This is all done without individualized budgets.

My office in ASPE funded a study of this program about 5 years ago that showed both people with disabilities and their independent service providers really like this approach because it gives all parties the choice of who they want to work with. The two major downsides were that wages were very low, and there were no health benefits, which are critical issues across the country regardless of how these services are being delivered and Congress needs to look and act on sooner rather than later.

Mr. GREEN. Thank you.

And is there a way that Congress can encourage these activities?

Mr. WILLIAMS. I think most critically it is to make certain that the Federal commitment and funding for Medicaid is not slashed either here or at the State level. I abbreviated my prepared comments somewhat to cut—Friday probably works best. What time is good for you?

Mr. GREEN. Madam Chairman, I would like to thank Mr. Williams.

Mr. WILLIAMS. I think most critically it is to make certain that the Federal commitment and funding for Medicaid is not slashed either here or at the State level.

Mrs. WILSON. Thank you, Mr. Green. And thank you, Mr. Williams. And I appreciate your patience with this committee, and I very much appreciate you being here.

Mr. Whitfield for 8 minutes.

Mr. WHITFIELD. Thank you, Ms. Chairman.

Secretary White, Mr. Williams in his prepared remarks made reference to the importance of national standards for budgeting, and I was wondering if you might have any comment on what he said about that.

Mr. WHITE. We believe that with respect to the budgeting issue, the individual counselor or the consultant that we work with, they are charged with the responsibility of assessing that individual client's needs. And with respect to that, they establish certain protocol in terms of services that the individual might be entitled to,

establish a monthly budget per se, and then they apply that to the program.

One of the issues that we—I will acknowledge is the fact that we are concerned about some of the issues in terms of when people transfer into this program, that there may be a potential for it to be like Christmas, so to speak, in terms of all of a sudden you have all of the services available to you. That is where we believe we need to do a better job in terms of training to the consultant to make sure we only purchase the services that are available to enhance that individual's ability to remain independent.

Mr. WHITFIELD. Now these consultants, would they be consulting with more than one person or one family?

Mr. WHITE. Consultants are like a case manager, and they would have a caseload. Yes, they would be. The beauty of the consultant's ability to coordinate with different families would be that they could take the information they learned with respect to one family and apply it to another. They might rely on some community resources and be able to market better in terms of that individual.

Mr. WHITFIELD. Ms. Gittens, did you have any say-so in who the coordinator for your child would be?

Ms. GITTENS. Yes, I did. Actually I was also a support coordinator before my child was put on the program, and I had a co-worker who I told, if Jewel ever gets on Med-waiver, I want you to be her support coordinator. So when Jewel was eligible, I was able to ask her to request that Jewel be put on. So I did have some say-so to it.

Mr. WHITFIELD. Did the State have to approve her being put in that position?

Ms. GITTENS. Jewel came in as a Med-waiver client already, so she was involved in that particular agency. And then the same person, that is the support coordinator, automatically becomes the consultant once they have received the correct training. At the beginning of the program, not all support coordinators were trained to be consultants. Sometimes the family did have to interview and select another one. But now I would believe almost all of the support coordinators are certified to become consultants.

Mr. WHITFIELD. How did they determine the actual monthly budget for Jewel?

Ms. GITTENS. I as a mother pretty much itemized everything that Jewel needed. And her being on Med-waiver, I had a good idea of the services from her past cost plan. I itemized everything, and I sat down with the consultant, and she helped me to figure out the amounts that Medicaid pays for those services. And then we completed a purchasing plan and submitted it for approval.

Mr. WHITFIELD. And then do you actually receive a check or—

Ms. GITTENS. For direct care? What happens is I submit the time sheets to my representative. She mails it to what we call, PASS, Personal Attendant Accounting Services, in Virginia and when they receive the time sheets, they actually serve as the bookkeepers for the project. So they compute the taxes, and they cut a check made out to the direct care worker, and then those checks are mailed to the representative's home, and the representative gives it to the worker.

Mr. WHITFIELD. Have you been satisfied with the way it has worked?

Ms. GITTENS. Yes. First it was sort of bumpy, and sometimes the checks didn't come on time. We were supposed to get a monthly budget report, and at one point we were not getting that on a regular basis. Now everything is going very smoothly, and everyone seems to be pleased with the way that it works because it gives a lot more accountability.

Mr. WHITFIELD. Now, if Jewel needs prescription drugs or medicine, that cannot be purchased through this program; is that correct?

Ms. GITTENS. No, it cannot.

Mr. WHITFIELD. But if you and the counselor decide that Jewel needs some particular equipment or service, then do you actually negotiate that service, or does the coordinator negotiate that service, or does a coordinator negotiate it?

Ms. GITTENS. I initiate the process, and I would call the coordinator or the consultant and tell her. For instance, I will use an example. On Jewel's regular purchasing plan, we never had respite because she will not eat for everyone, and I never felt comfortable leaving her with someone for that amount of time. Within the last couple of months, there has been a lady working in her classroom who is excellent with her. She does all her feeding as far as helping her to eat. So I called the consultant and I said, I think I found someone that would be a good respite worker. And my husband and I have not taken a vacation pretty much for the last 13 years. My parents were the ones that would keep Jewel, but as she got older, we just decided we are not going to do it. I called the consultant and I told her who I wanted the respite worker to be. I filled out a change form. I added the service. I mailed it to the consultant, and she forwarded it to the agency, I believe, in Tallahassee. And then when we got approval from them, she let me know that the funds were added to Jewel's budget.

Mr. WHITFIELD. Now if this program was stopped, and you had to go back the way it was before, would that upset you, or how would you feel about that?

Ms. GITTENS. I would be very disappointed.

Mr. WHITFIELD. Would you?

Ms. GITTENS. Yes.

Mr. WHITFIELD. Dr. Mahoney, I notice in your testimony or someone's testimony they mention in New Jersey a personal preference program. Is this the same thing as this cash?

Mr. MAHONEY. The Cash and Counseling program goes by different names in each State.

Mr. WHITFIELD. Ms. Gittens, what would you say is the—if you were going to talk to decisionmakers on one of the real problems with the current program that you are involved in, what would you say is the biggest practical problem that you face?

Ms. GITTENS. I am concerned about the families that come on. And being a former support coordinator, I know like in anything else, you have good ones, and you have not so good ones, and you have excellent ones. Jewel happens to have an excellent one. But I am concerned that the family doesn't get thrown out into the lion's den without any type of support. The consultant is supposed

to provide training until the family can do this pretty much with their eyes closed, and then they are supposed to back off. The consultant's rate of pay is the same as the support coordinator's. And I would love to know that every consultant is giving it all that they have and letting the family know that even though I am not controlling this anymore, I am there for you, and I am willing to give you all the help you need.

Mr. WHITFIELD. Thank you.

Mrs. WILSON. Gentleman from California Mr. Waxman.

Mr. WAXMAN. Thank you very much. I want to thank all the witnesses. This has been a very impressive hearing on an experiment that seems to be working very well for many people. It may not work for everyone, but it can work, and it ought to be looked at as a model that could be replicated for the purposes which it can serve.

But what I worry about, because we are facing a lot of attempts to cut the Medicaid program, the block grant, to give people vouchers, all sorts of ideas like that, but no one take a program like this one, Cash and Counseling, and then decide, well, that can be a model that can be easily expanded to cover medical and health care. That smacks of being a voucher. Maybe we can get for the record, Dr. Mahoney, what do you think about this? Is this a model for medical health care generally?

Mr. MAHONEY. You know, clearly Cash and Counseling, you could say three things about its success. One, it really did deal with, you know, basically your nonmedical services, the types of personal assistant services families provide for each other that wealthier people would buy for themselves. Second, it deals—because these people—individuals have chronic needs, it deals with a predictable, you know, type of a need. And the third one, you know, you have heard from everyone here, this isn't for everyone. It is very useful; that it is a choice. It has been a wonderful choice for a significant minority of people. People can return to the traditional system.

Mr. WAXMAN. The fact that that system is there is very important, isn't it? By that system, I mean that people can then look to the fact that Medicaid will stand behind them for other needed medical services.

Mr. MAHONEY. I think that is right. We have also started to look in—with certain managed care organizations as far as their, you know, interest in the future and consumer direction and meeting the needs of people with disabilities as well. And some of them—for instance, as you were saying, in New York City this independent care system, very interested in that approach.

Mr. WAXMAN. How does the Cash and Counseling model figure out how much cash someone needs, and could the same method be used for medical health care services generally?

Mr. MAHONEY. I find the first part easier to answer than the second. In all three of these States, people enter the system as they do now. They get the same care plan. Then the second step is a computation: What is the value of that care plan, what is the dollar value of that care plan. Then the consumer gets to choose. Hopefully they have information and choose what is best for them. But it is the same dollar value that that individual would have gotten.

Mr. WAXMAN. That is quantifiable.

Mr. MAHONEY. Right.

Mr. WAXMAN. And I am trying to get a response here if anybody tried to give any estimate for other services, they are hard to estimate, and they are hard to price. Mr. Williams certainly addressed this in his testimony, and I would like to see if he wants to add something to this very point.

Mr. WILLIAMS. I think the only analog that applies here is that a medical savings account—and there is a fairly fair bit of research on why those don't work particularly well for the kinds of humanity, people with disabilities and chronic health conditions, that we are discussing here.

Mr. WAXMAN. Thank you very much, Madam Chair. May I ask one question of Dr. Mahoney?

Some people suggested replacing the package of Medicaid benefits with a package that is like CHP or traditional private health insurance. How would a change like that affect low-income people with disabilities?

Mr. MAHONEY. I am not completely sure.

Mr. WAXMAN. Give it some thought, and maybe if you have a response, you can put it into the record. And I would like the others to respond to the record on that question as well because this is an issue that has been bubbling around. And some people suggested moving to CHP or a private health insurance kind of package with people with disabilities. And I would like to get a response of whether or not that is a good idea for the record.

Mrs. WILSON. The chairman of the committee, or the subcommittee, Mr. Bilirakis.

Mr. BILIRAKIS. Thank you very much, madam chairman. That sounds pretty good to me, madam chairman.

I see that there are 2 out of 4 Members from Florida, and I wasn't here to greet you and welcome you, and I apologize for that, but as you can tell, I am really under the weather, and I welcome you both here, Secretary White and Ms. Gittens. And Ms. Gittens comes from my part of Florida.

You know, I guess this program is a perfect example, I think, of the result of open-mindedness, creativity, having something that is pretty good, that is working well, that is doing the job it is intended to do, but at the same time always being open-minded to new ideas to maybe improve it. And if this were not available, Ms. Gittens would have the ordinary Medicaid, if you will, and that sort of thing, but certainly not the help she is now getting. So I think all of us should not be close-minded here and be open to new ideas.

I guess I would ask maybe some more of a follow up to Mr. Green's questions than anything else. I hate myself the way my voice sounds. Secretary white, did you have any trouble getting the waiver?

Mr. WHITE. The waiver process is long and enduring.

Mr. BILIRAKIS. It always has been, even with the President's brother being Governor of the State.

But, Dr. Mahoney, any response to that in terms of the waiver process?

Mr. MAHONEY. In many ways I agree. Certainly the Centers for Medicaid and Medicare Services have within this last year issued these model waivers for both 1915 and the 1115 research, calling them Independence Plus, and they are hoping for a more expedited process, but I hope it really will be.

Mr. BILIRAKIS. Well, that has been a bugaboo as far back as I can remember, the problems of States getting waivers. Well, the question again asked by Mr. Green was what—I think Mr. Whitfield also got into it—what can we do, what can Congress do—what should Congress do to facilitate the waivers? Three States have received it—an additional I don't know what, an additional 20 States are taking first steps toward it. I don't know whether they have applied for waivers. Do you all know what kind of problems they may be having? Are there suggestions—you have an opportunity here not to only to tell us about the program, but tell us what we can do legislatively or what we should do legislatively coming from grass-roots people like yourselves in order to help this program better succeed, if you will, to expedite the process, and to tell us maybe, going to Mr. Waxman's questions, whether something like this should be looked at in terms of expansion aside from just the disabled. Whoever wants to—Mr. White first, I guess.

Mr. WHITE. Yes. Included in my testimony is the Governor's commitment in terms of—we understand that there is a rising population of folks in the State that need this particular service; 47,000 people in the State of Florida are not able to participate in it because it is not available. The second thing of it is that we know that Medicaid costs are increasing rapidly, I believe it is 6 percent increase in enrollment each year, with a 13 percent increase in the overall costs.

It seems we have an opportunity here today to be able to not completely make the costs go away, but maybe to control them more acceptably in terms of forming some programs that allow innovations that would have otherwise forced people prematurely into a nursing home, \$42,000, versus a program that can do it for much less, and the client is much happier because they are with their familiar members. We are restoring their dignity. Seems to me that that is pretty commonsensical.

Mr. BILIRAKIS. You say there are 46-, 47,000 on a waiting list and not able to become a part of this program, right?

Mr. WHITE. That is correct.

Mr. BILIRAKIS. Why is that?

Mr. WHITE. In our model of consumer-directed care, we have a pilot in the State of Florida, and it is not available in all parts of the State at this point. However, the Florida Legislature last year did pass legislation that would allow us to go statewide. We have in the past year just received from CMS a preliminary approval of this to go statewide, and we are anxious to get that going.

Mr. BILIRAKIS. I thank you.

Dr. Mahoney, you are chomping at the bit.

Mr. MAHONEY. If I could expand, the requests that New Jersey and Arkansas have made to CMS of clarifying the definition of Medicaid's optional personal care benefit so it didn't have to be limited just to human assistance is one way without waivers, which is the beauty that New Jersey is seeing that an option like this

could be expanded. So I would speak highly of that. And, you know, it goes to the point made earlier. With these individualized budgets, it isn't just a matter of people being able to know who they can hire. It is the freedom to tailor assistive devices, home renovations, a chair that they can actually get up from so that they don't need someone to help them. That type of thing makes a difference.

The other one is as the Robert Wood Johnson Foundation, at their July board meeting, looks at whether to provide additional seed money and technical assistance to States to expand, I know it will make a difference that there be a partnership with Health and Human Services in the funding and operating and coordinating of that effort.

Mr. BILIRAKIS. Madam Chairman, just to take advantage. The Chair will ask you to respond to written questions that will be furnished to you. I would also add to that request that you furnish to us your ideas on what can be done to improve this type of a program and what we might be able to do legislatively and that sort of thing. Thank you for your indulgence.

Mrs. WILSON. The gentleman from Michigan Mr. Stupak for 8 minutes.

Mr. STUPAK. Mr. Williams, I would like to ask you a question. Mr. Waxman was asking some questions, and I would like to follow up on it a little bit further.

You have suggested that Cash and Counseling and the money follows the person's initiative, if properly implemented, can enable many people with disabilities to live in their own homes and communities, but all this is happening in a much larger, more disturbing context where we are seeing deep budget cuts at the State and also at the Federal level. As you know, the administration and some Governors have suggested or proposed that Medicaid be turned into a capped program. In response, a number of members of this committee have cosponsored the Strengthening our States Act, or H.R. 2000, which makes personal care and attendant services a new State optional service under Medicaid and would provide enhanced Federal funding for States that provide this service. The bill also provides enhanced Federal funding for all home and community-based care waivers.

I know also that many individuals with disabilities are also interested in the MCASA bill introduced by Congressman Danny Davis, which a number of us Democrats on this committee have also cosponsored.

I would like to hear what are your greatest fears with the current financial crisis at both the Federal and State level on some of these proposals. What do you believe the Federal Government's role should be in this regard?

Mr. WILLIAMS. Right now as we speak, about 300 people with disabilities from independent living centers across the country are marching and wheeling up Capitol Hill to protest the Medicaid cuts and call for the passage of MCASA. Now, that is not a large group by Washington standards, and given the times, it is easy to write it off as tilting at windmills. But it is important to understand why so many of us believe that MCASA is the only just and equitable solution to the problem and that you and others in Congress recognize the threats those with disabilities on Medicaid face everyday.

Though the 19 States made use of Medicaid waivers to expand home and community-based services, even by 2000, when most States have budget surpluses rather than deficits, only three States spent 50 percent or more of their Medicaid long-term care funds on community living services. In contrast, 29 States spent less than a third of such funds in this manner. This results in huge inequalities across and even within States as to what people with different disabilities but a common need for a community living service received.

What does this mean? Take two people with the same degree of need for daily help with things like eating, dressing and using the bathroom. Odds are that if one of the two is lucky enough to get even a limited amount of the help they need to live in the community, the other will have to go without it or enter a nursing home. Even in the 1990's, when many States were actually expanding community living services, many remained institutionalized. Many others lived in the community, but suffered the indignity and real harm that comes from having many of their needs go unmet. These problems are growing worse as States cut community services in an effort to deal with their massive deficits. The Bush block grant combined with the tax relief plan would further exacerbate what some have come to see what it is, a national disgrace which must be remedied on a consistent nationwide basis, not idiosyncratically by 51 different States.

A lot of people are calling for even greater flexibility for States as if that will solve these problems. Experience shows the opposite to be true. Flexibility leads to enormous inequities in respect to what Americans with disabilities receive in terms of community living services depending on what State they happen to live in.

I agree on one point with the Nation's Governors. The Federal Government should be playing more of the predominant role in financing Medicaid, especially community living services. But unlike the Governors, I believe and think that most Americans would likewise expect that in return for this, that the Federal Government should make certain that, as we guarantee, all those with disabilities who can live in their community with affordable supports have the equal opportunity to do so regardless of their age, disability or type of assistance they need. This is what MCASA is meant to achieve. And I believe H.R. 2000 contains many important powers and incentives particularly in providing Federal matching rate for community living services that would move our country in this crucial direction.

Mr. STUPAK. Thank you.

Anyone else care to comment on that, the capping or the block granting of the Medicaid?

Ms. Gittens, could I ask you a question? In your testimony earlier, you had indicated that one of your concerns was families coming on or who may be consultants under this program. It seems having well-trained counselors are critical to the success of these programs and success for the families. Could you comment on that? What are the pitfalls for consumers of having counselors who are not motivated or having committed to working hard for their clients? You sort of alluded to it, but is there something more you could explain?

Ms. GITTENS. I think that if the consumers are just coming on, they are experts on what they need. But as far as how to get it done, I think there is a lot that has to be learned in the area of paperwork and format. And so I think that is where the consultant comes in, to help them understand how to get what they need. And sometimes I am concerned that they don't know what to ask and don't know the right questions to ask. The control is given to them, but I think that the support needs to be there.

One of the things I mentioned is that a support group was something that was—during the enrollment process was promised to everyone who enrolled. So I would love to see that come in my area where we don't have a support group. If we had a support group of consumers and families, then I believe they could train each other and then still have that control, but right now we don't have that.

Mr. STUPAK. Dr. Mahoney, did you want to say something?

Mr. MAHONEY. In each of our States they use very different approaches. Some try to retrain existing care managers. Some try to use new groups. I think we have learned the importance of training, and we are actually negotiating with CMS—I don't know how to say—a best practice approach for training counselors. And I love her idea of the peer support network.

Mrs. WILSON. Mr. Stearns for 5 minutes.

Mr. STEARNS. As you know, I am not a member of this committee, but a member of the full committee, and I wanted to ask a question since I had a great deal of interest in consumer-driven health care. And, of course, I want to welcome my fellow Floridians, Secretary White with Tom Reimers and Patricia Gittens, and thank all of you for coming.

Let me just read the question I have for you, Secretary White. You say that States that implement consumer-directed programs should consider choice and quality issues, and I thought I would work off that. The multiple options for consumer supports are preferred. There are issues involving economies of scale and quality that need to be considered in a consumer-directed program design. If there are an unlimited number of consultants, and each consultant has only a limited number of consumers to assist, some consultants may not be able to acquire the experience and develop the skills necessary to truly empower consumers. So basically, an overabundance of consultants could also lead to challenges in—basically in the areas of training and technical assistance. While multiple options for fiscal intermediaries may benefit the consumers, too many options may create a financial hardship for each company, and I think ultimately harming the consumers.

So the question is, what is the balance, the balance in the latitude in hiring inherent in the CDC with the basic need for a level of training and technical assistance?

Mr. WHITE. In response to that, I believe that achieving that balance is going to be one of those things where we have to experiment a little bit. I think one of the concerns we had in being a fiscal intermediary, if you had too many lives, so to speak, in terms of the program, and you had too many intermediaries who had a very small portion of those lives, it is an economy of scale, so it is not effective to be a fiscal intermediary, and, therefore, you may

not be doing your job as well, or you may be slacking on the number of staff persons in order to handle these bills. Ms. Gittens talked about the fact that she has numerous bills that she turns in on a monthly basis to that fiscal intermediary, and they in turn generate the check that goes to those individuals.

The other concern is that we—going back to Ms. Gittens' testimony in terms of training those consultants to be the best that they can be, that we really train that core of folks so they can go out there and counsel effectively in terms of helping family members select the choices that are better for them.

Mr. STEARNS. Anyone else wish to speak?

Mr. MAHONEY. Just briefly. We have just about finished compiling about a 40-page paper of implementation lessons from the three States, and we are hoping that will be helpful to other States.

The other thing is within the next month, a guide for—of best practices for quality management in a consumer-directed system is one of the things, you know, that we have come up with. It is important to us—you know, this isn't just limited to people who have family and friends.

Mr. STEARNS. My time is going to expire—Mr. Williams, I will come back to you. And let me put this on the plate of Secretary White—Dr. Mahoney. Is it possible what we are talking about here for Medicaid could be an application for Medicare, just to narrow the inquiry, maybe not as an entire umbrella for health care, but something that we could do for chronic, predictable conditions like asthma in children or diabetes? It may seem a condition like this, to have a high degree of self-care and self-management would be good and so that we could have a consumer-directed in that area.

Mr. MAHONEY. I have been part of a day-long panel with people in Medicare of how this might be applied maybe in areas like medical equipment, DME, et cetera. For me, the three principles we have been working with—you know, the issue of nonacute care, nonpredictable and choice are sort of the principles that govern our thinking at this point.

Mr. STEARNS. That would be chronic, predictable conditions in which you think it could apply.

Mr. MAHONEY. Right. And not with acute care types.

Mr. STEARNS. Mr. Williams.

Mr. WILLIAMS. May I interject? One concern I have about Florida's consultant approach, which is that they are State employees, and whether or not conflicts of interest already exist—and I am not saying there are. The potential conflicts are there.

Mr. STEARNS. Anyone else like to speak? I think my time has expired.

Mr. WHITE. The consultants that we are speaking of are case managers that are in the field, they are not State employees, just to clarify that issue.

Mrs. WILSON. Thank you. My intention here, because there is a vote on the floor in about 12-1/2 minutes, is I think the only person who has not had a chance to ask questions is Mr. Brown, and unless there are other questions or second round of questions, I hope to adjourn the hearing before we go to these votes, if that is acceptable to people.

Mr. Brown.

Mr. BROWN. I have a question for Ms. Gittens and one for Mr. Williams.

Ms. GITTENS. It is pretty clear you are knowledgeable and understand how to negotiate the pitfalls and the obstacle course of this program. Could you discuss the—but many don't obviously have the skills and knowledge and ability you do to be able to figure all this out. Could you discuss the importance of having well-trained and committed counselors to help families navigate the program and get the benefits they need?

Ms. GITTENS. I think it would be very important for them to know who they can talk to and knowing their full range of opportunities. And the reason I say that is because sometimes, in my personal experience, a consultant may, out of—maybe out of ignorance or negligence, or maybe just being very busy, they may not give them the entire scope of the opportunities. And unless—like me, being on the inside, I was able to know some things.

I think the best way to do this would be through a support group, you know, having someone who volunteers, or to lead a group that whereas they have more experience and they are able to help the others, maybe they can be trained if they have no prior knowledge, maybe they can be trained by someone, and then they handle their group.

Mr. BROWN. Mr. Williams, under the Cash and Counseling demonstration, individuals, as you know, are given personal budgets to manage for their personal care services, as you outlined in your testimony and others have addressed. A couple of questions. Do you believe that the methods for calculating the individual budgets have been fair? What about individual budgets under the Independence Plus demonstration? Are there appropriate safeguards there to ensure that those budgets are adequate and that those budgets are fair? Would you answer that question, please?

Mr. WILLIAMS. I was lucky in asking when the waivers were approved, and what took the most time was grappling with this question of how to set an individualized budget. I think we got the elements right as far as we could back then. I would, however, like to look over the evaluations results more and submit a written response on whether what we thought was fair turned out to be adequate and something people with disabilities as well as States could understand and use effectively.

Mrs. WILSON. We would welcome explanation and expansion after you look at the results of the study.

I wanted to thank you all for being here today. Thank you for your research work. It has been very helpful to have those independent evaluations.

Thank you, Mr. Secretary, for the States' perspective, and thank you particularly to Ms. Gittens for being here and traveling here. I am glad you were to find family care or respite care to be here today. And, Mr. Williams, thank you for giving your unique perspective to this committee.

We are going to hold the record open for any members who would ask written questions over the coming days, and very much appreciate it.

This hearing is adjourned.

[Whereupon, at 12 p.m., the was adjourned.]

[Additional material submitted for the record follows:]

RESPONSES FOR THE RECORD FROM MR. BOB WILLIAMS TO QUESTIONS OF HON.
EDWARD J. MARKEY

Question 1. Thank you for your testimony at the Energy and Commerce Committee's Health Subcommittee. You provided the Subcommittee with important insights into the strengths and key areas for improvement within the Cash and Counseling demonstration project.

Given your expertise and substantial first-hand experience in Medicare and Medicaid policy, I'm interested to hear your views on another important program that has received considerable attention both in the Congress and the Administration: Medicare home health services for homebound beneficiaries.

As you know, patients with disabilities who are able to leave the home only with extreme difficulty and assistance from others may be deemed homebound by the Medicare program and therefore eligible for health services provided in their homes paid for by Medicare. To retain these services, the patient is required to remain in his or her home except for short, infrequent trips outside or to attend a doctor's appointment, religious service or adult day care. The purpose of these restrictions on departures from the home is to ensure that patients don't "game" the home health program—meaning that patients who are, in fact, physically well enough to leave the home don't take advantage of a program meant to help those who are legitimately homebound.

Unfortunately, these restrictions have produced an unintended consequence—they imprison severely and chronically disabled patients, such as those with Lou Gehrig's Disease and late-stage Alzheimer's, in their homes. That's because patients who are legitimately homebound and *unable to ever regain* the ability to leave their home without substantial difficulty and technological assistance are bound by these same restrictions on their movement.

This means that patients such as David Jayne, a courageous man from Georgia who continues to battle Lou Gehrig's Disease, cannot leave his house to attend his son's hockey game without fear of having his home health benefits terminated for violating the homebound rules. In fact, when David attended a University of Georgia football game a few years ago, his home health agency terminated his benefits when it found out about the trip. According to the home health rules, David's trip to the game indicated he must not really be "homebound," even though ALS has deprived him of the ability to move his arms or legs or breathe on his own.

As you know, last summer the Bush Administration issued additional instructions in the Medicare home health agency manual intended to clarify homebound criteria and prevent profoundly and chronically disabled patients like David Jayne from being caught up in restrictions on their movement. Specifically, the Administration announced that: "occasional trips to the barber, walk around the block, attendance at a funeral . . . or other infrequent or unique event" would not automatically trigger forfeiture of home health benefits. The Bush Administration also announced that a patient's overall physical condition should be considered when determining homebound status.

A) In your view, have these additional instructions resolved the problem in the Medicare home health program, which has had the effect of imprisoning severely and irreversibly disabled beneficiaries in their homes?

Response: Last July twenty-sixth at event commemorating the 12th anniversary of the ADA President Bush announced that his Administration issued guidance that day to "clarifying Medicare policy, so people who are considered homebound can occasionally take part in their communities, without fear of losing their benefits." The President stressed that the intent behind it is to ensure that "when Americans with disabilities participate in their communities, they should not be penalized." Unfortunately, the program instruction issued that day to home health agencies and Medicare carriers is even more restrictive than the already overly restrictive homebound definition in the statute.

In order to receive Medicare home health services, a beneficiary must have a post acute or chronic skilled care need and must be "homebound". To be considered "homebound": 1. The individual must have "a normal inability to leave home"; 2. "Leaving home requires a considerable and taxing effort by the individual," e.g., by relying on a wheelchair or cane or the assistance of another person; and, 3. Trips outside the home must be of an "infrequent or of relatively short duration". The exception to this is that the law permits an individual to be absent from their home to receive health care or to attend adult day care or religious services at anytime. The law likewise states that: "Any other absence of an individual from the home shall not so disqualify an individual if the absence is of infrequent or of relatively

short duration.” [42 U.S.C. ’1395n(a)(2)(F)]. In recent years, however, individuals with severe and permanent disabilities like ALS, muscular dystrophy, severe brain injury and quadriplegia are increasingly being thrown off the benefit for leaving home regardless of how short or infrequently they do so.

In attempting to address this problem, CMS’ new guidance cites examples of when “chronically disabled individuals who otherwise qualify as homebound should not lose home health services because they leave their homes infrequently for short periods of time for special occasions, such as family reunions, graduations or funerals.” CMS points out that its list of excused absences is meant to be illustrative rather than all-inclusive. Listing examples like these, though, creates more problems than it solves. The Medicare program should not be in the business of creating what will always be a finite list of “permissible reasons” any beneficiary can choose to leave their home that ultimately likely will be used to unjustly deny them their services and/or their personal freedom.

B) If the Administration’s instructions have not resolved the problem, why not?

Response: Even under current law, a beneficiary theoretically should be able to leave home to work, attend college, shop, go to the theater, and dine at a restaurant and a myriad of other reasons if such “absences” are of “infrequent or relatively short duration”. But, there is the rub. No one knows what the phrase “absences of infrequent or relatively short duration” means and any attempt to define it would be as arbitrary and capricious as developing a list of government approved reasons why law abiding Americans should be “allowed” to leave home and still retain the skilled home health services they need to literally stay alive. The program instruction issued last July puts CMS, Medicare carriers and home health agencies over the simple liberties of living in the everyday lives of people with significant disabilities and chronic health conditions like David Jayne than any of these entities have any real reason to exercise—all without adding anything to the integrity of the Medicare program.

Question 2. As you may know, I have introduced H.R. 1874, a bi-partisan bill cosponsored by Congressman Chris Smith and members of the full committee from both sides of the aisle. The purpose of this legislation is to create a three-year pilot project that would lift the restrictions on departures from the home only for those home health beneficiaries who are the most severely and permanently disabled—such as those with ALS and similar profound and debilitating conditions.

A) Given your expertise in demonstration projects, do you believe that such a demonstration project is an effective way to test whether providing this exemption for a tightly defined population would increase costs or have any adverse effects on the quality of care?

Response: I believe that it will prove to be an effective way to test whether implementing the stringent requirements set out in H.R. 1874—for certifying that certain individuals will always need skilled home health services and lifting the duration requirements of the homebound requirement for those persons—would increase costs and/or have adverse impacts on quality of care. The proposed demonstration would have an enrollment cap, which theoretically could deter some from applying to participate in it in the first place. This would be a problem if prospective participants had little to gain from signing up and going through the process of being screened to determine whether they meet the criteria. But, that’s clearly not the case here. The stark choice here for beneficiaries with the most significant disabilities and health conditions is whether to continue to be imprisoned within the 4 walls of their homes forever or to apply to participate in the project and enjoy the common freedoms of movement that all other Americans rightly take for granted.

For this reason, I am convinced that—if it is designed and implemented correctly—far more will apply to take part in this demonstration than the enrollment cap will permit. This is lead to tragic consequences for some individuals. But, in terms of the demonstration itself, I believe this will produce three fairly sizable groups of beneficiaries whose needs and characteristics can be assessed as part of the evaluation:

- Those who are found to meet the criteria and participate in the demonstration
- Those rejected from the demonstration because they fail to meet the criteria
- Those who apply to participate but are turned away because of the enrollment cap—regardless of need they met the criteria or not

It will be crucial in my judgement for Congress and the agency to examine the patterns that emerge both within and among these three groups in order to be able to determine:

- Whether the criteria can be administered the majority of the time in an fair, accurate and predictable manner

- Whether relaxing the current homebound restriction in this manner would increase cost or lower the quality of care
- Whether the number of types of Medicare home health users who apply and are found to meet the criteria will put increased administrative burdens on the program

A demonstration like the one envisioned in H.R. 1874 would yield informed responses to these policy questions and lead to better Medicare policy.

B) As a former deputy assistant secretary at HHS, do you believe, in your professional opinion, that the Department should support permanently lifting these restrictions for permanently and severely disabled beneficiaries?

Response: Yes, I do.

Question 3. It's my understanding that the *Medicaid* home health program for homebound beneficiaries does *not* limit departures from the home, although the *Medicare* program does.

A) Do you think that it makes good public policy sense for the *Medicare* program to restrict departures, but the *Medicaid* program to permit them?

Response: The vast majority of Medicare beneficiaries who use skilled home health services do so only for a short period of time when recovering from an acute illness or injury, the nature of which will not permit them to leave home until they recover. In these instances, the current Medicare homebound restriction can be applied in a consistent, fair and objective manner—i.e., when someone's illness or injury resolves itself to at least the point where skilled care is no longer required and they can leave home independently they are no longer homebound. In these situations I believe the current rule continues to serve a valid policy purpose. Where it becomes punitive and absurd is when its duration requirements (i.e., that an individual can only leave the home for periods of "an infrequent or of relatively short duration") is when it is applied to those whose significant disabilities and/or chronic health conditions are permanent and severe enough to task that they receive skilled home health services for the rest of their lives. In these instances, the homebound rule can only be seen as an arbitrary to put someone who has broken no laws under house arrest for the rest of their lives.

In 2000, CMS told States they could no longer impose a homebound requirement on people with significant disabilities and chronic conditions needing Medicaid home health services because: 1. Unlike in Medicare, there is no statutory provision in the Medicaid law that expressly requires or permits States to do so; and 2. More importantly, doing so infringes on the civil rights and everyday liberties to live their lives in the community like all others. Efforts to do the same in Medicare are vital.

Question 4. As you know, the Bush Administration's New Freedom Initiative is intended to enable persons with disabilities "the necessary supports to fully participate in community life."

A) In your view, does the homebound restriction—even with the Administration's modification last summer—appear to contradict the principles it established in the New Freedom Initiative?

Response: Yes.

B) Do you believe that elimination of the restriction—only for those beneficiaries who have severe and life-lasting conditions such as ALS—would be consistent with the intent of the New Freedom Initiative?

Thank you for your testimony and for providing responses to these questions.

Response: Yes.

RESPONSES FOR THE RECORD FROM MR. BOB WILLIAMS TO QUESTIONS OF HON. JOHN D. DINGELL

Question 1a. Under the Cash and Counseling demonstration, individuals were given personal budgets to manage for their personal care services. Do you believe that the methods for calculating the individual budgets have been fair?

Response: To respond to this question I have reviewed the final evaluations prepared by Mathematica on the implementation of the Cash and Counseling projects in Arkansas and New Jersey, which contained information on how both States determined the individual budget of each person who received cash in lieu of Medicaid personal care services. The final evaluation on the Florida project has not been released and information on how the State goes about determines the amount of person's individual budgets was not available for my review. Thus, my response is based on the reported experiences in Arkansas and New Jersey. Online versions of the final evaluations prepared by Mathematica of the projects in both states are available at <http://www.mathematica-mpr.com/3rdLevel/cashcounselinghot.htm>.

Both States took two quite different approaches to determining the individual budget amount each participant received: New Jersey determined it on the basis of a person's current need for personal care services as described in their "plan of care" (hereafter referred to as services plan), while Arkansas used a "discounting method" that is described further below.

New Jersey took the much more straightforward and potentially fairer approach by basing the individual budget on what the person's existing service plan said he or she required. According to the Mathematica evaluation:

New Jersey based the amount of the cash allowance on the current PCA care plan. Hours planned were cashed out at the hourly rates the state paid for weekday and weekend PCA services (in New Jersey, care plans differentiate between weekday and weekend hours). At about the time of our visit, the amount of the allowance ranged from about \$300 to about \$2,800 a month. The average was about \$1,300. (Mathematica's Final Report on New Jersey's Personal Preference Demonstration, page xiii.)

There are pro's and con's taking this basic approach. On the positive side, especially as a jumping off place, it seems a logical and "fair" way to set at least an initial individual budget amount for the person. But, it is only as fair to the extent that the plan accurately and objectively reflects the person's complete personal care needs.

This points up the negative side to this approach, which is that service plans can be based less on the actual needs of an individual and more on what State professionals and providers understand to be the "resources available" to meet those needs. Thus, an individual budget derived from the person's current service plan can only be as fair and accurate as the plan itself.

It is not possible—based on the results reported by Mathematica—to tell whether the service plans used in New Jersey were accurate in documenting the actual needs of those 875 persons that received the individual budget payments. (Note: The 875 number is half of the about 1,750 people participated in the Personal Preference Demonstration in New Jersey in evenly divided treatment and control groups between December 1999 and June 2002. See Mathematica's Final Report on New Jersey's Personal Preference Demonstration, page xiii.)

But, even if the New Jersey plans proved to be in the main an accurate basis from which to derive an individual budget amount, the point remain a critical one that Congress must recognize and address: Service plans developed in other States that desire to use individual budget to expand community living options may be flawed in the ways just described. Steps that the federal government should take to remedy this are listed in the Recommendations section below.

Arkansas used a practice known as "discounting" in determining the individual budget amount each participant received. In its final report on the Cash and Counseling project in that State, Mathematica explains the process used by Arkansas as follows:

Arkansas based the amount of the cash benefit on the care plan. The amount was based on the current care plan for treatment group members who were already PAS recipients, and the outreach/enrollment nurses developed care plans for those new to PAS. Both types of care plans were cashed out at \$8.00 an hour after "discounting." Discounting involves multiplying the care plan hours by the ratio of the cost of services actually received to the cost of services listed on the plan of care. It is intended to ensure the budget neutrality of the cash program by taking into account the fact that the amount of services received is generally less than the amount planned (due, for example, to hospital admission of PAS recipients and insufficient supply of aides). Arkansas developed provider-specific discount rates for current recipients of PAS by comparing care plans and claims for the previous year for random samples of those served by various providers of traditional personal assistance. These provider-specific discount rates ranged from about .70 to .91. A rate of .91 was applied to the care plans of new recipients of personal assistance. (See Mathematica's Final Report on Arkansas' Independent Choices Demonstration, page xii.)

Mathematica indicates that Arkansas relied heavily on using discounting to determine individual budget amounts for the following combination of reasons:

A major issue that arises in any program using care plans to set cash benefit levels concerns differences between the amount of service planned and the amount actually received. The amount of service received is generally less than the amount planned. The amount of service received is generally less than the amount planned. (The care plan typically represents the maximum amount of care authorized; thus, the amount of care received does not exceed the amount planned.) Because the cost of the care received is generally less than the cost of the care planned, a discount rate must be applied to ensure that the costs

of the cash program do not exceed the costs of the traditional program if the level of the cash benefit is to be based on care plans.

Care received is generally less than care planned for a variety of reasons. A client may be unexpectedly hospitalized and thus not available when an aide arrives. A home care aide may not appear for work when expected, or an agency may be unable to find enough workers to provide the care it had planned. Agencies sometimes plan for somewhat more care than they expect to render so that they can increase the amount of care without revising the care plan if the client's needs increase. That is, the total hours planned included a "hedge" against possible future increases in need. (Mathematica's Final Report on the Arkansas pages 30-31.)

The Final Report finds that Arkansas' use of the discounting methodology proved problematic in several ways, including the following:

Determining the discount rate needed to achieve budget neutrality can be difficult. The ratio of the cost of care received to care planned may differ for agencies and individual clients. (Note: Achieving budget neutrality was not a requirement this demonstration but Arkansas chose to use this method anyway.)

- As a result, using a single discount rate for all agencies and all clients may unfairly penalize some cash program participants.
- As the labor market tightened in the late 1990s, it may have been harder for traditional agencies and project participants to find enough workers.
- Discount rates developed for random samples of *all personal care* recipients may be inappropriate if those who choose to participate in the demonstration differ systematically from other personal care recipients.

(Mathematica's Final Report on the Arkansas project, page xvi.)

Through this process, the discounted care plan hours were cashed out at \$8.00 per hour. The difference between \$8.00 and the hourly rate the state paid to traditional providers (\$12.36) was used to cover the cost of counseling/fiscal services. (Page 32). This reduced the individual budget funds each person could use to actual another person to provide them needed assistance by slightly over a third.

It should be noted that "the discount rate for care plans following *reassessment* of cash recipients (.91) was more generous, on average, than their initial discount rates (which ranged from .70 to .91)" Mathematica's Final Report on the Arkansas project, page xvii). But, this appears to have had little to no positive effect on the purchasing power of those receiving the cash payments. The report says that those who had personal care needs that had gone partially or completely unmet by the "traditional program had a greater incentive to participate in IndependentChoices." (Page xvi). Yet, it also concludes that:

The average cash payment in Arkansas would not cover even half-time work (assuming an hourly wage of \$7.00 an hour). Only late in the demonstration did mechanisms begin to develop to help workers hired with the cash benefit find positions working for other cash recipients. Still other consumers found the cash program less attractive due to restrictions placed on the uses of the cash, according to staff of IndependentChoices. **Some consumers were disappointed that the full amount at which the discounted care plan was cashed out (\$8.00 per care plan hour) could not be paid as wages. After providing for payroll taxes, the maximum wage possible was about \$7.25 an hour (unless the number of hours was reduced).** (Mathematica's Final Report on the Arkansas project, page 66. Use of bolding not in the original.)

Clearly, if a goal of the project was to enable people with disabilities with significant unmet needs to purchase more services and supports, its use of discounting was ill advised. Moreover, in my view, the discounting penalizing people with disabilities for services that have not been provided for reasons that are outside their control (e.g., hospitalizations, workers not showing up, changes in the economy as a whole). This likely was not Arkansas' intent but the results speak for themselves and should not be repeated elsewhere. I strongly believe, therefore, that Arkansas' use of the discounting method produced unfair results and conditions and therefore, it should not be allowed to be used by any other State for this purpose.

Additional concerns and comments: My review of these evaluations prompts me to share the following concerns and comments with the Committee as well.

States should assure that whether an individual opts to receive personal care in the typical manner or through the use of an individual budget that both methods will enable him or her to receive equally effective services and supports—Only 10 to 15 percent of those eligible for personal care option services in Arkansas and New Jersey, respectively, signed up obtain an individual budget. Because of the design of the demonstration itself, only half of these received cash payments (3295 in all 3 States—see Cash & Counseling At A Glance, June 30, 2002

at <http://www.hhp.umd.edu/AGING/CCDemo/ata glance.html>. There are many reasons why participation rates in these projects were modest. Moreover, interest in using individual budget can be expected to increase as people gain more knowledge of the method. But, well into the foreseeable future most people with disabilities on Medicaid who need personal assistance will receive it through the existing system. The findings of the evaluations of the projects in Arkansas and New Jersey also confirm what I told the Committee when I testified: An individual budget works best for someone with an extensive network of family, friends and previous workers from whom they can purchase services and supports with their cash supplement. One of the major successes of both projects enjoyed was that participants were able to “tap a new source of personal assistance workers—family members and friends”. (Mathematica’s Final Report on the New Jersey project, page xviii).

But, Mathematica found the converse to be true in both States as well: Those without family and friends had a tougher time getting their needs met through using the monthly cash payments. There were a variety of reasons for this—the payment was not sufficient, the labor supply was tight, there were few supports in place to help with the recruitment and screening of potential workers. For example, in terms of the New Jersey project, Mathematica found that:

Recruiting is critical for those consumers who do not have family or friends available to hire as workers. Personal Preference program staff reported that the receipt of the cash allowance was delayed for consumers who had difficulty recruiting a worker and that those who could not recruit a worker tended to drop out of the program. (Mathematica’s Final Report on the New Jersey project, page xvix and see pages 123 and 153 for similar findings). (Emphasis is in the original).

Similarly, as previously pointed out those in Arkansas who had to hire and retain workers other than family or friends found it difficult to do so because of the paucity of the hourly wage they could pay to such individuals and the tight labor supply. There is also a separate body of research that shows people with disabilities without a network of family and friends generally have a harder time getting their personal care option needs met, have greater unmet needs and are at higher risk of institutionalization as a result. Improvements could no doubt be made to help mitigate many of these problems. **But, it cannot be assumed that even with modifications individual budget would work well for all people on Medicaid with personal care needs, particularly those who have extensive needs and/or a sparse substance abuse network of family and friends. Hence, it is imperative that States that choose to offer individual budgets also must be expected to provide equally effective access to personal care services through both this method and the existing Medicaid program. This is also why States that opt to use this approach likewise must be required to meet a strong and enforceable “Maintenance of Effort” requirement in respect to funding personal care services through more typical means as well.** To fail or refuse to do this would, in my view, be irresponsible.

States should offer individuals the opportunity and support to direct their personal care services through other means than through an individual budget—The disability community (i.e., people with disabilities ourselves) have long recognized and emphasized that there are and need to be many ways for individuals with disabilities to direct their own personal assistance services. See pages 5 and 6 of the final report on the implementation of the Arkansas demonstration for a concise discussion of the history of the concept and philosophy of consumer direction. The Medicaid Community-Based Attendant Services and Supports Act of 2003 (**S-971/HR2032**) includes the following definitions related to consumer directed services:

‘(B) CONSUMER CONTROLLED—The term ‘consumer controlled’ means a method of providing services and supports that allow the individual, or where appropriate, the individual’s representative, maximum control of the community-based attendant services and supports, regardless of who acts as the employer of record.

‘(C) DELIVERY MODELS—

‘(i) AGENCY-PROVIDER MODEL—The term ‘agency-provider model’ means, with respect to the provision of community-based attendant services and supports for an individual, a method of providing consumer controlled services and supports under which entities contract for the provision of such services and supports.

‘(ii) OTHER MODELS—The term ‘other models’ means methods, other than an agency-provider model, for the provision of consumer controlled services and supports. Such models may include the provision of vouchers, direct cash payments, or use of a fiscal agent to assist in obtaining services.

These definitions were developed with significant input from people with disabilities who use personal assistance extensively. The definitions make clear that people with disabilities can and must be able to exert choice and control over their services and supports in a variety of ways—not just via an individual budget. In spite of this, however, CMS has recently taken the position that it views consumer direction in a far more narrow and limiting way by stating that:

The Centers for Medicare and Medicaid Services (CMS) defines a self-directed program as a state program that presents participants with the option to control and direct Medicaid funds identified in an Individual Budget. (Home and Community Based Services: From Institutional Care to Self-Directed Supports & Services, page 11 online at <http://cms.hhs.gov/newfreedom/528hill.pdf>)

It is presumptive for CMS officials to circumscribe the definitions of self-direction and consumer direction—synonyms of each other—to fit with their own views of how Medicaid might be better operated as a voucher program. Unfortunately, I frankly think that this is an example of just that. It would be equally wrong to allow States to do the same thing. A State that give people the “choice” of using an individual budget should offer them the opportunity and support to direct their personal care services through other means as well.

States should provide adequate funding for benefits counseling, recruitment and personal assistance registries, fiscal intermediaries and other services essential to the success of consumer directed services in way that does not siphon off service dollars from people with disabilities—New Jersey and Arkansas funded their consumer consulting/counseling and fiscal intermediary services by charging those with individual budgets a set monthly user fee (NJ) or taking about a third of the rate that the state paid to traditional providers to defray such expenses and cashing out the rest (AR). Unfortunately, both of these approaches produced adverse impacts. New Jersey’s need of monthly users’ fees, for example, led it to limit participants to 19 hours of consulting a year for which project would pay after the cash plan was in place. This meant that some who needed substantially more consulting assistance than others did, and some needed substantially more than expected did not receive it. New Jersey, like Arkansas, also set funds aside from the personal care benefit before cashing it out to pay for these types of administrative services. Arkansas—practice of discounting in general and taking funds out of the base amount that it would have otherwise paid to a personal care agency to defer these costs and gave the remainder to the participant. As I previously noted, this meant that the discounted care plan hours were cashed out at \$8.00 per hour. The difference between \$8.00 and the hourly rate the state paid to traditional providers (\$12.36) was used to cover the cost of counseling/fiscal services. (Page 32). This reduced the individual budget funds each person could use to actual another person to provide them needed assistance by slightly over a third. While it might make some sense to have individuals using these services pay some share of the costs, it should be a very nominal one. If the federal government and States are genuinely interested in pursuing these approaches, funding—separate and above Medicaid services dollars—must be made available to develop and sustain them.

Conclusion: In terms of were whether the methods used by Arkansas and New Jersey for determining what a person’s personal care allocations were fair or not, I believe that many, if not most, participants with sufficient and stable support networks of family and friends that their respective processes proved to be fair much of the time. This is because most of these individuals had something to build and expand upon as well as support to fall back on when all else failed. But, for those without extensive support networks and/or those with extensive personal care needs I believe the evidence shows that the methods proved to be too rigid, unresponsive and ultimately unfair much of the time. That is not to say that such persons can never benefit from using an individual budget. Some likely have and more, I believe, can. It will, however, require significant time and effort to make this outcome possible and I offer the following recommendations with this and related aims in mind.

Recommendations: Based on my review of the results of the Cash and Counseling projects in New Jersey and Arkansas, I believe it is essential that if other States are to be allowed and urged to use individual budget as a way to expand community living services to people with disabilities, the federal government should make clear that:

—Setting a person’s budget at the same amount as called for in their service plan is permissible so long as:

- It is done in a manner that does not disadvantage the person in anyway;
- The State demonstrates that the amount is sufficient enough for the individual to pay for personal care services to an extent that is at least commensurate with those he or she would be able to otherwise receive from Medicaid;

- The service plan fairly and accurately reflects the person's complete personal care needs, including any that currently may not be being met;
- Each person who is considering receiving or currently is receiving a personal care cash supplement, has the right and opportunity to request and receive an independent adjustment in the budget based on needs that are not adequately addressed in the plan and/or have changed;
- The full costs of such an independent adjustment review are paid for by the State (perhaps with Medicaid administrative match) but carried out by independent experts whose findings are binding on the State and the person.
 - A State may not use the method known as “discounting” or similar practices to determine the individual budget of a person.
 - Prior to agreeing to receive a cash payment, a person and/or their representative, where appropriate, must receive a statement summarizing:
- The type and number of hour of personal care services he or she needs; and,
- An accurate estimate of what the monthly individual budget amount can be reasonably expected to purchase.
 - Adjustments must be made individual budgets based on changes in labor supply conditions as frequently as necessary. If reliable workers cannot be hired and retained at the rate permitted by the individual budget, the State should increase the monthly allotment as soon as possible.
 - A State that offers people with disabilities needing personal care the choice of receiving services or a monthly payment to purchase such supports must:
- Assure that whether an individual opts to receive personal care in the typical manner or through the use of an individual budget that both methods will enable him or her to receive equally effective services and supports.
- Offer individuals the opportunity and support to direct their personal care services through other means than through an individual budget.
- Assure that the choice of which method to use will be made on a well-informed, voluntary basis by the individual or their representative, where appropriate.
- Maintain current level of effort in respect to funding personal care under the State Medicaid plan.
- Provide adequate funding for services such as benefits counseling, recruitment and personal assistance registries, fiscal intermediaries and other services essential to the success of consumer directed services in way that does not siphon off service dollars from people with disabilities.

Question 1b. Do you believe the methods for calculating the individual budgets under the Independence Plus demonstration have been fair? Are there appropriate safeguards in the Independence Plus demonstration to ensure that individual budgets are adequate and fair?

Response: To respond to these questions, I have reviewed the two template waiver applications developed by CMS to allow States implement the Administration's Independence Plus initiative as well as other related materials—available online at <http://www.cms.gov/independenceplus/>. The initiative is meant to enable States to offer eligible families and individuals to receive a cash allowance (in the § 1115 Demonstration) or individual budget (in the 1915(c) Waiver) to obtain personal assistant services and related supports. Since the methods for calculating the individual budgets under the 1115 demonstration and the 1915c waiver authorities are different from each other I will comment on them separately.

The 1115 Independence Plus Demonstration Process:

To obtain an 1115 waiver for this purpose, a State must assure that: a. demonstration expenditures will not exceed what would have been incurred without the demonstration; b. the aggregate cost of services will be no more than 100% of the cost to provide these services without the waiver; and c. the plan of care and budget for plan of care will be developed in the demonstration exactly as they would have been developed without the waiver. The template further indicates that “Procedures for determining the amount, duration, and scope of Personal Care services are (to be) identical for Personal Care recipients, regardless of whether or not they are part of this voluntary demonstration program.”

Beyond setting these general parameters, however, the current CMS 1115 template and related materials I reviewed on its Web site do not lay out any other criteria a State must follow or even consider when determining what the personal care cash allowance should be. This is extremely troubling. The 1115 demonstration authority is meant to enable the federal government and the States to test both the effectiveness and the fairness of providing Medicaid services through a variety of means to those eligible to receive them. CMS has a critical role and responsibility to set out expectations and criteria in an initiative like Independence Plus to ensure that as States propose to test various ways of providing personal assistance cash

allowances to that there be nationwide, consistent guidance on how those allowances should be set in the most effective and fair manner possible.

CMS has already approved an 1115 Independence Plus demonstration waiver for one State, Florida, and other applications are likely pending or in development. It has been suggested that the 1115 template is a living document and that CMS may add additional terms and conditions to it as the need and opportunity to do so arise. Based on my review of the Florida 1115 waiver, I would respectfully suggest that the need to do this is already upon us and I would strongly urge Congress to convince the agency to move on this front immediately.

Florida's Independence Plus 1115 waiver:

Florida's approach to determining individuals' personal care cash allowances should be approved by the Administration this May and illustrates why CMS should issue clear guidance in this area.

Since Florida participated in the Cash and Counseling project there are roughly 1500 people with disabilities with individual budgets in the State already. For this reason, the State has decided to use—and CMS has approved—several different approaches to determining the amount of each participant's monthly allowance:

Setting the individual budget amounts of current individual budget users: Those who were in the Cash and Counseling project will receive a budget based on prior expenditures and historical claims information. The person's expenditures for the twelve months prior to enrollment in the new 1115 waiver will determine the annual budget. If a consumer was not been in the project for twelve months, the expenditures from at least 6 months will be used to determine the budget. When less than six months of data is available, the care plan or support plan will be the basis for determining the budget amount.

Setting the individual budget amounts of new individual budget users (i.e., consumers who have received waiver services for six months or less): The individual budget amount will be set at:

the value of the services authorized in the care plan or support plan. The value of the authorized services will be adjusted to accurately reflect the amount that would be spent on services in the Medicaid waiver Home and Community-Based Services program. An extensive discount analysis was conducted to determine what percentage of dollars authorized in a Medicaid waiver care plan or support plan is actually spent in each program. For example, on average 89% of the dollars authorized in a Medicaid waiver care plan for an elder is actually expended. An elder who has received waiver services for less than six months, would receive an annual budget equal to 89% of the value of the services in his/her current care plan. During the enrollment visit, consumers will be told the exact budget amount they would receive if randomized to the experimental group. Consumers will not be able to negotiate a budget amount with consultants.

Setting the individual budget amounts of persons with developmental disabilities: The approach requires that:

All individuals receiving services from the Developmental Services Waiver Program Will have their support plan and cost plan reviewed and revised as appropriate, providing access to increased funding appropriated by the 1999 Florida Legislature. Their budgets will be determined using the care plan method.

Setting the individual budget amounts of elders and adults with physical disabilities: The approach requires that:

Elders and adults with physical disabilities who have had substantial changes made to the value of their care plan before their enrollment will have their budgets determined using the "care plan method—described above. The Consumer Directed Care database will track which method is used for each consumer.

See page 9 of Florida's Operational Protocol for this project online at <http://www.cms.hhs.gov/medicaid/1115/flccoperot.pdf>.

Concerns with Florida's approaches to setting individual budget amounts: In my view, the approaches just outlined raise the following concerns relating to the adequacy, equity and fairness of the manner in which the State sets individual budget amounts:

Current individual budget users: As indicated previously in respect to the Cash and Counseling project in Arkansas, the concern that arises with regard to setting the individual budget amount based on a person's prior use of services (i.e., the number of hours of services that he or she "actually received") is that this method invariably penalizes for not receiving services that their plan documents they need for reasons well beyond their control—they are hospital for two weeks, aides

don't show up, they are unable to hire workers, etc. Simply put, individuals with significant disabilities are not managed care organizations and should not be subjected to the same utilization control and discounting methods to which profit making plans are subjected. If a State wants to base the amount of a person's "prior expenditures" and "actual hours of services received" over some period of time, there may be ways to build in a greater degree of fairness to the process. For example, a State could use prior expenditures as a general guide for setting the amount and then examine the reason(s) for any discrepancy between the numbers of hours that were "called for" in the person's services plan and the number of hours of services that the person "actually received" during the period. When such a discrepancy is due to factors that are beyond their control and unrelated to their documented need for services, the amount of the individual budget should be increased by the same amount as would have been spent on services that were called for in the plan but never delivered due to factors beyond their control. Similarly, a State could use prior expenditures as a general guide for setting the amount and then set the remainder aside in a "rainy day account" that the person could draw on if their current year spending increased over the previous year based on changes in their own needs or external conditions (e.g., a shortage of workers, the need to pay more for fewer hours of personal care services). Finally, a State could set the individual budget amount at a hundred percent of the amount required by the services plan. It could then give the person the discretion to spend up to the amount of services actually received during the prior 6 to 12 months period and require the person to seek further consultation if they believe they have to exceed this sum. In my view, absent taking these or similar steps, a State like Florida cannot reasonably assure—and the Administration has no cause to blithely assume—that basing the amount of an individual budget of a person with significant disabilities will yield adequate or fair results. I also could find no indication in the materials submitted by Florida to CMS that it plans to reinvest any savings generated by this method in improving or increasing community living services more generally. This troubles me as well.

New individual budget users: The concerns I have in regard to how the individual budgets of those in this group will be set are essentially the same as I have just outlined in terms of current users. I would add one more concern it raises in respect to the use of discounting. The original idea behind individual budgets was that they would be determined based on the looked needs of a specific person—not on the basis of some group "average"—and would, therefore, equip the person with both the sufficient resources and the sufficient authority to get personal assistance support needs met. Florida's approach to determining the budget of new participants resorts to a group averaging, take it or leave it approach that undercuts in my opinion much of the intent behind the concept and the potential good that might come from it as well as set people with significant disabilities up for failure or worse. Basing individual budgets on a group average hardly makes the process responsive to differences in individual needs. Moreover, most people with significant disabilities when given a budget with a finite amount and told to make it last for the next 12 months will—I have no doubts—make it last for that period even to the point of cutting back on needed supports. The Operational Protocol indicates that:

Adjustments will only be made in response to significant changes in needs. Consumers may call to inform the consultant of significant changes in level of care needs or other significant changes such as loss of caregiver. Or, a consultant may identify changes which would warrant an adjustment to the monthly budget amount. Changes in the budget will be granted to obtain more support when the health or safety of the consumer is at risk. (See page 9 of Florida's Operational Protocol for this project online at <http://www.cms.hhs.gov/medicaid/1115/flccoperot.pdf>.)

The terms and conditions for Florida's Independence Plus 1115 further specifies that it will provide CMS with: "procedures for how the State will work with families who expend their individualized budget in advance of the re-determination date to assure that services needed to avoid out-of-home placement and the continuation of the health and welfare of the individual are available;" Together these readjustment processes and procedures may address many, if not all of my concerns in this regard but having not seen them I can not draw a conclusion either way. It is disturbing, however, that CMS did not apparently have greater details in writing prior to granting the wide sweeping demonstration waiver on such fundamental issues impacting the fairness and adequacy of Florida's approach as how the State specifically intends to: 1. Define the key term "significant changes in needs"; and, 2. Inform all current and prospective participants of their right to request such a readjustment and the process they should follow to do so

Project participants with developmental disabilities, older persons and adults with physical disabilities: The concerns I have in regard to how the indi-

vidual budgets of those in these groups will be set are essentially the same as I have raised throughout my responses.

Establishing disability and age specific criteria for determining individual budget amounts: Depending on how they are structured developing and implementing separate and distinct criteria for determining individual budget amounts for people with different types disabilities (cognitive, developmental, physical or psychiatric) and/or those of different ages (children, working age adults or seniors) will likely produce polar opposite results. Such criteria can be and I would argue should be developed in a manner that both recognizes and remedies inequities which may exist with regard to the degree of access people in these different groupings have to Medicaid community living services in a State. Or, such criteria can be developed and put in place in a way that greatly exacerbates these types of inequities. It is not possible based on the information available to me, it is impossible to know what prompted Florida to develop 4 distinct ways to determine the individual budget amounts for people with different disabilities and different ages, much less to hazard a guess on what impact they might ultimately have upon improving or exacerbating access problems. What is disturbing, however, is CMS did not seem to even consider this question when granting this waiver and it is certainly not raised or addressed in the agency's 1115 template application either.

The 1915c Independence Plus Waiver Process:

As I noted at the start of my response, the methods for calculating the individual budgets under the 1115 demonstration and the 1915c waiver authorities are different from each other. In some ways, the template for the 1915c has "more flesh on the bones" in the sense that it gives States a bit more guidance on how individual budget amounts should be determined. Though as my comments will show I think CMS needs to provide even further guidance in this area and that any criteria it sets for determining individual budgets under 1915c should apply to 1115 Independence Plus demonstrations as well. To date, CMS has approved 1915c Independence Plus waivers in New Hampshire, South Carolina and Texas. Time has not permitted me to review the terms and conditions of any of these

Waivers. Thus, my comments will focus on the template itself. The template indicates that a State applying for a waiver of this type needs to:

- describe in detail EITHER:
- The State's uniform methodology for the calculation of individual budgets, OR
- The criteria and approval process for entities with which the State has contracted for day-to-day operations of the program.

This description addresses the minimum requirements that the methodology utilize actual service utilization and cost data, how the methodology is explained to the family or individual, the re-determination process, and how the methodology is open to public inspection. (Template for 1915c Independence Plus Waivers, page 26, <http://www.cms.gov/independenceplus/1915temp.pdf>.)

It further makes clear that: "Minimum requirements of the methodology (to be) are that the budget is built upon actual service utilization and cost data, the methodology is described to the individual and their family, the methodology is open for inspection by authorized public entities including, but not limited to, CMS, and there is a process for re-determination. Although the Medicaid Agency may contract with another agency or organization for the daily operation of the waiver program, it must retain the authority to issue policies, rules and regulations related to the waiver." (Template for 1915c Independence Plus Waivers, page 11, <http://www.cms.gov/independenceplus/1915temp.pdf>.)

Issues and Recommendations: Generally speaking, I believe the provisions in the template that were just cited—while perhaps representing at least a start at creating consistent, nationwide guidance in this area—need to be revised, refined and/or strengthened in each of the following key respects:

Establishing a uniform methodology for the calculation of individual budgets: CMS must make clear that the purpose of developing and following a uniform methodology is to assure both the adequacy and fairness of individual budgets. That is, CMS must make it explicit that it will evaluate the efficacy of each "uniform method" proposed by States on at least 3 crucial dimensions—whether it is sufficient to: 1. Assure that the individual budget amounts are derived on an individualized basis that makes certain that the resources allocated to each waiver participant can be shown to be reasonably adequate to meet his or her specific personal care needs; 2. Yield individual budget amounts that are fair and equitably distributed among different individual budget users and different classes of such users (i.e., people with different types of disabilities, of different ages, and/or those who live in different counties or are served by different government or private agencies); and, 3. Make certain that people with disabilities on Medicaid who are eligible but

do not choose to have an individual budget are not penalized by their decision and are offered other ways to exercise choice and control over their personal care services as I discussed in my response to Question 1a above.

Creating criteria and approval process for entities with which the State has contracted for day-to-day operations of the program: CMS must make clear that entities that a State contracts with to implement the waiver on a day to day basis must adhere to the uniform methodology the State sets for determining the individual budget amounts of each participant in a manner that assures the adequacy and fairness of the approach with regard to the three dimensions discussed immediately above and that it: 1. Assures that the individual budget amounts are derived on an individualized basis that makes certain that the resources allocated to each waiver participant can be shown to be reasonably adequate to meet his or her specific personal care needs; 2. Yields individual budget amounts that are fair and equitably distributed among different individual budget users and different classes of such users (i.e., people with different types of disabilities, of different ages, and/or those who live in different counties or are served by different government or private agencies); and, 3. Makes certain that people with disabilities on Medicaid who are eligible but do not choose to have an individual budget are not penalized by their decision and are offered other ways to exercise choice and control over their personal care services as I discussed in my response to Question 1a above.

Basing the individual budget on “actual service utilization and cost data”: I have raised considerable concerns around this approach already and believe strongly that CMS must take the types of steps I have recommended throughout my responses to anticipate and address the unintended and potentially very harmful impacts on people with disabilities relying on individual budgets set in this manner can and are likely to produce in my view.

Public participation: It is essential that CMS require the States to assure the active and informed participation of the public—particularly people with disabilities, families of children with disabilities and other representatives—in the design, implementation, monitoring and evaluation of all such uniform methodologies and related policies, practices and procedures. This requirement like all others I have recommended should be applied equally to both the 1115 and 1915c Independence Plus.

Question 1c. Do you believe federal standards are needed to ensure that beneficiaries are given enough money under these demonstrations? If yes, what should those standards look like?

Response. Yes, I believe further federal guidance in this regard and that it should incorporate and expand upon the recommendations I have offered in my responses to Questions 1a-1b.

Question 2a. The Independence Plus program, recently initiated by the Department of Health and Human Services, is an expansion of the Cash and Counseling program initiated by the Robert Wood Johnson Foundation. While the two programs share the goal of enabling individuals with disabilities to live in the community and providing an appropriate range of personal care services that individuals can self-direct, there are some important differences between the two programs. Could you please describe the key differences between the Independence Plus program and the Cash and Counseling demonstrations?

Response. The Cash and Counseling demonstrations had a very focused purpose and scope. It was meant to test whether people with disabilities and their families in appropriate cases could use individual budgets to purchase a fairly well defined and limited as well as predictable set of personal care services and whether doing so would result in getting their needs better met and increased satisfaction in general. However, there is an increasing concern that I share that States as well as the Administration will use the Independence Plus process to cash out basic health care benefits such as prescription drugs, physician and hospitalization services that: 1. Extend far outside the purpose and scope the original Cash and Counseling demonstrations; 2. The need for which, by their very nature, varies enormously over time and must not be predicated on past “actual services received” or similar methods; and, 3. Cashing such services out are likely to limit rather than preserving or increasing beneficiaries access to them for many of the same reasons I have discussed in my responses thus far. There are, however, differences between the 1115 and 1915c template in this regard as well; so I will comment on each individually.

The 1115 Independence Plus Template: I believe the potential for this to occur is the greatest with regard to the 1115 Independence Plus demonstrations. The 1115 template permits States to include—in addition to personal care and other recognized community living services that States can currently offer through Medicaid—any “(o)ther services requested by the State and approved by CMS as budget neutral and necessary to avoid institutionalization.” (Template for 1115 Independence

Plus Waivers, page 7, <http://www.cms.gov/independenceplus/1115temp.pdf>) There are clearly a number of ways where it could be argued that prescription drugs, physician and hospitalization services could be offered in a budget neutral manner under a 1115 and are, of course, essential helping many people with significant disabilities to avoid unjustified institutionalization. For the 3 reasons I cited in the last paragraph, though, I do think this is adequate justification for including them under such waivers.

The 1915c Independence Plus Template: The 1915c template contains similar language on this point but also says that for services already covered by the State plan that the waiver must described and presumably assure that any such services, including those that fall into the “other services as requested” category, will “differ in amount, scope, supervision arrangements or provider type or be utilized only when the state plan coverage is exhausted.” (Template for 1915c Independence Plus Waivers, page 15, <http://www.cms.gov/independenceplus/1916temp.pdf>). This is an extremely important and useful clarification to make and one that in my view should be included in the 1115 template as well. But, even this provision does not really address the deep concerns I and others have raised with regard to the harm that could come from cashing out the types of medical and health services that can only there be carried out by highly trained professionals and the need for which cannot be reliably predicted in advance nor predicated on past experience.

Recommendation:

For the reasons just given, CMS should make clear to the States and the Congress that it will not grant 1115 or 1915c Independence Plus waivers that would cash out medical and health care services such as prescription drugs, physician and hospitalization services.

Question 2b. What are your thoughts on whether the changes made under the Independence Plus demonstration are warranted?

Response. No, I do not for all of the reasons I have discussed.

Question 2c. How could these changes affect beneficiaries? What should policy makers be looking for in the design and evaluation of these demonstrations to ensure beneficiaries are protected?

Response. I believe I have addressed the first part of the question already. In terms of the policy questions that the evaluations of the Independence Plus demonstrations should be designed and carried out to help answer I think some of the most crucial ones include:

- What are the characteristics of people with disabilities and families of children with disabilities who are most likely to get their personal care needs met by using the individual budget approach?
- What are the characteristics of people with disabilities and families of children with disabilities who are only somewhat likely to get their personal care needs met by using the individual budget approach?
- What are the characteristics of people with disabilities and families of children with disabilities who are least likely to get their personal care needs met by using the individual budget approach?
- What promising practices exist for improving the chances of those in all 3 of these groups of getting their personal care needs met by using the individual budget approach?
- What impacts do these demonstrations have on those who are eligible for Medicaid personal care and other community living services but who not use the individual budget approach?
- What other opportunities and/or desires do persons who are eligible for these services but who do not have individual budgets have in terms of exercising increased choice and control over their services either through an individual budget or other means?
- What types of actions should the federal government; the States and others consider taking based on the responses to these types of evaluation questions?

Question 3a. Under the Cash and Counseling demonstrations consumers were given a cash amount to manage certain services provided under Medicaid, personal care services. These are primarily non-medical services to provide assistance with activities that are in many instances of a very private nature—like bathing or dressing. Can you draw any conclusions from the Cash and Counseling demonstrations about which services are most appropriate for consumer direction? Is there a minimal set of services that should be included to ensure that the programs serve their purpose?

Response: In addition to personal care services, I believe it would be both reasonable and useful to clearly delineate the only services that can be offered under an 1115 or 1915c Independence Plus waiver include other recognized community living

services that States can currently offer through Medicaid either through a State optional service or a waiver. As I said, the requirement currently in the 1915c template that services under the waiver “must differ in amount, scope, supervision arrangements or provider type or be utilized only when the state plan coverage is exhausted.” (Template for 1915c Independence Plus Waivers, page 15, <http://www.cms.gov/independenceplus/1915temp.pdf>.) should be incorporated in the 1115 template as soon as possible as well.

Question 3b. Are there services that do not lend themselves to self-direction? For example, do you believe it is appropriate to allow for consumer direction of acute care services?

Response. As I have said I believe it would have deleterious impacts on people with disabilities to include any health or medical services under the rubric of an Independence Plus waiver.

Question 3c. What are the advantages and disadvantages of including durable medical equipment and home modification costs in individual budgets and how would this work in practice?

Response. The goods and services that fall into the broad categories of what constitutes durable medical equipment or home modifications can range in costs widely from under \$50 for purchasing grab bars to perhaps a hundred or so for installing them to several thousands of dollars for putting in a roll in shower that enables a person with limited mobility to shower more easily. Similarly, purchasing a splint one uses to hold eating utensil or pen may cost a few dollars while purchasing a motorized wheelchair can cost tens of thousands of dollars. The practical implications of this I believe are as follows: It may be useful and reasonable to build in resources to purchase low to modestly priced durable medical equipment and home modification good and services into someone’s individual budget. Significant care must be taken, however, to ensure that if this is done that the resources included for this purpose are over and above those that the person needs to purchase personal care services. For expenditures on these types of goods and services a State should establish a separate fund or consumer friendly process individuals can use. Many States already have very low to no interest loan programs in place that people with disabilities can use to obtain needed DME and home modifications and then pay it back in small monthly installments over an extended period of 10 years or more. CMS and States should explore ways to tap or develop such mechanisms under both types of Independence Plus waivers. It is also extremely important that as States move in this direction that they and CMS do so in a way that affords people with disabilities who do not use individual budgets but use personal care services and need access to DME and/or home modification goods and services have an equally effective opportunity and way to obtain them.

