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HELPING FAMILIES WITH NEEDED CARE: MEDICAID'S CRITICAL ROLE FOR AMERICANS WITH DISABILITIES

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON ENERGY AND COMMERCE
HOUSE OF REPRESENTATIVES

ONE HUNDRED TENTH CONGRESS

SECOND SESSION

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HELPING FAMILIES WITH NEEDED CARE: MEDICAID'S CRITICAL ROLE FOR AMERICANS WITH DISABILITIES

WEDNESDAY, JANUARY 16, 2008

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

The subcommittee met, pursuant to call, at 10:05 a.m., in room 2123 of the Rayburn House Office Building, Hon. Frank Pallone, Jr. (chairman) presiding.

Members present: Representatives Towns, Eshoo, Green, Capps, Baldwin, Schakowsky, Solis, Hooley, Dingell, Deal, Wilson, Buyer, Pitts, Murphy and Burgess.

Staff present: Bridgett Taylor, Purvee Kempf, Amy Hall, Yvette Fontenot, Hasan Sarsour, Melissa Sidman, Robert Clark, Erin Bzymek, Lauren Bloomberg, Brin Frazier, Brandon Clark, and Chad Grant.

OPENING STATEMENT OF HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. PALLONE. The subcommittee hearing is called to order.

Today we have a hearing on "Helping Families with Needed Care: Medicaid's Critical Role for Americans with Disabilities." I will recognize myself initially for an opening statement.

Let me begin by welcoming everyone back from our Christmas and New Year's break. Today we are meeting—this is actually our first hearing of the new year and I realize how important this hearing is to so many people.

It goes without saying that today's hearing is long overdue. I now there are many people who are in the audience today who have been calling for this hearing for many months and even years, and I want to thank you for all the hard work you do to advocate on behalf of the disabilities community. Today's hearing is about you and your families. It is about ensuring you have the services and support you need to remain independent members of society.

Over the years Medicare has enabled millions of Americans with a wide range of disabilities to live independent lives by providing medical care as well as specialized support and services, but in spite of Medicaid's success, over the past year the Bush administration has launched an all-out attack on Medicaid, issuing a constant stream of regulations that seek to reduce the scope and breadth of

the Medicaid program, thereby restricting its ability to provide for disabled Americans.

These harmful regulations would, for example, restrict States' ability to provide rehabilitative services including those designed to enable individuals with disabilities to improve their mental or physical capacities and remain out of an institution; also, eliminate the ability of schools to provide administrative services such as enrollment, eligibility counseling and referrals for Medicaid children, and most recently, restrict States' ability to help manage the care and support services that are crucial to helping Medicaid beneficiaries live independently.

The combined effect of these regulations, should they be implemented, would be a loss of billions of dollars for State Medicaid programs, thereby putting in jeopardy critical services that millions of Medicaid beneficiaries rely upon.

Now, fortunately, in the recently passed CHIP extension, we were able to put a moratorium on the school-based administrative and transportation services rule as well as the rehabilitation services regulation but that was only a temporary measure to halt the administration's attack. If these rules and regulations are eventually implemented, they will have a disastrous impact on our safety net system's ability to provide services for disabled communities across the Nation. I am looking forward to hearing from our witnesses today about exactly what the impact of these regulations would be should they go into effect.

Today is not only about the administration's misguided policies. We also will be discussing a number of bills today that can have a positive impact on disabled Americans by strengthening Medicaid and offer alternatives to provide services for disabled Americans so they can remain in their communities. One proposal is legislation I introduced with Chairman Dingell and Senator Kennedy, the Community Living Assistance Services and Supports Act, or the CLASS Act.

Currently, there are 10 million Americans in need of long-term services and support, and that number is expected to increase to nearly 15 million by 2020. Most private-sector disability or long-term care insurance plans are constrained in the insurance protection that can offer at an affordable price and neither Supplemental Security Insurance nor Old Age, Survivor and Disability Insurance programs have any benefit differentials related to the extent and character of the disability.

Because of this, Americans who have, or develop, severe functional impairments can only access coverage for vital services through Medicaid. These services, however, including housing modifications, assistive technologies, transportation and personal assistance services are critical to their independence, and this fact creates perverse incentive, forcing many to live in poverty and remain unemployed so that they can qualify for Medicaid. With Medicaid paying 50 percent of the cost, increased expenditures on long-term services are expected to add $44 billion annually to the cost of Medicaid over the next decade.

And as America continues to age, we are faced with an impending crisis in long-term care. With the introduction of the CLASS Act last year, I aimed to offer a new approach that builds upon our

existing safety net system and helps our elderly and disabled finance the long-term care they need to remain active and productive members of their communities. This bill offers a new alternative path. It will create a national insurance program to help adults who have or develop functional impairments to remain independent and employed, and it also gives individuals added choice and access to supports without requiring them to become impoverished to qualify.

I think the CLASS Act is an important step in the evolution of public policy because it is a framework based on the principles of independence, choice and empowerment.

We also are going to hear about the Community Choice Act, and I see a lot of the orange shirts that indicate—we know there is a lot of support for that. That, as you know, was introduced by Congressman Davis. It aims to redirect the focus of Medicaid services from institutions to home and community settings, giving eligible individuals equal access to community-based services as to institutional supports and enabling people to make their own choices about the care that they receive.

And finally, I also wanted to recognize that Mrs. Capps has an important bill that she has introduced, the Direct Support Professional Fairness and Security Act, which will provide enhanced Federal Medicaid funding to those States that agree to match voluntary private direct support professional wages to the level of pay for comparable State employees.

Now, as you know, this hearing is not specifically on any of the bills, even those these three bills obviously will be highlighted, and other ideas will certainly come up and we certainly welcome them, and I again want to commend my colleagues for the work on these issues and all the bills that they have put forward and thank the witnesses.

I now recognize the ranking member, Mr. Deal.

OPENING STATEMENT OF HON. NATHAN DEAL, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF GEORGIA

Mr. DEAL. Thank you, Chairman Pallone, for holding this very important hearing today.

The Medicaid Program serves almost 10 million individuals with disabilities so I am glad we are taking an opportunity to evaluate possible reforms to improve the care of this population. Additionally in 2005, Medicaid spent $120 billion on individuals with disabilities, so we must be mindful of the most effective way to administer our resources.

For this reason, I have long been a proponent of community-based services in Medicaid. As part of the Deficit Reduction Act, I supported provisions such as cash and counseling, Money Follows the Person, and home and community-based care service. These programs provide States additional options for providing Medicaid-covered services to beneficiaries. Many believe community-based care is a cost-effective method, which I agree with, which not only can save money but also provides better quality care. As someone who with my wife, we took in our elderly parents, my mother lost a leg and was in a wheelchair and we cared for them for 8–1/2 years in our own home so I am very well aware of the importance

of being able to be care provided in an environment that is considered to be your home.

For instance, some States have achieved significant savings by transitioning beneficiaries out of nursing home facilities into community programs like Money Follows the Person and we have a very successful program in my hometown called Randy's House, named after the son of a close personal friend of mine who was injured when he was a very small child and has been confined and is able to now live in an independent living environment with assistance, and this is the kind of program that I think we all need to encourage.

I have also signed on as a cosponsor of H.R. 1621, the Community Choice Act, which, as you know, seeks to provide individuals with disabilities increased access to community-based attendant services through the Medicaid program. I look forward to the testimony by our witnesses about some of the benefits of this legislation.

We need to continue to pursue reforms which reverse Medicaid's institutional bias that has denied Americans with disabilities access to care in their homes. I look forward to the testimony of the witnesses today about ways to address this problem and the evaluation of some of the programs that we have already created.

I thank all of you for your attendance and look forward to the testimony of the witnesses, and with that, Mr. Chairman, I yield back.

Mr. PALLONE. Thank you, Mr. Deal.

Next we have our vice chair, the gentleman from Texas, Mr. Green.

OPENING STATEMENT OF HON. GENE GREEN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Mr. GREEN. Thank you, Mr. Chairman, for holding the hearing today on the role of Medicaid and Americans. This is a topic many members of our audience have been fighting for many years, and I am happy we are taking this important first step to addressing the challenges that individuals with disabilities face when accessing care.

Medicaid is the primary way we finance and deliver community-based health and long-term services to needy children and adults with disabilities. Medicaid offers many services that are not covered under traditional employer-based or private insurance. For those individuals with disabilities, Medicaid is the only way they can access the service they need. In some cases, the States have the ability to deliver community-based services to children and individuals with disabilities. We hear today that many people prefer community-based services because it offers them the opportunity to remain independent in their own homes. This is an important fact that many of us who are not disabled take for granted. For those individuals, having even a small amount of freedom is priceless.

The issue we face with the current Medicaid system regarding individuals who are disabled is that they are forced to enter institutionalized care for a period of time before they can access community-based services or they are placed on waiting lists by States, sometimes as many as 10 years. When faced with this daunting

choice, many people simply enter institutionalization which they do not want. As a cosponsor of the Community Choice Act, I am glad we are discussing this issue today. For those of us with private employer-based insurance, we have the ability to choose what type of care we want to receive, whether it is community-based or institutionalized. These folks spend years waiting for the type of care they would like to receive and most never receive or experience home-based and community care unless they forego treatment, find help to transition to home and community care.

On a corollary, I have introduced a bill that is on a related topic. People with disabilities are forced to wait 2 years after they receive a Social Security Disability award before they can receive Medicare benefits. Currently, Medicare disability waiting period is the second one people have to wait for. First, you have to wait months and sometimes years for Social Security to make a determination that you are eligible for disability. Then after that award you have to wait an additional 24 months. Now, Medicaid is typically the health care provider during that 24 months but I know we have had this bill and Senator Bingham in the Senate had this bill to lower that waiting period so it could be Medicare and Medicaid that would help people with disabilities. As a result of the 24-month waiting period, an estimated 400,000 Americans with disabilities are uninsured unless they qualify for Medicaid. Many more are underinsured during a time when quality health care is most critical.

It is hard to understand why we force these individuals who are most in need of treatment to wait for years before they can receive much needed care under Social Security, Medicare or Medicaid. Seniors, children and people with disabilities are the most vulnerable members of our society and we must work together to find a solution, offering those who are disabled the services they need and at the same time not restricting them to the type of care they do not want or take away their ability to remain productive members of our society, and again, Mr. Chairman, I am glad you called this hearing.

I yield back my time.

Mr. PALLONE. Thank you.

I recognize the gentlelady from New Mexico, Mrs. Wilson.

Mrs. WILSON. Thank you, Mr. Chairman. I will pass and reserve my time.

Mr. PALLONE. The gentleman from Indiana, Mr. Buyer.

Mr. BUYER. I pass.

Mr. PALLONE. OK. The gentleman from New York.

Mr. TOWNS. I will waive.

[The information appears at the conclusion of the hearing:]

Mr. PALLONE. The gentleman from Pennsylvania, Mr. Murphy.

OPENING STATEMENT OF HON. TIM MURPHY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF PENNSYLVANIA

Mr. MURPHY. Thank you, Mr. Chairman, for holding this important hearing for a group of Americans who too often are forgotten. We are here today to discuss the important role that Medicare plays in providing care for people with disabilities. It gives vital support for the 10 million individuals it services. This includes the

elderly who have physical disabilities and those that suffer with mental illnesses and intellectual impairments.

In my 25-plus years of practicing as a psychologist working with many children and families, I know firsthand the importance that Medicaid provides to those who struggle with mental retardation, autism, serious mental illness, physical disabilities. Over those years I have treated many starting in their infancy when their disabilities first began to take note. I worked with them as they faced a system that has been best characterized by barriers, bureaucracy and battles when it should have emphasized independence, not more dependence. It should have provided more support and services for self-sufficiency and not more walls that keep people from being able to hold jobs or work in their communities.

Community-based services increase people's quality of living but we know it is also more cost-effective and I hope to learn more about that today. With the thousands of patients and families that I have treated, I have learned that nobody gets better by being denied services and no disability is ever treated effectively by being put on a long waiting list. We have to have home-based care that is effective, saves money. Between 1999 and 2002, the average nursing home payment rose 13 percent, but in contrast, the average cost per home-based patient rose just 2.2 percent. That is not effective. Medicaid reimburses nursing homes between $35,000 and $75,000 per patient per year and we hear from nursing homes that that is often not enough to cover their care, but even so, compare that to only $25,000 for the average home-based care patient per year. That is not effective. Texas estimated it saved between 20 to 35 percent in State Medicaid spending, thanks to beneficiaries transferring out of nursing homes and into home care. I am pleased that Medicaid has shifted resources toward helping community and home-based care. The percentage of Medicaid funds available to these programs has doubled from 15 percent in 1992 to 36 percent in 2004 and is probably able to provide more access to community services.

With that said, I am also pleased that Three Rivers Center for Independent living back in the Pittsburgh area provides such excellent services but—my guess is that a couple are here—but there is more we need to be doing effectively. All of our hearts go out in compassion to helping those who struggle with the barriers of their disabilities but we must do more than offer our hearts. We must also work with them because many of them are able to provide great ideas of how we can be more effective as government working with people to do what Abraham Lincoln once reminded us that government should do that which people cannot do for themselves, not to increase dependency but to work effectively with them so that they can become more independent, more effective members of our community, and I yield back.

Mr. PALLONE. Thank you. The next is the gentlewoman from California, Mrs. Capps.

OPENING STATEMENT OF HON. LOIS CAPPS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mrs. CAPPS. Chairman Pallone, thank you for holding this very important hearing. The title of the hearing says it all. Medicaid

provides a fundamentally critical role in the lives of people with disabilities and their families, and I am pleased to see, building on the statements of the ranking member, that this is such a strongly bipartisan hearing and that there are many issues that we agree upon.

There are two specifically important issues that I want to address and hope that our witnesses will address as well. The first is the impact of the harmful Bush administration regulations that affect our ability to properly serve the Medicaid population. Particularly I am worried about the impact of the regulation regarding school-based health services. This is going to have a terribly negative effect on the students that I used to work with. Mr. Deal made a comment about his personal experience with this legislation. I want to mention my years of working as a school nurse and the many, many school districts across this country who have students in them attending classes according to the guidelines of IDEA and the Americans with Disabilities Act in the least restrictive environment. They can only do so because of critical services provided to them by the school district through special attendance. Without reimbursement for transportation and administrative costs, school districts will have to scramble for ways to provide special-needs children with necessary services. As the Children's Health Initiative of Santa Barbara puts it, schools are for many students and families the only gateway to health services. Furthermore, schools are an integral part of conducting outreach in order to enroll eligible students for Medicaid services. It is hard to see this directive as anything other than an attempt to shut these children out. We simply cannot allow these regulations to be put into place and take us so many years backwards in the Americans with Disabilities Act. I commend our chairman, Mr. Dingell, for introducing legislation to protect children's health in schools, and I am cosponsoring that bill.

The other topic I want to address in my opening statement regards the importance of community-based care for Medicaid beneficiaries with disabilities and the role played by direct support professionals who provide that care. There is a crisis in workforce recruitment and retention at the same time we are seeing such an important shift to promoting community-based care. We need to be going in that direction. We need to work harder to recruit and retain professional staff. Medicaid plays a critical role in providing home and community support, yet without an available care-giving workforce many beneficiaries will suffer and are already suffering. Caregivers are so vital to ensuring individuals can live independently, maintain jobs and participate in community activities.

Unfortunately, one of the biggest barriers to recruitment and retention is extremely low wages and compensation provided to people who perform these difficult jobs, and I have been working with my colleague Congressman Terry and several national organizations to improve this through legislation. Last year we introduced H.R. 1279, the Direct Support Professional Fairness and Security Act. The bill would provide funds to States to enable them to increase the wages of direct support professionals who care for disabled Medicaid beneficiaries. Maintaining a viable care-giving workforce is essential to our growing population of individuals liv-

ing with disabilities. I look forward to hearing from our witnesses today about these dedicated professionals and the impact of salaries on efforts at recruitment and retention.

I yield back.

Mr. PALLONE. The gentleman from Texas, Dr. Burgess.

OPENING STATEMENT OF HON. MICHAEL C. BURGESS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Mr. BURGESS. Thank you, Mr. Chairman, and in the interests of time, I too will submit my statement for the record because we do have an impressive panel of witnesses to hear from.

I would just make a couple of observations. In the late 1990's I purchased a long-term-care policy on the advice of my mother, who said if I didn't buy it when I was young I would not be able to afford it when I was old. But one of the main selling points was within the State of Texas at that time were I to rely upon what was available from the State, the only option I would have would be to be placed in an institution should I require care for a prolonged disability whereas if I had private insurance, I would have the option of community-based care or home care, and I thought that seemed like a more reasonable alternative, so I was grateful to sign up for that.

I was also grateful under the direction of Chairman Deal when we worked on the Deficit Reduction Act that we were able then to extend the partnership concept to many more States across the country and I am looking forward to the partnership concept being enacted in the State of Texas and I think that will go a long way towards helping people who have made the decision to purchase their own individual disability policy to be able to offset the cost of that care or protect assets up to the limit of their disability policy, and I think that is a powerful too we put in the hands of States to be able to help them cope with the growing amount of dollars that they are going to have to be devoting in their Medicaid programs to the care of individuals who are disabled. We also must understand that even though the hearing is focused on community-based care, it does not absolve of us any responsibility for oversight for those individuals who do not have the option but must rely on institutional-based care and that is an important part of our congressional oversight.

On our panel today, I am pleased to note we have two individuals from Texas, so I know it is going to be a good panel that we are going to hear from today. We have Stephanie Thomas, who is from Austin, Texas, and Austin is of course our State capital and we all love Austin, and we have Aileen McCormick, who is president of AmeriGroup, which is located in Houston, Texas, and we all know, even though I am from the northern part of the State, that we could not function well in Texas without our good friends to the south in Houston and Austin, so I welcome both of those witnesses and look forward to their testimony, and I will yield back, Mr. Chairman.

[The prepared statment of Mr. Burgess follows:]

Opening Statement
Congressman Michael C. Burgess, M.D.
Hearing on Medicaid Services for Individuals with Disabilities
House Energy and Commerce Committee Subcommittee on Health
January 16, 2008

It was not so long ago that Americans with disabilities were shunned from society, taken from their families, and hidden away in institutions. Mothers were told that it was impossible for them to care for their babies at home, and their limited choices were giving their children to the State or caring for them on their own with personal resources. Many parents decided to do what the doctors recommended, and many children were raised in institutions away from family and community relationships.

Institutions are no longer viewed as the best and only option for people with disabilities. Allowing people to receive care in their own homes and to live their lives as independently as possible is now recognized as the most dignified and appropriate way to help the disabled. This transition was not easy, and it took the most dedicated of activists to change our minds. However, I believe we must strike the right balance between community-based care and institutionalized care. Not everyone thrives in the community-based care system.

The most profoundly disabled individuals need constant, compassionate care. Many families are unable to function with this requirement, and the entire family suffers as a result. Yes, abuse has occurred in institutions, and the lack of oversight and accountability that allows the abuse must be corrected and avoided in the future. But, we cannot overlook the fact that abuse occurs in the community as well. Overburdened caregivers have less support in the community than in an institution with supervision and regularly scheduled off-time to help caregivers cope. Also, some individuals prefer to live in an environment designed for them. Many parents of severely disabled individuals prefer that their children live in institutions because of the great care the institution can provide. Parents do not need to worry as much about the supervision, environment, socialization, and health care their children receive in an institution like they do when the child lives at home.

One mother told me about her son who was born with an eating disorder called Pica where he ingests everything he can. He lives in a State School in my district where there is a special area for adults with this particular disorder. In this area, everything is safe to ingest. No poisons, sharp objects, or choking hazards are allowed in this area, and the staff is extra diligent in watching for possible complications and hazards. Medical care is done by specially trained medical staff in order to reduce stress on these patients. Before this man moved into the institution, he had to have frequent surgeries to remove objects he had ingested that become stuck in his digestive track or caused damage. Since he came to the institution, he has only had one of these surgeries. She told me how when she took him to the dentist, he had to be physically restrained and his mouth pried open, but at the institution, the dentists can treat her son without a problem. Quality of life should be the most important factor when individuals with disabilities or their guardians

decide which option to go with, community-based care or institutionalized care. We must maintain both options. After all, the freedom to choose from a wide variety of options is one of the hallmarks of our great American way of life.

Thankfully, Americans no longer view disabilities with the fear and stigma of the past. Parents are encouraged to raise their children in their homes with community assistance and government support. Adults with disabilities are working, getting an education, and participating in their communities. The Deficit Reduction Act of 2005 made several changes to the Medicaid program in order to better serve those who need long term care while allowing beneficiaries to maintain their homes and lives in their communities. I look forward to the discussion on how we can further improve the Medicaid program. Thank you.

Mr. PALLONE. Thank you.

I recognize the gentlewoman from Wisconsin, Ms. Baldwin.

OPENING STATEMENT OF HON. TAMMY BALDWIN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF WISCONSIN

Ms. BALDWIN. Thank you, Mr. Chairman, and I very much appreciate the fact that you are holding this hearing today.

Clearly we need to do a lot more to rebalance our system and the institutional bias in Medicaid, and I am an enthusiastic and strong supporter of the Community Choice Act. This bill would make community-based attendance care services an alterative for Medicaid beneficiaries who are institutionally eligible, or to put it more succinctly, the bill would allow Americans with significant disabilities the choice of living in their community among family, friends and other support givers rather than having to live in a nursing home or other institution. Now, I am proud to share that my home State, Wisconsin, has provide to those on Medicaid the option of community-based care for over 25 years. In 1981, we enacted a program called COP, the Community Options Program, in an effort to provide individuals with the option to live in the community. This program became an official Medicaid waiver program in 1987 and has been extremely popular. Unfortunately, though, there is a significant waiting list to get into the program, and when push comes to shove during State budget discussions, State legislators facing limited resources frequently turn to discretionary programs such as community-based care as places to trim State budgets. Because institutional care in Medicaid is a mandatory program and community-based care is not, they focus on the community-based care. And these cuts coupled with very long waiting lists mean that even though we have this great program, there is still way too many people who are denied the choice of where to receive their care. The Community Choice Act would provide States with the financial assistance needed to once and for all end the institution bias in Medicaid and establish systems that provide services and support in the most appropriate and integrated setting.

I want to thank you, Mr. Chairman, again for holding this hearing and allowing us the opportunity to delve much further into these important issues, and I also really want to thank and appreciate the many disability rights advocates who have been such great champions on this issue. Certainly there are many right here in this room this morning but I also know that many across the country are watching and participating in this hearing via the Internet, and your commitment to this issue is very inspiring to all of us and we are very glad to have you join us, whether in person or via the Internet.

Thank you, Mr. Chairman, again.

Mr. PALLONE. Thank you.

I next recognize the gentlewoman from Illinois, Ms. Schakowsky.

OPENING STATEMENT OF HON. JAN SCHAKOWSKY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ILLINOIS

Ms. SCHAKOWSKY. Thank you, Mr. Chairman. I am so glad that we are starting off the second session of the 110th Congress in this

committee with such an important topic, the provision of long-term care for low-income individuals and individuals with disabilities.

We have a lot to discuss today and some wonderful witnesses to hear from but I do want to take a moment to just recognize and thank all the advocates who have joined us here and around the country. You have worked long and hard for this day and it is because of you that we are here. I thank you for being here or listening in and thank you for your tireless work.

While we are having this hearing in a health subcommittee, actually it also would be appropriate if this were a human rights or a civil rights hearing as well because these issues extend into the whole area of quality of life. I have in my office over my shoulder a drawing of Justin Dart, really the father of the independent living movement, and I want to recognize his wife who is here today and has carried on that legacy as all of you are representing today.

As the primary source of public financing for long-term-care services and support for low-income individuals and individuals with disabilities, Medicaid provides long-term care services and support for over 8 million non-elderly people with disabilities and 5 million seniors, many of whom have disabilities. With the increasing demands of an aging population, a generation which is expected to live longer than ever before, the ability of Medicaid to provide quality, appropriate long-term care services is essential. And while the majority of Medicaid dollars used to serve this population still goes to institutionalized care, there has been both a shift in spending and an interest in directing more of those dollars toward home- and community-based service. This is an important trend and one that as a committee we must listen to. Individuals with disabilities want to and deserve control over where and how they receive care and support services. But the question shouldn't be just one of institutional care versus community care but rather of providing the resources and choices that people need throughout the entire continuum of care so that people get the care that they need and that they desire. Unfortunately, what we are seeing is an administration that prefers to reduce the pot for all rather than expand it. The Olmstead decision reflected the need to provide a full range of choices across the continuum, and I am glad that we will be discussing the Community Choice Act, which I know is of great importance to many of my constituents.

I would like to request, Mr. Chairman, for unanimous consent to include Congressman Danny Davis's statement for the record. He is a sponsor of this bill which would provide alternatives to institutions and support the momentum for individual choice.

Mr. PALLONE. So ordered.

Ms. SCHAKOWSKY. Unfortunately, rather than moving in that direction, this administration is trying to limit those choices through misguided regulations. Though a number of States that use the Medicaid rehabilitation services option to serve people with mental illness has increased significantly in recent years, the administration has issued a regulation that would place serious limitations on the kinds of services allowed under this program effectively restricting the rehabilitation services available to people with mental illness. The administration has also issued a regulation to reduce the capacity of case management services for children in foster care

and people with disabilities, services which help beneficiaries access needed medical, social, educational and other services that help them re-enter or remain a part of their community. And finally, I want to also mention the administration's efforts to terminate schools' ability to serve children with special needs by eliminating reimbursement for transportation services. These regulations are offensive and misguided, and I look forward to addressing them as soon as possible.

Again, I want to say how grateful I am for the advocates. I also welcome all of our witnesses and look forward to hearing from them. This is an extremely important discussion that we will have today, and with that, I yield back, Mr. Chairman, and thank you very much.

Mr. PALLONE. Thank you.

The gentlewoman from Oregon, Ms. Hooley.

OPENING STATEMENT OF HON. DARLENE HOOLEY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF OREGON

Ms. HOOLEY. Thank you, Mr. Chairman. I am very pleased the subcommittee is holding this hearing today. The issues affecting Americans with disabilities far too often remain out of the spotlight. Thanks to you and Chairman Dingell, we now have an opportunity to discuss these important issues.

Medicaid plays a vital role for the 8 million Americans with disabilities enrolled in the program. Medicaid provides not only traditional medical care through hospitals and doctors' offices and nursing facilities but also equally important services to help those with disabilities remain and maintain their independence. Those latter services include personal care and home- and community-based services that allow many people with disabilities the opportunity to live in less restrictive settings than would be possible without assistance. Medicaid must provide services effectively to beneficiaries with a wide range of disabilities including those with developmental disabilities, physical disabilities and intellectual disabilities. In order to ensure the needs of beneficiaries are met, Medicaid must be flexible enough to adapt to groups with needs as diverse as the disabilities that enable them to qualify for the program.

The Centers for Medicare and Medicaid Services have unfortunately taken steps recently to limit the flexibility in my State, Oregon, but other States as well, to meet the needs of people with disabilities. As a former teacher, I want to express my concern with the CMS rule that will eliminate reimbursement for school-based administration and transportation services. These transportation services play an important role in filling gaps in services to ensure children with disabilities can receive the same caliber of education as other students. School-based transportation services provided by Medicaid are very important but are still covered in only rather limited circumstances. But CMS has refused to continue providing even the limited range of services currently covered. No change to the underlying law has been made since 1988 when the agency began covering these services. CMS has nonetheless chosen to eliminate this important and narrowly tailored benefit for children with disabilities.

I am also concerned with significant new limitations on targeted case management, which are services designed to help Medicaid beneficiaries transition from institutions into the community. The CMS interim final rule on targeted case management would limit beneficiaries to case management service of only 14 days for those who have been in an institution for up to 6 months. In those 14 days, a case manager may have to find housing, job placement, personal care services and any other service that may be necessary to successfully transition a beneficiary into the community. Such tight time constraints harm beneficiaries and make it more difficult for people with disabilities to move into less restrictive settings.

I am anxious to hear from our witnesses about the impact these CMS rules will have on people with disabilities and also about how proposed legislation discussed today may improve services for those with disabilities.

Thank you again, Mr. Chairman, for this important hearing and for the discussion.

Mr. PALLONE. Thank you.

I next recognize the gentlewoman from California, Ms. Eshoo.

OPENING STATEMENT OF HON. ANNA G. ESHOO, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Ms. ESHOO. Thank you, Mr. Chairman, for holding this hearing. It is encouraging to me and to all of us that the very first hearing that the Health Subcommittee would hold in 2008, the second half of the 110th Congress, is on this issue.

We have many discussions on a whole variety of topics here, all of them important, but I can't help but think today is especially important. We have I think some of the strongest advocates from across the country here, and it is great to see—this is actually how things get done here is that people come here and push very, very hard, so we have to continue to see the orange tee shirts here. I can't help but think of what my father said for the better part of my life, and that is that there is only one class of citizenship in this country, first class, and if we are going to live up to that, then we are going to challenge the system in terms of what the recent rule changes that were adopted and how we strengthen Medicaid.

Medicaid is batted around by a lot of people but no one in this room is going to say that it isn't important. It is the last lifeline. It really is what helps to keep people living a life of dignity that have disabilities, and so I look forward to working with all of my colleagues on this committee on both sides of the aisle. If we can spend $10 billion a month on the other side of the world, we can fix this.

Mr. PALLONE. Thank you.

Next, the gentlewoman from California, Ms. Solis.

OPENING STATEMENT OF HON. HILDA L. SOLIS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Ms. SOLIS. Thank you and good morning, Mr. Chairman. I want to thank the witnesses and especially the advocates for being here. You know, without you, your voices wouldn't be heard so you are

to be commended for that. I know many of you have traveled from many parts of the country and I want to thank those especially representing the great State of California for being here as well.

Many Medicaid seniors and children, as you know, face additional burdens including mental illness, physical disabilities and challenges with the foster care system. Consequently, individuals in our communities who have disabilities often need medical, social, education and other vital services. Individuals with disabilities have different physical and mental conditions and our Medicaid program should respect those differences instead of mandating a one size fits all.

I oppose the harmful and restrictive CMS rules regarding Medicaid reimbursement. Instead of taking away funding, we should be investing in care for the uninsured, low-income children who are already eligible for Medicaid or the SCHIP program. In addition, reimbursement for transportation is needed to help students with special needs. I have seen firsthand the importance of Medi-Cal, Medicaid in California, and these new rules which would have a devastating effect on children in my district. The CMS final rule would result in a loss of $9 million to the Los Angeles Unified School District, the second largest district in the country. LA Unified would lose $7 million in funding to Medi-Cal administrative activities which include outreach, enrollment activities and referral to Medicaid-eligible services. LAUSD expects to lose about $2 million in funding for transportation services for children who access Medicaid services right now at our schools. This cut would reduce the availability of vital Medicaid services to the most vulnerable populations, and I have heard firsthand from our school that they will continue nevertheless to transport our students who need this care without Federal reimbursement but of course that means that money is going to have to come from somewhere else, and that is really unfortunate. At this time when States like California are facing dire economic conditions, our Federal Government has a responsibility to help our children.

I am deeply concerned about the impact of CMS's regulations for individuals who need case management to successfully transition from an institution to the community. A transition into the community, as you know, is a very difficult and complex process that involves multiple people and services. Our providers can't wait for determinations for successful transition and then to be reimbursed after. In addition, if we truly want to support individuals to stay out of institutions, States should have the ability to provide rehabilitative services and not face additional obstacles imposed by CMS.

I look forward to working with my colleagues on both sides of the aisle to remedy this situation, and I look forward to hearing from our witnesses today, and again, congratulations to the advocates. I yield back the balance of my time.

Mr. PALLONE. Thank you.

I recognize the chairman of our full committee, Mr. Dingell, but I would like to point out that it was Mr. Dingell who has been pressing very hard that we have this hearing today, and so we do have to thank him for that. I recognize the chairman of the full committee.

OPENING STATEMENT OF HON. JOHN D. DINGELL, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MICHIGAN

Mr. DINGELL. Thank you, Mr. Chairman, for your kind words and I commend you for this hearing, and I thank you for your leadership in this matter.

I would like to begin by welcoming our visitors and guests today. Thank you for being with us today. I would like to observe that your presence is helpful and I want to observe that the committee is going to do its best to move forward and see to it that we address your concerns today. I am compelled, regrettably, to advise you that there are rules of decorum with regard to the behavior of witnesses and members of the committee when they are present, and that does preclude, I regret, applause or other signs of approval or disapproval. So I hope that you will feel welcome and want you to know that you in fact welcome. But I would ask that you observe the rules of the committee and that we not have applause or other signs of approval or disapproval because it is not in conformity with the rules of the House or the rules of the committee or the dignities that this particular institution should have.

Having said that, our hearing today is going to focus on critical sources of concern and critical sources of healthcare for Americans living with disabilities. I refer to the Medicaid program. Millions of people with disabilities, seniors in nursing homes, children born with birth defects, children who are otherwise hurt, people struggling with mental illness or intellectual disabilities, and adults who disabilities occur later in life depend on Medicaid for needed services including services nowhere else available, especially from existing sources of insurance. Medicaid provides about 40 percent of the long-term-care services delivered in this country and covers nearly half of all nursing home expenditures in the United States, making it the Nation's largest single payer of healthcare, particularly in the long-term care.

One of the challenges that we face in the country is how to improve access to the services in the community rather than to require admission to nursing homes to receive them. Those who receive community-based services have an improved quality of life and are better able to live a decent life and to do so near family and friends. States have taken steps to improve availability of community services. The Money Follows the Person demonstration which provides States one year of enhanced funding for each person to transition back into the community is indeed a good first step. This has been a very, very interesting thing but it has been unfortunate that a person must first live in an institution 6 months in order to be eligible for this transition program. It appears to be very counterproductive of the goals that everybody follows. The availability of waivers and the new State option to provide community- and home-based services without waiver provides critical tools for transition to community care but again, the income and resource thresholds often mean that people with disabilities must choose between better paid employment and health services that allow them to remain in the community and yet tens of thousands of people are on waiting lists for waiver places, nearly

260,000 in the year 2005, a clear indication of the need and the workability of these programs and the need to expand them.

Unfortunately, while States have been making progress at transitioning individuals back into their communities, the administration is trying to hold this kind of progress back rather than to move it forward. It has proposed regulations that seriously curtail or eliminate the ability of people living in communities with disabilities to receive needed services. For example, limiting transition and transportation services for disabled children who receive health services in schools and restricting rehabilitation services to those with long-term disabilities because they may never fully recover is shortsighted and a source of harm for those affected by such regulations, and I want to repeat, the denying of long-term services to people with disabilities because they may never fully recover is, in my view, an outrageous thing which is indefensible in any company.

I again thank the witnesses who are here today. Their testimony is going to detail the challenging task of improving community options for people with disabilities. Medicaid has given us a fine foundation but more work is needed to update its provisions. Again, I welcome our visitors and guests who are present at this hearing or watching the broadcast of these matters. I am pleased and I am sure all the members of the committee are pleased that you are here and I commend you for your efforts in this worthy endeavor.

Mr. Chairman, I thank you for your kind recognition of me.

Mr. PALLONE. Thank you, Mr. Chairman, and that concludes the opening statements by members of the subcommittee. Other statements will be accepted at this point in the record.

[The prepared statements follow:]

HOUSE ENERGY AND COMMERCE SUBCOMMITEE ON HEALTH

HEARING: "HELPING FAMILIES WITH NEEDED CARE: MEDICAID'S CRITICAL FOR AMERICANS WITH DISABILITIES"

WENDESDAY, JANUARY 16, 2008 AT 10:00 A.M. IN ROOM 2123 RHOB

STATEMENT OF THE HON. EDOLPHUS TOWNS (D NY-10TH)

THANK YOU, MR. CHAIRMAN FOR HOLDING THIS VITAL HEARING ON, "HELPING FAMILIES WITH NEEDED CARE: MEDICAID'S CRITICAL ROLE FOR AMERICANS WITH DISABLITIES". I ALSO THANK THE WITNESSES, THE STAFF AND ALL THOSE WHO ARE HERE TODAY TO HELP US EXPLORE HOW MEDICAID SUPPORTS, OR NEEDS TO SUPPORT, COMMUNITY-BASED HEALTH AND LONG-TERM SERVICES TO AMERICANS WITH DISABLITIES. I GREATLY APPRECIATE THE COUNTLESS CALLS I RECEIVED ABOUT THIS HEARING FROM THOSE IN MY DISTRICT WHO VITALLY NEED MEDICAID.

AS A THIRTEENTH-TERM CONGRESSMAN FROM THE 10TH CONGRESSIONAL DISTRICT OF NEW YORK, I AM HUMBLED BY THE PLIGHT OF PERSONS WHO ARE FORCED TO COPE WITH A WORLD THAT STILL FUNCTIONS IN DARKNESS. WE OWE THESE AMERICANS BETTER.

AS A LEGISLATOR, SOCIAL WORKER, MINISTER, FAMILY MAN AND, AS A SENIOR, MYSELF, FACED WITH

AGING'S CHALLENGES, IT HAS BEEN MY SOLE GOAL TO IMPROVE THE CONDITIONS OF OTHERS. FOR THE RECORD, I WHOLEHEARTEDLY CHAMPION "THE COMMUNITY CHOICE ACT," H.R. 1621. THIS ACT PROVIDES AN OPPORTUNITY FOR INDIVIDUALS ELIGIBLE FOR SERVICES IN A NURSING FACILITY, INTERMEDIATE CARE FACILITY FOR THE MENTALLY RETARDED, OR INSTITUTIONS FOR MENTAL DISEASE TO CHOOSE TO LIVE AT HOME USING "COMMUNITY-BASED ATTENDANT SERVICES AND SUPPORTS". LIVING IN THE MOST INTEGRATED SETTING IS A PREFERRED ALTERNATIVE TO WAREHOUSING PEOPLE IN INSTITUTIONS.

AS A LONG ADVOCATE FOR THE ELDERLY AND PERSONS WITH DISABILITIES, I HAVE PROMOTED MEASURES SUCH AS H.R. 3195, *"THE ADA RESTORATION ACT OF 2007"*; AND H.R. 3294, *"PROMOTING WELLNESS FOR INDIVIDUALS WITH DISABILITIES ACT OF 2007"*; AND MANY OTHER MEASURES. I WILL CLOSE, HERE, SO THAT I MAY HEAR FROM THOSE WHO WILL TELL US EXACTLY WHAT WE NEED TO KNOW TO MAKE MEDICAID MORE FUNCTIONAL. THANK YOU, MR. CHAIRMAN.

Testimony of Rep. Danny Davis
Committee on Energy and Commerce
Subcommittee on Health
Hearing: Medicaid's Role for America's Disabilities
January 16, 2008

If you have not already, most of you and your constituents will confront a time when it is necessary to discuss long-term care for your chronically sick or aged loved ones. For decades, people with disabilities, both old and young, have wanted alternatives to nursing homes and other institutions when they needed long-term services. The reason is simple and yet seems to have been overlooked: Our forty year old long-term care system has a heavy institutional bias, and this antiquated system is sending the wrong message that a one size fits all long-term care system sufficiently addresses the increasing complexity of disabilities which desperately need medical support. From physical, to mental, to developmental disabilities and everything in between, we need a modernized system that adequately addresses the intricacies of providing the right care for each individual.

In addition, our archaic approach of placing the majority of long-term Medicaid dollars within institutionalized support systems is unnecessarily inefficient. While 63% of our total $94.5 billion long-term care Medicaid dollars ($59.34 billion) were spent on nursing homes and other institutional services, leaving only 37% for all community services (waivers, personal care, home health, etc.) in Fiscal Year 2005, community services have been shown to be less expensive on average than institutional services, and better liked by individuals.

Lastly, our bias toward institutionalization is characterized in the reality that every state that receives Medicaid MUST provide nursing home services, but community based services are optional. In the last several years, studies have begun to acknowledge the effects of racial segregation on medical treatment. Researchers have shown that blacks are more likely than whites to seek care at hospitals with higher surgical mortality rates, receive maternity services at hospitals with higher risk-adjusted neonatal mortality rates, and receive primary care from physicians who are less well trained than those who mainly treat white patients. Now, a new Commonwealth Fund-supported study entitled "Separate and Unequal: Racial Segregation and Disparities in Quality Across U.S. Nursing Homes," shows that poorer quality of care in nursing homes is linked to racial segregation. Black residents, the authors say, are more likely than whites to live in poor-quality nursing homes marked by significant deficiencies on inspection reports, substantial staffing shortages, and financial vulnerability.

Families of all races across this nation are in crisis. When support services are needed, there are no real choices in the community. Whether a child is born with a disability, an adult has a traumatic injury or a person becomes disabled through the aging process, we overwhelmingly prefer attendant services provided our own homes, not nursing homes or other large institutions. A family decision to place a family member in a nursing home is seldom an easy one, and nursing home care is not for everyone. Yet, given current policy,

institutionalized care is the only affordable and available option for many. People with disabilities and their families will no longer tolerate being forced into selecting institutions. It's time for real choice.

The Community Choice Act of 2007 provides an alternative that will fundamentally change our long term care system and remove institutional bias that now exists. Specifically the bill would allow individuals eligible for Nursing Facility Services or Intermediate Care Facility Services for the Mentally Retarded the opportunity to choose a new alternative, "Community-based Attendant Services and Supports." Building on the Money-Follows-the-Person concept from the Deficit Reduction Act, the two million Americans currently residing in nursing homes and other institutions would have a choice to receive services in institutions or in community settings, depending on one's needs. In addition, people would not be forced into institutions in order to get out on community services; once they are deemed eligible for the institutional services, people with disabilities and their families would be able to choose where and how they receive services. Instead of making a new entitlement, the Community Choice Act makes the existing entitlement more flexible.

The Community Choice Act establishes a national program of community-based attendant services and supports for people with disabilities regardless of age or disability, provides funds to support system change grants to help states increase their ability to provide home and community-based services, and creates a demonstration project to evaluate service coordination and cost sharing for dually-eligible persons with disabilities. Broadening the definition of long-term care increases the flexibility of the current program to better address the needs in a cost-efficient way, and enriches the lives of not only those who are directly impacted but also the communities in which they reside. Therefore I enthusiastically encourage members of the subcommittee on Health to integrate these new provisions into any upcoming revisions and markups regarding Medicaid policy.

Mr. PALLONE.We will now turn to our witnesses, and we have one panel and you are all seated, so I want to welcome you first of all, and let me introduce each of the panel members here.

First is Dr. Diane Rowland, who is executive director of the Kaiser Commission on Medicaid and the Uninsured from here in Washington, DC. And then to her right is Stephanie Thomas, who is national organizer for ADAPT and co-director of the Institute for Disability Access. And then we have next to her Mr. Ralph Gronefeld, who is present and chief executive officer of ResCare. He is from Kentucky. And then we have from my own State, Celine Fortin, who is associate executive director of the Arc of New Jersey from North Brunswick, New Jersey, and I want to particularly thank her because she was part of a roundtable that we had during the break in New Jersey earlier this week where I was trying to get an idea of how some of these Medicaid rules are directly impacting New Jersey. So thank you for being here and coming a second time for me. And then we have to her right is Aileen McCormick, who is president and chief executive officer of AmeriGroup Texas Inc. She is from Bellaire, Texas. And finally is Julie Beckett, who is director of National Policy for Family Voices and she comes from Cedar Rapids, Indiana—no, Iowa, Cedar Rapids, Iowa. I should know that after the Iowa caucus.

Let me just mention, we have 5-minute opening statements from the witnesses. Those statements will be made part of the hearing record. Each witness may in the discretion of the committee submit additional brief and pertinent statements in writing for inclusion in the record, and I will start by recognizing Dr. Rowland. Thank you.

STATEMENT OF DIANE ROWLAND, EXECUTIVE DIRECTOR, KAISER COMMISSION ON MEDICAID AND THE UNINSURED

Ms. ROWLAND. Thank you, Mr. Chairman and members of the committee. I am very pleased to join you today to discuss the evolution and current role of Medicaid for people with disabilities and the many challenges we have in meeting the diverse and extensive service needs of this population.

As you well know, the Medicaid program is our Nation's major public health coverage program, today covering some 58 million low-income Americans including 8 million persons with disabilities and 6 million low-income, frail, elderly and disabled Medicare beneficiaries who rely on Medicaid to fill Medicare's gaps. Medicaid is indeed a vital safety net for millions of Americans but a lifeline for many people with disabilities.

Since its enactment in 1965, Medicaid has been a predominant source of assistance to people with disabilities. Over the years a national floor for eligibility and common definition of disability was established with the implementation of the Federal Supplemental Security Income cash assistance program in 1972. Assistance in the community and at home has become more available as an alternative to institutional care over Medicaid's history. Improvements have been made in the quality of care in nursing homes and assistance was provided to enable people with disabilities to return to work while retaining Medicaid coverage.

To be covered by Medicaid, individuals must meet, however, both restrictive income and asset requirements and have a condition de-

termined to be permanent disabling. The average income level for eligibility is $7,500 a year with an asset level of $2,000, those embodied in the SSI cash assistance program. As a result, Medicaid is unable to cover people at higher income levels. The Medicaid disability population is diverse with a wide range of conditions and limitations including children with intellectual and developmental disabilities such as mental retardation and autism, young adults with spinal cord and traumatic brain injuries, HIV/AIDS or serious mental illness and older people with Alzheimer's or severely disabling chronic diseases such as diabetes and pulmonary disease. The needs of people with disabilities are extensive and complex, requiring many types of health services and support that are not traditionally covered by other sources of insurance but needed to maintain function and in some cases independence. Of the $103 billion dollars in Medicaid spending for people with disabilities in 2004, 38 percent was for long-term-care services, 19 percent for prescription drug coverage and 43 percent for medically related care, especially including mental health services often uncovered in other programs. Medicaid's strength has been its ability to provide a continuum of care and a wide range of supportive services.

Although Medicaid is principally recognized as a source of health insurance coverage for millions of low-income children and parents, the program is indeed the largest source of health insurance and long-term care for people with disabilities. Seniors and people with disabilities comprise only a quarter of enrollees in Medicaid but account for 70 percent of all program spending. The average per-person cost for persons with disability in 2004 was $12,364 compared to less than $1,500 for non-disabled children and a per capita expense of less than $2,000 for non-disabled adults. Moreover, the concentration of spending is very linked to high-cost beneficiaries. High-cost disabled beneficiaries incurring over $25,000 a year in expenditures represented 2 percent of overall Medicaid enrollees but accounted for one quarter of all program spending.

Medicaid plays a critical role in providing health services to people with disabilities by filling in the gaps in Medicare and private insurance and going beyond the medical model to offer a broad array of services needed by people with severe disabling conditions. Doctor visits and prescription drugs alone are insufficient to enable an individual with severe paralysis to get a job. Personal assistance, medical assistance devices, transportation and other assistive devices all covered by Medicaid are essential adjuncts to medical care. Extended eligibility for Medicaid coverage to individuals without requiring impoverishment can help to stimulate broader access to community-based care and enable people with disabilities to work without fear of losing the Medicaid support they need to function.

One of Medicaid's biggest challenges, however, in meeting the needs of people with disabilities has been that there are differences in functional and financial eligibility criteria between nursing home and community-based care that has steered people with disabilities into institutional settings. Consumer demand and the Olmstead decision have helped to promote expanded access to home- and community-based services. Through home- and community-based waivers now, Medicaid is helping nearly 3 million people to be able to

receive care in the home rather than in an institution setting but more options are needed. Some 280,000 people were on waiting lists for home- and community-based services in 2006. Institutionalization should not be the admission ticket to home-based services under Medicaid.

The Medicaid experience, however, clearly demonstrates the importance of providing a broad range of health and long-term care coverage for the population with disabilities and documents the lack of alternative forms of assistance. Reformers should build on the progress that has been made in providing coverage and access to care for those with disabilities and exercise extreme caution when making changes that could affect the health and well-being of many of our Nation's poorest and most disabled citizens.

Thank you very much.

[The prepared statement of Ms. Rowland follows:]

Medicaid's Role for People with Disabilities

Diane Rowland, Sc.D.
Executive Vice President, Henry J. Kaiser Family Foundation
And
Executive Director, Kaiser Commission on Medicaid and the Uninsured

Testimony before the
U.S. House of Representatives
Committee on Energy and Commerce
Subcommittee on Health

"Helping Families with Needed Care:
Medicaid's Critical Role for Americans with Disabilities"

January 16, 2008

SUMMARY OF TESTIMONY BY DIANE ROWLAND, SC.D

- The Medicaid program is our nation's major public health coverage program covering over 58 million Americans, including 8 million persons with disabilities and 6 million low-income frail elderly and disabled Medicare beneficiaries who rely on Medicaid to fill Medicare's gaps.
- Since its enactment in 1965, the major changes in Medicaid involved broadening coverage to people with disabilities through the federal SSI program, making assistance in the community and at home an alternative to institutional nursing home care, promoting improvements in the quality of care in nursing homes, and assisting people with disabilities to return to work while retaining their Medicaid coverage.
- The population with disabilities is diverse, with a wide range of conditions and limitations. To be covered by Medicaid, individuals must meet both income and asset requirements and have a condition determined to be permanently disabling.
- The needs of people with disabilities are extensive and complex, requiring many types of health services and supports that are not traditionally covered by other sources of insurance, but needed to maintain function and, in some cases, independence.
- Historically, differences in functional and financial eligibility criteria between nursing home and community-based care steered people with disabilities into institutional settings. Consumer demand and the *Olmstead* decision have helped to promote expanded access to home and community-based services.
- Although Medicaid is principally recognized as a source of health insurance coverage for millions of low-income children and parents, the program has become the largest single source of health insurance and long-term care and the largest source of public financial support for people with disabilities. Seniors and people with disabilities comprise only 24% of enrollees, yet they account for 70% of program spending. The average per-person cost of caring for persons with disabilities in 2004 was $12,364 compared to $1,474 for non-disabled children and $1,942 for non-disabled adults.
- Medicaid plays a critical role in providing health care services to people with disabilities - both filling in the gaps in Medicare and private health insurance and going beyond the medical model to offer the broad array of services needed by people with severe disabling conditions. Doctor visits and prescription drugs alone are insufficient to enable an individual with severe paralysis to get to a job—personal care assistance, transportation, and assistive devices, all covered by Medicaid—are essential adjuncts to medical care.
- The Medicaid experience clearly demonstrates the importance of providing health and long-term care coverage for the population and the lack of alternative forms of assistance. Reformers should build on the progress that has been made in providing coverage and access to care to those with disabilities and exercise caution when making changes that could affect the health and well-being of many of the poorest and most disabled among us.

Introduction

Mr. Chairman and members of the Health Subcommittee, thank you for the opportunity to testify today on Medicaid's role for people with disabilities. I am Diane Rowland, Executive Vice President of the Henry J. Kaiser Family Foundation and Executive Director of the Kaiser Commission on Medicaid and the Uninsured. I also serve as an adjunct professor at the Johns Hopkins Bloomberg School of Public Health. My testimony today will briefly review the history of Medicaid's development as a vital source of coverage for people with disabilities and provide an overview of its current role providing coverage and access to health services and supports for this population.

The Medicaid program is our nation's major public health coverage program designed to address the acute and long-term service needs of low-income Americans of all ages. It provides health coverage today to over 58 million Americans, including 8 million persons with disabilities and 6 million low-income frail elderly and disabled Medicare beneficiaries who rely on Medicaid to fill Medicare's gaps. Medicaid covers a broad spectrum of services, ranging from basic medical care to behavioral health and long-term services and supports to enable individuals with disabilities to live independently.

Medicaid is an integral part of our nation's health financing system, paying for 16% of overall health spending but nearly half (43%) of all nursing home spending and over half of all public spending on mental health services (Figure 1). It provides coverage for those in the low-income population who are unable to access private health insurance, have chronic conditions that require extensive medical care, and need assistance in the community or in a nursing facility for cognitive and physical disabilities.

Medicaid's History for People with Disabilities

Medicaid was first established in 1965 to fill distinct gaps in the private health insurance system – gaps that left those with the least income and the most extensive health needs without access to coverage and services. Over the years, legislative and policy changes to Medicaid have expanded its reach as needs for safety-net coverage have grown, due to economic and labor force dynamics, rising health care costs, and aging and disability trends. Medicaid has broadened from primarily providing medical care to the welfare population to the main source of health insurance for millions of low-income Americans and the primary program for providing access to acute and long-term care for aged and non-aged people with disabilities.

The most far-reaching change in eligibility and coverage of people with disabilities and the elderly came in 1972 with the enactment of two new federal programs—the Supplemental Security Income (SSI) program providing cash assistance for low-income people with disabilities and the Social Security Disability Insurance (SSDI) program. The implementation of SSI and SSDI brought a uniform national definition of "disability," and the link between Medicaid eligibility and SSI coverage brought a national income floor for Medicaid eligibility (roughly 74% of poverty) for the elderly and people with disabilities in Medicaid—substantially raising levels in many states.

Since its enactment in 1965, the major changes in Medicaid involved making assistance in the community and at home an alternative to institutional nursing home care, promoting improvements in the quality of care in nursing homes, and assisting people with disabilities to return to work while retaining their Medicaid coverage. In 1999, the landmark Supreme Court ruling in Olmstead v. L.C. required states to provide

community-based services to individuals for whom institutional care is inappropriate to comply with the American's with Disabilities Act (ADA) of 1990. Providing services in the community and giving people who need long-term services and supports more control over their care continue to be a central focus of Medicaid reform for both the elderly and people with disabilities.

In addition, in the face of the unfolding AIDS epidemic, Medicaid responded to the emerging health challenge by extending coverage to those with HIV/AIDS who met income criteria as part of coverage for people with disabilities. All of these changes have combined to make Medicaid the primary source of coverage for people with disabilities and the low-income elderly, especially those needing long-term services and supports.

Medicaid's Role Today

The population with disabilities is diverse, with a wide range of conditions and limitations and great variation in severity, symptoms, and overall impact on health and quality of life. These individuals include children with intellectual disabilities such as mental retardation or developmental disabilities such as autism; young adults with spinal cord and traumatic brain injuries or serious mental illness; and older people with Alzheimer's disease or severely disabling chronic diseases such as diabetes and pulmonary disease.

Individuals with these conditions have a range of needs for acute care as well as long-term services and supports. For example, people with intellectual disabilities have specialized needs that would not be met in a long-term services system developed to meet the needs of people with physical disabilities. The need for services ranges considerably and can change quickly.

Who Does Medicaid Cover?

To qualify for Medicaid, individuals must meet both income and asset (generally $2,000 for an individual) requirements and fall into one of the categories of eligible populations. To qualify on the basis of disability, an individual must have a condition determined to be permanently disabling. Most people with disabilities covered by Medicaid come into the program by being eligible for the federal SSI cash assistance program or another mandatory pathway.

States have flexibility to expand Medicaid eligibility beyond federal minimum standards to cover additional "optional" groups, including the elderly and people with disabilities with incomes up to 100% of the federal poverty level and the medically needy. And, because few people can afford the high cost of nursing home care, 38 states allow individuals needing nursing home care to qualify with income up to 300% of the SSI eligibility level. By raising the income standard for people with disabilities, states have allowed children and adults to receive services and remain at home or in the community as an alternative to institutional care. These policies, however, vary widely across the states.

In an effort to promote participation in the workforce, many states provide a means for higher income individuals to buy into Medicaid through the Ticket-to-Work option, enabling individuals with disabilities to work and retain their health coverage. More recently, the new Family Opportunity Act was designed for disabled children with family income up to 300% of poverty to provide community-based long-term services, recognizing that impoverishment to obtain coverage would not be in the best interests of disabled children and their families. Despite efforts to make Medicaid coverage more

available to people with disabilities, millions continue to fall outside its reach because coverage is often restricted to the poorest and most severely disabled.

What Services Are Covered?

People with disabilities experience problems with vision, hearing, communication, mobility, physical actions such as standing or stair-climbing, performing simple activities like bathing, dressing, getting out of bed, and eating, and managing money or a home. Consequently, the needs of people with disabilities are extensive and complex, requiring many types of health services and supports to maintain function and, in some cases, independence. Of the $103 billion in Medicaid spending for people with disabilities, 62 percent was for medically related care and 38 percent was for long-term services and supports (Figure 2).

Medicaid was designed as a program to provide health coverage to people with diverse health needs that includes adults and children with disabilities and, therefore, provides a comprehensive set of acute and long-term care benefits that include and extend beyond standard medical care. This includes supportive services that complement medical care and help people with disabilities maintain their independence—services which are not traditionally covered by other sources of insurance.

State Medicaid programs are required to cover certain "mandatory services" including physician and hospital services, laboratory and diagnostic testing and nursing facility services. States can also choose to cover certain "optional" services such as prescription drugs, personal care services and home and community-based long-term care services. Significant variations in eligibility standards and the scope of covered services across states make the program exceptionally complicated in ways that create gaps in coverage,

but many of the benefits offered at state option are particularly important for Medicaid enrollees with disabilities. For example, access to prescription drugs is essential to the management of acute and chronic physical and mental illnesses. Access to personal care services is important for people with disabilities who work, especially since these services are not provided in most private plans.

Historically, differences in functional and financial eligibility criteria between nursing home and community-based care steered people with disabilities into institutional settings. Many states have expanded access to home and community-based services driven in part by consumer demand and by the *Olmstead* decision that stated the unjustified institutionalization of people with disabilities is a violation of the 1990 Americans with Disabilities Act.

While the majority (59%) of Medicaid spending on long-term services and supports is concentrated on institutional care, reflecting the high costs of providing these services, an increasing share is attributable to home and community-based long-term services. The national percentage of Medicaid spending on home and community-based services has more than doubled from 15% in 1992 to 37% in 2005 (Figure 3). Today more than 2.7 million individuals receive Medicaid home and community-based services.

To address the institutional bias in Medicaid, there are three main ways a state can provide Medicaid home and community-based services (HCBS): through the optional HCBS waivers, the mandatory home health benefit, and the optional state plan personal care services benefit. In 2004, all states operated the Medicaid home health benefit and multiple HCBS waivers, and 30 states offered the optional state plan personal care benefit. HCBS waivers give states considerable flexibility to determine which services

and populations to cover. Consumer direction of personal assistance services has been an important component within home and community-based services for some Medicaid beneficiaries who desire greater control over hiring, scheduling, and paying personal care attendants.

Though HCBS waivers have increased access to services at home and in the community for people with disabilities, states may also set cost controls such as coverage limits, expenditure caps and apply waiting lists for services, regardless of need. The number of people on waiting lists for services continues to grow. In 2006, 280,176 individuals were on a waiting list for HCBS services, up from 206,427 individuals in 2004. Cost controls can prevent access to community services for many Medicaid enrollees with disabilities. In 2006, 34 states utilized some form of cost controls above and beyond the federally mandated cost neutrality formula for the waivers.

More recent efforts to expand access to community-based services include the Money Follows the Person demonstration that allows states to receive enhanced federal funding to transition people from an institution to the community, and the new state plan option for states to provide home and community-based waiver services without needing to get a waiver for seniors and people with disabilities up to 150% of poverty. While these programs are designed to promote greater access to community services, their scope is narrow and may not be sufficient to target all those whose desire is to live in the community. Few states have taken up this new HCBS option to date.

Quality of care is also an ongoing concern in Medicaid because the vulnerable population served has such complex health needs. Greater flexibility in benefit design, and over optional populations, will inevitably increase variability within and across states

in terms of who is covered and the services being received. This increases the importance of assessing and systematically monitoring person-level outcomes including unmet needs and satisfaction with care. Most attention to quality of care has been on nursing homes and not consistently or comprehensively evaluated in community-based settings. Identifying and remedying poor quality care requires mechanisms to monitor quality and incentives for implementing improvement. A recent poll shows the public is very concerned about the quality of long-term care in both nursing homes (51%) and community-based settings (59%, Figure 4).

Impact on Overall Medicaid Spending for People with Disabilities

Although Medicaid is principally recognized as a source of health insurance coverage for millions of low-income children and parents, the program has become the largest single source of health insurance and long-term care and the largest source of public financial support for people with disabilities. While low-income children and families represent the majority of Medicaid beneficiaries, people with disabilities and seniors (who are often people with disabilities over age 65) are responsible for most of the program's spending. Seniors and people with disabilities comprise only 24% of enrollees, yet they account for 70% of program spending (Figure 5).

They account for a greater share of spending because they are more likely to have chronic medical conditions that lead to more physician visits, higher rates of hospitalization, greater use of prescription drugs, and increased need for long-term services and supports, resulting in higher per capita costs compared to low-income families. The average per-person cost of caring for persons with disabilities in 2004 was $12,364. This compares to $1,474 for non-disabled children and $1,942 for non-disabled

adults (Figure 6). People with disabilities had higher per capita acute care spending as well as higher spending on long-term care services than low-income families.

Within the Medicaid program, spending is highly concentrated on a small percentage of beneficiaries. Four percent of the Medicaid population was responsible for 48% of program spending in 2001 reflecting their intensive health care needs, half of which are devoted to services for the disabled (Figure 7). Looking just at people with disabilities, the 11% of this group with costs over $25,000 accounted for 61% of all expenditures on people with disabilities (Figure 8).

Another way to identify high cost and high need Medicaid beneficiaries is to consider their use of long-term services and supports. Medicaid enrollees who use either institutional or home and community-based long-term care services account for the bulk of Medicaid costs. Fifteen percent of disabled Medicaid enrollees who use long-term services and supports account for 58% of all Medicaid spending on the disabled. Three quarters of these 1.2 million enrollees relied on community-based services, and have average total spending of $35,930; per enrollee spending for the disabled using institutional care averaged $76,331. This compares to an average of $6,277 for those with little or no long-term services spending.

Medicaid: Critical Assistance for People with Disabilities

Medicaid plays a critical role in providing health care services to people with disabilities - both filling in the gaps in Medicare and private health insurance and going beyond the medical model to offer the broad array of services needed by people with severe disabling conditions. Doctor visits and prescription drugs alone are insufficient to enable an individual with severe paralysis to get to his or her job—personal care

assistance, transportation, and assistive devices, all covered by Medicaid—are essential adjuncts to medical care. And, for those with chronic conditions that require long-term supports and services, Medicaid is the only source of financial assistance with long-term care within the community and in institutional settings.

Medicaid has come to be a critical complement to coverage from Medicare for low-income people with disabilities and the frail elderly. Dual-eligibles—the 7 million low-income Medicare beneficiaries who are also covered by Medicaid—are among Medicare's sickest, frailest, and poorest beneficiaries. Many suffer from cognitive impairments and chronic illnesses that require on-going help with the activities of daily living—bathing, toileting, dressing, eating, and transferring from bed to chairs.

Medicaid provides the services to fill Medicare's benefit gaps, enabling many to stay in their homes and communities and helping to offset the cost of nursing home care for those requiring greater assistance. Moreover, by offering coverage to low-income people with disabilities during the 29 month waiting period before Medicare coverage commences for those meeting the disability determination, Medicaid provides basic medical care coverage in addition to the broader long-term care services and supports.

Medicaid also helps fill the gaps in coverage available through the private health insurance system. Private health insurance in the individual market is inaccessible to those with severe disabilities due to prohibitions on pre-existing conditions and the very high cost of experience-related policies for people with chronic illnesses. People with disabilities are more likely to be enrolled in Medicaid than the general population. Individuals with disabilities covered by Medicaid are substantially more impaired than those covered by private insurance—almost 50% of Medicaid beneficiaries with any

disability are limited in major life activities compared with 26% of privately-insured persons with disabilities.

When individuals with disabilities have access to employer-sponsored group coverage, such policies are often limited in the scope of benefits to medical services as opposed to long-term supports. Covered benefits are often subject to substantial cost-sharing and strict utilization limits. Medicaid's comprehensive benefits enable people with disabilities who qualify for Medicaid assistance to obtain the fuller range of services they require to help maximize their independence, and, in some cases, support participation in the workforce.

By continuing Medicaid coverage when people with disabilities return to work, Medicaid both provides the personal care and supportive services necessary to engage in work, but also serves to keep the employer-based insurance more affordable by removing the high-risk, high-cost individuals from the insurance pool. Thus, rather than compete with private insurance for the disability population, Medicaid helps make employment and health coverage for people with disabilities possible.

Future Directions and Challenges

Medicaid plays an important role in the health care system, filling in gaps and providing coverage to millions of Americans who would be uninsured if not for Medicaid. Medicaid's role has grown substantially over the past 40 years with the federalization of cash assistance for the aged, blind, disabled; the shift to Medicaid from state-only coverage for the mentally ill and mentally retarded; the emergency of the AIDS epidemic; and greater reliance on home and community-based services as an alternative to nursing home care. As Medicaid's role has evolved, the program has been

under pressure to increase the availability of coverage, especially for the working disabled, and improve access to home- and community-based alternatives to institutional care.

Medicaid is a vital safety net for millions of Americans but a lifeline for people with disabilities. In the absence of universal coverage for health care and other forms of assistance with the cost of long-term care, Medicaid's costs and responsibilities will continue to grow. The challenge for the future is how to balance the substantial needs and costs for care of people with disabilities with fiscal realities.

The Medicaid experience clearly demonstrates the importance of providing health and long-term care coverage for the population and the lack of alternative forms of assistance. Reformers should build on the progress that has been made in providing coverage and access to care to those with disabilities and exercise caution when making changes that could affect the health and well-being of many of the poorest and most disabled among us.

Thank you for the opportunity to testify today and your continued attention to the vital role Medicaid plays in providing coverage to people with disabilities. I welcome your questions.

Figure 1

Medicaid Today

Health Insurance Coverage
29 million children & 15 million adults in low-income families; 14 million elderly and persons with disabilities

Assistance to Medicare Beneficiaries
7.5 million aged and disabled — 18% of Medicare beneficiaries

Long-Term Care Assistance
1 million nursing home residents; 43% of nursing home care

MEDICAID

Support for Health Care System and Safety-net
16% of national health spending

State Capacity for Health Coverage
43% of federal funds to states

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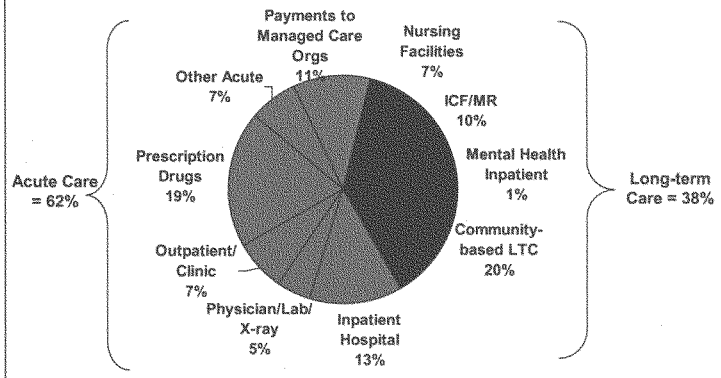
Figure 2

Medicaid Spending by Service for People with Disabilities, 2004



Total Spending: $102.7 billion

SOURCE: KCMU and Urban Institute estimates of 2004 MSIS data

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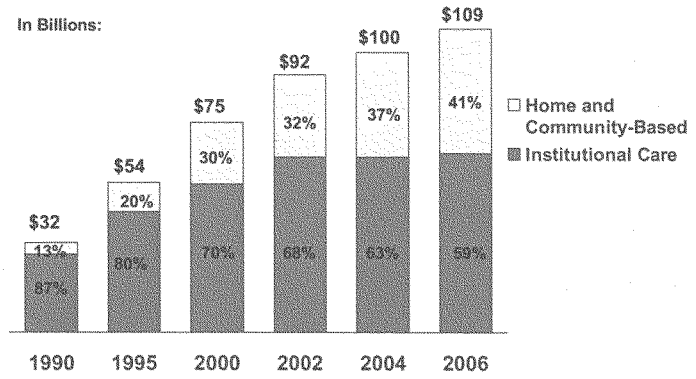
Figure 3

Growth in Medicaid Long-Term Care Services Expenditures, 1990-2006



Note: Home and community-based care includes home health, personal care services and home and community-based service waivers.
SOURCE: KCMU and Urban Institute analysis of HCFA/CMS-64 data.

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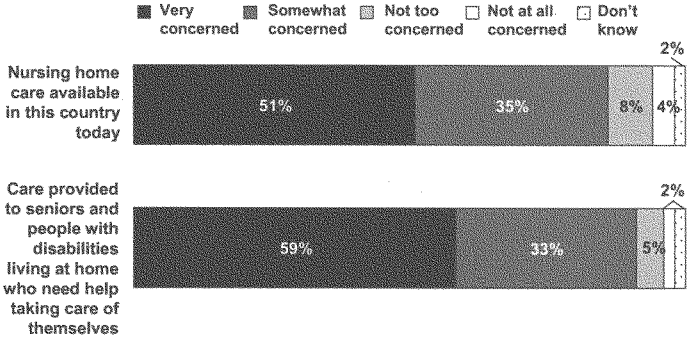
Figure 4

Concerns About the Quality of Long Term Care

How concerned are you if at all, about the quality of ...



Source: KFF *Update on the Public's Views of Nursing Homes and Long-Term Care Services* (conducted October 1 – October 10, 2007)

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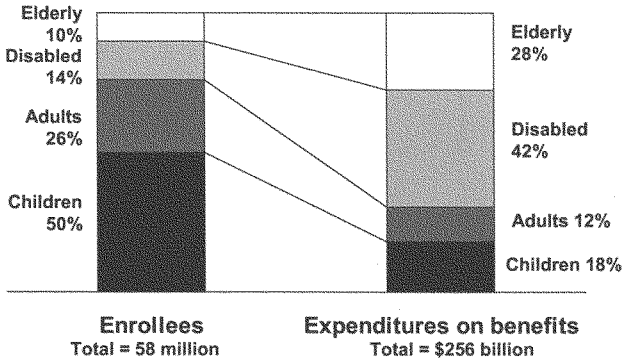
Figure 5

Medicaid Enrollees and Expenditures by Enrollment Group, 2004



SOURCE: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on FY 2004 MSIS data.

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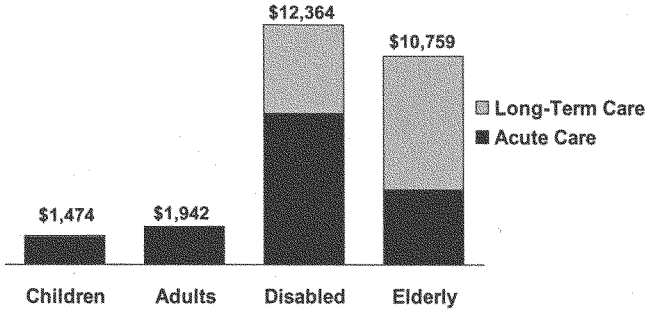
Figure 6

Medicaid Payments Per Enrollee by Acute and Long-Term Care, 2004



SOURCE: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on FY 2004 MSIS data.

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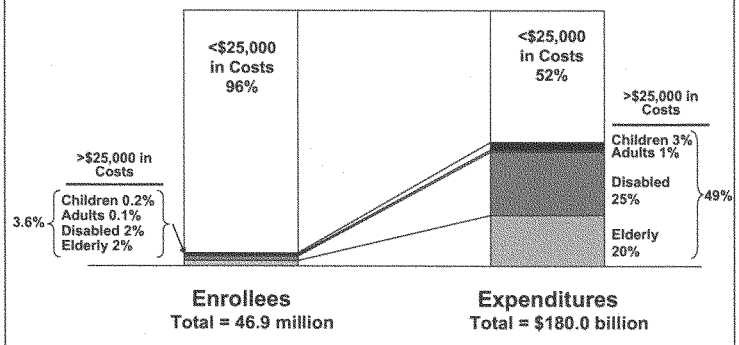
Figure 7

Role of High-Cost Enrollees in Total Medicaid Expenditures, 2001



SOURCE: Sommers and Cohen, *Medicaid's High Cost Enrollees: How Much Do They Drive Program Spending?* Kaiser Commission on Medicaid and the Uninsured, March 2006.

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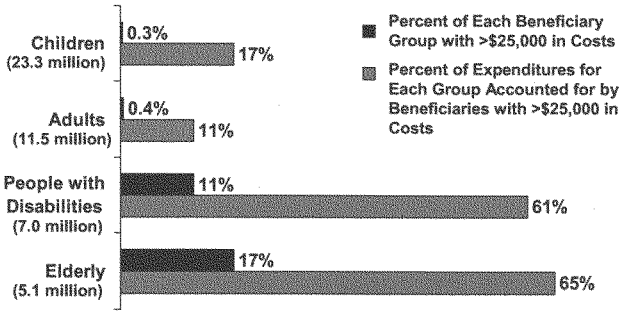
Figure 8

High Cost Beneficiaries Account for Large Share of Expenditures Among Groups



SOURCE: Sommers and Cohen, *Medicaid's High Cost Enrollees: How Much Do They Drive Program Spending?* Kaiser Commission on Medicaid and the Uninsured, March 2006. Data from 2001 MSIS.

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Mr. PALLONE. Thank you, Dr. Rowland. And I didn't stop you, but I should remind everybody 5 minutes if you can. And next is Ms. Thomas.

STATEMENT OF STEPHANIE THOMAS, NATIONAL ORGANIZER, CO-DIRECTOR, THE INSTITUTE FOR DISABILITY ACCESS, ADAPT

Ms. THOMAS. Thank you for the opportunity to be here. I appreciate also the opportunity to speak on behalf of ADAPT, a national grassroots disability rights organization.

Many of ADAPT's members have done time in nursing homes and other institutions, basically becoming a cash crop for an industry that wants to draw down dollars. Living in an 8 foot by 8 foot room with a stranger, being told when to get up, when to go to bed, what and when to eat, basically your life is not your own. I have been told many times I would rather die than go back. I have never in my life heard someone say I am looking forward to moving into a nursing home. Those who got out did not get better from their disabilities; they got out, and that is simply it, and they now live in the community with attendant services. They had to fight their way to get out for the most part to live in the community. We know of children born with disabilities who have been forced away from their families and into institutional placements. Children belong in families, not in institutions. Being institutionalized by one's own choice is one thing but being trapped there because you have no alternatives is something very different. According to CMS's own numbers, nationally over 300,000 people in nursing homes alone have expressed a preference for home- and community-based services yet they are stuck inside. They do not even count those trapped in other institutions and those in the community scraping by as they wait year after year to move up on a waiting list.

I urge you to take action. Words are great and what you said today was wonderful to hear but we need action. Pass H.R. 1621, the Community Choice Act. Squarely address the institutional bias in long-term care. Medicaid has helped millions of people with disabilities of all ages to achieve independence, dignity and health but awareness and values of our Nation are changing, and as medical breakthroughs promise more independence, the glaring problem of the institutional bias grows more pronounced. Even Money Follows the Person, a wonderful and important new demonstration program funded in the DRA, requires that people have to be in an institution to get out and receive services. You should not have to go in to get out nor should you be stuck inside because people want a better solution.

Our current system is backwards. Services are fragmented and based on disease categories and age instead of on functional need. The institutional bias has led to a system wherein institutional services are mandated and the community is optional for 63 percent of the Medicaid long-term-care funds go to institutions and just 37 percent are left for community services, all the community services, despite the facts of long waiting lists, sometimes as long as 10 years. Ironically, the same community services cost only about two-thirds of their institutional equivalent on average. We hear about the fear of the woodwork effect. This is an insulting

term that actually refers to the unmet need of real live human beings. We are not cockroaches and this is not pest control. Forcing people to live and get by on nothing is neither good policy nor does it solve the money issue in the long run. Many States would like to even the playing field but the Federal entitlement to nursing homes alone stops them.

The Community Choice Act would help to improve the services in nursing homes and other institutions as it would give them real competition. Over 700 organizations from across this Nation have signed on supporting the Community Choice Act, over 700. The bill is based on a simple concept. It allows individuals eligible for services in a nursing facility, ICFMR or IMD the opportunity to choose instead a new alternative, community-based attendant services and supports. CCA makes an existing mandated service more flexible to meet the needs of those who are currently eligible for its services. You could even use these services in schools. It doesn't force anyone to move out nor does it close any facilities, as some have claimed. It simply gives people a choice. In addition, the Community Choice Act assists States to reform their long-term services and supports. Women take heed: the vast majority of people in nursing homes, over 70 percent, are women. The vast majority of the underpaid direct care workers are women, over 70 percent, and the vast majority of those who provide free care are women. Is this issue swept under the rug completely because of this? I don't know, but I do know that most of you, men and women alike, will have to face this issue in the near future. I faced it when my father-in-law came to live with my husband and me, a diabetic who had a stroke, he stubbed his toe, and in the end he had to have both of his legs amputated. His eyesight was going and so was his memory of things like whether the stove was left on. Professionals urged us to put him in a nursing home but he lived with us with attendant services, but today he would be at the bottom of an over 40,000-person waiting list. He wouldn't have reached the top before he passed away.

As America grays, this issue grows larger and larger. It is not a question of if we will be dealing with long-term care; it is a question of how we will be dealing with it. Like most monsters under the bed, once we confront it we will find that it is not what we feared.

One more thing. Even as CMS encourages the States to assist people who want out of nursing homes or other institutions to move out, a great thing, it has bizarrely decided to cut case management services by almost 70 percent. This assistance is vital. This devastating cut shows the lack of understanding in the reality of people's lives and it distorts priorities. You need to reverse this terrible decision on case management and reverse the overall institutional bias in Medicaid. Passing the Community Choice Act is an important piece in this overall effort, so please pass it.

Thank you for the opportunity to speak today.

[The prepared statement of Ms. Thomas follows:]

Testimony of Stephanie Thomas, National ADAPT

Submitted to the Energy and Commerce Committee Subcommittee on Health

January 16, 2008

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Good Morning. I am Stephanie Thomas, a National Organizer for the grassroots disability rights organization ADAPT. I appreciate the opportunity to speak to you today.

Over 17 years ago the Americans with Disabilities Act was signed into law. The disability community celebrated, but as we celebrated we realized that there were members of our community who were being left behind. Stuck in nursing homes and other institutions, they had neither liberty nor pursuit of happiness; they were virtual prisoners of a system that basically uses them as a cash crop to draw down dollars for others to enjoy. Many of the members of the group I represent, ADAPT, have themselves been trapped in nursing homes and other institutions and had to fight their way out to live in the community. Many of the rest of us see this bleak picture as our future, a future that haunts us every day.

We have listened to our friends who have lived through being institutionalized against their will. They told us of living in an 8' by 8' room with another person – not of their choosing, being told when to get up, when to go to bed, what and when to eat. We have gone to visit them and been told they can not leave the building, that we cannot go to see them because we raise up their hopes. We have heard them explain how "your life is not your own." We have heard them say "I would rather die than go back." I have never in my life heard someone say, "I am looking forward to moving into a nursing home." We know of children born with disabilities who have been forced away from their families into institutional placements because this was the only "support" option available to their families; children belong in families, not in institutions. Being institutionalized by one's

own choice is one thing, being trapped there because you have no alternatives is something very different.

According to CMS' own numbers, nationally over 300,000 people, in nursing homes alone, have expressed a preference for home and community services, yet they are stuck inside – unable to connect with any community options that might exist. 8,787 are from NJ, 5,762 from GA.[1] This does not even count those trapped in other kinds of institutions, and those in the community scraping by as they wait year after year to move up a waiting list. What I want to talk to you about today is a way to give those people choices, and help the states and Federal government at the same time. Why do we invest so much to keep people locked away?

In 2005 ADAPT held a hearing in Nashville Tennessee and invited people who had previously been institutionalized to come and testify. People flocked from across the nation to give testimony, and the hearing lasted over six hours. You have all been given a DVD which summarizes what was said. [2]

People continue to have to move out of state - away from family and friends - to be free. They fight brain washing and intimidation. They believe in themselves beyond what all around them believe, in spite of the doubt and oppression from the current service system. And these are the lucky ones. Those who got out did not "get better" from their

[1] See appendix for complete list. Or go to www.cms.hhs.gov/MDSPubQIandResRep/
[2] See the ADAPT website www.adapt.org for a transcript of the entire hearing, or contact me at adapt@adapt.org. Excerpts of the testimony are attached to my written testimony.

disabilities, they simply got out – and now live in the community with attendant services and supports.

But I am not here to talk about how awful nursing homes or other institutions are. I am here to urge you to take action to give people a real choice in long term care, to pass Representative Danny Davis and John Shimkus' bill HR 1621 The Community Choice Act, CCA, and to squarely address the institutional bias in Medicaid long term care.

Medicaid has helped millions of people with disabilities of all ages; it has saved people from alms houses and even death. It has played a vital role in assisting people to achieve independence, dignity and health. But it has done this with its hands tied behind its back. The glaring problem of institutional bias grows more pronounced every day as the awareness and values of our nation change, as the medical and scientific breakthroughs promise more independence and autonomy for children, adults and seniors with significant disabilities – yet Medicaid stays so wed to the institutional mode. Even Money Follows the Person, an important new demonstration program funded in the DRA, requires that the person must be in an institution to get out and receive services.

Our current system is backwards. The institutional bias has led to a system wherein the institutional service is mandated, and the community is optional; where 67% of the Medicaid long term care funds go to the institutions and just 33% are left for community services, despite the fact that there are long waiting lists – sometimes as long as 10 years – for community services. Ironically, these same community services cost only about 2/3

of their institutional equivalent. We could be serving 3 people for every 2 we are serving now, and doing it more humanely.

Services are fragmented, based on disease categories and age, instead of on functional need. If you have a traumatic brain injury at the age of 18 you may be eligible for extensive support services, but if you have that same injury six years later you are out of luck. If you have a spinal cord injury, a boutique program may cover your needs, but if you have Multiple Sclerosis and need the exact same tasks done your only option may be Villa Siesta Nursing Facility. It makes absolutely no sense, unless you are into Byzantine policy history, and even then …

We hear about fear of the "woodwork effect," an insulting term that actually refers to unmet need of real live human beings. We are not cockroaches and this is not pest control. Let's look at the reality of this issue: People eligible for the Community Choice Act are people who are currently meeting the income and medical necessity requirements of nursing home or other institutional services. They are people with significant disabilities. Without any services they will eventually endanger their health and wind up using much more costly medical services: going without eating, staying in one position for too long, or consistently urinating or defecating on yourself leads to serious problems like malnutrition, bedsores, and worse. Getting by with no support services is not an option. Forcing people to get by on nothing is not good policy and does not solve the money issue in the long run.

Many states would like to even the playing field, but when the Federal Government says you **must** fund nursing homes -- and **if you want you can** fund these other community services, States are going to be darn sure the finite dollars they get go to covering the mandated programs first -- and community waiting lists will grow.

We even believe the Community Choice Act would help to improve the services in nursing homes and other institutions because it would give them real competition. If people knew they could go somewhere else, like their own home, nursing homes and other institutions would have to provide an option people would freely choose.

Over 700 national state and local organizations have signed on supporting the Community Choice Act, from the American Medical Association to the National Council on Independent Living; from the United States Conference of Catholic Bishops, and Service Employees International Union to the NAACP and NOW; from the Oglala Sioux Nation to the Christopher and Dana Reeve Foundation and Not Dead Yet. I could go on and on, but the list is included with my written testimony.

WHAT THE COMMUNITY CHOICE ACT, HR 1621, DOES

This bill is based on a very simple concept. By reforming Title XIX of the Social Security Act (Medicaid) it takes a huge step toward ending the institutional bias. It makes an existing mandated service more flexible, to meet the needs of those who are currently eligible for its services. The Community Choice Act allows individuals eligible

for services in a Nursing Facility, Intermediate Care Facility for the Mentally Retarded (ICF-MR), or Institutions for Mental Disease (IMD) the opportunity to ***choose*** instead a new alternative, "Community-based Attendant Services and Supports." It doesn't force anyone to move out, as some have claimed. It simply gives people a choice.

In addition, by providing an enhanced match and grants before October 2011 when the benefit becomes permanent, the Community Choice Act offers states financial assistance to reform their long term service and support system to provide services in the most integrated setting. This is already beginning to happen but in an ad-hoc, piecemeal basis, and often people must be in institutions in order to choose community services.

Specifically what does this bill do?

It provides community-based attendant services and supports that include assistance with:
* activities of daily living (eating, toileting, grooming, dressing, bathing, transferring),
* instrumental activities of daily living (meal planning and preparation, managing finances, shopping, household chores, phoning, participating in the community),
* and health-related functions.

CCA includes hands-on assistance, supervision and/or cueing (like reminding someone), as well as help to learn, keep and enhance skills to accomplish such activities.

It requires services be provided in the most integrated setting appropriate to the needs of the individual.

CCA provides Community-based Attendant Services and Supports that are:

* based on functional need, rather than diagnosis or age;

* provided in home or community settings like -- school, work, recreation or religious facility;

* selected, managed and controlled by the consumer of the services;

* supplemented with backup and emergency attendant services;

* furnished according to a service plan agreed to by the consumer;

and that include ***voluntary*** training on selecting, managing and dismissing attendants.

This bill allows consumers to choose among various service delivery models including vouchers, direct cash payments, fiscal agents and agency providers. All models are required to be consumer controlled and comply with federal and state labor laws.

For consumers who are not able to direct their own care independently, the Community Choice Act allows for an individual's representative to be authorized by the consumer to assist. A representative might be a friend, family member, guardian, or advocate.

It allows health-related functions or tasks to be assigned to, delegated to, or performed by unlicensed personal attendants, according to state laws.

It covers individuals' transition costs from a nursing facility, ICF-MR or IMD to a home setting, for example: rent and utility deposits, bedding, basic kitchen supplies and other necessities required for the transition.

CCA serves individuals with incomes above the current institutional income limitation -- ***if a state chooses*** to waive this limitation to enhance employment potential.

In addition, CCA provides for quality assurance programs which promote consumer control and satisfaction.

The bill also provides a maintenance of effort requirement so that states can not diminish more enriched programs already being provided.

CCA allows enhanced match (up to 90% Federal funding) for individuals whose costs exceed 150% of average nursing home costs. This protects against discrimination based on severity of disability, so people with more significant disabilities who require more services can still receive services on the community.

For the first five years (2007 through 2011) after which the services become permanent, CCA provides enhanced matches (10% more federal funds each) for states which:

* begin planning activities for changing their long term care systems, and/or

* include Community-based Attendant Services and Supports in their Medicaid State Plan.

And, in the area of systems change:

CCA provides grants for Systems Change Initiatives to help the states transition from their current institutionally dominated service systems to ones more focused on community based services and supports, guided by a Consumer Task Force.

It also calls for national 5 -10 year demonstration project, in 5 states, to enhance coordination of services for individuals dually eligible for Medicaid AND Medicare.

CONCLUSION

Ten years ago I and hundreds of other members of the disability community sat in the audience of this committee for a similar bill called MiCASSA. Mike Auberger and Justin Dart Jr. among others, testified to this Committee [several of you were here at that time too] about the urgent need to end the institutional bias in our long term care system. At that time the Congressional Budget Office gave the bill a fiscal note that included costs for people who are actually not eligible for the bill and services that are not included in this bill. Since then, the University of California at San Francisco has done a statistically valid and peer reviewed re-calculation of the cost and found it would be $1.4 to $3.7 billion dollars, a fraction of the original, erroneous CBO scoring.

In those past 10 years there has been a rising frustration as Congress refuses to act on this critical issue.

For the women on this committee, and the women who staff this committee and it's members -- take heed. The vast majority of people in nursing homes are women over the age of 65, the vast majority of the underpaid direct care workers are women, and the vast majority of women who are providing long term care to family and friends for "free" are women. Is this issue swept so completely under the rug because of this? Who can say? What we can say is that most of you, men and women alike, will have to face this issue in the near future from one of these angles – a recipient of personal care services, a family provider, or through paid service provision.

I faced it when my father-in-law came to live with my husband and me. A diabetic who had a stroke, he stubbed his toe and soon had to have first that leg amputated and then the other. His eyesight was going and so was his memory of things like whether he left the stove on. It would have been so simple for him to go to a nursing home; "professionals" of various ilks urged us to do it again and again! Despite the fact that my husband and I both have disabilities, we were able to keep him out of a nursing home, and living with us – with the help of attendant services. Today however, he would be on the bottom of an over 40,000-person waiting list and it is doubtful he would have reached the top before he passed away. I will face this again as my quadriplegic husband comes to need even a little more assistance, as my parents get older and -- hopefully last but not least, as I too age and need more assistance.

America is aging, and as America grays this issue looms larger and larger. It is not a question of ***if*** we will be dealing with long term care, it is a question of ***how*** we will be dealing with it. We must pull our heads out of the sand and face the issue. Like most monsters under the bed, once we confront this we will find it is not what we feared.

Long term care insurance may help some people, but for people who are eligible for the CCA, in other words eligible for Medicaid nursing home and other institutional services, it is not an option. They can not afford it, and frankly the community options such insurance offers are often woefully short of the need – despite the fact that they often offer much more expansive and expensive institutional services as a "benefit."

Vouchering the services for everyone is not the solution either. As my friend Doris put it "I don't want to have to become a small business, doing taxes, recruiting workers and all that, just to be able to get out of bed and take a bath!" Unlike many who would be eligible for services, Doris does not have any kind of cognitive disabilities which would make such a solution even more complex. And it is a lot easier to cut dollars for vouchers than to slash services for individuals. When Senior and disability advocates have sought vouchers, it has been as part of the system, not the entire system. We do not support block grants; we support choice.

Passage of the Community Choice Act would put these service choices in the hands of the individuals who are affected, not in the hands of a Federal Bureaucracy which has

ratcheted down on spending for Medicaid long term care, despite the growing need. We are facing a terrible example of this ratcheting down right now: Even as CMS is encouraging states to assist people who want out of nursing homes or other institutions to move out (a good thing!), it has bizarrely decided to cut Case Management Services by almost 70%. This assistance is vital for people who have lost everything once they have been institutionalized, who need help getting everything they need to move out -- from a social security card to an apartment. This devastating cut shows the lack of understanding of the reality of people's lives – the distortion in priorities and understanding of what long term care is all about. You need to reverse this terrible decision on Case Management and reverse the overall institutional bias in Medicaid. Passing the Community Choice Act is an important piece in this overall effort.

Thank you for the opportunity to speak today. I would be happy to answer any questions.

APPENDIX ONE

CMS MDS Active Resident Information Report: Third Quarter 2007
Q1a: Discharge Potential and Overall Status

Resident Expresses/Indicates Preference to Return to the Community

Responding Yes to the above question from States represented on the Energy and Commerce Subcommittee on Health:

Arizona	**3,683**	**people who want out**
Arkansas	**3,429**	
California	**24,772**	
Colorado	**3,611**	
Georgia	**5,762**	
Illinois	**18,319**	
Indiana	**7,800**	
Maine	**1,445**	
Michigan	**10,878**	
New Jersey	**8,787**	
New York	**22,584**	
North Carolina	**7,512**	
Oklahoma	**3,871**	
Oregon	**2,600**	
Pennsylvania	**15,003**	
Tennessee	**6,956**	
Texas	**18,403**	
Wisconsin	**7,448**	
Wyoming	**505**	

National Total 302,637

APPENDIX 2

The following are excerpted quotes from the testimony in Nashville. Over six hours of testimony was given on that day. The entire transcript of the testimony is available on the ADAPT website www.adapt.org Look for Nashville Testimony.

Samuel Mitchell >> I was an ordained minister and also a truck driver who became disabled. I had a ministry to nursing homes. I went in nursing homes and preached. I thought I knew a little bit about them. After becoming disabled, a year later I suffered a stroke. That's when I entered a nursing home, and I found out just how much I didn't know about nursing homes....
The prevailing atmosphere in nursing homes is that we now own you. We own you and everything about you. You become a non-person. Your rights, human rights and civil rights are routinely violated. ... Dignity, there was no dignity. I can remember sitting using the rest room and having a CNA come in the door and start washing something out and I told her "you can't be in here." She said, "I'm going to only be a minute, don't worry, Mr. Mitchell." I would say "get out." "I'm only going to be here a minute." "Get out!" I don't know anybody that wants prying eyes on them while they're sitting on the throne in all their glory.

LATONYA REEVES >> I'm originally from Tennessee. When I was younger I was put in a nursing home that was supposed to be a Rehab center. … The abuse I received was one day I had an accident and the aide made me wash my face in it. …a therapist from hell, she put me in the bathtub and turned cold water on me and on my face and made me stay there for two hours and said if you don't stop screaming I'll drown you. So I let relatives know about this and I got taken home for Christmas and never brought back… I was trying to get services in Tennessee, which I couldn't, so I went on my first ADAPT Action in Baltimore and met Wade Blank at Atlantis Community and he told me about Atlantis/ADAPT and I moved there, but I've been there for going on 16 years living in my own apartment and also my job there is to free our people from nursing homes!

Randy Alexander "I was continually told there wasn't the services I needed to live in an apartment. I couldn't get the hours I wanted. I couldn't get simply somebody to help me transfer in and out of bed, so I had to stay there. And during that time all my decisions were basically taken away from that point in time because there wasn't the option for me to have freedom to choose what I wanted.

Steve Schaefer >> Without insurance and not qualifying otherwise for assistance she needed to live there in order to stay alive. There was no choice. ...In a short time I watched her change from a spirited courageous intellectual to a compliant forgetful and timid woman. Finally after a six-month period, required period of wait she qualified for social security disability. As a disabled adult she now qualified for medical assistance in her home.

Jamie Ziegler >> when I first went there, I found that as a resident you have no locks. You know your bedroom has no lock, your bathroom has no lock. You have no privacy whatsoever and very, very, very few people knock on the door. And then, when I very first came, I still had modesty and dignity and it bothered me people walked in all the time.

Michelle McCandless >> When my friends would leave, I found out that the nurses got back at me by giving me cold showers, putting me in bed early, because the only way I could get around is if I was in my chair. Once they put me in bed, I was stuck. I couldn't get around. That was my punishment.

I'm Renee Ford from Memphis and I'm reading Michael Taylor's statement. He desperately wanted to be here but the nursing home would not let him out. "... Here they gave me a measly $30 every month and think didn't need more because they took care of all my needs. That's BS. For example, I can't always use their telephone so I have to have my own cell phone. If I didn't have a little extra help from somebody else I wouldn't even be able to make a simple phone call. "

Diane Scotin GA >> They kept me in a lock-up for an eight by eight and I had to use the rest room, both urine and the bowel, it had to go down a drain. I had no clothes on. It was freezing cold, sleeping on a cement floor. And, the one incident, she came in and said, are you ready to take your medication now? I said, no, I'm not going to take it. And she says, well, here is your water. You take a bath. And she threw a rag and it actually gave me third degree burns on my chest. And everybody has a -- everybody has a breaking point, and I guess at that time that was my breaking point…

Ed Hahn -- And then my grandfather died, and even though I had come from Philadelphia to Erie by myself in a manual wheelchair -- it's a 12-hour bus ride -- they wouldn't let me ride home on a train for two hours to go to his funeral. And that was the beginning of the end.

John Gladstone -- We have to end these nursing homes and we have to close these nursing homes. And I don't care -- they say it can't be done. I say it can. ... It won't happen over night. There will be lots of discouragement, but they can be closed. They can be shut down. They're warehouses. They're prisons. They're murderers.

Barbara Heinz -- When they found out I wanted out, they try and brainwash you into thinking you can't do nothing for yourself, but I got out. Since I've been out I have been on a board of directors for CBFL and I... so I'm not letting nothing hold me back.

Dawn Green from Milwaukee, Wisconsin >>The care there was awful and, I mean, I had to wait anywhere from half an hour to two hours to go to the bathroom, ... and the reason why I was discharged into the nursing home is because I couldn't wipe my butt or take care of myself in my home.... How about now? Life is great. It's nice to be home. Home is where -- home is where you should be. I have my own apartment and I'm independent with help from aides. I have help in the morning and help in the evening, so life is good.

JIMMY >> … from Four Corners area, Farmington New Mexico... I was brutally beaten on March 12, 2001…I was … with a closed head injury. I was hospitalized for three years on and off and after that I got released from the hospital. I didn't have no place to go and no insurance. So the next place I went to was a nursing home…. Which I can relate everybody that's been up here that these things do happen. And I complained a lot but they said,

you've got a brain injury, you don't know what you're talking about.

Kurt Breslaw – I spent 7 years in a nursing home. It was a corporate government center. … Now I'm out and I'm going to stay out.

JT TEMPLETON >> I lived in for 30 years. In a State School [a state institution for people with mental retardation - nothing to do with education]… I got out because, because of a lawsuit! … After I got out, I live in my own house…

Mike Clark >> As I look back, I can remember the only people who told me about my options of living outside the nursing home was my friend and advocate from independent living resource center. Without the option to live at home I might be dead or worse. [but] I'm alive and very well.

Daniel Remick >> I am 58 years old. I was institutionalized at 8 and a half. My rights were taken away from me because of my disability. My mom and dad were told that I would never be able to live on my own because I did not have physical ability to do normal activity. Which it was a lie. … I was sexually assaulted by an aide there…

Teresa Grove >> I'm from Illinois. I am emotionally and mentally disabled. I've been in an institution since I was 14 years old.... I was initiated in an institution by all the girls with a broom handle. I was told by a staff person and a security guard that I was with whining and I should be quiet and grow up... [Now] I live in the community, but I live under an ongoing threat of one more admission anywhere, and I will be placed forever in a nursing home. Thank you.

LARRY RUIZ >> Most of the people in the youth wing also grew up in institutions and we did not realized that we were living in substandard conditions. …We had an activities director named Wade Blank. He helped us form a residents council. Wade discovered that there were a lot of things to do for entertainment. We saw shows such as Elvis and Grateful Dead and our eyes were opened to the outside world and we began to grow restless. Wade had a vision of us being able to live on our own. He helped us realize this possibility. Once nursing home caught wind of our ideas of independence things began to get ugly. We were treated worse. We were even threatened by the administrator with a middle of the night eviction. Wade was fired and a restraining order was taken out against him. He used this time to look for an alternative for us. He found us apartments in the Las Casitas housing projects and then he came back to Heritage House the last time to break us out. It was June 1975 and the Atlantis community was born.

Carrie Fowler >> Shady acres is the nursing home I was in. At first everyone put on this act just like they do when people are there, when the people are there to check them out. All of you know what I'm talking about. You have been there. You know exactly what I'm talking about. Because when they are here to check the out for the month, the year, whatever, it's yes, ma'am, no, ma'am, yes, sir, no, sir. We'll do it just as fast as you want. But watch them leave and their attitude is what do you want now?

Angela Miller >> I thought about mainly getting out to be with my children. Now, after I did get out, I still have visitation with my children, but I think about it, I can't get up and run any more like I used to, but at least I can sit and be with them thanks to ADAPT.

Mike McCarty >> I was there for seven years and did a whole bunch of things there, very active, but there was like invisible bars at the doors, just like you can - you can only go so far until, like, some one sees you leaving and, oh, mike's leaving, you know, so they come out and tell you to come back...

Linda Merkle >> I'm a nursing home survivor. I was put in a nursing home after I suffered a stroke at the age of 45 because my family didn't know I could stay at home and get the same help that I was getting at the nursing home... And the nursing home -- the food was awful. Oh, it tasted terrible. There were nights when it was -- guess what you're having for dinner. Cause that's what it was; you couldn't tell what it was.

Sarah Wendell >> I have a psychiatric disability called multiple personality disorder. I was in and out of institutions for 3 years.... I would find myself in restraints, in what they would call the quiet room, which was a seclusionary room where people outside the room heard quiet. But for me it was a re-traumatizing and horrific event. I very rarely saw a doctor. The nurses and psychiatric aides would not speak to me unless I first identified myself as Sarah, adding to the confusion and stigma attached to my disability.

Sarah Wendell >> I was not allowed to leave without supervision. The basic civil rights I had were gone. I was a prisoner. So, how did I get out? I started picking up on what I had to do and say to get out. At first I started small. I noticed that smokers were allowed to go outside, so I picked up smoking. I was allowed to go outside under supervision for four-ten-minute breaks a day. The fresh air I longed for became a nasty addiction I did not need, but my experiment worked.

Glen Barnhill >> Sitting in my chair, I usually do pretty good [breathing] the whole day. But when I'm laying down is when I had the majority of my respiratory trouble. And when I'm in a bed, I am totally dependent on someone to come help me. I can't get back up to seek help. I can't -- I don't have enough use of either one of my arms to help myself. Anyway, there were more times that I could count that my nurses aide or CNA ...had been in my room as many as four times on countless occasions, realize I was in respiratory distress and go back and tell the nurse. A lot of the CNA's I had, I had good relationships with and I know these people went back and told the nurses that I needed help. But yet the nurse would not come. And sometimes -- usually it was at night when I was in bed, but I could hear the med cart usually right down the hall from my door and half the time it was simply a matter of the nurse doing her med pass and she was not going to come to my room until she made it up to my room passing her meds. and I was literally laying almost flat on my back gasping for air, scared to death, not knowing if I'm going to have a stroke, die, or you know, if I did wake back up, if I was going to be a vegetable or what. My life was filled with constant fear and we got to the point that I was scared to death to get out of this wheelchair and lay down in a bed, and that's no life for anyone.

Carol Jones >> I have worked in institutions and nursing homes for over 35 years… I've had many people in the community thank me, say how happy they are to be in the community. I have never in 35 years had anyone say "gee, I wish I was in an institution."

Spitfire >> I call nursing homes death camps. You see what I am wearing? No more T-4. I am Jewish, I qualify… What they did to me? Stage 4 bedsores, rape and torture sound familiar? I don't call it oxygen stew for nothing.
But I live independently now... I was rescued by a friendly visitor with an ADAPT T-shirt. I love living on my own. ... I'm a good cook. I do my own ADLs. I know when to go to sleep. I'm not going to be raped at night. I know I won't have bed sores. I have a wonderful attendant. … Nancy Salandra said I was at death's door. Well Nancy, I block doors.

APPENDIX 3

Community Choice Act Supporters

National

ABLED Publications: ABLED Woman Magazine
ADAPT
ADA Watch
Ad Hoc Comm on Healthcare Reform & Disab.
American Association of People with Disabilities
American Association on Mental Retardation
American Geriatrics Society
American Hospital Association
American Medical Association
American Rehabilitation Counseling Association
Americans with Disabilities Vote
Association of Health Insurance Plans - AHIP
Assoc of Programs for Rural Independent Living - APRIL
Association for Persons in Supported Employment, APSE
Association for Protection of the Elderly Exec. Advoc. Adv. Brd
Autism National Committee - AutCom
Bazelon Center for Mental Health Law
Brain Injury Association
Catholic Health Association (CHA)
Center for Self-Determination
Center on Human Policy
CHANCE, Center for Housing & New Comm Economics
Christopher Reeve Paralysis Foundation
Concrete Change
Consortium of Developmental Disabilities Councils
Consumer Research & Advocacy
Democratic National Committee
DIMENET
Disabled People's Direct Action Network, Great Britain
Disability News Service
Disability Rights Action Coalition for Housing
Disability Rights Center
Disability Rights Ed.and Defense Fund, DREDF
Dykes, Disability & Stuff Quarterly
Eastlake, Derry and Associates
Families USA
Family Voices
GnarlyBone News/GnarlyBone Productions
Gerstmann Syndrome Support Network

Gray Panthers
HalfthePlanet.com
Independent Living Research and Utilization, ILRU
Institute for Disability Access
Institute on Disability Culture
Justice for All
Mainstream Magazine
Mouth
NAACP
National Assn for Rights Protection & Advocacy
National Assn of Area Agencies on Aging
National Assn of DD Councils
National Assn of the Deaf
National Assn of Home Care
National Assn of Protection and Advocacy Services
National Assn of State Head Injury Admins.
National Catholic Partnership on Disability (NCPD)
National Catholic Office for People with Disabilities
National Center for Latinos with Disabilities
National Citizens Coalition for Nursing Home Reform
National Coalition of the Chemically Injured
National Coalition on Self-Determination
National Council on Independent Living
National Council on the Aging
National Family Caregivers Assoc.
National Home of Your Own Alliance
National Organization for Women, NOW
National Organization on Disability
National Rehabilitation Association
National Spinal Cord Injury Association
New Mobility
Not Dead Yet
Oglala Sioux Tribe
On A Roll Radio
Paralyzed Veterans of America, PVA
Post-Polio Health Int./Internat Ventilators Users Network
Ragged Edge
Research & Training Center on IL at Univ of KS
Rural Institute, University of Montana
SABE, Self Advocates Becoming Empowered
Senior Support Network
Service Employees International Union, SEIU
Shepherd Center
Socialist Party - USA
Southern Disability Law Center
TASH

The Arc
The Bridge
The Disabled Womyn's Educational Project
Universal Health Care Action Network UHCAN!
United Cerebral Palsy
United Spinal Association
United States Conference of Catholic Bishops (USCCB)
US Conference of Mayors
VSA arts
World Association of Persons with Disabilities
World Institute on Disabilities

STATE & LOCAL

Alaska
AK SILC AK State
Alaska Division of Vocational Rehab. AK State
Alaska Gov's Comm on Employment & Rehab of People with Disabilities AK State Alaska Transition Initiative AK State
Assistive Technology of Alaska AK State
Disability Law Center of Alaska AK State
Governor's Council on Disabilities & Special Ed AK State
Kenai Peninsula IL Center AK Local
Kenai Peninsula IL Center AK Local

Alabama
Birmingham Independent Living Center AL Local
AL Dept of MH/MR AL State

Arkansas
Delta Resource Center for Independent Living AR Local
Sources AR Local
Spa Area Independent Living Services AR Local
UPWARD PROJECT AR Local
Independent Living Council AR State
Arkansas Support Network AR State
The Arc of Arkansas AR State

Arizona
ABIL, A Bridge to Independent Living AZ Local
DIRECT AZ Local
AZ Governor's Council on D.D. AZ State
AZ Governor's S.I.L.C. AZ State
AZ State Rehabilitation Advisory Council AZ State

California
Alameda County DD Planning & Advisory Council CA Local
Californians for Disability Rights CA State
Center for Independence of the Disabled CA Local
Center for Independent Living South Valley CA Local
Community Resources for Independence, CRI CA Local
Disability Resource Agency for IL CA Local
Disability Rights Enforcement, Education, Services CA Local
East Bay Innovations CA Local
Glad to Be Here, Inc CA Local
Green Party of Santa Cruz, CA Local
Humboldt Community Access & Resource Center CA Local
Independent Living Resource Center-SF CA Local
Independent Living Resource of Fairfield CA Local
Mainstream Supported Living Services CA Local
Marin - CIL CA Local
Placer Independent Resource Services, Inc CA Local
Planning for Elders in the Central City CA Local
Resources for Independent Living CA Local
Rolling Start CA Local
So-Lo Center for Independent Living CA Local
Sun Valley Independent Living Center CA Local
UCP of Central CA Local
Valley Mountain Regional Center CA Local
CA Coalition of UCP Associations CA State
CA Disability Alliance CA State
CA SILC CA State
California Alliance for Inclusive Communities CA State
Jay Nolan Community Services CA State
People First of California CA State
The Oaks Group CA State

Colorado
Atlantis Community CO Local
Center for Independence CO Local
Center for People with Disabilities CO Local
Colorado Springs Independence Center CO Local
Connections for IL CO Local
Disability Center for IL CO Local
Disabled Resource Services CO Local
Rocky Mountain MS Cen King Adult Day Enrich Prog CO Local
Southwest Center for Independence CO Local
Assn. of CO Independent Living Centers CO State
CO Developmental Disab Planning Council CO State
CO Gov's Council for People with Disabilities CO State
CO Nurses Association CO State

CO SILC CO State
Colorado Democrats CO State
Lupus Foundation of Colorado CO State
PEAK Parent Center CO State
Speaking for Ourselves Colorado CO State
Denver City Council CO Local
CHANCE, Center for Housing & New Comm Econ. CO National
Colorado Cross-Disability Coalition CO State

Connecticut
Disabilities Network of Eastern Conn. CT Local
Disability Resources Center of Fairfield County CT Local
Independence Unlimited CT Local
Law Offices of Mark Partin CT Local
Office for Persons with Disabilities CT Local
Conn. Coalition of Citizens with Disabilities CT State
Conn. Council on Developmental Disabilities CT State
Conn. Legal Rights Project CT State
Conn. State Independent Living Council CT State
New England Health Care Employees Union Dist.1199 CT State
Office of Protection and Advocacy CT State
Rammler & Wood, Consultants LLC CT State

Delaware
Freedom Center for IL DE Local
Independent Resources Inc DE Local
DE Statewide IL Council DE State
Delaware Maryland PVA DE State
Easter Seals DE & MD's Eastern Shore DE State
State Council for Persons with Disabilities DE State
U DE Center for Disabilities Studies DE State

Florida
CIL of Broward FL Local
Leon Advocacy and Resource Center FL Local
West Coast FL MCS & Chemical Injury Support Grp FL Local
Florida Independent Living Council FL State
Florida SCI Research Center FL State
Paralyzed Veterans Assoc of FL State

Georgia
Access Center for IL GA Local
Arc Cobb GA Local
Bainbridge Advocacy Individual Network GA Local
Brain Injury Family Assistance Center GA Local
Disability Connection MGCIL GA Local

disAbility LINK GA Local
LIFE Inc GA Local
Savannah-Chatman County Fair Housing Council, Inc GA Local
Walton Options for Independent Living Inc GA Local
Concrete Change GA National
Shepherd Center GA National
Atlanta Alliance on Developmental Disabilities GA State
Coalition on Disabilities Education (C.O.D.E.) GA State
Demanding Equal Access for All (D.E.A.F.) GA State
Federation of Families for Children's MH GA State
GA DD Council GA State
Georgia Advocacy Office GA State
Georgia Parent Support Network GA State
Georgia State Independent Living Council GA State
Let's Get Together GA State
North GA Wheelers GA State
Osteogenesis Imperfecta Council of GA State
Roosevelt Warm Springs Institute for Rehab. GA State
People First of GA State

Hawaii
Environmental Illness Assn of Hawaii HI Local
Disability Rights Hawaii HI State
Environmental Illness Assn of HI State
HI SILC HI State

Iowa
Evert Conner Rights & Resources CIL IA Local
South Central Iowa CIL IA Local
Three Rivers Independent Living Center IA Local
IA Dept of Human Rights Div. of Persons w Disabilities IA State
IA Human Rights Commission IA State
Iowa Creative Employment Options IA State
Iowa SILC IA State
Iowans with Disabilities Exercising Advocacy Skills IA State
the Arc of Iowa IA State

Idaho
Disability Action Center - NW, Inc ID Local
Living Independently for Everyone, LIFE ID Local
Comprehensive Advocacy ID State
Idaho State Indpendent Living Council ID State
Intermountain Fair Housing Council ID State

Illinois
Access Living IL Local

CCE IL Local
Community Service Options IL Local
Council for Disability Rights IL Local
Headlines: Brain Injury Support Group IL Local
Health & Policy Research Group IL Local
Illinois Client Assistance Program IL Local
Illinois/Iowa Center for Independent Living IL Local
IMPACT IL Local
LIFE CIL IL Local
Metro Seniors in Action IL Local
Multiple Chemical Sensitivities: Health & Environment IL Local
Mycare Home Medical Supplies Inc IL Local
Northwestern ILC for IL Local
Options CIL IL Local
PACE Inc IL Local
Progress Center for IL IL Local
RAMP Center for Independent Living IL Local
Soyland Access to Independence IL Local
Springfield Center for IL IL Local
United Cerebral Palsy /Greater Chicago IL Local
Campaign for Better Health Care IL State
Coalition of Citizens with Disabilities in IL IL State
Equip for Equality IL State
Great Lakes ADA IL State
IL Network of C.I.L.s IL State
IL State Council of Senior Citizens IL State
IL State Rehabilitation Council IL State
IL Valley Center for IL IL State
Statewide Independent Living Council of IL IL State

Indiana
Everybody Counts IN Local
Indianapolis Resource Center for Independent Living IN Local
League for the Blind & Disabled IN Local
SICIL IN Local
IN Instititute on Disability & Culture - IU IN State
Indiana Council on IL IN State

Kansas
American Legion Post 400 SAL KS Local
CIL of SW KS Local
Coalition for Independence KS Local
Community Accessibility Awareness Task Force KS Local
Developmental Services of NW KS Local
Grandmothers, Aunts, Mothers, Sisters & Supports KS Local
Head Injury Support Group KS Local

Independence Inc KS Local
LINK KS Local
Prairie Independent Living Resource Center KS Local
Professional Home Health Services KS Local
Resource CIL KS Local
Self Help for the Hard of Hearing Western KS Grp KS Local
Southeast Kansas Independent Living KS Local
Three Rivers KS Local
Topeka IL Resource Center KS Local
Western KS Association on Concerns of the Disabled KS Local
Youth Advocacy KS Local
CLASS CTD KS State
Kansas Assn of Centers for Independent Living KS State
Kansas Association of the Deaf KS State
Kansas Commission on Disability Concerns KS State
Kansas Disability Rights Action Coalition for Hsg KS State
Kansas Nurses Association KS State
KS Council on DD KS State
KS SILC KS State
KS State Chapter WAPD KS State
KS TASH KS State

Kentucky
Innovative Solutions Inc KY Local
Access to the Arts KY State
KY DD Council KY State
KY SILC KY State

Louisiana
Absolute Care Enterprises, Inc LA Local
Families Helping Families LA Local
New Horizons Independent Living Center LA Local
Resources for Independent Living LA Local
Resources for Independent Living LA Local
Southwest Louisiana Independence Center LA Local
Vestial Home Health Care Resources Corp. LA Local
Families Helping Families of Greater New Orleans LA State
Advocacy Center LA State

Massachusetts
Boston Center for Independent Living MA Local
Cape Organization for Rights of/the Disabled CORD MA Local
Center for Living and Working MA Local
Greater Boston Arc, Inc. MA Local
ILC - the North Shore & Cape Ann MA Local
JAM Specialists MA Local

Metrowest Center for Independent Living MA Local
North Shore Arc MA Local
Northeast Independent Living Program MA Local
Rights for Equality and Dignity for the Disabled MA Local
Stavros ILC MA Local
Disability Law Center MA State
MA Arc MA State
MA Office on Disability MA State
MA Statewide Independent Living Council MA State
MA Statewide Personal Assistance Coalit MA State

Maryland
Baltimoreans Against disAbility Discrimination. MD Local
Calvert County Comm for Indivs w Disabs MD Local
Independence NOW MD Local
MCIL Resources for Independent Living MD Local
Montgomery Co Comm on People w Disabilities MD Local
Resources for Independence MD Local
Southern MD Center for LIFE MD Local
Southern MD Independent Living MD Local
The Freedom Center MD Local
Chemical Sensitivity Disorders Assn. MD State
MD Assoc. of Community Services MD State
MD Developmental Disabilities Council MD State
MD Disabilities Forum MD State
MD Statewide IL Council MD State
The Arc of Maryland MD State

Maine
Alpha One ME State
Maine Disabilities Coalition ME State

Michigan
Ann Arbor Center for Independent Living MI Local
ARC Detroit MI Local
Association for Community Advocacy MI Local
Blue Water Center for Independent Living MI Local
CIL of Mid Michigan MI Local
Kalamazoo Handicappers United Organization MI Local
People of Livonia Addressing Issues of Diversity MI Local
The Disability Network MI Local
Autism Society of Michigan MI State
MI Assn of Centers for Independent Living MI State
MI Developmental Disabilities Council MI State
MI Protection and Advocacy Service MI State
Michigan Disability Rights Center MI State

The Arc Michigan MI State
The Howell Group MI State
The Self Advocacy Network of MI State

Minnesota
Advocating Change Together MN Local
Center for IL of Northeastern MN Local
Independent Lifestyles, Inc MN Local
Metropolitan Center for Independent Living MN Local
S.M.I.L.E.S. MN Local
S.M.I.L.E.S. MN Local
S.M.I.L.E.S. MN Local
Southwestern Center for Independent Living MN Local
Stillwater Human Rights MN Local
The Disability Institute MN Local
MN Assoc. of Centers for Independent Living MN State
MN Governor's Council on Developmental Disability MN State
MN SILC MN State
Options IRCIL MN State
Out in the Valley MN State

Missouri
Access II Independent Living Center MO Local
Aging & Disability Coalition of Metro Kansas City MO Local
Bootheel Area Independent Living Services MO Local
Delta Center for Independent Living MO Local
Disabled Citizens Alliance for Independence MO Local
Independent Living Resource Center Inc MO Local
Jefferson County ARC MO Local
Living Independently for Everyone MO Local
Midland Empire Resources for Independent Living MO Local
NAPH Nat'l Assoc of Physically Handicapped MO Local
PARAQUAD Inc MO Local
Rural Advocates for Independent Living MO Local
St Francis Catholic Worker Community MO Local
St. Louis Civil Rights Enforcement Commission MO Local
The Whole Person MO Local
Tri-County Center for Independent Living MO Local
Warrensburg Independent Living Services MO Local
Disability Resource Association MO State
MO Governor's Council on Disability MO State
MO Head Injury Advisory Council MO State
MO Planning Council for DD MO State
MO Statewide Independent Living Council MO State
Special Education Associates, SEA MO State

Mississippi
Coalition of Citizens with Disabilities (MS) State
Living Independence for Everyone of Central MS Local
Living Independence is for Everyone of North MS Local
Living Independence is for Everyone of South MS Local
Parents United Together in Mississippi MS State

Montana
Living Independently for Today & Tomorrow LIFTT MT Local
Montana Independent Living Project MT Local
Summit Independent Living Center, Inc MT Local
Coalition of Montanans Concerned with Disabilities MT State
Montana Advocacy Program MT State
MT Independent Living Project MT State
Parents, Let's Unite for Kids PLUK MT State

Nebraska
The Arc of Lincoln/Lancaster County NE Local
League of Human Dignity NE State
NE Advocacy Services NE State
Nebraska Statewide Independent Living Council NE State

New Hampshire
Governor's Commission on Disability in NH State
Granite State IL Foundation NH State
Institute on Disability UAP @ UNH NH State
NH DD Council NH State
NH SILC NH State
NHHomeless@egroups.com NH State

New Jersey
Alliance for Disabled in Action NJ Local
Camden City ILC NJ Local
Center for Independent Living of South Jersey NJ Local
Disabled Advocates Working for Northwest DAWN NJ Local
Personal Assistant Service Program NJ Local
Progressive Center for Independent Living NJ Local
Warren County Advisory Council on Disabilities NJ Local
Monday Morning Proj - NJ DD Council NJ State
NJ DD Council NJ State
NJ MiCASSA Advocacy Coalition NJ State
NJ SILC NJ State

New Mexico
Independent Living Resource Center Albq NM Local
Independent Living Resources NM Local

San Juan CIL NM Local
Gov's Comm on Concerns o/t Handicapped NM State
NM DD Planning Council NM State
NM Legislative Health & Human Services Committee NM State
NM State Agency on Aging NM State
NM Statewide Independent Living Council NM State
Zia Chapter of the Paralyzed Veterans of America NM State

New York
SABE, Self Advocates Becoming Empowered NY
504 Democratic Club NY Local
Access to Independence of Cortland County NY Local
Action for a Better Community NY Local
Americans Demanding Access of NY Local
ARISE NY Local
Bronx Independent Living Services NY Local
Brooklyn Center for Ind. of the Disabled NY Local
Capital District Center for Independence NY Local
Cent. NY Self Adv. Grassroots Reg Organizing Prog NY Local
Center for Disability Rights NY Local
Disabled in Action of Greater Syracuse NY Local
Disabled in Action of Metro NY Local
Family Empowerment Council NY Local
Finger Lakes Independence Center NY Local
Greater Rochester Spina Bifida Association NY Local
Lakretz Creative Support Services NY Local
League of Women Voters of the Rochester Metro Area NY Local
Long Island Advocacy Center NY Local
Massena ILC NY Local
Mental Health Assoc. of the Southern Tier NY Local
Mental Health Association of Rochester/Monroe Co. NY Local
Metro Justice of Rochester NY Local
Niagara Frontier Center for Independent Living, Inc NY Local
North Country Center for Independence NY Local
Northern Regional CIL NY Local
P-FLAG Parents Family & Friends of Gays, Lesbians, Bisexuals & Transgendered NY Local
Public Interest Law Office of Rochester NY Local
Queens Independent Living Center NY Local
Resource Center for Accessible Living NY Local
Resource Center for Independent Living NY Local
Rochester Center for IL NY Local
Rochester Chpt. National Spinal Cord Inj. Assn NY Local
Rockland City Commission on Human Rights NY Local
Saratoga County Options for IL NY Local
Southern Tier Independence Center NY Local

Southwestern Independent Living Center NY Local
Staten Island CIL NY Local
Staten Island Independent Living Assoc. NY Local
Suffolk Independent Living Org. SILO NY Local
Taconic Resources for Independent Living NY Local
The Arc of Monroe County NY Local
The Health Association NY Local
Tomorrow's Future Self Advocacy Group NY Local
Westchester Disabled on the Move, Inc NY Local
Access to Independence & Mobility NY State
Grassroots Regional Organizing Program NY State
Mental Patients Liberation Alliance of NY State
NY SILC NY State
NY State DD Planning Council NY State
NY State Independent Living Council NY State
NY State Institute on Disability, Inc NY State
Self-Advocacy Association of New York State NY State

North Carolina
Gaston Residential Services Inc NC Local
Pathways for the Future NC Local
Ron Mace Center for Disability Community Devel. NC Local
Western Alliance NC Local
NC Statewide Independent Living Council NC State

North Dakota
Dakota CIL ND Local
Freedom Resource Center, Fargo ND Local
North Dakota Disabilities Advocacy Consortium ND State

Ohio
Ability Center of Greater Toledo OH Local
Access Center for Independent Living OH Local
Center for IL Options OH Local
Hamilton County Early Intervention Collaborative OH Local
ILC of N Central OH Local
LEAP Center for IL OH Local
Lorain County Coalition of Citizens w/ Disabs. OH Local
Mid-Ohio Board for IL Envirn. MOBILE OH Local
Services for Independent Living, Inc OH Local
Society for Equal Access OH Local
the Inclusion Network OH Local
Tri-County Independent Living Center OH Local
Irene Ward & Associates OH State
Ohio Assoc. of Centers for Independent Living OH State
Ohio DD Council OH State

Ohio Personal Assistance for IL, OPAIL OH State
Ohio Personal Assistance Services Coalition OH State
Ohio Statewide Independent Living Council OH State
OH Disability Action Coalition OH State

Oklahoma
Ability Resources OK Local
Progressive Independence OK Local
National MS Society - OK Chapter OK State
Office of Handicapped Concerns OK State
OK SILC OK State
Oklahoma Conference of Churches Impact Committee OK State
Oklahoma Parent Network OK State
Oklahomans for IL OK State

Oregon
Community Partnerships OR Local
Independent Living Resources OR Local
OR SILC OR State
Oregon Developmental Disabilities Coalition OR State
Oregon Disabilities Commission OR State

Pennsylvania
Abilities In Motion PA Local
Anthracite Reg Cen for Independent Living PA Local
Area Agency on Aging Office of Human Services PA Local
Bucks County Area Agency on Aging PA Local
CARIE Cent for Advcy f/t Rights Intrts of the Elderly PA Local
CIL of Central PA Local
CIL of North Central PA PA Local
CIL of South Central PA Local
Citizens for Independence and Access PA Local
Consumer Connection PA Local
Disabled in Action of Philadelphia PA Local
Freedom Valley Disability Center PA Local
Lawrence County Comm on Disability PA Local
Lehigh Valley Center for Indpendent Living PA Local
Liberty Resources PA Local
LIFT PA Local
Lupus Foundation of SE PA Local
National MS Society - Greater Delaware Valley Chpt PA Local
NE PA Center for Independent Living PA Local
Partnership for Choice PA Local
Pittsburgh Area Brain Injury Alliance PA Local
Three Rivers Center for Independent Living PA Local
TRIPIL PA Local

United Cerebral Palsy of Philadelphia PA Local
United Cerebral Palsy of Pittsburgh PA Local
Voices for Independence PA Local
Disabilities Law Project PA State
PA Action Coalition in Disability Rights in Housing PA State
PA Assn of Area Agency on Aging PA State
PA Coalition of Citizens with Disabilities PA State
PA Council of the Blind PA State
PA Council on Independent Living PA State
PA Developmental Disabilities Council PA State
PA Statewide Independent Living Council PA State
Speaking for Ourselves PA State
UCP of PA State
Interfaith Specialty Services PA Local

South Carolina
Access Resorts Inc. SC Local
Disability Resource Center SC Local
Pathways For the Future SC Local
SC SILC SC State
SC State Chapter WAPD SC State

Tennessee
Buffalo River Services TN Local
CIL of Middle Tennessee TN Local
Disability Resource Center TN Local
East TN Technology Center TN Local
Memphis Center for Independent Living TN Local
Restructuring for Inclusive School Environments TN Local
Tennessee Disability Coalition TN State
Tennessee Network for Community Economic Devel TN State
TN Association for Disability Rights TN State
TN DD Council TN State

Texas
ABLE Area Base for Living Enrichment CIL TX Local
Austin Mayor's Committee for People w Disabilities TX Local
Austin Resource Cen for Independent Living TX Local
Brazoria County Center for IL BCCIL TX Local
Central TX Coalition on Aging & DD TX Local
Central TX Rehab Assn TX Local
Crockett Resource Center for Independent Living TX Local
GMSA Management Group TX Local
Greater Austin PVA TX Local
Houston Area Women's Center TX Local
Houston Center for Independent Living TX Local

Panhandle Independent Living Center TX Local
Parents as Case Managers TX Local
REACH Resource Centers on IL TX Local
RISE TX Local
San Antonio Independent Living Services, SAILS TX Local
TATP TX Local
Volar Center for Independent Living TX Local
Advocacy Inc. TX State
Advocates for Texans with Brain Injuries TX State
Brain Injury Association of Texas TX State
Coalition of Texans with Disabilities TX State
Disability Policy Consortium TX State
Disability Services of the Southwest TX State
Mental Health Association in Texas TX State
National Assoc of Social Workers - TX Chapter TX State
Texas Advocates TX State
Texas Advocates for Supporting Kids with Disabilities TX State
Texas Assn of Centers for Independent Living TX State
Texas Mental Health Consumers TX State
Texas Nurses Association TX State
Texas Planning Council for Devel Disabs TX State
Texas Rehabilitation Commission TX State
TX Civil Rights Project TX State
TX Health and Human Services Commission TX State
TX PVA TX State
TX SILC TX State
TX State Chapter WAPD TX State
United Cerebral Palsy of Texas TX State
University Affiliated Program, UT TX State

Utah
Active Re-Entry UT Local
Area Agency on Aging of Price UT Local
Concerned Citizens with Disabilities CCDC UT Local
Disabled Rights Action Committee, DRAC UT Local
Options for Independence UT Local
Red Rock Center for Independence UT Local
Utah Independent Living Center UT Local
ADA Consortium of Utah UT State
Association for Independent Living of Utah UT State
Disability Law Center UT State
Legislative Coalition for People with Disabilities UT State
Utah State Democratic Committee UT State
Utah Statewide Independent Living Council UT State

Virginia
Blue Ridge Independent Living Center VA Local
Brain Injury Services Inc VA Local
disAbility Resource Center of the Rappahannock Area VA Local
Endependence Center - Norfolk VA Local
Commonwealth Coalition for Community VA State
VA Statewide Independent Living Council VA State
VA TASH VA State
Virginia Assoc of People in Supported Employment VA State

Vermont
Vermont CIL VT State
Vermont Coalition for Disability Rights VT State

Washington
Coastal Community Advocates WA Local
CORD WA Local
disAbility Resource Center WA Local
Inclusion Daily Express WA Local
Tacoma Area Coalition of Individuals w Disabilities TACID WA Local
Alzheimers Society of Washington WA State
Arc of Washington State WA State
disAbility Resources of Southwest WA State
Gov's Comm on Disability Issues & Emp - WA State WA State
Project PAS-Port for Change WA State
WA Protection and Advocacy WA State
WA SILC WA State
Washington Coalition of Citizens with Disabilities WA State

Wisconsin
Access to Independence, Madison WI Local
ARC-Milwaukee WI Local
Aurora Community Services WI Local
CIL for Western Wisconsin WI Local
Community Living Alliance WI Local
Disabled Womyn's Education Project WI Local
Easter Seals of SE Wisconsin WI Local
Employment Resources Inc. WI Local
Independence First WI Local
North Country Independent Living WI Local
Options for Independent Living WI Local
Pierce County Dept. of Human Services WI Local
Ranch Community Services WI Local
St. Clare Management, Inc WI Local
United Cerebral Palsy of SE Wisconsin WI Local
ARC - Wisconsin WI State

Aurora Residential Services WI State
Brain Injury Assoc. of WI State
Client Assistance Program of WI State
National Multiple Sclerosis Society of WI State
Older Adult Service Provider's Consortium WI State
People First Wisconsin WI State
Rehabilitation for Wisconsin WI State
State Independent Living Council WI State
State Rehabilitation Planning & Advisory Council WI State
United Cerebral Palsy of WI State
WI Coalition for Advocacy - Milwaukee WI State
WI Coalition of IL Centers WI State
WI Council on Developmental Disabilities WI State
WI Council on Physical Disabilities WI State
WI Gov's Comm for People w Disabilities WI State
WI Nurses Assoc WI State
WI Rehabilitation Assn. WI State
WI SILC WI State
WI Coalition for Advocacy - Madison WI
Parents Education Project of WI State

West Virginia
Huntington WV Grassroots Advocacy Project WV Local
Mountain State CILs - Huntington WV Local
Northern WV CIL WV Local
WV SILC WV State
WY SILC WY State

Appendix 4

MEDICAID LONG TERM CARE DATA – 2005

(September 2004 through September 2005)

Total Medicaid	***$300.3 billion***	
Total Long Term Care (LTC)	***94.5 billion***	
	LTC - 31.78% of Medicaid	
##########		
Nursing Homes	***$ 47.24 billion***	***50.0% of LTC***
ICF-MR (public)	***7.54 billion***	***8.0%***
ICF-MR (private)	***4.56 billion***	***4.8%***
Total Institutional	***59.34 billion***	***62.8%***
Personal Care	***$ 8.57 billion***	
HCBS Waivers	***22.70 billion***	
Home Health	***3.57 billion***	
Home and Community Services	***.32 billion***	
Total Community	***$ 35.16 billion***	***37.2%***

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HCBS WAIVER BREAKDOWN 2005 BY CATEGORY

Total HCBS Waivers	***$ 22.70 billion***	
MR/DD	***$ 17.03 billion***	***75.34%***
Aged/Disabled	***3.942 billion***	***17.44%***
Physical Disability	***.722 billion***	***3.20%***
Aged	***.470 billion***	***2.07%***
Tech Dependent	***.109 billion***	***.48%***
Brain Injury	***.230 billion***	***1.02%***
HIV/AIDS	***.062 billion***	***.27%***
Mental Illness/SED	***.040 billion***	***.18%***

Numbers are taken from a report by MEDSTAT (www.medstat.com)
The MEDSTAT Group Inc. – (617)492-9300
MEDSTAT data taken from CMS 64 reports submitted by the states
Compiled by ADAPT – July 2006 (All numbers are rounded off)
www.adapt.org 512/442-0252

Mr. PALLONE. Thank you, Ms. Thomas. I am going to ask again that, everyone is running over, try to limit it to 5 minutes. Next is Mr. Gronefeld.

STATEMENT OF RALPH GRONEFELD, PRESIDENT AND CHIEF EXECUTIVE OFFICER, RESCARE

Mr. GRONEFELD. Good morning, Chairman and members of the subcommittee. Thank you for inviting me to be here today.

It has been our privilege to provide services to people with intellectual and developmental disabilities in nearly every setting for more than 30 years. During that time we have been a Medicaid paid provider and have successfully forged public-private partnerships in 37 States. We also operate job centers, workforce and one-stop services and provide home care to senior citizens. We are a human services company whose mission is to maximize independence for all populations who rely on us. We serve more than 65,000 people every day with more than 42,000 dedicated employees.

The efforts by Congress, the administration and the States to rebalance the long-term-care system to more home and community services have led to more flexibility, individual control, desirable options and cost-effective services. As you know, Medicaid is the only funding source for services to most individuals with disabilities. The Medicaid budgets are strapped. The demand for services is exploding while at the same time the available workforce is shrinking.

For years individual States have essentially been running pilot programs testing different waiver options. Currently there are hundreds of waivers spread through 50 States and yet in some States there remains significant deterrence to home and community services. States continue to fund institutional services at higher rates, offering cost reimbursement, room and board subsidies and other incentives that are not given to waiver services. At the same time, many of the waivers have become overly complex, inflexible and very expensive. As the cost of care rises, States have responded by limiting services, restricting eligibility and reducing payments. Under these pressures, the waiting lists have grown along with Medicaid budgets and services to those with disabilities who must look at all models of care and find the few that provide the best outcomes for the most people. We must move away from models that are ineffective and costly.

Refining our service models is one solution but the greatest challenge to all services is the Nation's workforce crisis. We must have a competent and caring workforce. Any discussion of changes or improvements to Medicaid policy should focus on this fundamental issue. High turnover rates, low wages, shortage of available workers and increased demand are pervasive problems for families, individuals receiving services and the people who provide those services. Barely 10 percent of the 4.3 million people with intellectual and developmental disabilities receive Medicaid services. That 10 percent demands on more than 874,000 caregivers. By 2020, we will need nearly a million and a half workers. That is a 37 percent increase in need but there will be a corresponding decrease in the number of people available to do the jobs. Soon we won't be able to find the people willing to care for the individuals that we serve.

One solution to the workforce crisis is the Direct Support Professional Fairness and Security Act, H.R. 1279, which was reintroduced in the 110th Congress by Representatives Lois Capps and Lee Terry. This bill, which now has 107 cosponsors, gives States a much-needed option to secure additional Federal Medicaid dollars for the workforce. This bill is an investment in a workforce that is needed to ensure the stability of home- and community-based services.

Congress should also consider legislation to develop incentives such as training programs and career advancement opportunities which would enable more people to enter this field. Such efforts should make better use of the public workforce system by getting the Department of Labor to change its guidelines for civil employment and recognize direct support professional as an accepted job classification.

We also need to address our service models to more effectively use our workforce. New models of care such as ones that use technology to provide safe, secure services with fewer caregivers can be the answer. An example is Rest Assured, which is currently being piloted in Indiana which is a public-private partnership between ResCare, the Wabash Center, a nonprofit organization, and Purdue University. It is a web-based telecare system that is proved to be very successful. Through this pilot we have found that individuals who receive remote care-giving services show greater satisfaction with the added independence they experience. Savings can be realized that would enable us to serve more people for the same amount of money.

There are many people and organizations involved in providing services and supports to those with intellectual and developmental disabilities. I ask that providers been included in the search for solutions. The challenges I am suggesting today can assure the safety, security and independence for those we serve, simply the system, therefore it would be more cost-effective, standardize best practices, therefore providing better outcomes, and attract committed, dedicated caregivers.

Thank you for your time today. I will be happy to answer questions to provide additional information.

[The prepared statement of Mr. Gronefeld follows:]

TESTIMONY OF RALPH GRONEFELD

Good morning Chairman and members of the subcommittee. Thank you for inviting me to be here today. I am Ralph Gronefeld, president and CEO of ResCare. It has been our privilege to provide services to people with intellectual and developmental disabilities in nearly every setting for more than 30 years. For all of that time we've been a Medicaid paid provider and have successfully forged public/private partnerships in 37 states.

We also operate Job Corps centers, have workforce and one-stop services, and provide home care to senior citizens. We are a human services company whose mission is to maximize independence for all the populations who rely on us. We serve more than 65,000 people every day with more than 42,000 employees.

The efforts by Congress, the Administration and the States to "rebalance" the long term care system to more home and community services have led to more flexibility, individual control, desirable options and cost-effective services. As you know, Medicaid is the only funding source for services to most individuals with disabilities. But Medicaid budgets are strapped, the demand for services is exploding at the same time the available workforce is shrinking. Let me talk about some of the challenges and some solutions as we see them.

For years, individual states have essentially been running pilot programs testing different waiver options. Currently, there are hundreds of waivers spread through 50 states. And

yet, in some states there remain significant deterrents to home and community services. States continue to fund institutional services at higher rates offering cost reimbursement, room and board subsidies and other incentives that are not given to waiver services. At the same time, many of the waivers have become overly complex, inflexible and very expensive. As the costs of care rise, states have responded by limiting services, restricting eligibility and reducing payments. Under these pressures the waiting lists have grown along with the Medicaid budgets. In services to those with disabilities, we must look at all the models of care and find the few that provide the best outcomes for the most people We must move away from models that are ineffective and costly.

Refining our service models is one solution, but the greatest challenge to all services is the nation's workforce crisis. We have to have a competent and caring workforce. Any discussion of changes or improvements to Medicaid policy should focus on this fundamental issue. High turnover rates, low wages, shortage of available workers and increased demand are pervasive problems for families, individuals receiving services and the people who provide those services.

Barely 10% of the 4.3 million people with intellectual and development disabilities receive Medicaid services. That 10% depends on more than 874,000 care givers. By 2020, we will need nearly a million and a half workers. That's a 37% increase in need but there will be a corresponding decrease in the number of people available to do the jobs. Soon we won't be able to find the people willing to care for the individuals we serve.

One solution to the workforce crisis is the Direct Support Professionals Fairness and Security Act (H.R. 1279), which was re-introduced in the 110th Congress by Representatives Lois Capps (D-CA) and Lee Terry (R-NE). This bill, which now has 107 co-sponsors, gives states a much needed option to secure additional federal Medicaid dollars for the workforce. This bill is an investment in a workforce that is needed to ensure the stability of home and community based services.

Congress should also consider legislation to develop incentives, such as training programs and career advancement opportunities, which would enable more people to enter this field. Such efforts should also better use the public workforce system by getting DOL to change its guidelines for successful employment and recognize "direct support professional" as an accepted job classification.

We also need to address our service models to more effectively use our workforce. New models of care such as one that uses technology to provide safe, secure services with fewer caregivers can be an answer. For example, Rest Assured©, which is currently being piloted in Indiana through a public/private partnership among ResCare, the non-profit Wabash Center and Purdue University. It is a web-based, telecare system that's proved to be very successful.

We found that individuals who receive remote caregiving services show a greater satisfaction with the added independence they experience. And savings can be realized that would enable us to serve many more people for the same amount of money.

There are many people and organizations involved in providing services and supports to those with intellectual and developmental disabilities. I ask that providers be included in the search for those solutions.

The changes I'm suggesting today can ensure the safety, security and independence for those we serve, simplify the system; standardize best practices; and attract committed dedicated care givers.

Thank you for your time today. I will be happy to answer questions or provide addition information.

Mr. PALLONE. Thank you, Mr. Gronefeld, and now Ms. Fortin.

STATEMENT OF CELINE FORTIN, ASSOCIATE EXECUTIVE DIRECTOR, THE ARC OF NEW JERSEY

Ms. FORTIN. Good morning. I am Celine Fortin, an associate executive director of The Arc of New Jersey. We are New Jersey's oldest and largest advocacy organization for children and adults with intellectual and developmental disabilities and their families. I want to thank Chairman Pallone and the distinguished members of the subcommittee for recognizing the concerns of this most vulnerable population.

You have received my written statement so I am only going to highlight two issues now: recent rule proposals made by the Centers for Medicare and Medicaid Services, CMS, that will have a potentially catastrophic impact on individuals with intellectual and developmental disabilities, and pending Federal legislation that will positively impact this population.

At the outset, it is important to underscore that despite improvements that can be made, Medicaid works, and it is a critical lifeline for our country's most vulnerable populations. For many people with disabilities, Medicaid is the only source of funding that helps ensure that they can live and work in their own communities and avoid costly and segregated alternatives. With that said, we have serious concerns with CMS's recent proposed rule changes. First, CMS's interim final rule on case management goes well beyond the policies established by Congress in the Deficit Reduction Act of 2005. The Arc of New Jersey has many concerns with regards to this rule, which are included in my written testimony. For example, current Medicaid policy provides Federal reimbursement for States for transitional case management services for the last 180 days of an individual's stay in an institution. This funding is critical to ensure that people move from institutions into community settings successfully. The interim final rule reduces reimbursement from 180 to 60 days, which is not even close to sufficient for these difficult transitions.

Second, CMS's proposed rule on rehabilitative services is also of great concern as it creates new obstacles for Medicaid beneficiaries to receive medically necessary rehabilitative services. The proposed rule would severely harm people with intellectual and other developmental disabilities by eliminating longstanding day rehabilitation programs for many people with disabilities. It also imposes a discriminatory and arbitrary exclusion from receiving many rehabilitative services for many people with intellectual disabilities and related conditions. These services enhance the independence of people with disabilities and removing them is extremely problematic.

Third, CMS published a final rule to address school-based services and transportation. While the final rule is attempting to address legitimate policy issues, we believe that it constitutes bad fiscal and social policy. The savings to the Federal coffers will be miniscule compared to the enormous impact on school systems which rely on appropriate Medicaid reimbursement to serve children with disabilities. This rule will likely result in greater need for Medicaid services and expense in the future since services not delivered to children can exacerbate their disability and result in more costly

treatment in adulthood. It is important to note, however, that the Protecting Children's Health in Schools Act of 2007 would provide a commonsense solution to this dilemma without unduly harming school systems and students with disabilities.

In addition, we would like to thank you, Chairman Pallone, for your leadership in securing a 6-month moratorium on rehabilitative services and school-based services transportation regulations. We strongly urge Congress to either extend this moratorium and include the case management regulation for at least 12 months or pass legislation to fix the policy changes embodied in these Medicaid regulations.

I would now like to briefly address pending legislation that will positively impact people with disabilities. In particular, thank you to Chairman Pallone for sponsoring the Community Living Assistance Services and Supports Act. The CLASS Act creates a national insurance program to help adults who have or develop functional impairments so that they may remain independent, employed and a part of their community. Funded through a modest voluntary payroll deduction, the CLASS Act would allow individuals to access supports and services without requiring them to spend down their assets and become impoverished to qualify for Medicaid.

A second piece of important legislation which we strongly support is the Community Choice Act, which emphasizes person-centered planning and self-directed services. As you have heard, the Community Choice Act is a step in the right direction for both the Medicaid program and individuals requiring long-term supports.

The Arc of New Jersey urges Congress to swiftly pass these two critical pieces of legislation as well as other legislation which I mentioned in my written statement. We look forward to working with you, Chairman Pallone and other members of the subcommittee, on these and other issues affecting individuals with intellectual and other developmental disabilities and their families.

[The prepared statement of Ms. Fortin follows:]

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Testimony of Celine Fortin, Associate Executive Director
The Arc of New Jersey

Before the House Energy and Commerce Committee
Subcommittee on Health

Helping Families with Needed Care: Medicaid's Critical Role for
Americans with Disabilities

Wednesday, January 16, 2008

The Arc of New Jersey is the largest statewide advocacy organization in New Jersey for individuals with intellectual and other developmental disabilities and their families. We serve over 18,000 member families statewide, and advocate on behalf and along side of more than 200,000 individuals with developmental disabilities in New Jersey. The Arc of New Jersey is a chapter of The Arc of the United States which includes more than 140,000 members affiliated through more than 850 state and local chapters across the nation, whose mission, like our own, is to advocate for the rights and full participation of all children and adults with intellectual and developmental disabilities.

The Arc of New Jersey thanks Chairman Pallone and distinguished members of the Subcommittee on Health for recognizing the concerns of individuals with intellectual and other developmental disabilities and their families.

Our comments today will focus on pending federal legislation that will impact individuals with developmental disabilities as well as recent rule proposals made by the Centers for Medicare and Medicaid Services (CMS) that will have a potentially catastrophic impact on individuals with intellectual and other developmental disabilities three of which are most alarming: case management and targeted case management services, the rehabilitative services option, and school based services and transportation.

Medicaid is a critical safety net for low income children and adults with disabilities. Medicaid works and it is the critical life line for our country's most vulnerable populations. However, improvements need to be made and Congress must address the harmful actions CMS is taking that will likely sever this critical line for many.

For children with all types of disabilities, access to the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit, with its variety of screenings, services, and therapies, can often make a major difference in their lives. Access to these critical services is what enables them to lead healthy and more active lives; avoid additional disabilities; continue to live at home with their families; and make it through school. Children with disabilities also receive educationally related services such as occupational, physical, or speech

therapies through Medicaid that help them succeed in school. These children can then grow up within their own communities and can get jobs and be contributing members of society.

Medicaid works and is the critical life line for our country's most vulnerable populations. With that said, the recent CMS rules discussed below could sever access to critically-needed services for many of the individuals who so desperately need them.

For many people with intellectual (formerly referred to as mental retardation) and other types of disabilities, Medicaid generally is the only source of funds for them to live and work in their community with friends and families and avoid costly and segregated nursing homes or institutions.

For people with epilepsy, mental illness, HIV, and a variety of other conditions, Medicaid is very often the only source of access to essential prescription drug coverage.

For people with a variety of physical disabilities, such as spinal cord injuries, traumatic brain injuries, cerebral palsy, or amputations, Medicaid usually is the only way they can get access to durable medical equipment like wheelchairs or prosthetic devices, as well as assistive technology.

CMS Rule Proposals

Optional State Plan Case Management Services

Case management services are a critical Medicaid benefit that help millions of low-income children and adults with disabilities gain access to necessary services. Forty-nine states plus the District of Columbia provide targeted case management services to some populations of adults with disabilities and all states, in compliance with the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate, provide medically necessary case management services to children.

CMS has published an interim final rule (Optional State Plan Case Management Services, Federal Register, December 4, 2007) which goes well beyond the policies established by the Congress in the Deficit Reduction Act of 2005 (DRA). This rule needs to align with the statutorily-enacted policies of the DRA. According to CMS's projections, the interim final rule would save $1.28 billion over five years, an impact well

above the $760 million in savings projected by the Congressional Budget Office (CBO) when scoring the policy changes enacted by Congress in the DRA. This difference in the estimated impact on Medicaid spending itself is one indication that the rules go beyond what Congress intended.

Current Medicaid policy allows states to provide case management and targeted case management services to assist in the transition of a Medicaid beneficiary from an institution to the community. Federal reimbursement is available for case management provided during the last 180 days of the stay in the institution. This policy was issued in response to the U.S. Supreme Court's decision in L.C v. Olmstead, which found that the Americans with Disabilities Act requires states to provide services to individuals in the most integrated community settings that are appropriate to beneficiaries' needs. The interim final rule reduces federal reimbursement from 180 days to 60 days – an insufficient time, in many cases, to transition from an institution to the community.

Moreover, the interim final rule seriously undercuts the Bush Administration's Money Follows the Person Initiative. Transitioning people into the community is a difficult and complex process. It is necessary to assess an individual's support needs, arrange for Medicaid services, identify and obtain safe, affordable, and accessible housing, and arrange for other non-Medicaid services and supports. It is not reasonable to restrict case management services to a 60-day period.

Additionally, the provision in the interim final rule that providers can only be paid for transition case management services once an individual has successfully transitioned into the community undermines the system in place to provide necessary transitional services. This policy limits the pool of providers to those who could shoulder the financial delay and risk in order to serve as case management providers. The Arc of New Jersey is concerned that some case managers may be especially effective at providing case management services, and they may have unique capacities to work with certain populations yet they will be unable to serve as case managers because they do not have the financial resources to bear the risk that they will not be paid for

the services they provide. This will create a very real problem in New Jersey where community provider agencies are already underfunded and have not received sufficient cost of living increases in over a decade.

The Arc of New Jersey is also deeply concerned that CMS is imposing new restrictions that will limit access to medically necessary case management services to Medicaid-eligible individuals. We believe that these policies were not authorized by the Congress and will be extremely harmful to Medicaid beneficiaries.

The rules would also limit state flexibility by prohibiting a state from providing a beneficiary with more than one case manager even when the complexity of the beneficiary's condition demands the expertise of more than one program. In most cases, having one case manager would be beneficial to avoid duplication. However, if a beneficiary has multiple conditions, a single case manager may not be able to coordinate housing, health care, and social needs across multiple systems.

A central principle of the federal-state partnership to operate Medicaid is that states must follow federal guidelines but retain broad flexibility in establishing payment rates and determining payment policies. Disregarding this precept, the rules restrict state flexibility to determine payment methodologies in a way that could make Medicaid payments less efficient.

The rules would prohibit states from making fee-for-service payments for case management services in any way other than paying for units of service that do not exceed 15 minutes. States often use case rates, per diem rates, or other payment methodologies to pay for case management.

The DRA includes a list of activities that may not be included in case management under Medicaid, because they are services that are part of the foster care services delivered by child welfare agencies. While this is a policy established by the Congress, the interim final rule goes substantially further and would prohibit federal Medicaid funds for *all* case management services provided by child welfare and child protective services agencies and contractors of these agencies, regardless of whether the contractors are qualified Medicaid providers.

All children in Medicaid are eligible for case management services when the services are medically necessary. Some states provide medically necessary case management services to children with disabilities in school settings as part of a free and appropriate public education. The interim final rules would allow the provision of case management for children with disabilities in schools only when case management is designated as a required service in the child's Individualized Education Program or an infant or toddler's Individualized Family Service Plan. The rule specifically disallows the provision of case management when it is part of a child's plan under Section 504 of the Rehabilitation Act.

Taken together, these proposed limitations on case management services will have a significant impact on the ability of individuals with developmental disabilities to access critically-needed services.

Coverage for Rehabilitative Services

CMS's proposed rule (Coverage of Rehabilitative Service, Federal Register, August 13, 2007) is unnecessary and would not further the purposes of the Medicaid program. A central objective of the Medicaid program is to provide rehabilitative services. Not only does the proposed rule not further this core goal of Medicaid, it creates new obstacles for Medicaid beneficiaries to receive medically necessary rehabilitative services. This proposed rule would narrow the scope of services that providers have been providing under Medicaid, and impose requirements that will have a significant financial and administrative impact on providers.

We believe that the proposed rule would severely harm people with intellectual and other developmental disabilities in two major ways: 1) it eliminates longstanding programs for providing day habilitation services to many people with developmental disabilities by removing those services from the rehabilitative option and transferring them to a waiver thus capping the services; and 2) it imposes a discriminatory and arbitrary exclusion from receiving many rehabilitative services for many people with mental retardation and related conditions (a statutory term for people with intellectual and other developmental disabilities). These services

enhance the independence of people with intellectual disabilities and are critical to enabling them to move from institutions into the community.

In addition, The Arc of New Jersey believes that the proposed rule does not fully comply with Medicaid's Early Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate for children and would have a serious impact on children who are Medicaid beneficiaries. The EPSDT mandate requires that all Medicaid beneficiaries under age 21 must receive all necessary services listed in section 1905(a) of the Social Security Act to correct or ameliorate physical or mental illnesses and conditions, regardless of whether those services are covered under a state's Medicaid plan. CMS failed to include the EPSDT requirement, which if omitted could prohibit children from receiving services.

Elimination of Reimbursement under Medicaid for School Administration Expenditures and Costs Related to Transportation of School-Age Children between Home and School

CMS published a final rule on December 28, 2007 which is attempting to address legitimate policy issues in the proposed regulation, however, The Arc of New Jersey believes that the final rule constitutes bad fiscal and social policy. The "savings" to the federal coffers, $3.56 billion over 5 years, will be miniscule compared to the impact on those school systems which rely on appropriate Medicaid reimbursement to serve children with disabilities. Worse, the ultimate losers in this policy shift will be the children since we have no confidence that the school systems will come up with the lost funds to maintain the level of service they now provide. Thus vital related services will disappear based on funding availability, not service need. Knowing the value of related services for many special education students, this rule will likely actually result in greater need for Medicaid services and expense in the future since services not delivered to children can exacerbate their disability and result in more costly treatment in adulthood.

This new rule would usurp current and previous guidance provided by CMS to school systems. There is no basis for this rule – except to make a tiny dent in the federal deficit on the backs of poor children with disabilities – which in fact, will have a disproportionate impact on minority students who are overrepresented in special education.

While there may be a small number of school systems which are inappropriately billing Medicaid, the solution to this problem is not to punish all school systems by curtailing legitimate transportation and administrative expenses. The solution should be to eliminate the abuse by systematic enforcement of the current rule and guidance school system by school system, something we don't believe that CMS has seriously attempted. Rather than implementing its own policies, CMS instead chooses cut $3.6 billion over five years, thus imposing a huge and insurmountable burden on the schools. The vast majority of school systems affected by these cuts will have only one option: reduce services to the children. This proposed policy flies directly into the face of the Bush Administration's New Freedom Initiative which promises more, not less, services to make children and adults with disabilities more independent.

The local school is often the first and only avenue for families to learn about Medicaid and the services it offers. Yet this discriminatory rule would seriously damage the inter-relationship between schools and Medicaid, particularly for those school systems that have never violated a Medicaid rule or guidance. If the Congress does not act to extend the moratorium or pass legislation to fix CMS's proposed policy changes children with disabilities may not receive necessary services. Many children receive speech, language, hearing, occupational, and physical therapies. This rule could either totally eliminate or drastically reduce these services. In addition key personnel could possibly be eliminated including the therapists that provide those therapies previously mentioned, as well as school nurses, social workers, classroom aides, bus drivers and special education teachers. School buses will be less accessible affecting student with the most serious disabilities. School districts and parents could be pitted against one another if school authorities offer fewer services because of funding cuts.

The Arc of New Jersey would be remiss, if we failed to recognize the efforts and leadership of Chairman Dingell for his sponsorship, and Subcommittee Chairman Pallone's co-sponsorship, of H.R. 1017 or the Protecting Children's Health in Schools Act of 2007. The provisions of this bill would provide a common sense fix without unduly harming school systems that have never violated Medicaid policy and students with

disabilities who are doing their best to learn and become more independent. We urge the Congress to act immediately on this legislation.

In addition, The Arc of New Jersey would like to thank Chairman Pallone for his leadership in securing a six month moratorium on the rehabilitative services and school based services/transportation regulations in the "Medicare, Medicaid and SCHIP Extension Act of 2007." We also urge members of this Committee and the Congress as a whole to either extend the moratorium to include the recently proposed Medicaid regulations addressing case management and targeted case management for at least 12 months, or pass legislation, such as H.R. 1017 to fix the policy changes embodied in the proposed Medicaid regulations being discussed today.

Pending Federal Legislation

Despite the proposed Medicaid rules, the Congress has before it legislation that will positively impact individuals with disabilities and The Arc of New Jersey is grateful for the opportunity to discuss three of those bills. In particular, The Arc of New Jersey thanks Chairman Pallone for sponsoring H.R. 3001, better known as the "Community Living Assistance Services and Supports Act" or "CLASS Act."

Community Living Assistance Services and Supports Act (CLASS Act)

Many, if not most, Americans who have or develop severe functional impairments can only access coverage to services necessary for them to maintain their independence through the Medicaid program. In order to access critical services through the Medicaid program, individuals are forced to "spend down" assets, and to be blunt, impoverish themselves.

The CLASS Act provides an alternative to impoverishment and sole reliance on the Medicaid program. It creates a national insurance program to help adults who have or develop functional impairments so that they may remain independent, employed, and a part of their community. This legislation, funded through a modest voluntary payroll deduction, would help remove barriers to independence and choice that can be costly beyond imagination, by providing a cash benefit to those individuals who are unable to perform two or more functional activities of daily living such as communicating, taking medications, household management and basic money

management. The CLASS Act would allow individuals to access supports and services without requiring them to become impoverished to qualify for Medicaid.

The Act will also provide savings to individual states. As we all know, many states, including New Jersey, are facing soaring debt and limited revenues. If a person is eligible for benefits through the CLASS Act as well as long term services under Medicaid, CLASS Act benefits could be used to offset the costs to Medicaid, therefore producing savings for a state's Medicaid program.

Community Choice Act

The second piece of important legislation which The Arc of New Jersey supports, is H.R. 1621 or the Community Choice Act sponsored by Congressman Davis. This legislation would amend Medicaid to mandate state Medicaid plan coverage of community-based attendant services and supports for certain Medicaid-eligible individuals.

The support available under this bill would include services to assist individuals in accomplishing activities of daily living (ADLs), instrumental activities of daily living (IADLs), and health-related tasks through hands-on assistance, supervision, or cueing. Services must be provided in a home or community setting based on a written plan.

States would be required to establish a Development and Implementation Council to work with the state in developing and implementing the state plan amendment necessary in order to provide the services. The Council must have as a majority of its members people with disabilities, elderly individuals, or representatives of such individuals, and must collaborate with providers and advocates. Services must be made available statewide and must be provided in the most integrated setting appropriate for the individual.

With an emphasis on person-centered planning and self-directed services, the Community Choice Act is a critical piece of legislation for individuals with disabilities. The Medicaid program receives great attention for its cost. A major cost driver to the Medicaid program is nursing home care which is a mandatory service in the Medicaid program. Many individuals living in nursing homes do not want to be there nor would they need to

be there if attendant services and supports were available in a community based residential setting. The Community Choice Act is a step in the right direction for both the Medicaid program and individuals requiring long term supports.

Direct Support Professionals Fairness and Security Act

Another important piece of legislation is H.R.1279 or the Direct Support Professionals Fairness and Security Act of 2007 and we want to thank Congresswoman Capps for her sponsorship of this legislation. Direct support professionals are the keystone to the service delivery system for our most vulnerable populations.

Direct support professionals are personal care assistants, home care aides, or staff in community residential supports programs who assist people with disabilities with medications, preparing and eating meals, dressing, mobility, and their most intimate needs. Yet, there is a crisis in the availability of professionals to provide these direct supports. Many workers find that they can earn higher hourly wages, and receive better benefits, in far less demanding jobs. As a direct result, people with disabilities experience a revolving door of direct support workers causing trauma to the individual and their family.

Self-advocates, families, advocates, and service providers have worked for decades to ensure successful community living for all people with disabilities. When there is safety, security and stability in community based services and supports, people do better. We are all too familiar with the impact on quality of care when staff are provided with low wages and no benefits and high staff turnover results. It is also important to note that workers in the least desirable service setting - state-run institutions - are typically paid higher wages and receive better benefits than their counterparts providing highly valued community-based services and supports.

In short, this legislation would amend the Medicaid program to provide funds to states to enable them to increase the wages paid to targeted direct support professionals in providing services to individuals with disabilities. The program is designed as an option to states and would provide enhanced federal medical assistance percentage (FMAP) for five years to states to increase wages. It is designed to increase wages and eliminate the gap between wages paid to private employees and wages paid to public employees in the state.

The Administration and many in Congress are looking for ways to limit the Medicaid program. However, without enactment of this legislation, people with disabilities who need direct supports will continue to be made more vulnerable by the failure of the system to pay direct support professionals a living wage with critical health care and other benefits. This legislation is also in line with the Administration's New Freedom Initiatives intended to remove barriers to community living for people with disabilities.

Despite our fiscal constraints, community provider agencies continue to utilize cost efficient business practices to stretch dollars and provide quality services to vulnerable populations. Currently, the social services non-profit industry in New Jersey is nearly $1 billion in size, employs more than 8,000 people and engages and relies on the services of approximately 20,000 volunteers. In addition, community provider agencies have had to rely more and more on unstable sources of funding including fundraisers and private donations. Community provider agencies continue to provide essential services based on their commitment to their mission and values – the needs of New Jersey's most vulnerable populations must be met, crises notwithstanding. However, it is unclear how long they will continue to be able to do so.

Revisions to Deficit Reduction Act of 2005

While there is no specific piece of legislation pending, we believe that it is critical that Congress make some adjustments to the new Section 1915(i) home and community based services option which was enacted as part of the DRA (Section 6086, Expanded Access to Home and Community-Based Services for the Elderly and Disabled). Section 1915(i) establishes a new option for states to provide home and community-based services (HCBS) without states needing to use a waiver process and, with the requirement that states establish stricter eligibility (level of care) criteria for institutional services than for community-based services, for the first time, states will be able to offer services to people who would not otherwise qualify for the intuitional services. However, there are some barriers to full implementation by the states and concerns of consumers which need attention.

Section 1915(i) allows states to provide, under the new option, a few, but not all, of the services now covered under HCBS waivers. Section 1915(i) limits services to people with incomes below 150 percent of the federal poverty level. Further, Section 1915(i) allows states to cap the number of people to be served under the new HCBS Medicaid option, to provide these services in limited geographical areas of the state, and to maintain waiting lists for these services. Currently HCBS waiver beneficiaries who do not meet any new criteria established by the state in the future would have grandfather protection for as little as only one year.

To ensure that the HCBS option can provide optimal coverage for home and community-based services, we urge that the provision be amended to achieve the following:

- Remove the authority for states to cap services and maintain waiting lists;
- Allow states to provide the full range of services that can currently be provided under the HCBS waiver, including other services approved by the Secretary;
- Remove the limit on coverage of people with incomes up to 150 percent of poverty and allow the full range of income eligibility allowed for people in facility-based settings; and
- Eliminate the states' ability to limit services to certain sections of the states.

In conclusion, The Arc of New Jersey supports all three bills discussed above and improvements to the new home and community-based services option. We urge the Congress to act swiftly to pass legislation which would relieve the pressure on our Medicaid system and ensure employees and their families are covered by an affordable, premium-based long term support insurance program, can live in the community while receiving necessary attendant services, and assist states in the recruitment and retention of direct support professionals. We also strongly urge you to extend the current rehabilitative services option and school based services/transportation moratorium adding the interim final rule on case management and targeted case management, or to pass legislation to fix the policy changes embodied in these rules. We look forward to working with you, Chairman Pallone, and other members of this Subcommittee to better the health, safety and wellbeing of individuals with developmental disabilities, their families, and those that provide support services.

Summary

In addition to underscoring the importance of Medicaid to children and adults with intellectual and other developmental disabilities, The Arc of New Jersey will focus on pending federal legislation that will impact individuals with developmental disabilities as well as recent rule proposals made by the Centers for Medicare and Medicaid Services (CMS).

CMS Rule Proposals

Optional State Plan Case Management Services

CMS has published an interim final rule (Optional State Plan Case Management Services, Federal Register, December 4, 2007) which goes well beyond the policies established by the Congress in the Deficit Reduction Act of 2005 (DRA) and will have several deleterious effects on individuals with developmental disabilities.

Coverage for Rehabilitative Services

CMS's proposed rule (Coverage of Rehabilitative Service, Federal Register, August 13, 2007) is unnecessary and would not further the purposes of the Medicaid program. A central objective of the Medicaid program is to provide rehabilitative services. Not only does the proposed rule not further this core goal of Medicaid, it creates many new obstacles for Medicaid beneficiaries to receive medically necessary rehabilitative services.

Elimination of Reimbursement under Medicaid for School Administration Expenditures and Costs Related to Transportation of School-Age Children between Home and School

This new rule would usurp current and previous CMS guidance to school systems. There is no basis for this rule – except to make a tiny dent in the federal deficit on the backs of poor children with disabilities – which in fact, will have a disproportionate impact on minority students who are overrepresented in special education. To address CMS' policy concerns, Congress should pass the Protecting Children's Health in Schools Act of 2007. which would provide a common sense fix without unduly harming school systems that have never violated Medicaid policy and students with disabilities who are doing their best to learn and become more independent.

The Arc of New Jersey strongly urges Congress to:

1) Extend the recently passed 6-month moratorium on Medicaid's Rehabilitative Services and School Based Services/Transportation for at least 12 months and include provisions of the interim final rule on case management/targeted case management; or pass legislation, like H.R. 1017, that would fix the policies in these regulations

2) Pass the: Community Living Assistance Services and Supports Act (CLASS Act), Community Choice Act, Direct Support Professionals Fairness and Security Act of 2007 and make improvement to the Deficit Reduction Act of 2005.

Mr. PALLONE. Thank you. Exactly 5 minutes.
Ms. McCormick.

STATEMENT OF AILEEN MCCORMICK, PRESIDENT AND CHIEF EXECUTIVE OFFICER, AMERIGROUP TEXAS, INC.

Ms. MCCORMICK. Good morning, Chairman. I appreciate the invitation to be here today and I am from Houston, Texas, but I must admit, I got there via New Jersey and specifically Middlesex County, where I was born and raised.

I represent America's health insurance plans. If I may, I have expanded written testimony that I would like to submit for the record.

Mr. PALLONE. Where were you born in Middlesex County?

Ms. MCCORMICK. New Brunswick.

Mr. PALLONE. Oh, terrific.

Ms. MCCORMICK. We are here to discuss the crucial role that Medicaid plays in meeting the needs of people with disabilities. AHIP is a national trade association composed of 1,300 health plans which provide coverage to more than 200 million Americans. More than 300 AHIP plans bring health services to almost 20 million people served by Medicaid. I am CEO of one of those health plans, AmeriGroup Texas and southwest region CEO of AmeriGroup Corporation. Our company provides healthcare coverage to 1.7 million people in 10 States and the District of Columbia, all of whom are enrolled in Medicaid and other publicly funded programs. We have been working for 9 years to help Medicaid better serve people with disabilities through a nationally recognized program in Texas called Star Plus. AmeriGroup's chief executive officer, Jim Carlson, recently said, "We recognize that healthcare is often a cause of dependency for people with disabilities. Healthcare should not be the end for these individuals, it should be a means to an end, in this case, a full, self-sufficient and independent life." Star Plus has taught us that through innovation and hard work, Medicaid can offer Americans with disabilities a full, self-sufficient and independent life.

To explain what that really means, I want to tell you about Henry. Henry is 75 years old and lost everything in Hurricane Katrina. He relocated to Austin, where he knew no one. He had many major health problems including an aortic aneurysm and a history of seizures. When he got to Austin, he was suffering from dehydration and exhaustion. He was on 11 different prescription drugs. He was hospitalized and then went directly to a nursing home. Henry didn't want to be there. He wanted to take care of himself but he needed a little help. The expansion of Star Plus into Austin in February was a catalyst for that help. AmeriGroup service coordinators completed a detailed individual assessment of the kinds of services Henry needed to live independently. Working close with ADAPT, a wonderful organization and a valued partner of ours that is well represented here today, we helped him find and furnish an apartment. We connected Henry with attendant services, Meals on Wheels and an emergency response system to support his transition to the community. We again worked with ADAPT and made sure he saw a doctor and got his prescriptions filled when were faced with an obstacle from the nursing home in

trying to get him out. The result is that 9 months after leaving a nursing home, Henry is living on his own and hasn't been admitted to hospital care once. He is living the life he wants to live, and Star Plus is not only working for Henry, it is working as well for Texas taxpayers. By helping Henry avoid unnecessary stays in hospitals and nursing homes, Star Plus saves a lot of money.

The Texas Health and Human Service Commission has concluded that Star Plus sharply reduces inpatient hospital admissions and cuts overall healthcare costs by 6.5 percent. That is why after years of carefully nurturing Star Plus as a pilot program in Houston, the State recently expanded it to three more major metropolitan areas. Enrollment has more than doubled to 153,000. Star Plus is a rarity in American healthcare, a program that helps people live better, healthier lives and at the same time saves money. It does this by tailoring the healthcare system to fit the needs of individuals instead of forcing individuals into institutions that do not offer the right care or services for them.

There are other programs in other States like Star Plus but there are far too few of them. Star Plus is one of the oldest and most advanced. Others are still in various stages of development. We strongly urge Congress to support programs like this. For example, AmeriGroup has endorsed the Community Choice Community of 2007, House Resolution 1621. It would eliminate the historic bias in Medicaid, as has been discussed at length here, in institution-based healthcare and fund more community-based programs like Star Plus.

We at AHIP understand that Medicaid is not for everyone. Those who have adequate financial means must secure healthcare coverage that meets those needs. However, millions of Americans with disabilities cannot do this alone. As folks have said, Medicaid is their lifeline. We must and can make Medicaid work better both for Americans with disabilities who depend on it and for American taxpayers who finance it.

Thank you again, Mr. Chairman. I will be happy to take questions.

[The prepared statement of Ms. McCormick follows:]

Testimony on

"Helping Families with Needed Care: Medicaid's Critical Role for Americans with Disabilities"

by

Aileen McCormick
CEO, Southwest Region, AMERIGROUP Corporation
Representing America's Health Insurance Plans

Before the
U.S. House Energy and Commerce Committee
Subcommittee on Health

January 16, 2008

I. Introduction

Mr. Chairman, Congressman Deal, and members of the subcommittee, I am Aileen McCormick, CEO of the Southwest Region of AMERIGROUP Corporation. My company provides health care coverage to 1.7 million people in 10 states and the District of Columbia, all of whom are enrolled in Medicaid and other publicly funded programs. We have been working for nine years to help Medicaid better serve people with disabilities through a nationally-recognized program in Texas called STAR+PLUS.

I am testifying today on behalf of America's Health Insurance Plans (AHIP), which is the national association representing approximately 1,300 health insurance plans that provide coverage to more than 200 million Americans. AHIP's members offer a broad range of health insurance products in the commercial marketplace and also have demonstrated a strong commitment to participation in public programs.

We appreciate this opportunity to testify on the role Medicaid plays in meeting the health care needs of Americans with disabilities and, additionally, the innovative insurance products AHIP's members offer as financial protection for consumers against the high costs associated with long-term care and disability. We strongly support Medicaid's role as a health care safety net and we also are committed to ensuring that consumers have private sector options for meeting their future needs.

Our testimony today will focus on the leadership AHIP's members have demonstrated in three important areas: (1) providing high-quality health coverage to beneficiaries in state Medicaid programs; (2) offering long-term care insurance to provide Americans with financial protection against the risk of needing long-term care services; and (3) offering disability income insurance to help consumers replace lost income in the event that a disabling condition forces them to leave the workforce.

II. Health Plan Participation in Medicaid

Health insurance plans are making important contributions toward helping state Medicaid programs use their limited resources to expand access, improve quality, and better serve the health care needs of beneficiaries. In 2006, 19.8 million Medicaid beneficiaries – accounting for 43 percent of the Medicaid population – were enrolled in health plans providing comprehensive coverage. Nationwide, 314 health plans participate in state Medicaid programs.

Improved Care for Beneficiaries

Medicaid health plans have developed systems of coordinated care for ensuring that Medicaid beneficiaries receive health care services on a timely basis, while also emphasizing prevention and providing access to disease management services for those with chronic conditions. In general, each Medicaid beneficiary is encouraged to establish a relationship with a primary care physician who helps makes arrangements for specialty visits, hospital care, home health care, or other care he or she may need. The primary care physician ensures that each patient receives the best available care in the most appropriate setting, and oversees all of a patient's treatments and medications.

Coordinated care systems provide for the seamless delivery of health care services across the continuum of care. In other words, physician services, hospital care, prescription drugs, and other health care services are integrated and delivered through an organized system whose overriding purpose is to prevent illness, improve health status, and employ best practices to swiftly treat medical conditions that occur.

This approach is far superior to a system of uncoordinated care in which patients are forced to navigate a fragmented health care system on their own. Coordinated care provides the opportunity to reduce emergency room visits for routine care, and ensure prompt access to primary care physicians and specialists when care is needed. It also promotes communication between treating physicians about various treatments and medications a patient receives.

Innovative Programs

In a number of states, AHIP's members have partnered with Medicaid to create innovative programs for persons with disabilities and chronic conditions. These programs typically focus on decreasing the need for nursing home care, reducing hospitalizations, and increasing the number of elderly and persons with disabilities who can be better served in home and community settings. For beneficiaries, this means improved health outcomes and the opportunity to receive care in a familiar setting of their own choice.

The Texas STAR+PLUS program, for example, helps people live better, healthier lives and saves money at the same time. It does this by tailoring the health care system to fit the needs of individuals, instead of forcing individuals into institutions that do not offer the right care for them. This nationally recognized program currently serves 153,000 Medicaid beneficiaries.

From a budgetary standpoint, the Texas STAR+PLUS program reduced costs by 6.5 percent relative to FFS Medicaid[1]. The program also reduced emergency room use by 40 percent and inpatient admissions by 28 percent[2]. In addition, utilization of hospital services was reduced for beneficiaries with ambulatory care sensitive conditions (ACSC) – such as asthma, diabetes, and hypertension – that can be treated more effectively in an outpatient setting. Beneficiaries served by the Texas program include those who are dually eligible for both Medicare and Medicaid and beneficiaries eligible for Supplemental Security Income (SSI) benefits.

Another initiative, the Minnesota Senior Health Options program, combines health care and support services into a seamless package. According to the Centers for Medicare & Medicaid Services (CMS), dually eligible beneficiaries served by this program had fewer preventable emergency room visits and were more likely to receive preventive services after enrolling in a Medicaid health plan. The success of the Minnesota program is further evidenced by the fact that Medicaid enrollees reported a 94 percent satisfaction rate with their care coordinators.

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[1] Presentation by the Texas Health and Human Services Commission to the House Select Committee on Health Care Expenditures, February 2003

[2] Texas Health and Human Services Commission, Financial Impact of Proposed Managed Care Expansion in Texas, February 2005

We encourage Congress to support the expansion of these types of innovative programs. We thank several subcommittee members who have cosponsored legislation, H.R. 1621, the Community Choice Act, that recognizes the important role of personal care services in enabling individuals with disabilities who require an institutional level of care to receive services under state Medicaid programs in a home or community setting.

Value Demonstrated by Research Findings

Numerous research findings demonstrate that Medicaid health plans – by coordinating care, by emphasizing prevention, by offering disease management services to the chronically ill, and by developing innovative programs – are improving health care for many of our nation's most vulnerable citizens. For example:

- One study found that 77.5 percent of Medicaid health plans in northeastern states offered a registered dietician or certified nutritionist for obesity consultations, compared to 57.1 percent under Medicaid fee-for-service (FFS) programs. This study also showed that Medicaid health plans were almost four times more likely than FFS to offer obese patients other services such as discounted or free access to exercise facilities or weight loss centers[3].

- Hospitalizations for people with chronic conditions such as asthma, diabetes, and hypertension often can be reduced with timely and effective treatment in an outpatient setting. Over a six-year period, the average number of hospitalizations for beneficiaries with these chronic conditions was one-third lower for California Medicaid health plan enrollees than for those in FFS Medicaid[4].

- New York Medicaid health plan enrollees are much more likely to receive many critical preventive services than beneficiaries enrolled in FFS Medicaid. For example, 71 percent of

[3] Tsai, et al, Availability of Nutrition Services for Medicaid Recipients in the Northeastern United States: Lack of Uniformity and the Positive Effect of Managed Care (Am J Managed Care 2003;9:817-821).
[4] Bindman, et al, The Impact of Medicaid Managed Care on Hospitalizations for Ambulatory Care Sensitive Conditions (Health Serv Res. 2005 February; 40(1): 19-38).

women enrolled in Medicaid health plans were screened for cervical cancer within a three-year period, compared to 39 percent in FFS Medicaid[5].

- One commonly used indicator to measure the effectiveness of the health care system in delivering prenatal care is the incidence of low-weight birth rates. During 2004 and 2005, women who received care from Medicaid health plans in Washington experienced lower rates of low-weight births than women who received their services through FFS Medicaid[6].

Cost Savings for Medicaid

In addition to improving quality of care, Medicaid health plans help to ensure that the federal government and the states receive maximum value for the dollars they spend on Medicaid. Plans are advancing this goal through a variety of strategies, including encouraging preventive health care, managing prescription drug benefits, and providing disease management services that improve quality of life in a cost-effective manner. Several research studies have concluded that these strategies are generating savings for Medicaid:

- A 2004 synthesis of fourteen studies commissioned by AHIP found that savings of up to 19 percent are possible by effectively implementing Medicaid managed care programs. This study also found that these savings were achieved at the same time that Medicaid health plans demonstrated access and quality improvements.[7]

- A Lewin report found that the HealthChoices program in Pennsylvania saved the state more than $2.7 billion over a five-year period. This report also found that Medicaid health plans have significantly enhanced access and quality for beneficiaries, including those with special needs.[8]

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[5] Roohan, et al, Quality Measurement in Medicaid Managed Care and Fee-for-Service. (American Journal of Medical Quality, 2006; 21:185-191).

[6] Washington State Department of Social and Health Services, First Steps: Data Base Reports, 2004 and 2005.

[7] AHIP Report: Medicaid Managed Care Cost Savings – A Synthesis of Fourteen Studies, The Lewin Group, June 2004

[8] Comparative Evaluation of Pennsylvania's Health Choices Program and Fee-for-Service Program, The Lewin Group, May 2005

- The U.S. Department of Health and Human Services (HHS) estimated that the New York Medicaid managed care program created savings of nearly $6 billion over an eight-year period while expanding care to more than 400,000 people.[9]

AHIP/ADAPT Initiative

Recognizing that additional steps can be taken to meet the unique needs and circumstances of Medicaid beneficiaries with disabilities, AHIP has collaborated with ADAPT, a national disability rights organization, to develop principles for serving individuals with disabilities through Medicaid health plans. These principles address the following priorities:

- Training should be designed and conducted to ensure that community integration principles are advanced by the integration and delivery of acute and community long-term services.

- An ongoing dialogue with stakeholders, including individuals with disabilities, should be maintained in the development of Medicaid health plan contract requirements and in the design of Medicaid managed care programs.

- State Medicaid programs should include requirements and adequate funding to ensure that: (1) Medicaid health plans provide beneficiaries with the option for services to be delivered in the most integrated setting; and (2) services are based on a functional assessment outlined in a person-centered plan.

- An aggressive outreach and education strategy should be implemented to ensure that individuals with disabilities have the information they need to be knowledgeable about the programs and services available to them.

- Medicaid managed care programs that serve individuals with disabilities should offer home and community-based services as an option for beneficiaries regardless of their age or the extent of their disability.

[9] HHS Secretary Leavitt and New York Governor Pataki Announce Important Step Toward Medicaid Reform, U.S. Department of Health and Human Services Press Release, March 16, 2005.

- Beneficiaries should have the option of developing, negotiating, and implementing plans to accept risk for and take control of their activities of daily living, instrumental activities of daily living, and health maintenance activities.

- Funding should be provided for Medicaid coverage that allows individuals access to appropriate medically or functionally necessary durable medical equipment (DME) and assistive technology that would enhance independent functioning and promote independent living.

Looking forward, these principles will serve as a foundation for our ongoing collaboration as health plans work with states and individuals with disabilities to address their interests and concerns.

III. Long-Term Care Insurance

Approximately 7 million Americans have purchased private long-term care insurance and are benefiting from the peace of mind and higher quality of life this coverage provides. This includes some 5 million policies purchased in the individual market and up to 2 million in the group market.

Value for Consumers and Taxpayers

Long-term care insurance offers significant value to policyholders, family caregivers, and taxpayers.

According to an AHIP study, consumers with long-term care insurance are 66 percent less likely to become impoverished to pay the costs of long-term care. For elderly people with disabilities, long-term care insurance reduces out-of-pocket expenses by an average of $60,000 to $75,000. Our study also found that those with private long-term care insurance receive an average of 14 more hours of personal care per week than those who have similar needs but lack private insurance. Another benefit of long-term care insurance is that it allows persons with chronic

illnesses and disabilities to remain in their homes. Approximately half of patients and family caregivers interviewed by trained nurses and social workers said that in the absence of their long-term care insurance benefits, the patients would not be able to remain in their homes and would have to seek institutional alternatives[10]. Another AHIP survey, conducted in 2007, found that 97 percent of claims are approved by long-term care insurers[11].

Long-term care insurance also can reduce state and federal Medicaid expenditures and federal Medicare home health expenditures. According to the AHIP study[10] mentioned above, Medicaid savings are projected to total about $5,000 for each policyholder with long-term care insurance and Medicare savings are estimated to exceed $1,600 per policyholder. Aggregate savings to Medicare and Medicaid are estimated at about $30 billion. These savings will grow as more people acquire policies and the average age of purchasers continues to decline.

Long-term care insurance policies contain a wide range of benefit options at moderately priced premiums. For example:

- Long-term care insurance plans offer coverage of nursing home, assisted living facility, home health care, and hospice care. On a case-by-case basis, plans also provide certain alternate care services not listed in the policy (e.g., covering a stay in a special Alzheimer's facility or building a wheelchair ramp to allow the individual to remain in his or her home), subject to the policy's benefit limits.

- Other common benefits include care coordination or case management services, support with activities of daily living, medical equipment coverage, home-delivered meals, spousal discounts, and survivorship benefits. Plans also commonly cover caregiver training to ensure that caregivers learn basic techniques for safely caring for patients in their homes (e.g., transferring patients from their bed to a chair). In addition, virtually all plans cover respite care, designed to pay for brief periods of formal care to provide relief to caregivers.

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[10] AHIP, *Benefits of Long-Term Care Insurance: Enhanced Care for Disabled Elders, Improved Quality of Life for Caregivers and Savings to Medicare & Medicaid*, September 2002
[11] AHIP, Long-Term Care Insurance Claims and Rescissions, July 2007

The value of this coverage is particularly clear when costs are examined on an individual level. Genworth Financial, an AHIP member, has commissioned annual cost of care studies since 2001. The most recent study[12], based on information gathered in January and February 2007, includes the following findings:

- The average annual cost for a private nursing home room (single occupant) is $74,806 (a daily rate of $204.95).
- The average annual cost for a semi-private room (double occupancy) is $65,985 (a daily rate of $180.78).
- The average annual cost for a private one-bedroom unit in an assisted living facility is $32,572 (a daily rate of $89.24).
- The average hourly rate for certified home health aides is $32.37, while the average hourly rate for homemaker services is $17.46.

Many families do not have the resources to meet these high costs. However, for millions of Americans who purchase private long-term care insurance, these costs can be covered without depleting the patients' assets while providing them peace of mind in knowing that their families will not be burdened by unbearable financial obligations.

Who Buys Long-Term Care Insurance

AHIP recently commissioned a study[13], conducted by LifePlans, Inc., to identify who buys long-term care insurance in the individual market and understand what motivates them to do so. Ten insurance companies participated in this study, representing more than 80 percent of total sales of long-term care insurance policies in 2005. This study builds upon similar work completed in 1990, 1995, and 2000.

[12] Genworth Financial, 2007 Cost of Care Survey, March 2007
[13] LifePlans, Inc., Who Buys Long-Term Care Insurance? April 2007

The study's key findings include the following:

- The average age of individual purchasers of long-term care insurance declined from 67 years to 61 years between 2000 and 2005. Two-thirds of all individual long-term care policies sold are now purchased by people younger than 65. The major demographic differences between buyers and nonbuyers are that the latter tend to be somewhat older, less likely to be employed, and have lower incomes than buyers of long-term care insurance. In 2005, 71 percent of buyers had incomes exceeding $50,000, 13 percent had incomes between $35,000 and $50,000, and another 13 percent had incomes between $20,000 and $35,000.

- Buyers are twice as likely as nonbuyers to strongly agree that "it is important to plan now for the possibility of needing long-term care services." On another key statement, nonbuyers are twice as likely as buyers to agree that "the government will pay for most of the costs of long-term care if services are ever needed." Nonbuyers also were much more likely than buyers – 70 percent versus 14 percent – to underestimate the cost of nursing homes in their area.

- In examining the coverage offered by long-term care insurance policies, the study found a trend toward the purchase of comprehensive coverage. In 2005, 90 percent of policies sold were comprehensive (i.e., covering both institutional care and home care) – compared to 77 percent in 2000 and 37 percent in 1990. In addition, more than three-quarters of buyers chose some form of inflation protection in 2005, up from 41 percent in 2000.

- A highly significant finding from the 2005 study is that more than 80 percent of current nonbuyers would be more interested in buying a policy if they could deduct premiums from their taxes.

LTC Partnerships

AHIP strongly supports the expansion of public-private long-term care partnerships that Congress enacted under the Deficit Reduction Act of 2005 (DRA). The partnerships authorized by the DRA are allowing many Americans to receive the financial protection provided by long-

term care insurance while also ensuring that Medicaid will play a role in meeting the needs of those who require extended long-term care stays.

Building upon the innovative partnerships that originally were implemented in New York, California, Connecticut, and Indiana, the DRA creates powerful new incentives for more Americans all across the nation to prepare for the future by purchasing private long-term care insurance that coordinates with Medicaid. Specifically, in states adopting the partnership approach, individuals can purchase private long-term care insurance policies with the assurance that Medicaid will cover long-term care costs incurred beyond the terms of their private coverage. In these states, under the terms of the partnership, people with private insurance are not required to "spend down" their remaining assets to qualify for Medicaid.

At the end of 2007, nine states (Idaho, North Dakota, South Dakota, Minnesota, Nebraska, Ohio, Florida, Kansas and Virginia) had established operational partnership programs. All of these states modeled their partnership implementation rules after the *AHIP Qualified LTCI Partnership Proposed Implementation Guidelines*. Rollouts of additional partnership programs are expected in other states throughout 2008.

AHIP has been working closely with the states to assist in implementation of the partnership programs. We also worked with CMS to develop a uniform data set for state reporting on long-term care partnership programs and standards for reciprocity. Additionally, AHIP collaborated with the Robert Wood Johnson Foundation on a project that provided grants to the states to help with their implementation of partnerships.

In January 2007, AHIP released a study[14] projecting that the expanded long-term care partnerships could lead to federal budget savings of $6 billion annually (using constant 2005 dollars) in the Medicaid program by 2050. This is equivalent to $60 billion in federal savings over ten years in today's terms – and $100 billion if state budget savings are included.

[14] AHIP, Long-Term Care Insurance Partnerships: New Choices for Consumers – Potential Savings for Federal and State Government, January 2007

This study is based on assumptions that translate into the enrollment of approximately 35 million people in long-term care insurance by 2050 – compared to a baseline of fewer than 20 million that would be enrolled without the expansion of partnership programs. This increased sales of long-term care insurance is projected to reduce Medicaid costs because private long-term care insurance will be covering much of the care that otherwise would be paid by Medicaid.

Outreach and Education

In November 2007, AHIP released new survey findings showing that many Baby Boomers have misconceptions about who pays for long-term care services and have not thought about long-term care insurance. The survey, conducted for AHIP by StrategyOne, includes the following findings:

- Most Baby Boomers have not focused on planning for long-term care expenses. The survey data show that even among Baby Boomers nearing or at the age of 60, only one in four say they are "very familiar" with long-term care insurance. In addition, 41 percent say they have not had any discussions about long-term care in the past twelve months.

- Many Baby Boomers erroneously believe they have coverage for long-term care expenses. The survey found that 30 percent of Baby Boomers think they have long-term care coverage. However, even if all current long-term care insurance policyholders were Baby Boomers – which they are not – that would only account for less than 10 percent of the Baby Boomer population, suggesting that many Baby Boomers have misconceptions about their coverage.

- Fifty-four percent of Baby Boomers think Medicare will pay for long-term care services, and 44 percent believe "other health insurance" will pay. These findings show that many people are unaware that Medicare does not cover long-term care indefinitely and that Medicaid will cover these services only after requiring individuals to spend down nearly all of their assets to qualify for assistance.

Recognizing the challenges raised by these survey findings, AHIP and our members are strongly committed to educating consumers about the importance of long-term care coverage. In addition

to developing a consumer's guide to long-term care insurance, we work on an ongoing basis to highlight our survey and research findings in our communications with the media, policymakers, and others.

AHIP also is an enthusiastic supporter of the "Own Your Future" Long-Term Care Awareness Campaign, which is working to increase awareness among the American public about the importance of planning for future long-term care needs. As of March 2007, 15 states have participated in this joint federal-state campaign through mailings to households with family members between the ages of 45 to 70. Other elements of this awareness campaign include the development of state-based information, such as long-term care websites, and dissemination of other resources.

IV. Disability Income Insurance

Private disability income insurance provides tens of millions of Americans with protection that complements the safety net provided by the Social Security Disability Insurance (SSDI) program.

Approximately 38 million U.S. workers are covered by employer-sponsored group long-term disability coverage[15]. Some three million American workers have individual disability income coverage. In addition to extending benefits to many persons who are not eligible for SSDI, this coverage provides a level of benefits that spares many Americans from financial hardship.

Value for Consumers

In 2006, more than 650,000 individuals received long-term disability payments from private insurers totaling more than $9 billion. One-third of these individuals did not qualify for SSDI. Moreover, 95 percent of reported disabilities were not work-related and therefore not eligible for coverage under workers compensation[16].

[15] JHA, 2006 U.S. Group Disability Market Survey
[16] 2006 Council for Disability Awareness Claims Review

Private disability insurers resolve claims within 30 days or less for approximately 75-80 percent of claimants, thus ensuring that benefits can be paid promptly to replace an eligible claimant's lost wages. Our members' track record exceeds the requirements set by federal regulations, which establish a 45-day timeframe for the initial resolution of private disability claims and allow an extension – of up to a total of 105 days – if, for reasons beyond the control of the insurer, more time is required to gather information.

In addition to replacing lost income for claimants in a timely fashion, private disability insurers play a key role in restoring disabled workers to financial self-sufficiency and maintaining productivity for America's businesses. By investing in rehabilitation and return-to-work programs, private disability insurers are actively engaged in helping workers with disabilities return to the workforce. In fact, a survey by Milliman, Inc. found that private disability insurers spent an average of $3,200 in 2005 on each disabled employee receiving rehabilitation and return-to-work services[17].

These innovative programs include a wide range of strategies in recognition of the fact that persons with disabilities are highly diverse and face varying circumstances. Services offered by rehabilitation and return-to-work programs include medical case management, vocational and employment assessment, worksite modification, purchase of adaptive equipment, business and financial planning, retraining for a new occupation, and education expenses. The Milliman survey found that annual budgets for these programs, which vary by company, range from $450,000 to more than $10 million.

Additionally, private disability insurers have been very proactive in designing policies that help claimants return to work. As a result, persons receiving private disability payments often have access to work incentive benefits, rehabilitation benefits, workplace accommodation benefits, and child or dependent care benefits during rehabilitation. These innovative benefits reflect our members' strong commitment to promoting employment and self-sufficiency among persons with disabilities.

[17] Survey of Rehabilitation and Return-to-Work Practices Among U.S. Disability Carriers, Milliman, Inc., May 2007

National Education Campaign

AHIP has launched a national education campaign to promote awareness about the importance of disability income protection and to highlight the value disability insurance provides for workers, employers, and taxpayers.

Recognizing that more than 100 million Americans lack private disability income protection, our campaign has created a website – www.yourincomeatrisk.org – focused on educating consumers about a wide range of disability-related issues. The need for such education is highlighted by survey findings showing that many American workers have misunderstandings about their likelihood of experiencing a disability and the resources that would be available if they become disabled.

In 2004, AHIP released a survey by Ayres, McHenry and Associates which found that 58 percent of working adults believe they are covered by disability insurance, even though only one-third of workers nationwide are covered. The survey also found that workers overestimate the proportion of disabilities that are covered by workers' compensation insurance. Although only 10 percent of disabilities are covered by workers' compensation insurance, 59 percent of those surveyed believe that the proportion is higher. Additionally, 47 percent of respondents to the AHIP survey said they were not concerned about a potential disability or illness that could keep them out of work for an extended period of time. However, data compiled by AHIP and the Society of Actuaries show that one in three workers over the age of thirty will become disabled for at least three months at some point during their careers.

Over the coming year, AHIP will be taking additional steps to continue our national education campaign. These steps include a retooling of our "Your Income At Risk" website, an updated consumer guide on disability income insurance, a new publication for policymakers and the media, a survey of key disability claims information, and additional research on key disability issues.

Partnering With the SSA

Finally, our members also are demonstrating leadership, on behalf of persons with disabilities, by engaging the Social Security Administration (SSA) in a dialogue about advancing a public-private partnership to employ the tools and techniques of private disability insurers in improving the administration of the SSDI program.

There is a great deal of common ground joining the SSDI program and the private disability insurance industry. Both face the same daunting demographic and morbidity trends and both must deal with a highly complex claims adjudication process addressing both functionality and medical factors. Additionally, both public and private disability income programs must carefully strike a balance between the entitlement of individuals and the overall costs of providing disability income security.

We believe this common ground makes private disability insurers and the SSA natural partners and, additionally, that there may be core competencies and tools that private disability insurers can bring to bear to help the SSA further improve the efficiency and effectiveness of the SSDI program. Accordingly, we are interested in advancing private-public partnerships to:

- speed and improve SSDI claim adjudication through new processes/systems for providing the SSA with key claims information regarding the medical condition and functionality of private claimants who apply for SSDI benefits; and

- ensure the timely, accurate, and fair coordination of private and public disability income benefits by modernizing the process for providing private insurers with the necessary SSDI benefit status information.

AHIP and our members are committed to working with Congress and the SSA to design initiatives addressing both of these priorities.

V. Conclusion

Thank you for this opportunity to testify on these important issues. We look forward to working with the subcommittee to continue to address the health care and other needs of individuals with disabilities. AHIP's members are strongly committed to serving this population through their participation in Medicaid and by offering innovative insurance products.

Mr. PALLONE. Thank you, Ms. McCormick.
And last is Ms. Beckett.

STATEMENT OF JULIE BECKETT, DIRECTOR OF NATIONAL POLICY, FAMILY VOICES

Ms. BECKETT. Thank you, Mr. Chairman and members of the subcommittee. My name is Julie Beckett and I am the policy director for Family Voices, a national grassroots organization of families and friends speaking on behalf of children with special healthcare needs and their families, but in particular, I am Katie Beckett's mother, and as you know, Katie was the first home- and community-based waiver child in 1981. She sits behind me today and about to turn 30 years old, scaring me to death, and the important part of this is that we have been fighting for this for almost these full 30 years, and what I would like to see is something actually done about providing home- and community-based care for individuals with disabilities.

Family Voices' families include a number of individuals who are transitioning to the adult system of care and who are anxiously awaiting a life filled with work and play and active participation in their communities. You see, when given the types of services needed, many of these children and youth can live long and prosperous lives but access to important programs such as Early Periodic Screening, Diagnosis and Treatment, EPSDT, and special education are critical, especially at an early age. Life-and-death decisions depend on access to the necessary services required by this very vulnerable population. EPSDT provides the best benefit package for our children and youth with special healthcare needs. Frequently it is necessary to access Medicaid, even if a child or youth has access to private health insurance. Private insurance is increasingly unwilling to provide access to the types of care that these children and youth need. It is only the protection of EPSDT and the mandate to cover all medically necessary services that guarantees our children access to these necessary services. The Federal Medicaid program has taken steps to limit access to this vulnerable population by proposing dangerous regulations that could limit the important therapies needed to sustain mobility and important physical and mental and life-sustaining therapies that allow these children and youth to grow in their communities and participate actively. These therapies and treatments offer the hope of a better future. It also allows children and youth with special healthcare needs and their families to participate more fully in the life of their communities. These services allow us all to experience children and youth with special healthcare needs an all they are capable of so that we as a society define them not by their limitations but by their capacity for success despite their mental and physical limitations, and you will note there are several stories that I have attached to my testimony. The one about Shane Hafely should demonstrate the importance of these services.

The Maternal and Child Health Bureau has just released the latest statistics from the National Child Health Survey, which is a random telephone interview with households across the United States. This survey demonstrates that increasingly these children rely on public health insurance because there has been no public

outcry in response to the denial of medically necessary services. There also has been no law passed that mandates that when a physician orders treatment or services that are medically necessary, that those services should be paid for by private insurance. The Maternal and Child Health Bureau's goal to achieve a medical home for every child has eased some of these concerns as it cuts down on emergency room care because they now have a consistent source of care and the services are better organized. In fact, the Medicaid commission that I was honored to serve on made a recommendation that all individuals covered by Medicaid receive their care for ma regular source of care as used in the Maternal and Child Health Bureau's medical home model. This goal of achieving a medical home for every child must not be attached to complicated payment structures like those used in managed care. Payment incentives can have a negative impact and can limit care that should be provided. Again, this demonstrates as shown in the Maternal and Child Health Bureau's national survey. Children and youth do best when they are part of a medical home and the cost of care either stays or the same or decreases as families are financially able to provide for the extensive care needs of their child or youth.

This too can apply to adult care when targeted case management helps access the right kinds of services necessary for an individual to stay in their community and actively participate in work. The Family Opportunity Act that was built on the Ticket to Work and Work Incentives legislation provides for families and individuals with disabilities to access a Medicaid buy-in program so that these families and individuals are employable when a company does not have to use all of their health benefits to pay for services that these workers may need. I am proud of the fact that my daughter Katie served on the advisory panel for several years and actively participated in the beneficiary summit that identified barriers young people with disabilities face when forced to remain on the Social Security program that present barriers to their work participation. The Medicaid buy-in programs give them hope that some day they may not have to rely on these outdated programs that restrict what individuals can do.

The Community Choice Act approaches many of these concerns but families need options. Improvements in Medicaid delivery certainly would provide them with some choice in helping their children and young adults survive and prosper. It is agreed that it would be much more beneficial to efficiently and effectively manage a benefits program that helps our children and youth survive rather than relying solely on a cash payment subsidy and restrictions that limit their options. I hope that you will look long and hard at the final report of the Ticket to Work and Work Incentives advisory panel even though this committee does not have jurisdiction and think about the decisions you make that could impact its success.

Finally, removing targeted case management from the list of options makes no sense nor does restricting school-based incentives that help special-education students achieve in schools, and of course it makes no sense to limit reimbursement for therapies that keep their bodies moving in a direction that keeps them able. Again, EPSDT provides for the most essential medically necessary services no matter where those services are provided. Limiting the

nature of this program to simply cure would certainly fly in the face of Congressional intent. I would hope this committee would examine your options to learn more about what these initiatives do and the impact of proposals on real lives and real families.

I have included recommendations for the Subcommittee on Health and I certainly hope that you will review those. Thank you very much.

[The prepared statement of Ms. Beckett follows:]

Julianne Beckett: National Policy Director, Family Voices

Testimony Presented to the Health Subcommittee

U.S. House of Representatives Energy and Commerce Committee

January 16, 2008

Mr. Chairman and Members of the Committee:

My name is Julie Beckett and I am the Policy Director for Family Voices, a national grassroots organization of families and friends speaking on behalf of children with special health care needs and their families. These families include a number of individuals who are transitioning to the adult system of care and who are anxiously awaiting a life filled with work and play and active participation in their communities. You see when given the types of services needed many of these children and youth can live long and prosperous lives. But access to important programs such as the Early Periodic, Screening, Diagnosis, and Treatment (EPSDT) and special education are critical especially at an early age. Life and death decisions depend on access to the necessary services required by this very vulnerable population.

EPSDT provides the best benefit package for our children and youth with special health care needs. Frequently, it is necessary to access Medicaid even if a child or youth has access to private health insurance. Private insurance is increasingly unwilling to provide access to the types of care that these children and youth need. It is only the protection of EPSDT and the mandate to cover all medically necessary services that guarantees our children access to these necessary services. The federal Medicaid program has taken steps to limit access to this vulnerable population by proposing dangerous

regulations that could limit the important therapies needed to sustain mobility and important physical, mental and life sustaining therapies that allow these children and youth to grow in their communities and participate actively. These therapies and treatments offer the hope of a better future. It also allows children and youth with special health care need and their families to participate more fully in the life of their communities. These services allow us all to experience children and youth with special health care needs and all they are capable of; so that we as a society define them not by their limitations but by their capacity for success despite their mental and physical limitations. (story)

The Maternal and Child Health (MCH) Bureau has just released the latest statistics from the National Child Health Survey which is a random telephone interview with households across the United States. This survey demonstrates that increasingly these children rely on public health insurance because there has been no public outcry in response to the denial of medically necessary services. There also has been no law passed that mandates that when a physician orders treatment or services that are medically necessary, that those services should be paid for by private insurance.

The MCH Bureau's goal to achieve a medical home for every child has eased some of this concern as it cuts down on emergency room care because they have now have a consistent source of care and the services are better organized. In fact, the Medicaid Commission that I was honored to serve on made a recommendation that all individuals covered by Medicaid receive their care from a regular source of care as used in the Maternal and Child Health Bureau Medical home model.

This goal of achieving a medical home for every child must not be attached to complicated payment structures like those used in managed care. Payment incentives can have a negative impact and can limit care that should be provided. (STORY-ED) Again, this demonstrates, as shown in the MCH Bureau's National Survey: Children and youth do best when they are part of a medical home and the cost of care either stays the same or decreases as families are financially able to provide for the extensive care needs of their child or youth.

This too can apply to adult care when targeted case management helps access the right kinds of services necessary for an individual to stay in their communities and actively participate in work. (story) The Family Opportunity Act that was built on the Ticket to Work and Work Incentives legislation provides for families and individuals with disabilities to access a Medicaid buy-in program so that these families and individuals are "employable" when a company does not have to use all of their health benefits to pay for services that these workers may need. I am proud of the fact that my daughter Katie served on the Advisory panel for several years and actively participated in the beneficiary summit that identified the barriers young people with disabilities face when forced to remain on Social Security programs that present barriers to their work participation. The Medicaid buy-in programs give them hope that someday they may not have to rely on these outdated programs that restrict what individuals can do.

The Community Care Act approaches many of these concerns but families need options. Improvements in Medicaid delivery certainly would provide them with some choice in helping their children and young adults survive and prosper. It is agreed that it would be much more beneficial to efficiently and effectively manage a benefits program

that helps our children and youth survive rather then relying solely on a cash payment subsidy and restrictions that limit their options. I hope that you will look long and hard at the final report of the Ticket to Work and Work Incentives Advisory Panel even though this committee does not have jurisdiction and think about the decisions you make that could impact its success.

Finally, removing targeted case management from the list of options makes no sense. Nor does restricting school based incentives that help special education students achieve in schools. And of course it makes no sense to limit reimbursement for therapies that keep their bodies moving in a direction that keeps them able. Again EPSDT provides for the most essential medically necessary services-no matter where those services are provided. Limiting the nature of this program to simply "cure" would certainly fly in the face of Congressional intent. I would hope that this committee would examine your options to learn more about what these initiatives do and the impact of the current proposals on real lives and real families.

Mr. PALLONE. Thank you, and we certainly will, and that concludes our opening statements. Now we will have questions from each of the Congressmen and -women.

I am going to recognize myself for 5 minutes initially, and I wanted to start out by asking Ms. Rowland, some have advocated making Medicaid look more like private insurance, scaling back benefits and raising cost sharing on beneficiaries. Others believe in only providing a capped amount of money to a disabled individual and letting them contract for their own personal care services as maybe a better path. My concern is, what happens when States give people vouchers and send them off for managed care plans. I know that Kaiser has done some work on the Florida experience where unfortunately people with disabilities had difficulty in the counties where services for people with disabilities were so-called reform. So would you tell us about these models, whether they fit the needs of the vulnerable beneficiary and then tell us about the Florida experience. I am not necessarily trying to put a bad light on it but I want you to talk about these options.

Ms. ROWLAND. Well, we have clearly seen that the role Medicaid plays for people with disabilities is very different than what is available through employer-based private health insurance or unavailable really through the individual insurance market where pre-existing conditions and the cost of coverage would keep people from coverage so that Medicaid really does provide for both medical care, which is what traditional health insurance does, and for all the kinds of transportation and long-term-care supports that are necessary. So when we look at people who have private health insurance coverage and have disabilities compared to those on Medicaid, we see that those on Medicaid are far more likely to have serious conditions and those with disabilities covered by private insurance are less disabled and more able to function without additional supports.

What we have been evaluating and looking at in Florida is in the new capitation demonstration where in two counties, now extended to five, individuals are given a choice of health insurance managed care plans to participate in. Many of the people with disabilities have been included in this program and they tell us that they were very confused about whether they were even enrolled in the program. They were asked to make a choice of plans, and the forms they were using looked very similar to the forms people got on Medicare part B to choose for their prescription drug coverage so there was a lot of confusion about where to go. They got enrolled into plans, and when they went to their counselors found out that their counselors were giving them some misinformation about whether they could change or get out, and I think it really does point out that while choice of plans may be ideal, information and good counseling on what is available through those plans is critical. Moreover, in Florida, those plans have the ability to adapt the benefit package to live within the capitation rate so we are now going back to evaluate after a year whether the benefits promised to these individuals when they joined the plans were actually realized, and many of the people with disabilities have said that the range of services they need were not covered within those plans and that some of the doctors that they were used to seeing, some

were in the plan, some were out of the plans, and we know for people with ongoing chronic illnesses and severe disabilities, maintaining coordinated care from the range of providers they need is critical.

So we really do think one should take great caution in changing some of the care arrangements and we think case management and a broad range of community-based services is perhaps a better way to go than putting people into a capitated situation where the plan may not be able to meet their full needs.

Mr. PALLONE. I wanted to go to Ms. Fortin because, as you know, when we had our roundtable in New Jersey, you talked and some there talked about flexibility in the context of independent living arrangements versus institutionalization and that if there is a certain amount of flexibility, then perhaps that allows States and programs to get away from institutionalization and more towards independent living.

Mr. Gronefeld mentioned in his testimony the need for more flexibility in Medicaid waiver services and I know when we had that roundtable, there was talk about that being a good thing, but other times that flexibility may come at the expense of beneficiary needs. In New Jersey we have this cash and counseling demonstration that was very successful in giving people a budget to manage their personal care services but the question is, is that good or has that been a problem? Because if you have vouchers like they have in Florida, the flexibility may actually make it more difficult to get services. So I just want you to talk about that in the context, the whole idea of flexibility versus caps and how that relates to trying to get people to avoid institutionalization.

Ms. FORTIN. Well, I think that we have to balance the idea of the flexibility with the oversight, and of course, we are very concerned about any system that is in place that has the capitation rates. Individuals with disabilities are just that: they are individuals and their needs are very individualized and we can't look at a program where it is the same for all. Our cash and counseling program in New Jersey is a very successful program. We feel that the individuals having the ability to direct and choose their services has allowed them to get the right services for the individual. We also feel that in many ways it can be a very cost-effective program as individuals are able to choose what meets their needs best. For some individuals with significant intellectual disabilities, we have some concerns about making sure that there is appropriate case management and oversight so that the individual is getting the best services that they can and the ones that properly meet their needs. So there is a need for a real balance in the program as well. But obviously as advocates for people with disabilities, flexibility and that whole idea of self-directed services is extremely important to us.

Mr. PALLONE. Thank you.

Mr. Deal.

Mr. DEAL. Thank you, Mr. Chairman. Thanks to all of you for your testimony and your presence here today.

Let us set the stage, because we have alluded to it from time to time. When we were working on the Deficit Reduction Act, then-governor of Virginia, Mark Warner, was the chairman of the National Governors Association, and one of the primary motivating

forces for the DRA was that Chairman Warner made the statement that Medicaid was in a meltdown and he was talking about the pressure that was on States to come up with their portion of the Medicaid dollars. Now, in that context we still have that concern. My concern is that knowing those pressures are there both at the State level and at the Federal level, I am concerned that when I see statistics like only 15 percent of Medicaid enrollment is with people with disabilities, isn't that a significant percentage reduction from what Medicaid used to be in terms of covering those with disabilities? And when those pressures are there on these State Medicaid directors, aren't they sometimes put in a position of making choices that are not always favorable to those with disabilities? And do we need to have some pressure to refocus Medicaid emphasis on those with disabilities? I think we seem to have lost some of that focus.

Ms. Thomas, am I on the right track about this, and how do we refocus what Medicaid initially was trying to deal with, which was in large part the disabled?

Ms. THOMAS. Well, I think that other people that get services like children are also very important and needs to be done but I think that by passing the Community Choice Act, you would allow people with disabilities to pick what they want, and because the services are generally less costly in the community, you are going to be able to serve more people. What happens at the State level now is that they are required to do the nursing home services, and I have sat in the conference committee rooms where they are struggling with this issue, and I can tell you that that mandate creates a barrier, and instead of being for people with disabilities or children or other what you might call consumers of the services, it winds up being about providers, and while providers are essential, if you put more of the choice in the hands of the individual to pick the kinds of services that they want, then that really helps and getting rid of that institutional basis is going to be a big step in the right direction.

Mr. DEAL. I was handed during the course of testimony here today the Medicaid release that was released the day before yesterday, I think, saying that on Friday of this week the cash and counseling regulations will be in the Federal Register and comment will be open for a 30-day period, and I think that is a good indication obviously they are going forward with implementing the cash and counseling portion of the DRA and trying to shift more money into that area so people can do things like decide who they want to hire, who they want to fire instead of it being some administrator or some bureaucrat making those decisions for them because not everybody who is disabled has the—doesn't have the ability to think for themselves. They ought to be able to make the choices when they want to make the choices, and I think that is in the right direction and I would urge all of you to comment on that as it opens the comment period as of Friday of this week.

Let me though go to one thing that—as I told you, for 8–1/2 years my wife and I cared for our family, our mother and father, her mother, who had Alzheimer's, and my mother, who had a leg amputated and was in a wheelchair. Her mother and father and my mother were all retired schoolteachers so therefore their income

level, they were never Medicaid eligible but we faced the problem of having, how do you get people to help because I was up here most of the week. My wife was still an active schoolteacher. Trying to find qualified people, and Mr. Gronefeld, you mentioned—well, Ms. Thomas too mentioned the lack of available personnel to assist, and that is true both in the Medicaid setting and in the private pay setting of people making these choices. I often ask the question, why don't we have some people that are just given the basic training to individuals who want to work but they don't know where to go and nobody seems to be filling the gap but just basic training. It doesn't have to—they don't have to be an RN, they don't even have to be an LPN. They just need some basic instruction, because not everybody needs that degree of assistance.

Mr. Gronefeld, what is being done to provide these people that we need to fill these slots?

Mr. GRONEFELD. Well, of course, the first thing is introduction of H.R. 1279 to provide that funding for workers. You know, there is a lot that can be done. One of the biggest issues is attracting people to this field. The 42,000 employees that we have at ResCare are very dedicated and hardworking and mission driven. We explain their job as being the toughest job they are ever going to love because they do appreciate what they do. They are very dedicated to the folks that they serve and that they support and they become part of their family and their friends, but one of the issues is the wages, and our—what we pay in wages is limited by what we are reimbursed. In addition to that, there is plenty of programs available now in which we could attract future direct service professionals. However, because of the requirements within job corps centers which we are a contractor and workforce investment services and one-stop services, they don't qualify as part of our outcomes because of their starting wage rate. The expectation is higher than what the starting wage is for direct service professionals. So we could currently be training people in this field, spending dollars that already exist, that are already being spent, not spending any more dollars and yet attract more people to the field. Now, that doesn't solve the living wage issue. The living wage issue has to be addressed and there has got to be ways that we look at addressing that and there is many ways to do that, as I mentioned in my testimony. But at the end of the day I think there is a lot of people that want to do this work. There is a lot of caring people in the United States that would be more than happy to provide these services but they have to take care of their own families and then that becomes an issue.

Mr. PALLONE. Thank you.

We next have our resident advocate for healthcare professionals, Mrs. Capps.

Mrs. CAPPS. Thank you, Mr. Chairman.

I want to thank you each of the witnesses for your excellent testimony. It is wonderful to see different stories to tell but on the same page. I want to divide my time between Ms. Fortin and Ms. Julie Beckett for my time.

Ms. Fortin, as a nurse myself and having extensively worked on critical issues surrounding the nurse shortage, I am particularly sensitive to recruitment and retention difficulties faced amongst

the direct support professional service. This is going to be a carry-on after the ranking member but I will put it on to you to ask you to see a connection between the delivery of quality services and the wages of direct support professionals. Help us understand the negative impact that low wages have on quality support and on the choices people with disabilities have for when and where they receive supports, the choices being a predominant theme. Just a brief answer on that, please.

Ms. FORTIN. From our experience in New Jersey with recruitment and retention of direct care workers reaching critical stages, it creates a revolving door for the direct care workers to work within the individuals. It affects the quality of care. If you have a different person coming in each month or each 6 months, that person has to start all over again to learn about the significant needs, especially for the folks that we work with who have intellectual disabilities. What we are looking at in New Jersey is, we have a statewide coalition for a direct professional workforce. We are looking at ways in which we can professionalize the career of a direct support professional through training, through support, and of course, we are very, very supportive of the Federal legislation which you sponsored because we can see that those funds being able to come into New Jersey will help to create added funds to compensate the direct care workers. If we are able to stop that revolving door of direct support professionals coming through the system, we are going to be able to build that base, create the stability, and in the long run have the funds. Right now just within The Arc of New Jersey, we can look at vacancy rates in programs anywhere from 15 to 40 percent in some of our residential programs. It costs thousands of dollars every time a direct support professional leaves and a new person has to be trained. We can take those funds, we can invest them in the salaries for the direct care workers and we can begin to catch up on that system.

Mrs. CAPPS. Such a good response. Thank you. Just for the record, what is your greatest competition for qualified direct support personnel? Where do they go to work instead of coming to work for you?

Ms. FORTIN. They go into the private sector, and not necessarily in healthcare.

Mrs. CAPPS. Right.

Ms. FORTIN. It pains me very much to hear people say how much they love their work but they are going to have to go work for a private company in things like administrative support just because it pays the bills and it has the benefits.

Mrs. CAPPS. Some of our workforce tell me that they get recruited by fast food places, and that is a sad day when we compare ourselves with the kind of work that you do to sell hamburgers.

Well, I could ask this question of any of you but I want to speak now to the disabilities in school. A number of years ago there was some controversy with Medicaid services provided to children with disabilities in school. Some rather unscrupulous consultants traveled around the country, sold States and schools a bill of goods with less than satisfactory results. This mess was fortunately straightened and things were put back on track. However, right after Christmas CMS put out a final rule that would severely re-

strict access to Medicaid coverage for certain legitimate activities and particularly specialized transportation for severely disabled children who receive medical services during the school day in school and administrative outreach and enrollment activities to find and enroll more children in our schools. Ms. Beckett and anyone who would want to comment on what CMS's rule would mean for children with disabilities, for example, a child who needed a respirator-equipped bus to get to school.

Ms. BECKETT. Well, thank you very much for asking that question. I think that the impact in particular would be on the types of things that children need such as the therapies and all of that. The transportation issue is getting them where they can get the best services, and the different requirements by different individuals, particularly young children, forces school districts to think about instead of serving them in school-based programs actually serving them at home, which then restricts the socialization and all the things that are necessary. So it is extremely important for us to look at what this proposal or what this implementation could possibly mean, and I would hope that somebody would be monitoring what the impact would be, particularly on school districts.

I just was in Olwine, Iowa—it is about an hour and a half north of Cedar Rapids—the other night as they talked about closing a particular program for second graders simply because of the cost and the mothers who came out in droves saying how important it was for them not to think about this as a cost issue as much as to think about it as a personal issue for their child and that these were children who needed that kind of care. It is important for us to think about the types of administrative costs that currently schools endure to help provide the best special-education services they can for these children and their families, and in many ways, in many areas, that is the only thing they are qualified for.

Mrs. CAPPS. Exactly.

Ms. BECKETT. They are not qualified for Medicaid, they may not be qualified for any other program, and it is really appalling that we could take that kind of a service away from those kinds of kids.

Mrs. CAPPS. Thank you so much. In other words, the CMS ruling goes directly against the principles of IDEA and so we do need to address it, and I thank you for your answer and for my time.

Mr. PALLONE. Thank you. We have our other healthcare professional on the other side of the aisle here, Mr. Burgess.

Mr. BURGESS. Thank you, Mr. Chairman, and I want to take just a moment—Chairman Dingell discussed the visitors and guests that we have in the hearing today and, Mr. Chairman, with your indulgence, I want to point out we have visitors and guests from my district back in Texas. Marsha Gray has brought her history and government class with her from South Lake, Texas, Carroll High School. Is it Carroll High School?

Mr. GRAY. Carroll Senior.

Mr. BURGESS. Carroll Senior High. They wanted to learn and see what government looked like firsthand up close and personal, and I said it doesn't get any more up close and personal than the Energy and Commerce Subcommittee on Health. So I appreciate them traveling all the way from Texas to be here today and to witness the hearing that we have going on.

Ms. Beckett, I just wanted to follow up on a point that you just made on the CMS rule, and that rule has been put out, the notice of proposed rulemaking has gone forward and now that rule has been finalized by CMS?

Ms. BECKETT. Yes.

Mr. BURGESS. So this is something that would take legislative activity on the part of the Congress to reverse that?

Ms. BECKETT. Well, I think there is an opportunity for you to address it in a hearing to begin with how the impact itself could—we have a current moratorium on it so we have like 6 months to collect some information about what is going on, and I think that would be very helpful if we could look at what the impact could be on that.

Mr. BURGESS. Well, just on a structural question, and maybe, Mr. Chairman, I should ask you this. Things move with such glacial speed around here. Perhaps we could ask for another moratorium in the labor HHS appropriations bill when that comes up this summer. Is that where this came from, the moratorium came from in the first place?

Ms. BECKETT. Yes.

Mr. BURGESS. Mr. Chairman, are you aware, is there an actual proposed piece of legislation out there that will deal with this rule from CMS, the rule that affects the caregiver statute, the levels of funding. Is that correct?

Mr. PALLONE. I am not aware of anything but obviously we are trying to address some of these with the committee as well but no, I am not aware of any legislation.

Mr. BURGESS. Well, it may be a joint project the committee can take up as we approach the appropriation this summer so we can get a little bit more time to study what the actual impact of this will be and make certain we don't do something in a vacuum of knowledge which of course would never, ever happen up here.

Mr. Gronefeld, I wanted to just—and probably Dr. Rowland, I need to involve you in this, and I am sorry I stepped out when you were talking to Chairman Deal about—or Ranking Member Deal about the inflexibility issue. You brought up the point and made a point of talking about the inflexibility of some of the waivers with which you have to deal and I mean, I will just tell you, not having been here that long, but looking at a system that provides care to some of the most vulnerable citizens in the United States and requires, what, 28 waivers for it to work properly? I mean, on the face of it, it is not a sound basis that we built it on. But talk to us a little bit more about the inflexibility of waivers that you have had to deal with.

Mr. GRONEFELD. Well, a lot of the inflexibility that we speak of does not necessarily deal with providing services. It deals with the administration. It deals with costs that are outside of actually delivering the services, the amount of time and effort it takes to document the services provided. We have seen situations where every 15 minutes a direct support professional has to fill out what they have done, which takes away from providing care. In Indiana few years ago, they actually reduced our rates and cut $14 million out of their budget but with that cut, they simplified the system and they were able to spend that $14 million to serve more people, and

what I mean by that is that they went to a per diem-type system based on level of need, so not everybody fit in the same category. It wasn't a capitated type of system. But it took away the necessity of all the documentation, all the paperwork.

Mr. BURGESS. Let me just ask you, I don't mean to interrupt but I am going to run out of time. Is the move to more electronic record keeping, would that be an enhancement in your mind in that type of activity? Does anybody actually read the reports that are generated every 15 minutes?

Mr. GRONEFELD. Well, that would be an enhancement but to kind of simplify things and oversimplify things to a point, outcomes are about the people receiving services. Ask them and their families what they think. Don't read that on a piece of paper. They can tell you if they are receiving the quality of services or not, and that is what outcomes should be about.

Mr. BURGESS. Very good.

And with the seconds I have left, Dr. Rowland, I mean, I have never been a big fan of capitation but tell me again what are the concerns you had with the capitated system that you were discussing?

Ms. ROWLAND. Well, we were looking at the Florida reforms that were put into place in Broward County. Specifically, there was a lawsuit actually filed yesterday by some of the beneficiaries of that program about the fact that it is very difficult when you are dealing with people with severe disabilities to establish the right level of risk adjusted capitation and the way in which that program was structured, the health plans were given the ability to modify the benefit package to live within the capitated amount.

Mr. BURGESS. Let me interrupt you again. Is that because there wasn't a correct assessment of risk going in?

Ms. ROWLAND. I think that it is a very new area of trying to do the assessment of risk, right, and I think the risk assessment was not necessarily going to match the beneficiaries' needs so the plans were given under the waiver additional discretion to modify the benefit package and several did but it meant that the beneficiaries felt they were not getting the full range of services they needed. And I think it just points out the very difficulty of figuring out in advance prospectively for some of the most disabled people exactly what the right capitation amount would be and calls for the need to have some flexible corridors around which you operate.

Mr. BURGESS. I don't disagree. Of course, that is the whole tentative of capitation but at the same time, a system that learns ought to be capable over time of making those adjustments so that if capitation is what the State decides they want to do, is there not a way——

Mr. PALLONE. Let me ask you, Doctor—I am sorry, Dr. Burgess, but I wanted to get one more person in before we——

Mr. BURGESS. I am going to submit that question in writing and I will yield back, Mr. Chairman.

Mr. PALLONE. Let me just mention to the subcommittee, we have I guess 8–1/2 minutes left. We are going to have a 15-minute vote and then two 5-minute votes, so what I am going to ask is, Ms. Baldwin if she would go next and then we will recess until we come back for those votes. So I recognize Ms. Baldwin.

Ms. BALDWIN. Thank you very much, and I will try to be brief with my questioning so we can get to the Floor in a timely manner.

As I said in my opening statement, I am a very strong supporter of the Community Choice Act and I know that ADAPT has been working a long time on this bill, in fact, ever since it was first introduced by a different name as MICASA. It is my understanding that in 1997 the CBO estimated that that proposal would cost between $13 and $25 billion but that a recent study published in the Journal of Aging and Social Policy found that the proposal would be much less costly, maybe between $1.4 to $3.7 billion, and I wonder, Ms. Thomas, are you familiar with that study and could you—are you able to explain how the approach of the CBO researchers and the ones who did the recent study differed in terms of arriving at their conclusions?

Ms. THOMAS. Yes. Basically the difference was based on the fact that the original CBO scoring staff was I think somewhat unclear about who was going to be covered and they included people that were not eligible because of assets or other—because of the level of their income, and also their severity of disability, and that was a very big problem. And then in addition, that study also—that the CBO did also included services that are not covered under the bill and so we tried to clarify the language to clarify what was and wasn't covered but in addition, I think that the people at University of California San Francisco who did the study were more careful in their information and I think their estimation is actually a lot more accurate.

Ms. BALDWIN. Thank you. I think in the interests of time, I will hold off on any further questions.

Mr. DEAL. Mr. Chairman, could I quickly ask unanimous consent that the testimony of Autism First be included in the record. I think both sides have reviewed it. I think we need to hear from many in the disability community, and certainly his is an aspect that needs to be heard.

Mr. PALLONE. So ordered.

Mr. DEAL. Thank you.

[The information appears at the conclusion of the hearing.]

Mr. PALLONE. And as I said, we will stand in recess until after these votes. I would assume that would be—I don't know—about half an hour or so. The subcommittee stands in recess.

[Recess.]

Mr. PALLONE. I am asking unanimous consent that the statement by Mr. Waxman be included in the record. Without objection, so ordered.

[The information appears at the conclusion of the hearing.]

Mr. PALLONE. We were going to go to Mr. Towns because he is the last person. I think he is in the back room. So we will do a second round of questions. I think it is just going to be myself and Mr. Deal and then we will go back to Mr. Towns as soon as he comes in.

I wanted to ask—go back to Dr. Rowland again. This is with regard to-oh, he is back. All right. I am going to hold my questions until after Mr. Towns has had an opportunity. I will recognize the gentleman from New York.

Mr. TOWNS. Thank you very much, Mr. Chairman. Let me also congratulate you and of course Mr. Deal for holding this hearing. I really, really feel that this is a very important topic that we are discussing. I also want to thank the witnesses for being here as well.

I would like to ask Ms. Thomas a question. As you noted, there are many, many people with disabilities currently in nursing homes or other institutions that would like to instead live in the community. In addition, there are many others who are at home with an informal caregiver network who are barely getting by or who are going without needed services and supports because there is no available slots in a Medicaid program to serve them. Could you give me information on how many people are on the waiting lists for community-based services? I know the availability of these services has been increasing over time but how can we help move more people into the community and make certain that those in the community are also having their needs met? Because I think that sometimes we move them out without the necessary support system. So could you answer that, Ms. Thomas?

Ms. THOMAS. Well, it is my understanding that there is about 280,000 people on waiting lists for waiver services. About 150,000 of them are people with—who are waiting for what they call MRDD services. About 120,000 are waiting for aged and disability services, and there are about 11,000 children with disabilities waiting for services. And really, if we could end the institutional bias and the mandate for nursing homes and institutional services and just allow, say these are the people that we want to serve and we will let them choose how they get the services that they need. We could go a long way towards ending that waiting list. We would be saving money on the people that are in institutions and want to get out because the cost is about two-thirds of what it is—it is about two-thirds in the community for what it is in the institution so you could be serving three people for every two that you are serving now. And we would really make a big, big difference in people's lives. It would be much more humane, much better services.

Mr. TOWNS. It is easy to say let people move to the community but if everyone all at once left institutions for the community, would we have enough affordable housing options for people with disabilities? Are there other pieces of the puzzle that we need to fit in here to ensure that we have a smooth transition?

Ms. THOMAS. I would love it if everyone could do it all at one moment and everything was—but it isn't going to happen like that. It is going to happen in a lot more piecemeal way, and one thing that is a concern to us is that the perfect become the enemy of the good or we wait for every piece to be in place before we move. But that said, there are other pieces that do need to happen.

Mr. TOWNS. Ms. Beckett, let us switch roles just for a moment. What should we be doing? Let us switch roles. You are now a member of Congress. What should we be doing? We are switching roles.

Ms. BECKETT. Well, I think there are several things that Congress can do, I think looking into expanding the possibilities for individuals with disabilities. I think Stephanie is absolutely right, housing is a really an important aspect of it. Transportation is an important aspect of it. Instead of looking at how these people qual-

ify, we ought to be looking at whether we can do more for more people to remain in their communities and at home. That means supporting their families when they are young, supporting young adults so that they can go to work, supporting individuals with disabilities so that they can live in their communities, making that available to them. Katie was denied access to Section 8 housing because she was working on an advisory panel for the Social Security Administration. We totally understood that. But to try to gain access to anything, you have got to meet this level of absolutely no income whatsoever to even participate. That was a county-based program. I mean, it is very frustrating that everything is so piecemeal that you can't ever put anything together for everybody. I think one of the things that Aileen mentioned was the importance of case management services or care coordination. Having someone who can help you work through the system with you and provide those kinds of services is extremely important. It think having that—getting attendant care is really important. It is a major aspect of this. You really have to look at the broad-based spectrum of what individuals with disabilities as young adults are facing out there and move every obstacle you possibly can that are barriers to try to get them into the workforce. Working with the private sector to talk about the importance of their ability to work and their willingness to work, I think overcoming some of those barriers. A lot of times people don't know how to deal with that. And Katie has been very lucky in the fact that she is in her own apartment. She lives in a building downtown. It is not ideal per se except it is close to public transportation, it is close to the public library. It is where she is going to volunteer. Getting her a job has been extremely difficult because she has been serving on this advisory panel but now that has finished and so we are facing where her next steps will be. Why is it so complicated and why is it so difficult? It is time to partner with the private sector. Public government needs to work with the private sector to come up with ways of helping individuals with disabilities succeed in their community, and work as a natural aspect to that, but if you restrict school-based funding, if you restrict rehabilitation services, they are not going to be able to do that, and that just is wrong, and special education is the precursor to work. It should be. It should be what gets people ready to go, and those kinds of services are absolutely necessary. Medicaid should not be restricting reimbursement for those kinds of things.

Mr. TOWNS. Thank you. Thank you very much.

Mr. PALLONE. Thank you. We are going to have a second round here with just a few questions and then we are going to—then we will finish today. Did you have a comment?

Ms. BECKETT. Mr. Chairman, could I just add one thing? Earlier Congressman Burgess asked about the moratorium on school-based services. There is—in the final slew of things that went on, there was a moratorium put into the final bill and there is a moratorium on implementation of that regulation. That is a final rule but it was put on hold for 6 months.

Mr. PALLONE. Six months, yes.

Ms. BECKETT. But, if after 6 months if we don't do something about it, it is going to go into effect and that is really deadly.

Mr. PALLONE. We are very much aware of that and that is one of the reasons why we are having this hearing today actually.

Ms. BECKETT. I just wanted to make sure.

Mr. PALLONE. Absolutely. I just wanted to ask—oh, I am sorry. You are next. I am next? All right. I am next. OK.

I wanted to ask about the CLASS Act, and I guess I would ask Dr. Rowland or Ms. Fortin again. Part of the reason I introduced the CLASS Act is because I recognized that utilization of long-term-care services is on the rise and is going to increase as the population continues to age, and I think many Americans are under the impression all their healthcare needs including long-term-care needs will be covered by Medicare when they are older. I know that sounds incredible because you are all so knowledgeable but it is true. A lot of people really believe that. What they don't realize is that Medicare doesn't really provide these types of services, only in limited instances, and as a result they don't plan ahead. So if I could ask Dr. Rowland or Ms. Fortin, could you comment on why it is important to get Americans to think about their long-term needs sooner rather than later and how a voluntary opt-out system like the CLASS Act might work, whether you think it would be beneficial to achieve that goal?

Ms. ROWLAND. Well, I certainly think that we are facing an aging issue and a disability issue that cannot be solved by Medicaid alone, and one of the real challenges that has always been there is that when we get to the kind of long-term-care services and supports that people need, they don't get them through the Medicaid program and they can only get them through Medicaid if they meet the most strict income and asset tests and therefore have to be virtually impoverished to be able to get any assistance. So as we look at the challenges of an aging society and the challenges of a society where people with disabilities want to live at home and in the community and not be forced into institutions, I think anything we can do to promote broader options to help improve access to these kinds of services at levels of income that are not so means tested as the Medicaid program. It is not to say that Medicaid isn't critical and isn't an underpinning but I think we really need to begin to look more broadly at how we can build some of these services either into a Medicare-related program or into a more Title—we used to call it Title 21. Title 21 is now being used for something else. But to really try to have a way in which people can early on begin to contribute toward having the security of a broad and long-term-care and supportive services set of programs to wrap around just as well as the Medicare medical benefits are there.

Mr. PALLONE. Thank you.

Ms. Fortin, did you want to comment?

Ms. FORTIN. Well, we are really supportive of this because working with people with intellectual and developmental disabilities, one of the huge issues is their ability to buy into a long-term-care program so this would remove some of the biases that they might face, and again, we go back to the whole issue of everybody needs to worry about long-term care, whether it is for a family member or for themselves, eventually the majority of people are going to need these services in the future. If we can put a program in place that will reduce the need for the Medicaid system and also for indi-

viduals so they don't have to impoverish themselves in order to be eligible for the Medicaid system. So the CLASS Act goes a long way to meting several of the needs.

Mr. PALLONE. All right. Let me just finish up, and going back to—thank you—Ms. Beckett's point about the 6-month moratorium on the CMS rule that limits rehab services under Medicaid. Would you talk about the consequences, if you will, if this were to go into effect. I mean, obviously we don't want it to but if you would talk about that.

Ms. BECKETT. Well, I think one of the major consequences is, school districts in this country will be forced to choose between healthy kids and kids in special education. I don't think that is right and it is absolutely against the ideal of education and the importance of education in this country. I think in many ways what it will do is, those administrative costs allow for the ability for them to do some kind of care management in a school classroom, whether it is paying for a school nurse, helping to pay for a school nurse in that building or what is going on but I think it is really important for us to think about the therapies that these kids really need, in particular physical therapy, occupational therapy, speech therapy in particular. Those kinds of things will be restricted and we can't afford to have that happen. We really want our young people, our young adults to be ready to go into the workforce and they are not going to be ready if what we do is restrict those kind of reimbursements for those types of services.

Mr. PALLONE. OK. Thank you.

Mr. Deal.

Mr. DEAL. I will try to be real quick. I mentioned that we have a private facility in my hometown that is a not-for-profit designed to try to assist young adults who are disabled in a home setting and ran into quirky rule—and I am not sure where it comes from, maybe some of you can tell me—that one of the residents was on the initial board and lived in the facility and apparently it violated the rules and he had to move out in order to stay on the board. Now, this is sort of contrary to what we have with public housing in which your board has to be made up of a certain percentage of the residents. Have any of you run into that before? I am still trying to track down where that is coming from. OK, anyway, to another issue.

Ms. Beckett, I certainly agree with you on the employment side of it. I think one of the important things is to make life as full as possible and people with disabilities who can work ought to be encouraged to do so. That sort of ties in through the Department of Labor situation with something that Mr. Gronefeld mentioned earlier about the personnel and some of the impediments to employment there. Are there Department of Labor restrictions that you encounter in the employment of disabled people, and if so, what are they?

Ms. BECKETT. It is not really the Department of Labor although labor is a part of all of this. One of the—I think the biggest thing is the fear that they are going to lose the types of benefits that they need when they go to work plus it is also on the part of the employer, their concern about having to pay for the health benefits of an individual with a disability. Katie doesn't have a very good

track record and so an employer looks at her as a liability as opposed to a positive aspect of what it is she can provide. When you are going up against that, that is just totally irrational, when you think about it.

Mr. DEAL. Well, I agree with that.

Ms. BECKETT. I think it is really important for us to make sure that the Department of Labor is reaching out to different employers and talking about—and helping them to work through some of the issues that people with disabilities really have that could be beneficial employees to them.

Mr. DEAL. We have a rehabilitation workshop in our community which does pay at a reduced rate but it does provide employment there, and I suppose they come under some kind of a labor standard waiver. You are saying it probably needs to be expanded?

Ms. BECKETT. It absolutely needs to be expanded. We have Goodwill in Cedar Rapids. That is not an appropriate placement for Katie. She really needs to be in the workforce. She has been a receptionist in the past. She has done—she has worked from the time she was 16 years old, and as a matter of fact, the person who hired her was the manager of a record shop. As a teenager, you can imagine what that meant. And she asked her if she would like to work for her because Katie knew all of these things about when releases were supposed to take place and who are the best artists and the whole 9 yards. Well, that is what we need is somebody who is not afraid of that.

Mr. DEAL. I agree.

Ms. BECKETT. And at the time, because we are in a small community, that is something you can overcome but over time it is really difficult when there is more and more fear about healthcare and the rise of healthcare costs. That becomes a real problem. Katie is now meeting with Rockwell International, has a new government contract. They build airplanes and do all that kind of stuff, communications, and they need 310 employees and they are meeting with Katie to talk about how they could hire people with disabilities and not have to worry about the healthcare costs because it is very difficult. Well, we have a wonderful Medicaid buy-in program in the State of Iowa. It is not overly utilized. We would like to see it utilized more. But it is an opportunity, and our State Medicaid director says it is too difficult to figure out how to do those premium things and all of that. If people really need Medicaid, they should be able to buy into the program and not have to pay the premium for it. So he doesn't—they don't charge premiums in the State of Iowa, even on a Medicaid buy-in program. So to me, those are the kinds of things that States can really be encouraged to do that would help individuals, young adults in particular, get to work.

Mr. DEAL. I think we all need to work on that.

Very quickly, Mr. Chairman, if I might just ask Mr. Gronefeld to elaborate once again on—you say that we have programs in place that are trying to put people in an employable status and yet we have the shortage in this healthcare arena. Would you elaborate specifically about the kind of impediments that are there?

Mr. GRONEFELD. Well, there are two primary impediments. One is, the average wage rate that is expected in order to be a success-

ful placement. Both the job corps program and programs under the Workforce Investment Act and TANF require specific wages in order to measure success of the contractors putting people to work. Unfortunately, the wages for direct services professionals are below that threshold and so that hurts the outcomes. And, again, as I mentioned earlier, we need to get those wages up and we could get a lot more people into the system and providing services in this field if we could remove some of those impediments to getting people trained and into the programs.

Mr. PALLONE. I just wanted to ask one question, then we will wrap it up. When you were talking about Katie's track record, do you mean in terms of services that are available to her? What were you referencing?

Ms. BECKETT. Well, what I was referencing is the fact that she was a million-dollar baby before she was 2½ years old.

Mr. PALLONE. Oh, OK.

Ms. BECKETT. So her track record is not very good when it comes to healthcare services and needing that healthcare. What a lot of people don't realize is, once I became a University of Iowa employee and that was in 1984, because they are a large group employer, they could not—they had to accept Katie as a part of their plan so she actually—while she has the Medicaid waiver and now she has a little bit of Medicare because she is old enough to do that, she also has private health insurance, and private health insurance has paid most of Katie's bills as opposed to Medicaid because I went to work for the University of Iowa. I no longer teach, and the teachers who were here earlier—and I have to tell you, that has been a really difficult situation for me. Every September I miss going to my classroom and I miss my kids because that is what my life should have been. Instead, I am here. I am thankful that I get to be here but it is also not my life, not the way I would have liked it to be, but I can't help that. I work for—everybody in this country anymore works for their benefits and Katie's benefit is that she gets to be covered by health insurance, private health insurance. Even though she has this wonderful Medicaid waiver program that is very, very helpful to her, even Medicaid doesn't get coverage for everything you absolutely need to have. But you would think she would be covered on everything if she has all three of those, and she is still not. So I just—that is what I meant by track record. When I say she is my million-dollar baby, I am mean she is my million-dollar baby. Thank you.

Mr. PALLONE. Thank you so much. Thank you, all of you. We really appreciate your being here today. Understand that this is basically a broad hearing because we wanted to her about some of the problems relative to these rules that might go into effect and also wanted to hear some comments about legislation but we do intend to follow up, and I would just remind everybody, my colleagues as well as the panel, that you may—members are allowed to submit additional questions for the record within 10 days or so, so you may get some additional questions that we would ask you to respond to in writing.

But again, thank you all and thank you for all the advocacy. I should say that in my district over the years, and of course Ms. Thomas, your group in particular, but everyone has always been

very effective in bringing attention to disability issues ha are our district office or whenever I have a town meeting, I always have representatives from the community that show up and I think that that advocacy is really important, so please, I am sure you will continue to do it but I do want you to know that it is effective.

And without objection, the subcommittee hearing is adjourned.

[Whereupon, at 1:05 p.m., the subcommittee was adjourned.]

[Material submitted for inclusion in the record follows:]

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STATEMENT FOR THE RECORD

SUBMITTED TO THE

HEALTH SUBCOMMITTEE
OF THE
HOUSE ENERGY AND COMMERCE COMMITTEE

ON

HELPING FAMILIES WITH NEEDED CARE: MEDICAID'S CRITICAL ROLE FOR AMERICANS WITH DISABILITIES

January 16, 2008

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On behalf of AARP's nearly 40 million members, we thank you for holding this hearing today on the Medicaid program and the important role it plays in meeting the health and long-term services and support needs of individuals with disabilities of all ages. Americans with disabilities or other needs for long-term assistance should have the services and supports they need, live in the homes and communities they choose, and control decisions about services that enable them to live as independently as possible. We are pleased that this subcommittee is focusing attention on these critical issues that impact the lives of millions of Americans and their families every day.

Reform of our nation's long-term care policies should be a national priority, because long-term care is a critical part of health and financial security for all Americans and their families. Individuals should also be able to live life to the fullest -- not just receive care. Attached to this testimony is AARP's Long-Term Care Vision about what is needed to make this goal a reality.

Medicaid Home and Community-Based Services and Institutional Bias

Among individuals age fifty and older, 89 percent say they want to remain in their homes for as long as possible. Yet Medicaid, the largest payer of long-term care, has an institutional bias – individuals who meet specific eligibility criteria are entitled to care in a nursing home but not necessarily to home and community-based services (HCBS). HCBS is optional, and in many cases, states have been

required to seek waivers to provide HCBS under Medicaid. Individuals should not be forced to receive services in nursing homes when they prefer and are able to receive services in a home and community-based setting. Individuals with low incomes and assets and those who have spent down and impoverished themselves to be eligible for Medicaid should have more HCBS options.

Over time, states and the federal government have begun to rebalance Medicaid to bring greater attention, efforts, and resources into HCBS. National data for fiscal year 2006 indicate that about 61 percent of Medicaid long-term care expenditures went to institutions and about 39 percent went to HCBS. Comparatively, in 1996, about 79 percent of Medicaid long-term care expenditures went to institutions and about 21 percent went to HCBS. Factors such as consumer demand, the *Olmstead* Supreme Court ruling, the desire to stretch Medicaid dollars further, state initiatives, Real Choice Systems Change grants, and the Money Follows the Person Demonstration are fueling this gradual trend of rebalancing.

The Committee is hearing today about the Community Choice Act (H.R. 1621) introduced by Representatives Danny Davis (D-IL) and John Shimkus (R-IL). This bill further expands access to HCBS by requiring states to provide community-based attendant services and supports (assistance with daily activities) to individuals eligible for Medicaid who require an institutional level of care and choose to receive community-based attendant services and supports. In some

cases, states would receive an enhanced federal match for providing these services. The bill also would provide grants to states to address a variety of issues including implementation of the legislation, gaps in services, reducing unnecessary institutionalization, and expanding consumer-directed HCBS.

Lessening and removing the institutional bias in Medicaid is an important part of long-term care reform. The committee should also examine additional potential barriers to HCBS in Medicaid, including repealing or modifying the potentially harmful asset transfer and home equity provisions enacted in the Deficit Reduction Act (DRA). The committee should also revisit the Medicaid HCBS option in the DRA to modify some of its provisions, including increasing the income eligibility, to make it an option that states are more likely to implement to expand HCBS.

We also note that while most individuals prefer to receive services in home and community-based settings and this access needs to be expanded, some individuals will continue to receive care provided in nursing homes. Ensuring that nursing home care is high quality should be an important consideration even as quality HCBS options are expanded.

Consumer-directed care is a promising trend in long-term care and can give consumers new options. Consumer direction gives consumers more choice and control over the services they want, where they are provided, and who provides

them. Often, consumers may hire family members, friends, or neighbors to provide care at home.

One successful example of consumer direction is the Cash and Counseling program that began in Arkansas, Florida, and New Jersey and is now in 15 states. The Cash and Counseling program provides individuals with a flexible monthly allowance, and participants use individualized budgets to make choices about the services they receive. Consumers could choose to hire a worker, including a family member, to provide personal care assistance or use the money for items such as home modification. Individuals can also have the assistance of a fiscal agent to help with payroll and tax withholding. Participants in the three original states have reported greater satisfaction with services they received, a higher quality of life, and fewer unmet needs than individuals in a control group.

We hope the committee's discussion of the Community Choice Act and other ways to expand access to HCBS will serve as a catalyst for further conversations and debate in both the House and Senate about how to increase access to HCBS and make long-term care a priority for Congress to address in a serious and thoughtful way.

As the subcommittee examines ways to increase options for HCBS, other issues must be addressed in order to truly make these services available to those who need them and enable individuals to live in the homes and communities they

choose. The critical elements include: support for family caregivers, an adequate workforce, financing options, quality supports and services, and livable communities.

Family Caregiving

The contributions of America's family caregivers, along with those of friends and neighbors, are the foundation of the nation's long-term care system. These unpaid caregivers provide by far the majority of HCBS received by persons with disabilities of all ages. According to a recent AARP Public Policy Institute analysis, the contributions of unpaid caregivers represent an important component of the U.S. economy, with an estimated economic value of about $350 billion in 2006. That amount is considerably greater than the nation's total spending on Medicaid, including both federal and state contributions and both medical and long-term care.

The "typical" caregiver in the U.S. is a 46-year old woman who works outside of the home and spends more than 20 hours per week providing unpaid care. Caregivers face multiple challenges – financial, emotional, and physical. Many caregivers experience significant economic losses due to changes in work patterns, including lost wages, loss of health insurance and other job benefits, and lower retirement savings. A recent Urban Institute study found that caregiving reduces paid work hours for middle-aged women by 41 percent. In addition,

caregivers' own physical and mental health may be placed at risk. They are more likely than non-caregivers to have chronic health conditions, including depression, as well as medical bill problems or medical debt.

Preventing caregivers from being overwhelmed is essential for both moral and economic reasons. Family caregivers reduce pressure on both Medicaid and Medicare budgets by helping to delay or prevent the use of nursing home and home health care. In addition, family caregivers are at the center of efforts to encourage greater home and community-based support.

Caregivers can benefit from supports such as respite care, education, counseling, training, and financial assistance that enable them to address their own needs and continue to care for their loved ones. Examples of policies to support family caregivers that could be implemented at small fractions of the value of their unpaid contributions include:

- assessments of family caregivers' needs, particularly for family caregivers who are critical to the implementation of a beneficiary's care plan in a Medicaid HCBS program;
- better identification of family caregivers of Medicare beneficiaries and links to supports for these caregivers;
- adequate training of informal caregivers;

- adequate funding for the National Family Caregiver Support Program and the Lifespan Respite Care Act; and
- tax credits for family caregivers.

Long-Term Care Workforce

An adequate, stable and well-trained workforce is also critical to long-term care and the expansion of HCBS. Direct care workers, such as personal care assistants, home care and home health aides and certified nursing assistants, provide the bulk of paid long-term care. They assist individuals with daily tasks such as bathing, dressing, meal preparation, and housekeeping. Compared to the general workforce, direct care workers are more likely to be women (about 90 percent of the direct care long-term care workforce), non-white, and unmarried with children.

Direct care workers are often paid low wages with limited or no benefits and have high workloads, unsafe working conditions, inadequate training, a lack of respect, and limited opportunities for advancement. All these factors contribute to the high turnover rate among these workers, in some cases more than 100 percent. While family caregivers provide a great deal of long-term care and paid family caregivers can expand the long-term care workforce, it is imperative that an adequate direct care workforce is also available to provide services. Family caregivers cannot do it alone.

Long-term care workers should receive adequate wages and benefits; necessary training and education, including opportunities for advancement; more input into caregiving; more respect for the work they do; and safer working conditions. These issues should be addressed across all settings, whether HCBS or institutional. Addressing these issues will not only strengthen the long-term care workforce, but also improve the quality of care and continuity of services for consumers. In addition, culture change, a movement to transform institutions into more resident-centered, homelike settings, can also improve working conditions and empower direct care staff in long-term care facilities.

Financing Options

Individuals also need more and better public and private financing options. A broader array of affordable financing options could make HCBS more accessible to more individuals. Planning for long-term care should be an important part of retirement planning, but many individuals are in denial that they may need long-term care and current financing options are limited. Consumer education is needed regarding existing financing options. Medicare and private health insurance generally do not cover long-term care. Family caregivers may not always be available. Medicaid only assists those with low incomes and assets and those who have "spent down" their assets and impoverished themselves to qualify. Long-term care insurance is an option for some individuals, but it can be expensive and some individuals cannot qualify due to pre-existing conditions.

Reverse mortgages may be an option to help some people stay in their homes and pay directly for HCBS, but reverse mortgages have high costs.

In addition, individuals often face many competing demands for their incomes – mortgage payments, monthly bills, saving for a child's college education or other large purchase, paying off debt, and general retirement savings. Yet, the average annual cost of a private room in a nursing home in 2006 was $75,000, and a 2006 AARP survey found that less than 1 in 10 Americans age 45 and older could come close to estimating the cost of nursing home care. The national average cost for a 4-hour in-home visit by an aide was $76 in 2006 or over $27,000 per year if the care is provided daily. Over time, these costs are more than most people can pay on their own.

Providing individuals with adequate, stable, and flexible financing options that give consumers more choice and financial protection is critical. Financing should be affordable to individuals and to society as a whole, with shared responsibility among the government, individuals, and the private sector. A stable system will require a combination of sustainable public and private resources. Legislation such as the Community Living Assistance Services and Supports Act (H.R. 3001) can help stimulate debate and conversation in this committee and in Congress about long-term care and its financing.

Private long-term care insurance is one way to pay for HCBS, but it should have strong consumer protections. Inflation protection is critical, especially for those who buy policies at younger ages. Without such inflation protection, the value of the insurance benefits can erode over time. A $150 daily benefit will not buy as much care in 2028 as it does today. Premium stability helps protect consumers whose premiums increase above a certain threshold. Long-term premium affordability is an important reason why persons may drop long-term care policies or not buy them in the first place. While states can adopt their own consumer protections, such as those included in the National Association of Insurance Commissioners' (NAIC) Long-Term Care Insurance Model Act and Regulations, there are also consumer protections mandated by the Health Insurance Portability and Accountability Act of 1996 for federally tax qualified long-term care insurance policies. AARP supports efforts to update and strengthen these consumer protections that are based on the NAIC standards.

The Long-Term Care Partnership Program allows individuals who buy private long-term care insurance policies under the program to protect a certain amount of their assets and become eligible for Medicaid if they meet all of Medicaid's other eligibility criteria. Under the Deficit Reduction Act, states can establish a Partnership program if certain criteria, including some consumer protections, are met. While the Partnership program may provide a new financing option for some individuals, consumer education is absolutely critical for consumers to make a fully informed decision about whether or not a Partnership policy is right for them. Due

to the complexities of long-term care insurance and its interaction with Medicaid under this program, strong consumer protections and education are essential.

Reverse mortgages are also a potential long-term care financing option for some individuals who may wish to tap their home equity to directly purchase HCBS. A reverse mortgage is a loan against a home that requires no repayment until the borrower dies, sells the home, or permanently moves out of the home. Consumer protections for reverse mortgages are also important, such as required independent counseling and protections against those who might take advantage of reverse mortgage borrowers. Individuals can use these loans to directly pay for services such as home health care, chore services, respite care, and home modification that enable the individuals to remain at home. However, reverse mortgages currently have high costs that are a significant barrier to their use. Congress should examine ways to reduce the costs of reverse mortgages for individuals with long-term care needs, such as a public-private approach of providing lower cost reverse mortgages to individuals with long-term care needs through competitive demonstration programs in selected states.

Quality Supports and Services

Consumers need quality services and supports whether they are in an HCBS or an institutional setting. AARP supports legislation pending in this committee that would help improve the quality of long-term care for consumers -- the Elder Justice

Act (H.R. 1783) -- introduced by Representatives Rahm Emanuel (D-IL) and Peter King (R-NY). The Elder Justice Act would strengthen coordination of existing federal, state, and local resources to detect, prevent, and respond to elder abuse, neglect and exploitation. It would also authorize additional resources for improved protective services that could assist individuals in home and community-based settings. We urge this committee to swiftly approve the Elder Justice Act early this year to help ensure enactment of this important legislation before the end of the 110th Congress.

Low-income, minority, and other diverse populations may have even more limited access to quality services and providers, whether HCBS or institutional. In some cases, services that individuals need may not be available, or when services are available, they are of poor quality. These barriers must be addressed to ensure access to quality services and supports for all individuals.

Other important quality issues for HCBS include: care coordination for individuals with chronic conditions, including better coordination as individuals move from one setting to another (e.g. hospital to skilled nursing facility to home); greater recognition of the importance of family caregivers in ensuring better care and smoother transitions among settings; back-up systems for situations when home care workers are unable to work; information technology and electronic medical records with appropriate privacy protections; reliable quality information for

consumers and their families; and ensuring adequate oversight of care provided in individuals' homes.

Livable Communities

Finally, once consumers are to receive the services and supports they need to enable them to remain at home, they also need to have livable communities that enhance their independence and social connection. Accessible and affordable housing is critical, as is accessible public transportation and mobility options that enable individuals to get around their communities and to essential places such as the grocery store and the doctor's office. Accessible businesses, service providers, and cultural opportunities also enable an individual's full participation in the community. Assistive technologies can also enhance independence, whether they are mobility aids, hearing and vision aids or personal emergency response systems.

Conclusion

AARP appreciates the committee holding this important hearing about Medicaid's important role in providing long-term services and supports, especially HCBS, to individuals with disabilities and other long-term care needs. Long-term care is a vital part of the health and financial security of American families. We hope that this is one of many upcoming opportunities to discuss and address long-term

services and supports in this committee and enact bipartisan legislation that will help older adults and individuals with disabilities of all ages live life to the fullest in the homes and communities they choose. AARP stands ready to work with members of this committee and your colleagues on both sides of the aisle to make this vision a reality.

AARP's Long-Term Care Vision

Reform of our nation's long-term care policies must become a national priority. **Our goal is to enable people to live life to the fullest, not just provide long-term care. AARP envisions that all Americans with disabilities or other needs for long-term assistance will have the services and supports they need.** Those receiving such assistance will live in homes and communities they choose and control decisions about services that enable them to live as independently as possible. To make this vision a reality, AARP will work at the national and state levels to put consumers in control by emphasizing home and community-based services such as assistance with meal preparation, bathing, and dressing as well as assistive technologies and modifications to home and community environments. Achieving AARP's vision will require:

Maximum Consumer Choice and Control: Options available and services directed by consumers. We envision an accessible system of supports so that when the need arises, all Americans will be able to choose those services and supports which will help them remain independent, where to receive services, and who provides these services.

Financing Options: Adequate, stable, and flexible financing options that give all consumers more choice and financial protection. Services and supports will be financed through an expanded array of public and private sector funding sources. Financing should be affordable to individuals and to society as a whole, with shared responsibility among the government, individuals, and the private sector.

Support for Family Caregivers: A system of information, financial, training and social supports for caregivers. Families and friends, who currently provide the vast majority of needed long-term services and supports to persons with disabilities, will receive assistance when they need it, such as: respite services; financial assistance; more flexibility in the workplace; assessment of their own needs; and training in the skills needed to provide care.

Livable Communities: Homes and communities that enhance independence and social connection. Americans will have support for remaining active in their homes and communities, including: accessible and affordable housing and public transportation; accessible community buildings and services; and assistive technologies that enhance independence.

High Quality: A system that respects consumer preferences and focuses on quality outcomes for consumers. Assisted living facilities and nursing homes will become homelike settings with improved quality of life for residents, and the quality of services will improve in all settings. Care coordination and management of chronic conditions across settings will improve. Information technology with appropriate privacy protections will enhance care, and information on provider quality will be widely available to consumers. Providers that improve quality outcomes will be rewarded; oversight of providers will be strengthened and those that fail to provide acceptable quality services will be penalized or closed down.

An Improved Workforce: An adequate, stable, and well-trained workforce. Nursing aides and other direct care staff will be offered: more input into caregiving and more respect for the work that they do; higher wages and improved benefits; necessary training and educational opportunities; and safer work conditions. These changes will benefit consumers by improving the quality and continuity of services.

Helpful Information: Timely, effective information, legal advice and legal protections. Americans will have the information and tools they need to plan in advance for their long-term care needs, and in times of crisis, timely advice and counseling. All consumers will be able to readily access clear information and comparison tools, easy one-stop shopping for help in locating services in their communities, and legal advice. Vulnerable older adults will have enforceable legal protections.

AARP, January 2007

TESTIMONY OF AUTISM SPEAKS

BEFORE THE HEALTH SUBCOMMITTEE OF THE U.S HOUSE OF REPRESENTATIVES COMMITTEE ON ENERGY AND COMMERCE

HELPING FAMILIES WITH NEEDED CARE: MEDICAID'S CRITICAL ROLE FOR AMERICANS WITH DISABILITIES

JANUARY 16, 2008

Autism Speaks greatly appreciates the opportunity to present this written testimony to the Subcommittee. Medicaid plays an extremely important role in the lives of the many thousands of American families that are affected by autism.

Summary:

- Both by design and default, Medicaid plays a critical role in the lives of persons with autism.
- The Centers for Medicare & Medicaid Services ("CMS") has been pursuing policies contrary to the needs of persons with autism.
- Rather than limit autism services in the schools and out, the CMS should support successful state service models.

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Autism Speaks, the world's largest autism advocacy organization, welcomes the opportunity to offer written testimony on Medicaid's critical role for Americans with autism. A complex neurobiological disorder that typically lasts throughout a person's lifetime, autism is part of a group of disorders known as autism spectrum disorders. Today, one in one hundred and fifty individuals is diagnosed with an autism spectrum disorder. Autism spectrum disorders are more common than pediatric cancer, diabetes, and AIDS combined. They occur in all racial, ethnic, and social groups and are four times more likely to strike boys than girls. Autism spectrum disorders impair a person's ability to communicate and relate to others and are associated with rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines. Autism spectrum disorders vary greatly in severity. Some people with autism spectrum disorders need little or no support. Others need a great deal of help to live safely in their communities.

Private health insurance often fails to provide the assistance needed by people with autism spectrum disorders. Some private health insurance policies even contain blanket exclusions for the treatment of autism. Even when private health insurance provides some benefits, it almost always denies benefits for the behavioral treatments long established as effective. Autism Speaks is advocating for change in state laws that allow insurers to deny or severely limit coverage for autism spectrum disorders. For instance, Autism Speaks strongly supports Pennsylvania House Bill 1150, which would require private health insurers to provide medically necessary coverage. In Pennsylvania and elsewhere, the inadequacy of private health insurance coverage has focused attention on the critical role of Medicaid in serving persons with autism spectrum disorders.

Medicaid spending for services for people with autism spectrum disorders and other developmental disabilities has increased substantially in recent years. Children with disabilities comprise a significant portion of all Medicaid recipients, and an even more significant portion of disabled children use the Medicaid system as their primary insurer. While the number of persons with autism spectrum disorders served by Medicaid is not known, studies suggest that the prevalence of autism spectrum disorders among Medicaid enrollees has increased over time. This rise parallels disturbing trends in school census and epidemiological data of ever greater numbers of affected children.

Medicaid serves persons with autism spectrum disorders through state plan services to low-income persons and persons with disabilities, and through specialized waiver programs that serve targeted populations without regard to the income of anyone other than the individual served. Five states have waivers targeted solely at persons with autism spectrum disorders. One such state is Maryland, the first state in the nation to target Medicaid services specifically to children with autism spectrum disorders. Maryland's waiver provides intensive individual support services, after-school activities, respite care, supported employment, case management and other services to the most severely affected children in the state. Like all waiver programs, Maryland's program is capped. Approximately nine hundred children are served by the waiver. Another twenty-three hundred children are on a waiting list. Unless the number of waiver slots is expanded, these children may wait years for services.

In contrast to waiver services, Medicaid plan services are not limited to a fixed number of slots and can be delivered in schools. The Medicare Catastrophic Coverage Act of 1988 allows school districts to receive payment from Medicaid for health services listed in an individualized education program that are delivered to Medicaid-eligible children. When necessary services are

covered by a state Medicaid program, the financial responsibility of the state Medicaid agency precedes that of the school system.

Recent actions by the Centers for Medicare & Medicaid Services call into question the agency's commitment to fulfill that responsibility. For instance, proposed agency rules would deny federal financial participation for habilitation services, as well as for rehabilitation services furnished as "intrinsic elements" of educational programs. Autism Speaks and other disability groups have been actively engaged in this rulemaking, and have submitted comments to CMS criticizing the proposed rules. Although the Medicare, Medicaid, and SCHIP Extension Act of 2007 blocks them from being implemented before June 30, 2008, the proposed rules are especially worrisome in light of the cutoff in 2007 of federal financial participation for applied behavioral therapy services for Medicaid-eligible South Carolina school children with autism spectrum disorders. Autism Speaks understands that CMS acted in part because services were limited to school settings. The cutoff led South Carolina to discontinue funding services for almost 3,000 children and brought to an end a successful eight-year old state program.

Autism Speaks is also concerned about interim final regulations on optional state plan case management services. These regulations, which become effective on March 3, 2008, would limit claims for federal financial participation for case management services. This could only exacerbate the problems school and public health systems face in financing services for children with autism spectrum disorders. The Maryland State Department of Education, for instance, estimates that the new regulations will reduce federal financial participation for autism waiver services by $700,000.

Autism Speaks fears that restrictive CMS policy will chill state efforts to provide appropriate services to persons with autism spectrum disorders. We worry about a bureaucratic Alphonse and Gaston routine, with the federal government looking to the states to fund services, the states looking to the federal government, and persons with autism spectrum disorders suffering in consequence. There is no real economy in engendering service cutbacks to a vulnerable and growing population of disabled Americans.

Finally, Autism Speaks urges the Subcommittee to act on H.R. 1881, the Expanding the Promise for Individuals with Autism Act of 2007 (the "EPIAA"). This legislation authorizes funding for a comprehensive set of federal-state partnerships to provide evidence-based treatments, interventions, and services for those with autism spectrum disorders. H.R. 1881 will fill gaps in Medicaid services and provide help to those not eligible for Medicaid. The EPIAA is an appropriate and necessary follow-up to the Committee's profound work in 2006 on the Combating Autism Act, for which the autism community will be forever grateful.

Again, Autism Speaks greatly appreciates this opportunity to present its views, and stands ready to assist the Subcommittee in any way it can to ensure that American families receive all necessary assistance in dealing with autism spectrum disorders.

POSITION ON LONG TERM CARE and PERSONAL ASSISTANT SERVICES: NCIL Submits Written Testimony to House Energy & Commerce Health subcommittee

1/15/2008

SUBCOMMITTEE ON HEALTH, HOUSE ENERGY & COMMERCE THE UNITED STATES HOUSE OF REPRESENTATIVES

HONORABLE REPRESENTATIVE FRANK PALLONE, CHAIRMAN

TESTIMONY ON HOME AND COMMUNITY SERVICES AND SUPPORTS

The National Council on Independent Living is submitting written testimony to the House Energy and Commerce Subcommittee on Health for community living and long term services and supports for people with disabilities.

The National Council on Independent Living (NCIL) is the oldest cross disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL represents over 700 organizations and individuals including: Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), individuals with disabilities, and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.

NCIL was established four years after the 1978 amendments to the Rehabilitation Act of 1973. The 1978 amendments added statutory language and funding for the formation of Centers for Independent Living. The Executive Directors of the newly federally funded CILs met regularly with Rehabilitation Services Administration (RSA) to discuss issues related to the development and expansion of CILs nationwide. Believing that the views of CIL consumers and people with disabilities, as a whole, were not being heard by the federal government, the Administration or the Congress, the CIL executive directors worked to organized and establish the National Council on Independent Living - an organization governed by people with disabilities advocating for the development and expansion of a nationwide network of centers for independent living.

We support Insurance Reform acts such as the Class Act, which would assist people with disabilities who need long term assistance or supports by providing a flexible cash insurance benefit that could be used creatively to purchase services, supports and technology. Beneficiaries would choose how to best meet their own needs. NCIL applauds the creative approach of the bill in addressing the issues around long term care services. We believe an insurance program that is available nationwide and that is affordable and not tied to poverty and unemployment is a laudable goal and a much needed piece of the long term service puzzle.

NCIL also strongly supports The Community Choice Act of 2007 (S.799 & H.R. 1621) by Senator Tom Harkin (D-IA) and Representative Danny Davis (D-IL-7th). NCIL endorses the Community Choice Act of 2007 because the bill addresses provisions that would provide a range of community-based supports that would include activities of daily living such as eating, toileting, grooming, dressing, bathing and transferring; and could include meal planning, shopping and preparation, financial management, and household chores. The legislation also addresses hands-on assistance, supervision and cueing. Supports will be based on a functional needs assessment and all services are furnished in accordance with a plan agreed on by the consumer. The Community Choice Act of 2007 will provide many people with disabilities the opportunity to choose where and how they receive personal assistance services in their homes and communities across the nation.

The balance of our testimony will acquaint you with the National Council on Independent Living, our membership, activities and commitment to ending the institutional bias over the last twenty years. We will also explain our principals and goals for a national system of consumer control and home and community based services.

In terms of long term care policy, instead of "liberty and justice for all" the situation is liberty and justice for some depending on your age or the type and severity of your condition and the budget cycle of the state you happen to live in. It is shameful that people with disabilities who need long term services and supports have

CMS has encouraged states to rebalance long term care (LTC) systems and enable money to follow the person through grants to states as well as making policy changes, providing guidance and proposing legislation. Unfortunately, even with the resources, funding opportunities and technical assistance from CMS, many states have not made meaningful LTC system changes and the institutional bias remains prevalent. Many states that have applied for HCBS waivers have long waiting lists for PAS programs. State officials report many groups are not being served, such as traumatic brain injury, HIV/AIDS, or mental illness. The cost of unmet need for Medicaid HCBS is estimated at $1.9 billion for those living alone and $4.7 billion for those living with others.

The NCIL asserts the institutional bias on the part of the federal government and state governments must be reversed and that people of all ages with all types of disabilities must have the option of obtaining assistance with daily living in their homes and communities through a national consumer controlled personal assistance service program. Americans with all types of disabilities and all citizens of the United States deserve no less.

NCIL believes that a national personal assistance service program must have certain characteristics to most effectively and efficiently meet the needs of people with disabilities in their home and communities, that a comprehensive range of services must be available for an effective, efficient personal assistance service program. Personal assistance service, along with assistive technology such as wheelchairs, text readers, and hearing aids, enable people with disabilities to participate in activities at home, at work, and in the community.

Personal assistance service coverage must extend to people of all ages with all types of disabilities including cognitive, sensory, mental and physical disabilities and that eligibility criteria must not discriminate based on age, type of disability and/or any other factor unrelated to need. NCIL's position is that individuals must be eligible for a national personal assistance service program if they experience a functional disability of a temporary or permanent nature resulting from injury, aging, disease or congenital condition which requires personal assistance services.

Eligibility criteria must be developed that do not exclude people based on age; type of disability; onset of disability such as congenital, injury, disease, or later age onset; and health, family status, race, national origin, cultural background, religion, gender, sexual preference and/or geography.

Eligibility criteria must not include disincentives for employment and/or marriage.

Eligibility must not be based on income factors. Although, cost sharing is acceptable based on a sliding income.
No person must be forced into or kept in an institution because of the denial of Personal Assistance Service.

NCIL believes that the views of personal assistance service users must be paramount in the design, delivery, and evaluation of a national personal assistance service program.

NCIL believes that whatever national program design and funding mechanisms are employed, states should be required to adopt the definition and provide the basic services, program models, coverage and eligibility criteria, governance mechanisms, and grievance and appeal procedures cited in this position paper in order to provide uniform coverage for people with disabilities across the states. NCIL further believes that a gradual phase in of a personal assistance service program would be desirable in order that a personal assistance service infrastructure can be developed to meet the demand.

NCIL believes that financing mechanisms and regulations for a national personal assistance service program should not in any way reflect a bias toward institutionalization and away from Home and Community Based Services.

Cost sharing and/or tax credits must be part of a national personal assistance service plan based on a sliding scale relative to income, but with a cap on out-of-pocket consumer expenditures at a percentage of income and/or on tax credits. The families of children who receive personal assistance service benefits must be treated the same as direct personal assistance service users in terms of cost sharing and/or tax credits.