S. HRG. 110–815

HOME- AND COMMUNITY-BASED CARE: EXPANDING OPTIONS FOR LONG-TERM CARE

HEARING

BEFORE THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDRED TENTH CONGRESS

FIRST SESSION

SEPTEMBER 25, 2007

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HOME- AND COMMUNITY-BASED CARE: EXPANDING OPTIONS FOR LONG-TERM CARE

TUESDAY, SEPTEMBER 25, 2007

U.S. SENATE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 10:08 a.m., in room SD–G50, Dirksen Senate Office Building, Hon. Max Baucus (chairman of the committee) presiding.

Present: Senators Kerry, Lincoln, Wyden, Schumer, Salazar, Grassley, Snowe, Smith, and Bunning.

OPENING STATEMENT OF HON. MAX BAUCUS, A U.S. SENATOR FROM MONTANA, CHAIRMAN, COMMITTEE ON FINANCE

The CHAIRMAN. The hearing will come to order.

In July of 1776, the bell of Philadelphia's Independence Hall rang to summon Americans to the birth of an independent Nation. On that bell were cast the words from Leviticus: "Proclaim liberty throughout all the land, unto all the inhabitants thereof."

Americans value freedom. Americans value independence. The people from my own State of Montana have an independent spirit. They take pride in taking care of themselves. But not all Americans have the freedom to live independently. People with disabilities and the elderly, especially those who are also poor, face barriers to living independently. They face barriers to living where they choose, and they face barriers to traveling across town.

Medicaid provides the bulk of services to low-income elderly and people with disabilities, but Medicaid's payment limitations can restrict where people live or receive health care.

For example, Medicaid pays for personal care assistance only when it is provided in an institutional setting, like a nursing home. When people with disabilities need these services and cannot afford to pay for them, Medicaid pushes them into an institution.

Many low-income people with disabilities pay for Medicaid services with their independence. They lose the right to decide when they use the phone, they lose the right to decide what food they eat and when they eat it, and they lose the right to decide what time to wake up or to go to bed.

Mark Bowman faced that choice. Mark was born with muscular dystrophy. He was eventually put on a respirator. He needed assistance with his respirator, but he did not need the intensive care that a nursing home provides. Mark wanted to continue living on his own, but was unable to arrange or afford in-home care.

To receive the care that he needed to stay alive, Mark entered a nursing home at the age of 25. But Mark was determined to find another way. Five years later, he moved to Montana. There, a State Medicaid waiver allows him to receive these services in his own apartment. Today he lives independently, attends college, and has more control over his own life.

Long-term care can enable many individuals with disabilities to work or return to work. The Finance Committee heard about these issues at a field hearing just this past June.

Jim Brown testified at that hearing. Jim broke his neck on a trip to Hungary. He testified that, if he received more help with personal care, he could return to work. Like Mark, Jim did not need a high level of care, he just needed help with some of his daily care. He was not asking for a handout; he just wanted to be a productive member of his community.

Limitations on independent living also affect the elderly. A recent study showed that nearly ¾ of people over age 50 prefer to receive care in their homes. More people today are choosing to “age in place.” The share of people over 75 years old in nursing homes fell from 9.5 percent in 1985 to 6.5 percent in 2004. This shift reflects the growth of less restrictive types of care, from assisted living to adult day care.

These alternatives are usually less expensive than nursing homes, and these alternatives often provide a better quality of life. Assisted living and adult day care often require more from family caregivers. It has been estimated that unpaid caregivers provide $350 billion worth of services a year. That is nearly as much as the Nation spends on all of Medicare.

As the baby boom generation ages, providing long-term care to the elderly will be a growing challenge. States are increasingly concerned about the costs. States view community-based services as a way to control those costs. States that have enabled people to move out of nursing homes and back into the community generally save money.

The need for long-term care does not discriminate. Any one of us, or a loved one, could need long-term care at any time. Today we focus on an important component of long-term care, that is, home- and community-based services. We will hear from Senator Harkin, author of the Community Choice Act. Then we will hear from individuals with experience with accessing, providing, and evaluating home- and community-based services.

I want to acknowledge that Senator Grassley took great strides to expand State flexibility in offering home- and community-based services through the Deficit Reduction Act of 2005. He did so at a time when the Finance Committee was charged with finding savings in the Medicaid program. So I commend him. I commend you, Senator, for taking those steps, and certainly at the time that you did.

Senator GRASSLEY. Thank you.

The CHAIRMAN. And so let us look for ways to summon Americans to the birth of a more independent Nation. Let us strive to give new life to the words from Leviticus cast on the Liberty Bell. Let us work to extend liberty and independence throughout the land to all Americans. [Applause.]

The CHAIRMAN. I appreciate the feelings of people in the audience, but I do urge all of us to keep our demonstrations at an absolute minimum, because we have lots of work to conduct here. I just want to thank all of you, and I thank Senator Grassley. Thank you.

OPENING STATEMENT OF HON. CHUCK GRASSLEY, A U.S. SENATOR FROM IOWA

Senator GRASSLEY. Well, thank you very much, Mr. Chairman, for your recognition of what I accomplished in the Deficit Reduction Act. But more importantly, what we are talking about now is the future, not the past. So I want to thank Senator Harkin for being here as well, because he is a long-time leader in this area.

Then both of us have the privilege of having Dr. Kevin Concannon here from our State Department of Human Services in Des Moines, IA. We have had the good fortune of Dr. Concannon having been in similar positions in other States, so we got a real professional when he came to Iowa. I am glad to have him be a witness.

Today's hearing is one of a series over the past several Congresses on this very important topic of home- and community-based care. Over time, we realize that many, many physically challenged people would prefer to live in the community. Many of these people have been placed in institutions because of payment bias in Medicaid. In addition, our population is aging, and we, of course, need to face the fact that more of us will need help in the most basic aspects of living.

Just as I endorsed choice of health plans for Medicare beneficiaries, I endorse a choice for those needing long-term care. For some people and their families, an institution may be their choice for long-term care. Many others, however, prefer to receive care at home or in the community.

In fact, that is the trend. In the Deficit Reduction Act of 2005, referred to by Senator Baucus already, we included $1.75 billion in grants for major demonstration programs. This year, CMS awarded $1.4 billion to 31 States, including our State of Iowa. These States intend to move more than 37,000 people from institutions to community.

In addition, we have given the States the option to allow people to manage their own care. They get a budget and they may contract with caregivers and providers however they decide to do. This option may not be for everyone, but in Iowa the State Department of Human Services is demonstrating that it can work. We also included in the Deficit Reduction Act the Medicaid State plan option for home- and community-based services.

Now, for people who are handicapped by mental illness, States have a new option to use Medicaid funds for home- and community-based services without even having to go to the bother of getting a waiver. Iowa is the first State to receive approval of this benefit. The State plans to serve 3,700 people in the 1st year, and nearly 4,500 people by the 5th year.

That is, of course, thousands of people who would have been in institutions. I believe that we are moving in the right direction. We are working to enable people to stay in their communities, and we are allowing them greater responsibility and choice in yet another key area of their lives. So, once again, Senator Baucus, I appreciate your holding this hearing and moving this ball forward.

The CHAIRMAN. All right. Thank you, Senator.

I would like, now, to welcome our good friend and colleague, Senator Harkin.

Senator SCHUMER. Mr. Chairman?

The CHAIRMAN. Senator Schumer?

Senator SCHUMER. Mr. Chairman, I know that it is not usual for non-chairman and ranking members to make an opening statement. I would like to just briefly welcome, if I might, Mr. Chairman, the more than 50 constituents who got on a bus yesterday from Rochester, NY. [Applause.] They are from the Center for Disability Rights and the Regional Center for Independent Living. And the reason I am a proud co-sponsor and fighter for this bill is these people alerted me to the real need. So, thank you for being here.

The CHAIRMAN. Thank you, Senator, very much. [Applause.] Thank you.

I now welcome Senator Harkin, who is chairman of the Labor, HHS Subcommittee of the Senate Appropriations Committee, and also chairman of the Agriculture Committee, and quite a remarkable man in many ways. I very much welcome you, Senator. Again, thank you very much for your strong work in the Community Choice Act.

You have been a real leader. In fact, I cannot think of another member of this Senate who is anywhere close to you in the work that you have undertaken in this area, and many others, and we thank you very much for having the opportunity to listen to your statement. Thank you.

STATEMENT OF HON. TOM HARKIN, A U.S. SENATOR FROM IOWA

Senator HARKIN. Mr. Chairman, thank you for those kind words. And thank you for your leadership, and Senator Grassley, both, in moving this ball down the field over the last few years. We have made some progress. I think what we are talking about here today is finally getting to the goal line.

I want to thank all of the CCA activists who are out here in back of me coming from different parts of the country—obviously more from New York than anywhere else. [Cheering.]

I want to thank NCIL, the National Council on Independent Living, ADAPT and their leader, Bob Kafka, who was going to be here but was in the hospital, and is now out, and others for their very long and persistent struggle for fairness, equity, and opportunity.

Mr. Chairman, it was 17 years ago this summer that the Americans With Disabilities Act was signed into law by President Bush. There were four goals set out in that bill, enunciated very clearly: equal opportunity, full participation, independent living, and economic self-sufficiency.

At the time when this passed the Senate and the President signed it later into law in 1990, I said at the time on the floor, since I was the chief sponsor of that bill, that this opens the door, but the next, most important thing we have to do is provide personal attendant services to people. I said that in 1990.

So it has been 17 years since ADA and since we started this push. It has been over 10 years since MiCASSA (the Medicaid Community Attendant Support and Services Act) was first introduced. Now, MiCASSA was a precursor of this bill. I might just add, for those who maybe do not follow this or maybe came later, it was first introduced in the House by none other than Newt Gingrich himself, who was then Speaker of the House. He is still a supporter of this, I might add, of the Community Choice Act.

So, really, Mr. Chairman, you outlined, I think, very succinctly, very clearly, very eloquently in your opening statement, what this is about. It is about giving people choice about where they want their Medicaid dollars to be spent. That is really all it is about. As you will see on the shirts, what people have been saying for years, "Our Homes, Not the Nursing Homes." Let us decide where that money should be spent.

Right now, and as you are all aware—I am just repeating things I am sure you know—there is this bias in Medicaid. Two-thirds of the money in Medicaid goes to nursing homes, one-third goes to communities and home-based care. That is because, under Medicaid, they shall, they have to, they must provide the funding for that. But under community- and home-based, they may. That is the difference.

Now, also, I might just point out that a lot of States have waivers. Most States have some kind of a waiver program, and some States do it better than others. I think Iowa does a pretty good job of waivers; obviously Montana has a good waiver program. I am not familiar with all the waiver programs, but it is a hodgepodge of different things around the country, some States better than others.

But even with a State that has a good waiver program, you have almost a web of entanglement of things that people have to go through to try to figure out if they can qualify. Now, you take Iowa, for example. Mr. Concannon can speak about this. If you get in the physical disability waiver program, you have a $500 a month cap. Well, then you have to think about, well, maybe I need more than that. I cannot get all the attendant services I need so I can get up and go to work every day.

Well, but there is a cap there. So then you apply to another program, you try to get in under another waiver, under the Ill and Handicapped program. Well, maybe you can get into that. Well, but that has a year's waiting list. Well, maybe there is another program. So what happens in these States with waivers, when someone enters the system, they apply for every waiver. Then it kind of becomes a bureaucratic entanglement. Again, it should not be that way, that people have to go through that.

So when you apply for a waiver program, a person with disabilities hopes they are eligible. They hope they meet the eligibility requirements. Second, they hope that there is space for them in that waiver. Third, you hope that it is not capped so that you might get 2 or 3 weeks of service, but not the last week.

So with all due regard to waivers, it is time now to move beyond that. The ball has been moved down the field. The time has come to move beyond that and to have broad-based community-based services to lift that bias in the Medicaid program.

With appropriate community-based services, we literally can transform the lives of people with disabilities. They can live with their families and friends. They can be the neighbors down the street, not someone warehoused down the hall with strangers whom they do not know.

Now, I would just close with a story about my nephew, Kelly, to give you an idea of the differences. My nephew Kelly was injured 27 years ago. He was a young man of 19. He got injured and became a quadriplegic. Well, he wanted to go to college, so he went and he got good service. He went to college and he got his degree. He then became independent and he has lived in his own home ever since. He got the use of his arms back and he can actually drive a van with a lift. He gets in the van and he goes to work every day.

A nurse comes in every morning. Every morning, a nurse comes in, gets him out of bed, does his exercises, does the other things he needs, drains him, all that kind of stuff, gets him ready to go to work. Kelly gets in his van and he goes to work. He comes home, he makes his own meals. He invites friends over to his house. Then he has someone who comes in and helps him get ready for bed. The next morning, he gets up, the nurse comes in and gets him ready to go, and he goes to work. He pays taxes. He is a contributing member of society.

Now, how does he afford to do all this? Is his family rich? No. His mother, my sister, died many years ago. A family of very modest means. His dad is now 88 years old. They do not have any money. How does Kelly afford to do all this? He got injured in the military. The VA picks it up. The VA picks up everything, gives him the opportunity to go to school, to live independently, to have his own life, to get a job and pay taxes.

If Kelly, at age 19—I say to my friends, if he had gotten injured in a car wreck, he would never have been able to live the life that he has lived. He would not have those services available to him. That is the difference. He had his choices simply because he was injured in the military.

I say it is now time to give every disabled person in this country the things that Kelly had, the kind of choices to make, the freedom to live their own lives, not warehoused in a nursing home. That is why this is so timely. This is so timely. We have been waiting a long time, as I said, 17 years; 10 years since it was first introduced, 8 years since the Supreme Court said in the *Olmstead* decision that the State had to provide the least restrictive environment under the Americans With Disabilities Act.

So now it is time for us to take that final step and to at least provide that those who are on Medicaid, they get the choice to do what they want to do. It really is, as you said, Mr. Chairman, what that Freedom Bell says. It is time. It is time to do it. It is past time to do it. It is time to look ahead, as you said, Senator Grassley. It is time to look ahead and get the Community Choice Act through and give people the freedom that they deserve. Thank you, Mr. Chairman. [Applause.]

The CHAIRMAN. Thank you, Senator, very much.

Do Senators have any comments? Thank you, Senator. You have been a real leader here. We deeply appreciate it.

I see Senator Wyden wishes to be recognized.

Senator WYDEN. Mr. Chairman, thank you. I want to congratulate our colleague. It seems to me that this cause is very straightforward. This is an opportunity to give vulnerable Americans more of what they want, which is to stay at home at a cheaper price than the alternative, which is institutional care. That is what this is all about. I want to congratulate you on your effort.

The proposal that you have offered is very much consistent with what Senator Bennett and I are offering in our Universal Coverage Plan, and I want to commit to you and to all the folks who have journeyed far and wide, we are going to fight to make sure that your just cause is part of any universal coverage proposal that gets through the U.S. Congress, and I congratulate you. [Applause.]

The CHAIRMAN. Thank you, Senator. Thank you very, very much. Thank you, again, very much for your contributions.

Senator HARKIN. Thank you, Mr. Chairman.

The CHAIRMAN. You are a real leader, and many people deeply appreciate it.

Senator HARKIN. Thank you very much, Mr. Chairman.

The CHAIRMAN. Thank you.

The next panel. Our first witness is Bob Liston. Bob is director of Montana Fair Housing, and he will provide the committee with his experiences both as a person with a disability and as an advocate for home- and community-based services. Bob, welcome to the committee. Next, Mitchell LaPlante. He is an associate professor at the Institute of Health and Aging at the University of California, San Francisco. He will discuss his research on the cost estimates of home- and community-based services. Then we will hear from Patrick Flood, director of Vermont's Agency of Human Services, and then Kevin Concannon, director of Iowa's Department of Human Services. He will describe their State's challenges and successes in expanding home- and community-based services.

Thank you all for coming. I would remind you all that your written statements will automatically be included in the record, and I urge you to confine your oral statements to 5 minutes. All right. Mr. Liston?

STATEMENT OF BOB LISTON, DIRECTOR, MONTANA FAIR HOUSING, MISSOULA, MT

Mr. LISTON. Thank you, Chairman Baucus, Ranking Member Grassley, and members of the Senate Finance Committee. Thank you for the opportunity to testify today on assuring that home- and community-based care is at least an equal option as we move forward to reform our broken long-term care system.

My name is Bob Liston, and I am proud to be a person with a disability and proud to be from Montana, the last best place. I am testifying today as an individual who has lived with a disability for 37 years and am part of the disability community that is 17 percent of the Nation's population.

I am also testifying as one of the legion of baby boomers beginning to knock on the doors of the Nation's public and private long-term care systems. I will tell you that, in all my 53 years on this planet, I have never met anyone of any age or any disability who said they want to live in a nursing home, an ICF/MR (Intermediate Care Facility for the Mentally Retarded), or any kind of institution.

Finally, I am also testifying as a professional who has worked and volunteered over the course of a lifetime to assist people with even the most significant disabilities to move out of nursing homes and other institutional settings and to live in their own homes, in their own communities with the necessary services and supports.

I am not an academic, a researcher, or a bureaucrat. I have been in the trenches, partly for selfish reasons: I do not want to go to a nursing home. So, I have worked to figure out the best ways for people to stay in the community. I want to guarantee a level playing field so I have a choice to live where I want, and from whom I purchase my long-term care services.

While assisting others, I have learned more than I could ever imagine about supporting people to live in the community. I can say with complete confidence that I know what is possible. When I was an invulnerable 16-year-old high school student athlete, I rolled a pick-up down a mountain on the outskirts of Helena.

Montana being a rural and frontier State, trauma centers were few and far between. I was taken to a hospital in Great Falls, nearly 2 hours away, though my mother insists it was about a 15-minute drive. After spending 3 months there immobilized in a Stryker frame, the doctor came into the room on the last day, casually telling me, oh, by the way, you'll never walk again, and then signed the order sending me to a nursing home.

Once there, it took me about 30 seconds to realize, this is where people come to die. During the 4 months I spent there, they were dying all around me. In fact, two boys with Duchenne muscular dystrophy, who were younger than I was, were admitted to the nursing home. The staff told me I should not be depressed about my disability, because at least I would be leaving. They were there to die.

I know firsthand what it is like to be sent to a nursing home, so I am sure you will not be surprised when I tell you that I would rather die than ever go back to a nursing home again. In many ways, I represent every man and every woman in this country. I am not a man of means; I work full-time and then some for a small, nonprofit organization that exists to ensure that no Montanan experiences discrimination in housing.

I work very hard, but my organization runs on a shoestring, a shoestring that does not include health insurance, retirement, or a long-term care program. My wife and I save for our eventual retirement, but it is unlikely that we will be able to cover all of our long-term care costs out of our own pockets, no matter how much we scrimp and save now.

I have been surprised to learn that Medicare does not cover any ongoing community-based long-term care services. That means it is very highly likely that at some point we will be reaching out to Medicaid-funded long-term care services. This is the situation of many aging baby boomers.

Right now, according to CMS, about 70 percent of Medicaid long-term care dollars go to nursing homes and other institutional settings, and just over 30 percent go to home- and community-based services. This ratio has been gravely concerning for my own future, because it means I do not even have a 50/50 chance of being able to choose to stay in my own home as I age and become increasingly disabled.

The institutional bias in the Nation's Medicaid program gives me 2-to-1 odds of being forced into a nursing home. The Community Choice Act would help level the playing field and give me real choice. This institutional bias also means that a creative State like Montana does not have the flexibility it needs and deserves to stretch precious Federal and State dollars in a way that is most efficient, cost-effective, and in keeping with the needs and desires of its citizens.

Montana is the fourth-largest State in geography, with one of the smallest populations in the country. In a rural, frontier, and tribal State like ours, or a number of other States, offering people only the choice of a distant institutional setting is cruel to the individual and cruel to the families and friends.

Real choice, as provided in the Community Choice Act, would not only serve us better and more cost-effectively overall, but it would give the State the tools it needs to be good stewards of public money, while being responsive to its citizens.

While I was on the Montana Statewide Independent Living Council, one of my colleagues who lived on the Fort Peck Indian reservation had a sister who needed extensive support. When his sister got to the point where the family could no longer provide all of the support she needed, she was placed in a nursing home 5 hours away.

This was the closest nursing home that said that they could provide the services that she needed and had an open bed. This is also a place where many folks have been sent when they age out of State developmental disability and mental health facilities.

This facility was closed about 4 years ago for extensive abuse and neglect of persons living there. Needless to say, this was an incredible blow to my colleague and his family. They felt they had abandoned their loved one, violating not only family values, but also Native American traditional and cultural values.

This scenario is a frequent one in rural, frontier, and tribal States. People are placed far away from loved ones. Mr. Chairman, you have already expressed one of my stories about a good friend of ours, Mark, who moved from North Dakota to escape a nursing home. It is a pleasure to say that he has just started attending the University of Montana and, hopefully in a few years, will be earning a good living in journalism, writing about disability rights and the movement as we go forward.

The CHAIRMAN. Bob, I see you have a lot of pages left in your hand.

Mr. LISTON. Not really. Not really.

The CHAIRMAN. If you could figure out how you are going to summarize, that would be very helpful.

Mr. LISTON. All right. I hope you will read about some of the other scenarios in the written testimony that I have submitted, and also watch the DVD that I submitted to all of the members.

The CHAIRMAN. We have it here. Right.

Mr. LISTON. The DVD is a summary of testimony that was taken in Nashville a little over a year ago.

I have had the opportunity to assist people with some of the most significant disabilities to live and thrive in the community after long stays in various institutional settings. The Community Choice Act will allow people to stay in their homes while they pursue the lives they choose.

I cannot tell you the number of people across the country who have had to move from their home States to another State just to receive community-based services. If they had not moved out of State, they would have been forced into a nursing home or institution. This is wrong.

People with disabilities, whether newborn or grandparents, deserve a level playing field that does not enforce only one solution for people, but instead lets us have a choice personally and lets our States have the flexibility to make responsible decisions that make the best use of public dollars.

The Community Choice Act does not create a new, unfunded mandate. We already pay for this assistance when people are forced into nursing homes and other institutions by the Medicaid institutional bias. The Community Choice Act simply makes the existing mandate more responsive to consumers, and in the aggregate will prove to be a more cost-effective use of public dollars. It does not make more people eligible. It does not force the closure of nursing homes or institutions, it simply means that people who are eligible——

The CHAIRMAN. I am really going to have to ask you to summarize if you could, Bob.

Mr. LISTON. All right. I urge you to pass S. 799 out of committee and to the full Senate. The disability community has been waiting for over 15 years, and over that time so many of us have become seniors with disabilities, still waiting for community choice.

In closing, I would like to thank Senators Schumer and Salazar for their co-sponsorship of the Community Choice Act, and I encourage all of you to look at the attachments, as I have already mentioned. Thank you again for this opportunity to testify. I would be happy to answer any questions that you have.

The CHAIRMAN. Thank you, Bob, very, very much. I appreciate that very much. Thank you. [Applause.]

[The prepared statement of Mr. Liston appears in the appendix.]

The CHAIRMAN. Mr. LaPlante?

STATEMENT OF MITCHELL LaPLANTE, ASSOCIATE PROFESSOR, DEPARTMENT OF SOCIAL AND BEHAVIORAL SCIENCES, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, CA

Mr. LAPLANTE. Chairman Baucus, Senator Grassley, members of the Senate Finance Committee, I am honored to speak today on expanding the options low-income people with disabilities have to choose between living in an institution and living in the community.

In our Nation's history, deinstitutionalization occurred first for persons with mental illness in the 1960s. As a result of the Medicaid waiver program, a second wave of deinstitutionalization occurred in the 1990s for persons with intellectual and developmental disabilities.

We appear to be entering a third wave of deinstitutionalization in which persons with physical disabilities and older persons can remain in the community instead of going to a nursing home or similar facility. As our population ages, we must find ways to provide home- and community-based services of sufficient quantity and quality so that individuals can choose where and how they want to live.

The Congress, the administration, and the Supreme Court all agree, people should be able to choose where and how they live. As we have heard, Medicaid, in its design, rules, and procedures favors placement in institutions over home- and community-based services, what we call the "institutional bias." The key aspect is that the institutional services are mandatory, while HCBS is optional. Some States use their options, but many States do not.

The fraction of a State's population that is provided personal care services ranges from a low of 3 persons per 10,000 State residents in the lowest State, to 84 persons in the highest State. That is a ratio of 28:1.

About 30 States use the personal care services optional benefit, which funds personal care services and attendants. In States that do not use the personal care services option, those services are only available if the State has a waiver that provides personal care. Unlike the personal care services benefit, the waivers are often restricted in who they will serve, and there are long waiting lists, as we have already heard.

While additional HCBS opportunities can be created through the Deficit Reduction Act of 2005, which I think is an excellent opportunity, these too are optional. This maintains the significant bias towards institutions, and individuals are not provided a real choice in certain places of the United States.

Given the situation, it is not surprising that there is unmet need for personal assistance among low-income persons. The fraction of people who need help with two or more activities of daily living who have unmet need for personal assistant services and are poor is 31 percent among working ages, actually a little bit higher than the elderly, which is 25 percent.

Unmet need is important because it is associated with a host of adverse consequences, such as injuries from falling, poor nutrition and dehydration, and others, all of which are unnecessary and add significant cost to the health care system.

The Community Choice Act is a proposal for people with low incomes who have an institutional level of need—not for everybody, just for those with an institutional level of need—to help them avoid institutions, allow them to choose community services, and reduce unmet need.

By making personal care services a mandatory benefit, the Choice Act would greatly reduce the institutional bias. However, this idea, this piece of legislation, has had an albatross around its neck since the idea was first introduced in the Senate.

The Congressional Budget Office estimated in 1997, for an earlier version of this bill, that new Federal expenditures would be $10 to $20 billion a year if only a quarter of those who could be eligible obtained the benefit. I have to say, frankly, that estimate is inflated and erroneous.

Based on research I and my colleagues have published, we estimate a range from $1.4 to $3.7 billion, depending on a rate of participation from 30 to 80 percent. Adjusting for inflation, it is about one-tenth the CBO estimate.

Now, the key difference is the number of people who would be eligible. Assessment of institutional need is typically based on having two or more of the basic activities of daily living, which include bathing, dressing, transferring, toileting, and eating. The CBO estimate included people who need help with a much broader set of instrumental activities, including shopping for groceries or getting to places outside of walking distance.

However—and I think we would all agree—someone who only needs help shopping for groceries certainly is not a candidate for an institution. Including these activities greatly inflated the CBO estimate.

There has been concern over a "woodwork" effect. I think I will just say that the Community Choice Act will generate some woodwork effect, no doubt, but it will not be a large woodwork effect because it restricts the benefit to people with an institutional level of need. We estimate 600,000 persons would be eligible, not several million.

I am concerned that the institutional need criteria should be more specific. We know some States use loose criteria—in one State you only need a doctor's letter to be admitted to a nursing home—while others use strict criteria, such as needing three or more activities of daily living for determining need. I think institutional need criteria should be more specific in the CCA, such as needing help in two or more ADLs, so that this does not become an Achilles heel for the legislation.

While it is often claimed that HCBS is cheaper, the argument is rarely made that HCBS costs any more than institutional services. One study concludes that Medicaid could be saving $44,000 per person by providing HCBS instead of a nursing home stay.

Our ongoing research at the center where I work, the University of California, shows that several States that have greatly expanded their HCBS programs in the 1990s have been able to reduce their institutional expenditures within 5 years. States that have established HCBS are ahead of the curve in controlling their costs. States that are reluctant to explore their options are behind the curve and experiencing increasing costs.

I am aware that States do not like Medicaid mandates, but, given ample options, many States apparently did not have the wherewithal to rebalance their long-term care systems. Twenty States, for example, are not participating in Money Follows the Person 2 years after the grants were first announced. I will just mention again the 28:1 ratio fraction of the population getting personal care services by State. It illustrates that some States are doing much more than others.

It is my professional opinion——

The CHAIRMAN. I am going to have to ask you to——

Mr. LAPLANTE. I am going to wrap up.

The CHAIRMAN. All right. I appreciate it.

Mr. LAPLANTE. Just two sentences left.

It is my professional opinion that the CCA is socially and fiscally responsible legislation. It would replace the safety net that varies depending on which State a person lives in with one that is more uniform for persons with significant disabilities, reducing that ratio from 28:1 to closer to 1:1, and is likely to save money in the long run, while improving people's lives. Given that the oldest baby boomers are 61 years old today, there is not much time left to get rebalancing done. Until the institutional bias in Medicaid is remedied, choice will remain constrained.

The CHAIRMAN. Thank you, Mr. LaPlante.

[The prepared statement of Mr. LaPlante appears in the appendix.]

The CHAIRMAN. Mr. Flood?

STATEMENT OF PATRICK FLOOD, DEPUTY SECRETARY, VERMONT AGENCY OF HUMAN SERVICES, WATERBURY, VT

Mr. FLOOD. Good morning.

The CHAIRMAN. Good morning.

Mr. FLOOD. I thank you for the opportunity to come and talk to you about the State of Vermont today.

I would like to tell you, first, a little bit about myself. I was a nurse for 7 years. Before that, my first job in health care was as a nurse's aide in a nursing home. I subsequently was an advocate for people in nursing homes, a long-term ombudsman. I then licensed and regulated nursing homes, and I have run home- and community-based programs for a long time now.

The point is, I have been on the inside and I have been on the outside. I am here to tell you today that there is, indeed, a better way to run a long-term care system than what we have today. We are doing it in Vermont today, and it works.

We have a system in Vermont where people can choose whether they want to live in a nursing home or get their services at home, and we have managed to do that in a cost-effective way. It is not a theory, it is not pie-in-the-sky. In fact, it can be done, and it is being done in my State today.

The key point here is, not only is this what people want—people want to stay at home and they prefer home-based alternatives—but that it is cheaper. Now, how often is this body going to encounter a public policy question where you can give the people of this country what they want and save money? You do not have too many opportunities, and this is one of them right before you. The time has come to implement that nationwide.

You have heard about the institutional bias in Medicaid, and I want to touch on it for just a minute. Let us examine the way the current system works today. If you want to go to a nursing home and you are Medicaid-eligible, you get to go if the bed is open. If you want to stay at home and get those services, which are cheaper, you have to get in line and you have to wait.

Now, this makes absolutely no sense. Why would we make the most expensive service that people do not even want the entitlement, while the service people want, which is cheaper, you have to wait in line for and it is capped across the country? It makes absolutely no sense, yet that is the system we have today.

Some people argue that home-based care is not cheaper. I just want to tell you very quickly, in my State we got tired of hearing this, and in 2002 we did a comprehensive study where we looked at not just the costs in the nursing homes or the costs for the home-based services, we looked at the cost for everybody, all the Medicaid costs for the people in these systems, their doctors' costs, their transportation costs, their hospital costs, their medication costs.

We added them all up and we compared them. When all was said and done, the costs for keeping an elderly person, on average, in their own home was two-thirds the cost of being in a nursing home. We have a very generous program, a very generous home- and community-based program in Vermont—two-thirds the cost. The cost for a younger disabled person was about the same. So as far as I am concerned, that question has been answered a long time ago. It is, in fact, on average, cheaper to keep people in their own homes or in alternative settings.

So if for no other reason than economics, it made sense for us to move in this direction. But I would remind you, of course, that it is absolutely the right thing to do for elders and people with disabilities as well.

We made a lot of progress over the years in reducing our reliance on nursing homes and increasing our home- and community-based services, but we kept running up against this institutional bias. We had people waiting on the waiting list. At some point they cannot wait any longer and they go in the nursing home, and they cost us more money. It really made no sense.

So we asked the Federal Government for what is called an 1115 waiver. I will not go into explaining what that all means, but it gave us a lot of flexibility to redesign our Medicaid system.

In our system, we created equal access to either a nursing home or home-based service, and we did it in the context of a manageable budget. All I am going to say about that is, in simple terms, what it lets us do is create a waiting list if we have to. We appropriate a certain amount of money. If we need to, we can put people on the waiting list.

The people who would go on the waiting list are the lighter care people, not the people who have heavy needs. We serve them first. But the more important point about a waiting list is that there has always been a waiting list. There is a waiting list in every State in this country right now for people for home- and community-based services. That is not fair. There is no waiting list for nursing homes. If there is going to be a waiting list, it should be equalized so that it is either for people waiting for nursing homes or for home-based services.

Frankly, we do not have a waiting list today in our program because we have been able to reduce nursing home utilization by enough that, if you take that money and you put it on the home- and community-based side, in effect you can serve twice as many people for the same amount of money. So you do not end up with much of a waiting list because you can, in fact, deal with the so-called "woodwork effect" that Mr. LaPlante mentioned. People do not come out of the woodwork that you do not know anything about. You can manage the system. It is achievable.

The numbers in Vermont—I always have to apologize for this, because we are a small State, so you might want to add a zero or two to whatever I say. But I think the Senator from Montana would appreciate the small numbers.

In the 2 years since this program started in October of 2005, we have added nearly 500 people to our home- and community-based waiver system. That is twice as many as we could have otherwise, and that is a critical point: twice as many as we ever could have in the old system. So, in fact, it does work. Our nursing home utilization is down, our home- and community-based services are way up. So, the service has basically worked exactly as we designed it.

I am just going to touch on this very briefly and tell you that any home- and community-based system has to have a portfolio of services. It has to have a lot of options, because everybody's needs are different and you have to be flexible to meet those needs.

I would also say, we need to emphasize consumer direction, because consumers know better than any agency or any bureaucrat what they need for services. Those things are both emerging in our systems across the country. I would also say that there is a lot of worry all the time about, what is going to happen to the nursing homes?

First of all, we are not going to need these nursing homes in 15 or 20 years when the baby boomers are coming on because the baby boomers are not going to move into nursing homes, number one. Number two, in 15 to 20 years when baby boomers need that care, those nursing homes are going to be obsolete. So what we do need is alternatives that the baby boomers, in fact, will use and will support.

So what I would like to say is that, in fact, any State can do what we have done, except for Federal law. The Federal law prohibits States from taking the steps that Vermont has taken in creating equal access because of the nursing home bias, and we need to change that. Congress has to find a way to give States permission to equalize access to either home-based care or nursing home care, and I think that the bill that you have before you may very well be that vehicle.

The CHAIRMAN. Thank you, Mr. Flood.

Mr. FLOOD. Can I make one final comment, Senator?

The CHAIRMAN. Briefly. You care very passionately, and I really appreciate that. But I must say, your panel is having a little harder time limiting itself to the 5-minute rule. That is fine. That is great. There is not many more.

Mr. FLOOD. I only need 35 seconds here.

The CHAIRMAN. You got it. Thirty-five.

Mr. FLOOD. It is almost 11 o'clock here in Washington. That means it is 10 o'clock in Iowa, and it is 9 o'clock in Montana.

The CHAIRMAN. Right.

Mr. FLOOD. Right now, there is a family having to take their mother or their son to a nursing home to live because there is no alternative. It is high time that that is stopped. That is happening all over this country, and it is not necessary. There is a better way, and the State of Vermont stands ready to help Congress, CMS, or any other State design and develop a system that truly does serve people. [Applause.]

The CHAIRMAN. Thank you very much.

[The prepared statement of Mr. Flood appears in the appendix.]

The CHAIRMAN. Mr. Concannon?

STATEMENT OF KEVIN CONCANNON, DIRECTOR, IOWA DEPARTMENT OF HUMAN SERVICES, DES MOINES, IA

Mr. CONCANNON. Good morning, Senator Baucus, Ranking Member Grassley, and members of the Finance Committee. I very much appreciate the opportunity to meet with you today. We are very fortunate in the State of Iowa to have Senator Grassley and Senator Harkin, whom you heard from earlier this morning. But I also note on this committee today, and personally, Senators that I have had the privilege to work with in the past, Senator Snowe in the State of Maine, Senator Wyden in Oregon, and Senator Smith in Oregon.

So, in some respects I feel like an alumni association here today. These are three States actually that I think are notable in terms of their efforts to provide alternatives to institutional care for their populations. I appreciate having the opportunity to comment today on some of the efforts under way in Iowa to divert people from institutional care.

First of all, I should mention that the Department of Human Services in Iowa has a variety of responsibilities, not uncommon to other States with such organizations. But importantly, the Medicaid program is by far, I think, the most important and far-reaching of all of our responsibilities.

Iowa has been steadily moving, going back to 1984, its first home-based care waiver, into availing itself of options to divert people from institutional care. We currently have about 23,000 persons enrolled in HCBS waivers compared to 13,000 Medicaid residents in nursing homes, or ICF/MRs in our State.

HCBS programs have grown, both in terms of their reach and importance. Now they are growing, both in terms of numbers of persons, but also in terms of the percentage of the Medicaid budget. It has moved from $176 million in 2003 to $348 million in 2007.

But I also want to note that, as I think we have heard in the testimony starting with Senator Harkin this morning, and with the chair and the ranking member, what has changed, I think, in terms of policy over time in our country for both frail, elderly persons and people with disabilities, are the values, the recognition of the values of autonomy of choice, of being able to live and remain in one's own community. Gradually—certainly not fast enough for anybody, but gradually—the public financing programs are being tailored to support that. I am going to speak to that in a few minutes.

I have asked the staff to hand out a brochure—I hope members have it here—that describes the various Iowa programs, both the seven HCBS waivers that we have, but importantly, on the back, the last page of that, it describes the consumer choice option. I think that responds to many of the concerns that people have noted here today.

Innovative approaches are certainly part of the effort we are making in our own State to say, what else can we do for, again, assisting and accommodating the needs of people who are frail, elderly, or people with disabilities? We have introduced something called Consumer Choices, which in some States is referred to as Cash and Counseling. I avoid using that term in my State because I do not want people to misunderstand really what it is intended to be.

But the Consumer Choices, we have gradually introduced this over the past year. It is now available State-wide. We are now one of approximately 18 States that have this option. It is a Medicaid waiver. Within that waiver, individuals are allowed to purchase the services directly. They may hire the person providing that care. They may hire the agency directly. It speaks to, I think, a very basic American value: he or she who pays, people pay attention to the source of that pay.

When individual persons who are eligible for any one of our waivers, excluding the Children's Mental Health Waiver, they are allowed to, in effect, have the dollar resources that we would typically spend for them, including if they were to be admitted into a nursing home, deposited. In Iowa's case, we have the State's largest credit union, I am happy to say, serving as the fiscal agent. That is part of their social mission, as well as being a very responsible banking institution.

We have caseworkers who work with them who are so-called support brokers. But what is notable in this program, I think, that one often hears in terms of concern, it provides the opportunity for people to pay family members and it also lends itself to rural areas where there may be workforce shortages, and we have certainly experienced that in some of our rural counties. So, we are very excited about the Consumer Choices option.

A second area of implementation that I wanted to bring to this committee's attention—I realize you have a responsibility as well for child welfare programs—is our Children's Mental Health waiver. In nearly half of the States in this country, for a child with a serious continuing mental health need, if that family is not poor enough to be on Medicaid or possibly the SCHIP program, or rich enough to have the resources to be able to provide for that care, in order for public health to come to that child over time, custody relinquishment must occur. They must relinquish the custody of the child in the court system, something in our State we call a CINA (Child in Need of Assistance) program; some States call it CHINS (Child in Need of Services).

To me, about half the States in the country still require that. We sought a waiver 2 years ago. I am happy to say we changed our State law. The courts are very happy with this, families are very happy with this. We are diverting children from residential care. We are helping children with serious mental health issues, providing them better, more tailored care in their own families.

A third area I wanted to mention is the Money Follows the Person. I think that was referenced in Senator Grassley's testimony. We are a State that has the fifth or sixth highest rate of ICF/MR, Intermediate Care Facilities for People with Mental Retardation. We received a 5-year grant within the last year. We had determined to provide better alternatives to individuals, in keeping with the *Olmstead* decision, again, previously cited here today. I think that is a very important opportunity for us.

Finally, I wanted to mention the Deficit Reduction Act opportunities. We, like many States, had previously in our Medicaid program something called Adult Rehabilitation Option. Unfortunately, that option was adopted by our State in 2001, acting in good faith, and provided a lot of needed services to people with disabilities, but it was one of the first such programs audited by the OIG, and Iowa ended up repaying the Federal Government about $6 million because a number of those services really did not adequately fit the rehabilitation standard, so to speak.

Now, the Deficit Reduction Act has provided an opportunity for us in a particular section to create basically what we are referring to as "habilitation," a functional need for many of the people in our population. In Iowa's case, the principal beneficiaries of that, about 3,700 this first year, are people with chronic or persistent mental illness.

The committee may be well aware of the fact that within Medicaid programs there are many more options for people with mental retardation, principally because, going back to the 1970s, of the introduction of something called Intermediate Care Facilities for people with Mental Retardation. That, and the waivers or the options for those kind of services.

We do a better job in this country for people with mental retardation. We do not do nearly as well for people with chronic mental illness. The Deficit Reduction Act, cited by Senator Grassley in his comments, created a section that allows us to really provide much better habilitation and services to that population in our State.

Finally, I wanted to note the efforts we have been making, in cooperation with CMS, to ensure the quality of care in our home-based care programs. I would admit that in the early years, I do not think there was sufficient attention paid in our State to making sure that quality was provided in the alternative programs. I think people were happy to have alternatives, and it was a faith-based initiative, by intent or not.

We pay much more attention now to the quality issues that are faced by people. We are happy to have the alternatives. We are pleased with the general direction of providing alternatives, as has been cited by virtually everybody here today. People would much prefer to have a safe, quality alternative than to be required to be institutionalized.

Thank you.

The CHAIRMAN. Thank you, Mr. Concannon, very much.

[The prepared statement of Mr. Concannon appears in the appendix.]

The CHAIRMAN. Senator Grassley?

Senator GRASSLEY. I thank the Chairman for letting me go first.

Mr. Concannon, how many people would you expect to join the option, the Consumer Choices option, that we have already referred to? Is there an optimal number of enrollees that you would want to have?

Mr. CONCANNON. Senator, the experience in States that have had this option—Arkansas is one of the first. There were three States that have provided this option now for about 8 years, as I understand it. Typically, in the States that provide the option, somewhere between 15 and 18 percent of the Medicaid-eligible population opts to take that.

Now, to me, the important aspect of that is, that is an option that is given to people. But it is also, I think, happily, a competitive element that is introduced into the service system, because the existing agencies that provide these services, knowing that, if I do not respond to you and your need, you will have some different choices, versus the sort of franchise.

I hate to overstate that, but the notion is that there is one local agency and you have to live with it, good, bad, or indifferent. So our current estimate in Iowa is that within several years we would expect to be, based on our current waiver population, somewhere in the 3,000-person range.

Now, again, those States—Arkansas cited that it was particularly useful in obtaining a health care workforce for individuals in rural areas. We have examples in Iowa where we have dollars set aside for home care, but we do not have sufficient providers. I am anxious to see what impact this may have in that regard.

Senator GRASSLEY. All right.

And for you and Mr. Flood, a second question. Many times when people think about home- and community-based care, they think about it in areas with concentrated populations. Yet, your two States are rural, and you have strong home- and community-based programs. Have you faced barriers unique to rural States in implementing programs to encourage home- and community-based care?

Mr. CONCANNON. Yes, we have. I mean, we have had current examples of some of our smaller rural counties where they do not have the concentration of health agencies or home nursing agencies. As an example, one of the steps that Iowa has taken, the legislature last year passed laws to make it easier for existing nursing facilities to also provide home-based care. We think there are two aspects to that.

One, it can help those facilities be less dependent on just inpatient care, analogous to hospitals. Many hospitals have really developed their outpatient capacity in recent years. Second, we think they have a workforce that is already stationed there, and that this may be a way of responding to some of the rural needs.

Senator GRASSLEY. What is your experience in Vermont?

Mr. FLOOD. There are a number of issues related to being a rural State. I will just hit on some key ones, quickly. The consumer-directed option that Mr. Concannon was referring to is critically important when you are a small State, because you cannot rely on agencies of nurses, like home health agencies, to provide all the services, because they tend to be in the cities or the big towns. By allowing people to hire their friends, their neighbors, their family members, you expand the pool of caregivers tremendously.

So you have people who will never go to work for an agency, but they might go to work for you for 4 hours a week, or twice a week, or something like that. So a consumer direction really expands the ability for us to deal with these issues in small States. I also think that, instead of having 150-bed nursing homes, we can find affordable assisted living facilities that you can have in smaller communities of 30, 40, or 50 people that are much more home-like and much preferable to a big nursing home, and they can fit in some of your smaller communities. That is another option.

One of the biggest challenges is transportation, because, when you do expand home- and community-based services, you do want to get people out of their homes into, say, for example, adult day centers. That is a challenge. I think we are doing a pretty good job in Vermont, but it is a constant struggle.

Senator GRASSLEY. Mr. Concannon, does a shift to—well, these questions are about the quality of nursing home care and whether it is going to be affected. Does a shift to home- and community-based care affect the quality of care in nursing homes? Since you have implemented this, what is the experience in Iowa? How are you ensuring that we get the quality of care that we want in home- and community-based settings?

Mr. CONCANNON. Senator, to date, as you may know, the Department of Inspections and Appeals works directly with us in the State of Iowa to oversee quality of care in facilities, but we regularly consult with them. I am mindful of, happily, a rare issue, a failing nursing home over on the eastern side of the State that we are working directly with, and have been the last several weeks.

But I might say, as I mentioned earlier in passing, the regimen for nursing home care has been much more heavily, if you will, regulated and sort of understood over a period of years. I think for home care, again, there was such a welcoming to this alternative, that in the early years, at least, I do not believe we paid sufficient attention to assuring quality.

We have been working very closely with the CMS office, in our case, out of Kansas City. We are very focused. We pay attention to incidents. For example, we have a meeting each Monday morning in our Medicaid program in which they review any incidents that have come to our attention across the State in home care. The purpose of that is not only to pursue that, but to ascertain whether there is a systemic issue here in terms of quality of care.

We do consumer surveys. As has been noted again here today, it is most important in this. You will learn much by talking to the people who are the beneficiaries of this care. We also want to make sure that people are receiving an adequate amount of care. Again, I am mindful of a current situation involving a number of children with disabilities who are not receiving a sufficient number of hours of care from the two organizations that were charged with providing that. So, we track those issues by talking to consumers, interviewing them, auditing records, convening incident report groups weekly.

Senator GRASSLEY. Thank you all very much.

The CHAIRMAN. Yes. Thank you, Senator.

A key question here is cost. Mr. LaPlante, you addressed it, in saying that your estimates are that the cost of the Community Choice Act will actually be about one-tenth the CBO estimate. That gets to other questions, like, what kinds of services would the community, the more rural communities, provide? Are those institutional? Would that be for a person who would otherwise qualify for an institution, or not?

Could you tell me, Mr. LaPlante, again, how you arrive at your one-tenth of CBO and whether you have had any discussions with

CBO, and what some of the misunderstandings might be? If we are going to proceed here, to some degree it is going to depend upon the cost here, partly because Congress is now operating under, as you know, pay-go principles. If we spend more money, we have to pay for it somehow. If we get the bill down a little bit, that would help.

Mr. LAPLANTE. Well, I think the issue is simply how many people would be eligible for this benefit and what the average cost of the benefit would be per person. That is essentially how our estimate is derived. In fact, there is——

The CHAIRMAN. What is the difference, though, between you and CBO?

Mr. LAPLANTE. Well, the difference is how many people would be served. I think someone lost sight of the fact that the Community Choice Act would apply to people who have an institutional level of need. I am not sure if you are familiar with the CBO estimate, but it was transmitted in a letter to then-Speaker of the House Newt Gingrich. It was quite clear that the perception was that the Choice Act would be an expensive piece of legislation, and it is framed that way.

The CHAIRMAN. Do you know of a request for re-estimate lately? Do you know?

Mr. LAPLANTE. Well, I think there ought to be a request. I think this preceding and window of opportunity around the Choice Act, I would hope, would precipitate a new request from CBO. That is just how much money would be spent on people. I think, from the idea of savings, as Mr. Flood and Mr. Concannon have pointed out, those should be considered too because, quite frankly, if you can save potentially $44,000 by avoiding a nursing home stay for someone by providing them $11,000 or something like that for home- and community-based services, you can provide home- and community-based services to five people who would not go into a nursing home by diverting one person from a nursing home. I think Mr. Flood said it was sort of 2:1. So, there is great potential for savings. My point is, the expenditures are not as high as CBO said they would be. If you include the savings, I think you could meet your pay-go requirement.

The CHAIRMAN. Mr. Flood, do you want to respond to that?

Mr. FLOOD. Well, I would, because I think there is plenty of money in the system today. We are missing the point if we are just looking at what these services would cost. Now, I have not done a detailed analysis of the bill before you, but as has just been stated and is my experience, you save money when you keep people out of nursing homes. That money gets reinvested, and you can serve a lot more people. I have already said that.

I think there are other methods, though, that the Senate and the Congress can take, in my opinion, to try to control the costs. In our State, as I say, we come up with a budget, we live within the budget. There is a lot of money there if you divert people from nursing homes. I think just giving States permission to do what we have done would empower States to do almost everything that is in this bill. It does not have to be any more complicated than that.

The CHAIRMAN. You do that primarily through a waiver?

Mr. FLOOD. We have a waiver.

The CHAIRMAN. Is that the primary tool that the government can give to help Vermont set up the program that it wants?

Mr. FLOOD. Yes. We got what is called an 1115 waiver. It is a very broad, flexible waiver. What I understand is, CMS is not going to offer that opportunity to other States right now. I do not know why. But as I said, you should not need a waiver, basically. You should not need a waiver to stay in your own home, if you stop and think about it.

The CHAIRMAN. Right.

You made an interesting statement, if I heard you correctly, that you thought in the future there may be no more nursing homes, at least not very many.

Mr. FLOOD. Well, I am a pragmatist. I have been in this system a long time. I know that we are not going to do away with every nursing home in this country any time very soon.

The CHAIRMAN. Should we?

Mr. FLOOD. What?

The CHAIRMAN. Should we?

Mr. FLOOD. Well, frankly, I think that the institutional—I have worked in nursing homes. I do not think we should have nursing homes as we know them today. [Applause.] Can those buildings be transformed? Yes, they can. [Applause.]

The CHAIRMAN. How would you transform them?

Mr. FLOOD. Well, for example, they could be down-sized. One of the most deleterious things about going into a nursing home is, you have to share a room. If you are on Medicaid, you share a 20 × 20 room with a stranger, and that stranger may change every 2 or 3 months. It is not a very humane setting. If we could create an option where nursing homes could at least have private rooms for people, if their environments could change, if the culture and how they provide the care and who provides the care could change, then there is a place for residential settings for certain people.

I am not saying that everybody can stay in their own home at the end of the dirt road in Vermont forevermore. It is not possible. So in answering your question, one of the things we have to do, besides expand home- and community-based services, is change those buildings so they are not the nursing homes of today or yesterday, but the nursing homes of tomorrow. It is very possible.

The CHAIRMAN. Thank you.

Senator Wyden?

Senator WYDEN. Thank you, Mr. Chairman.

I thank all our panel. In a sense, this debate has not changed a whole lot in the last 2 decades. Mr. Liston, you come today and make a powerful statement about the need for independence and dignity, and that is what all the folks who are behind you are seeking. For 2 decades, the government has essentially come back and said the same thing.

The government has said, oh, my goodness, if we do what you are saying, Mr. Liston, there will be this huge problem of woodworking, this idea that so many people will come out of nowhere to get this benefit, and then it will be very costly to the government.

So I wanted to ask a couple of questions. I have tried to review the literature very carefully on this, and I do not see any studies that have been done that would suggest, with concrete evidence, based on everything that has gone on, that woodworking would be an enormous problem under what you are talking about. I want to ask a few questions, and get them in quickly, for you three.

Are there studies that make this argument of woodworking which would undercut what Mr. Liston, correctly, wants to do? Gentlemen? You three.

Mr. FLOOD. Let me answer first, quickly, by saying we have been doing a study on it for 2 years. We opened the door to home- and community-based services and we did not see a woodworking effect. Other than that, I know of no study, because you cannot test the negative.

Senator WYDEN. Right.

Mr. FLOOD. Until you open the door, you have no idea.

Senator WYDEN. I am going to quit while I am ahead. [Laughter.]

Gentlemen, is there any evidence, based on the last 2 decades, that Mr. Liston and all these good people here are somehow trying to rip off the government? I cannot find any studies. The government does lots of studies on fraud. I cannot find any studies that suggest that there have been significant problems with fraud in any of these programs. Gentlemen, are there studies that suggest that? Mr. Concannon, so I can get it on the record, no?

Mr. CONCANNON. Not that I am aware of, Senator.

Senator WYDEN. Very good. Well, again, I just want to congratulate the four of you. You are doing the right thing for people. You are on the right side of history. I would just point out to our friend from Vermont, Mr. Flood, what Senator Bennett and I are doing is, we make our long-term care provision in this Healthy Americans Act modeled after what you all are doing in Vermont. I think you are laying out the future. God speed to you, Mr. Liston, and all the people who are with you. We are going to fight for this at every single opportunity we have in the U.S. Senate, and I thank you. [Applause.]

The CHAIRMAN. Senator Bunning?

Senator BUNNING. Yes. I would like permission to put my opening statement in the record.

The CHAIRMAN. Without objection.

[The prepared statement of Senator Bunning appears in the appendix.]

Senator BUNNING. Mr. Flood, you have discussed Vermont's approach to home- and community-based care that involves moving people out of Medicaid institutional care, while putting them into home- and community-based care, which saves money and gives seniors an option that they seem to prefer very much. This seems like an obvious path to take. Could you please elaborate on why this is not done more often if it makes people happier and saves taxpayer dollars?

Mr. FLOOD. To be honest with you, I think the problem is—and this is coming from somebody whose job it is to manage these services and stay within a budget, so I am very pragmatic about this. I understand how the world goes around. What happens in most States is, they look at the potential woodwork effect, and they are afraid to take the leap. States know they are stuck with the nursing home entitlement. They are going to pay that money every year. They are afraid to take the leap into expanding home- and community-based services because they are afraid of a woodwork effect.

Now, I think our experience has shown that it is very manageable. There are a number of ways to manage it and to keep control over those expenditures. I could spend probably an hour, if you wanted me to, explaining all that, which I do not think you want me to do. But there are ways to manage it.

I think States are waiting for the Federal Government to give them the kind of control that CMS gave us through our waiver. That is what they are waiting for. Until they get it, and they are going to need the Congress to give it to them, then they are going to be very cautious about expanding their home- and community-based services.

Senator BUNNING. Is it true, or is it not true, under the Deficit Reduction Act, that any State can apply for a waiver of their Medicaid system in their State?

Mr. FLOOD. I actually thought you were going to ask me another question, which I will come back to in a minute. It certainly is true, and it has been true for a long time, you can apply for a waiver. But there are limited kinds of waivers, and we will not go into all the alphabet soup of waiver numbers.

But the kind that we have is the most flexible and gives us the opportunity to do what we have done. Nobody else has that opportunity today, nor apparently can they get it. So there are waivers, yes, but they are limited. What most States do is, they cap their waivers. So, the interesting question about the Deficit Reduction Act is, the Federal Government has already done a little bit of what I am asking for.

In the Deficit Reduction Act, they created a new State plan under Medicaid for personal care. For the first time ever, they said it is a State plan service, but you can cap it. You, the States, can cap it. So they have really limited this option just to personal care for people at 150 percent of poverty, so they tried to control it. But then they said, you can cap it.

That has never been said before in a Medicaid State plan service, so really all I am asking for is to take what Congress has already done in the Deficit Reduction Act for personal care and expand it to all home- and community-based services, and, with the savings the States can generate, I think you will see many, many doors open.

Senator BUNNING. Mr. LaPlante, in your testimony you discussed your estimates of cost on the Community Choice Act. Why is it that this legislation would use additional funds, where a program like that used in Vermont by Mr. Flood seems to save money? Are there significant differences in these approaches?

Mr. LAPLANTE. No, I do not really think there are significant differences. It is just a case where sometimes you have to spend a little money to save money, and I think that is what we are talking about. It would increase the number of beneficiaries under Medicaid who would obtain personal care services, because there is unmet need for that service that exists throughout the country. But by providing that extra care or service that people need, there is the ability to save money, save money by reducing nursing homes.

One of the things is, Money Follows the Person, and waivers, and these approaches, they are all great, but they just do not go that far. One thing that they do not do, often, is keep people out of nursing homes in the first place. That is what the Community Choice Act can do, or something like that legislation, is help people to stay in their homes longer and avoid nursing home stays. That will also be a great vehicle for saving money.

Senator BUNNING. Mr. Liston, in your experience with the disability community, do you feel that the administration's Money Follows the Person program has helped the development of home- and community-based services?

Mr. LISTON. In my experience, those States that have taken advantage of Money Follows the Person have benefitted. The problem that we see is, if we do not have something that is national, States can choose to pick a waiver. States can choose to take the Money Follows the Person. But then what happens if somebody wants to move from Tennessee to Colorado, and Colorado does not provide what Tennessee did, or vice versa, in this case?

We need to have something that is offered across the Nation so that everybody can have at least a basic minimum of services without being penalized for where they move to or where they move from, and potentially lose services or be put on a waiting list when they move there. So, I think that is something that is missing out of the discussion here, too.

Senator BUNNING. The national program you were talking about.

Mr. LISTON. Right. The Community Choice Act.

Senator BUNNING. It will be consistent.

Mr. LISTON. Have it across the board. Every State has waivers, but they can pick and choose who they want to serve, pick and choose what services they provide. People should be able to know what is available across the board and they should be able to choose. All we are asking for is what you all have, equal choice in where you can go, and ensure that you have the services and supports that you need at home, no matter where your home is.

Senator BUNNING. Thank you very much, all of you. [Applause.]

The CHAIRMAN. Thank you, Senator.

Senator Lincoln?

Senator LINCOLN. Well, thank you, Mr. Chairman. Thanks for bringing up such a critical issue for all of us. I do represent the State of Arkansas, where we have waivers and we have been trying to bring a little bit of balance to what options are available to individuals. Arkansas is much like other rural States, like the Chairman's. We are full of a lot of wonderfully independent-minded people in rural States. They like where they live, and they want to stay there.

I, myself, as a caregiver with my grandparents, and then as we journeyed with my father almost 9 years with Alzheimer's, realize how important it was for them to stay in their home, in the surroundings, in the woods where they grew up. It was important to them, it was important to us, just as I am sure it is important to other families and their loved ones, and how critically important it is to work to make that happen. This week, we celebrate my husband's grandmother's 110th birthday. She is still living in her own apartment, and none of us would argue with that, either. [Applause.]

We also know firsthand so many of the trials and tribulations that family caregivers can face when need arises to care for complex medical needs of loved ones, and certainly being able to find the appropriate caregivers who are out there in rural areas. I know that was an issue for us.

We were very blessed to find a woman who—my dad was her 6th Alzheimer's patient. It was a blessing to us. But I know that there were often times when I would see friends of mine, or families, who would say, where did you find her? How do we find someone like that? Where do they train these people?

How do we come across those? And then also looking through the unbelievable web of programs that would be available. How do we access those for our dad? How did we find the lift chair? How is it made available to us? The different types of things that are so important to that quality of care can sometimes be more challenging in rural areas than they are in the bigger areas, there is no doubt. So, hopefully we are working to make that kind of information available.

I think it can be difficult, even for experts, to navigate the system to locate services. I know we have many people who call our 800 number in the office, and I am fortunate and blessed to have two incredible women who know how to navigate that system very well, and they spend a lot of time assisting constituents in that.

The high stress, the emotional period of dealing with family members who are in need or just diagnosed, that is critically important. Maybe you have some advice from your own program experience for addressing, or even determining, the need for caregivers, those who are family members and others, but also the search for caregivers and the programs. To what extent do you think comprehensive caregiver assessment would help? Are some of the programs you have discussed today using those comprehensive caregiver assessments? Is that an option? Is that something that is helpful?

Mr. FLOOD. If I could start to answer the question. It is helpful. In fact, I do not know what your experience has been in Arkansas, but in most places in this country where I would send all family members, is the Area Agencies on Aging, or the State Unit on Aging in each State, because the Older Americans Act network across this country is really the only substantial and universal network where people can go to get help. In fact, those agencies do run caregiver support programs. I do not think that is widely known. They also are the source for a lot of advice; they are a source for respite dollars, which is crucial.

I think one of the key elements in all of this long-term care reform is that the dollars have to be flexible, because what your family needs is going to be different than the family down the road. We are not as flexible as we need to be yet. So, there are some options there. I think the Older Americans Act and the Area Agencies on Aging are the places to go. Caregiver respite, caregiver support, and caregiver assessment are all an important part of the puzzle.

Senator LINCOLN. One of the things we found is, obviously with the—I do not know that it is obvious, but certainly in all of the medical schools across our country, each one has a Department of Pediatrics. I think there are only six now that have a Department of Geriatrics. One of the things we have done at one of those medical schools in Arkansas is to design outreach through our Don Reynolds Center on Aging and connect with different groups in different areas of our State—the Schmieding Center is one—where they will actually train family member home caregivers in the basic necessities of care giving, and really take the opportunity to get some professional training as a caregiver.

It has been wonderfully successful. People have just been awed by the fact that there is actually someplace to go where someone will help them begin to better understand the needs of their loved one and how they can provide that care themselves. So, I think that is really important.

One of the other things that I just would like to touch on, I continue to work with my colleagues here on the committee in facilitating the purchase of long-term care insurance, including providing tax incentives for doing so. In addition to the difficulties many face now in saving for their future and whatever their special needs may be, I understand that one barrier to purchasing long-term care insurance is the lack of education on the products. There is a lot there to be done. I know Senator Grassley and I talked about the pieces in the paper recently about products that have been sold and some that have not produced what people anticipated they would.

But thinking about what those products are, what they provide, educating people on that, as well as educating them on what Medicare and Medicaid will or will not pay for, is important. For, I guess, any of our panelists, in your opinion, what are some of the things that we can be doing better to educate the public on long-term care financing options?

Because it is going to become a bigger issue as the baby boomers get there and they do not, maybe, like the options that they have. I know we have a greenhouse that will be dedicated, or the groundbreaking takes place, in November and we are real excited about that new alternative and option for long-term care.

Mr. CONCANNON. Well, if I might offer something. It would take Congress to do something about it, but I think it would systematically facilitate better-tailored choices for people across the country. It would be to consider giving States the opportunity to blend their Medicare and their Medicaid financing. We have heard testimony today about the institutional bias of Medicaid. It exists very strongly in the Medicare program as well. There was a previous director at CMS who was interested in doing this in the six New England States. I was there at the time.

They were very interested in taking that on as a challenge, of saying to the Federal Government, let us pool these funds so that the person gets what they need. You are not subject to the gerrymandering of the way you finance programs.

I believe we could better serve people in this country if we gave the opportunity, just blend those two programs, and say to States, you cannot withdraw any money from it, and say to the Federal Government, you cannot withdraw any money from it, keep it in the pool to serve that person. Even though CMS has both Medicare and Medicaid responsibility, they are like two different countries. They really are very, very different.

I think it is an opportunity we should pursue as a country that actually, I believe at the end of the day, might well lend itself to the Congressional pay-go sort of rubric as well, saying we could do more for people by blending these programs without necessarily spending more money.

Senator LINCOLN. If that were to be a road we would take, my biggest concern would be, as we began to move, particularly dual eligibles and others, that we have a program in place that actually embraces that and has the facilities and the personnel to make that happen. That would be a huge concern, that we do not make that bad mistake that was made.

Mr. LAPLANTE. If I might add a consumer perspective. On my own, I do not have an interest, really, in purchasing long-term care insurance because the premiums are high, and I do not know what is going to be out there when I need long-term insurance. Long-term care insurance has a role, but it has been difficult to prove that it is going to be the solution for people.

Senator LINCOLN. It is not going to be the whole solution. Absolutely.

Mr. LAPLANTE. I still think it plays a role, but I think there are some other ideas about social insurance options under the CLASS Act that was introduced that also have merit, which would enable people to realize that they need to do something about this, and while they are working, save a few dollars in premiums that can provide for them in their later years.

The CHAIRMAN. Thank you, Senator, very much.

Mr. Liston, I wonder if you could give us some thoughts about another hat you wear. You wear many hats in your family, and I commend you and your whole family and all that you do. But that is housing, because you head the Montana Fair Housing Board. How does that play into this discussion here, that is, the availability of housing for people?

Mr. LISTON. Senator, boy, that is a whole other hearing. I mean, clearly there is going to be a greater need for accessible housing. We need HUD to enforce the regulations, both 504 and the Fair Housing Act regulations on accessible housing so that there are places for folks to move when they decide to move out of nursing homes and institutions. But I think that that is a smaller issue in the grand scheme of things.

If I could, I would like to go back to Senator Lincoln's question about caregivers for just a minute. I think one thing that folks need to know is that Centers for Independent Living are the leaders in independent living. A lot of them run personal assistance programs and can hook folks up with a personal assistant when need be, and a lot of them are getting folks out of nursing homes and institutions.

The other thing that I think is really important in this equation, and I think it goes into some of what Mr. LaPlante talks about in needing more funds, potentially at the get-go, is we need to look at people who are caregivers, personal assistants, whatever title we give them, with respect. People who go into personal assistance need to be thinking about it as going into a career. People should not get paid as much money to flip a hamburger as they get to flip a person in a bed because they have a disability. [Applause.]

We need to pay people a liveable wage, with benefits. I think that that is a real key to the future of long-term care, whether we are talking nursing homes, institutions, or community-based services. We need to pay people a real wage. Unfortunately, the unions are on the institutions' side, and they have a head up.

The CHAIRMAN. You are getting a little advice there. Do you want to read that?

Mr. LISTON. Getting back to the housing, there are a lot of folks—again, I think we have kind of focused in on folks with physical disabilities to a large extent. It is important to realize that this is for people with disabilities, whether they have mental illness, cognitive, developmental disabilities, or physical disabilities.

So a lot of folks, as they move into housing, may need assistance with learning how to do things in the house, issues for folks with cognitive disabilities. Folks who are moving out of nursing homes or institutions into a home, possibly for the first time, where they have never had an opportunity to save money, so they are not going to have money for deposits, first month's rent, pots and pans, furniture, those kinds of things, so there needs to be some assistance in helping people get into that first home, or moving back into a home.

The CHAIRMAN. I appreciate that. I do not know if Senator Kerry is ready to ask questions at this instance. If you are, fine, Senator. If you are not, fine, because I have a question I want to ask Mr. Flood.

When other Senators and people ask me, why has Vermont done a good job, if you could just boil it down to one or two sentences, basically what did Vermont do, or what is Vermont doing, that is helping to bring costs down, yet provide home- and community-based services to people? Around here, we just go with the bottom line.

Mr. FLOOD. Yes. Two sentences.

The CHAIRMAN. You have lots of great details and you can fill in the filler, but just, what is the bottom line that is working in Vermont? What are you doing in Vermont that is working?

Mr. FLOOD. Number one, we have a State government that is actually committed to helping people live independently and have the highest quality of life, regardless of their age or disability. That is number one. You have to have that leadership.

Number two, we have a community-based system that is pretty collaborative. People work together. We form coalitions, we come to consensus, and we get things done as a community. It is neighbor helping neighbor. You take those two things and put them together, and you can do a lot of good things.

The CHAIRMAN. Is the size of your State helpful?

Mr. FLOOD. Well, it is helpful in the sense that we can move faster than Texas. The principles we are operating under are exactly the same principles, because they are very basic.

The Chairman. All right. Fine.

I might say to Mr. LaPlante, I am going to ask CBO to update an assessment. You can help, too, by helping us. [Applause.] The last analysis was some time ago, and there is a lot more sophisticated analysis available today based upon States' experience, and your research, et cetera that we are going to utilize to help get a much more realistic estimate.

Senator, I am through with asking questions. Senator Kerry, do you have questions? Do you want me to wait? I can keep asking more questions. I can return to you later if you wish.

Senator KERRY. No, that is fine. Is that all right?

The CHAIRMAN. You've got it.

Senator KERRY. Thank you. I appreciate it.

I apologize. I was here earlier and then, like often happens, we have so many competing hearings and meetings. But I very much wanted to come back and be able to share some thoughts.

The CHAIRMAN. Senator, if you could just briefly suspend, and I will let you finish up. You can run the rest of the hearing.

Senator KERRY. Sure.

The CHAIRMAN. I have a matter I have to attend to, and am late already.

But I thank all witnesses, very, very much. Thank you, Bob, Mr. LaPlante, Mr. Flood, Mr. Concannon, very, very much for all that you are doing. It is clear, the time is right for renewed discussion on this. It is here in the bill before us. Senator Harkin is pushing it, as he should. It is a good hearing. You have just added a lot of new life and blood in all this, and I deeply appreciate that. I am going to get that estimate, too, as I mentioned, Mr. LaPlante.

Thank you, too, Mr. Flood, expressly for your State experiences. That adds a lot. And, Mr. Concannon. I might say, too, that we are going to work vigorously on this to try to find a good way to really make this work this year. That is in the short term. But longer term, I also urge you to be thinking about how this fits into long-term health care reform in America.

As you know, many presidential candidates are, correctly, espousing universal coverage. There is going to be a major change in the American health care system in the next couple, 3 years. Whoever is elected president is going to probably have a major proposal.

We in the Congress are going to be working aggressively, addressing not only coverage, but also costs. So I am encouraging you in the interim, you might be thinking about how to deal with home-based, community-based care and how that might all fit in. But thank you so much for what you are doing.

I also want to thank all of you folks from Rochester for getting on a bus to come here. [Applause.] You get all the orange shirts, but Bob is the head of the yellow shirt team. Montana is a little further away. If we were a little closer, we would probably have a few yellow shirts here, too. Thank you all very much.

I will turn the hearing over to the Senator from Massachusetts, Senator Kerry. Thank you, Senator, for participating here. The hearing is yours.

Senator KERRY. Thank you very much, Mr. Chairman.

Well, again, first of all, Mr. Chairman, thank you for having this hearing. I really am impressed and grateful for the crew that has come down from New York. Thank you for doing that. It is a terrific effort, and it makes a big difference to us.

For a lot of folks, it seems as if the long-term care component of the health care system has just been a kind of shunted-aside, not-paid-attention-to, not-cared-about component of it. Obviously it should not be. When you talk with families, or with any individual who is affected by a long-term care issue—and more and more families are nowadays—it just does not make sense, what has been happening.

We have this system that is just tilted towards the more expensive care, and the care with less independence, with less dignity, with less caring, in many cases, and then, of course, given the budget issues, so much more expensive. It just does not make sense. But institutionally breaking through has always seemed so difficult. You measure that against the idea of providing quality, affordable health insurance, obviously, for every American.

I think everybody in this room would agree it ought to be just a fundamental starting point, it ought to be a right. At least we ought to begin with the 9 million uninsured kids in this country. They deserve to get that health insurance long before the wealthiest people in the country walk away with another tax cut.

So, these inconsistencies are just kind of staring at us, and it makes a lot of folks pretty angry. I think people have been very restrained, considering the absurdity of this contradiction that is staring at us.

Now, obviously we all know that, when you get into complicated home care for certain kinds of disabilities or illnesses, it can really be expensive. The upcoming crush of demand of baby boomers, many of whom by virtue of their lifestyles, are going to demand a different kind of care, is going to pose us with a very, very significant challenge.

I think that up until now, obviously, a lot of folks have looked to long-term care insurance to fill the void that that market is just unable to provide, an affordable, reliable option that is attractive to a broad range of the public—and by attractive, I mean also affordable.

So many people wind up using the payor of last resort: Medicaid. It, as we know, has this strong bias towards institutional care. Not to mention that is strains State budgets, and then you wind up with all of these inconsistencies and problems in who gets what, when, and how.

So our guiding effort, and I think you have articulated it—I saw some of your testimonies previously—is this crying demand for control, for personal control, over these choices, for availability, access, for independence, for affordability, for high quality, and, in the end, for dignity. Those are the things we have to be fighting for.

Senator Harkin has put forward a very comprehensive and admirable effort, but I think everybody here knows that, given the fiscal constraints we are operating under and given the divisions of the U.S. Congress right now, that is going to be a heck of a fight to get that. A lot of us do not want to wait in the interim to provide some of the changes that we think we can, even as we fight for that mandatory and comprehensive coverage. And we will.

So, as we kind of rebalance the system, it is not just about the choice of home care versus nursing home care. It is really about choice and appropriateness of the things that we make available.

I hope this committee, the Finance Committee, will consider options to expand HCBS, including legislation that I am developing. I want to just throw out three quick pieces of what it is before I ask a couple of questions.

One, I want to immediately try to see if we could increase access to HCBS through the State plan amendment option that was passed in DRA. That is one of the rare, bipartisan provisions of the bill, and it ought to provide a basis for us to be able to grab something quickly, but it needs to be amended in order to make it more attractive to the States. To date, as I think came out in the course of the hearing, only one State, Iowa, has implemented a State plan amendment.

Two, we ought to fund immediately evidence-based programs that we know now help to prevent or delay the onset of disability. For instance, investing in things like chronic disease self-management or nutrition, falls prevention, all of these things will not only save money for Medicaid, but they are going to improve the health of beneficiaries as well.

Third, we need to ensure, immediately, greater quality in HCBS by building on the important work already being done at the Federal and State level, including data collection and reporting, as well as provide more resources for States that want to empower their workforce, including informal caregivers, whom we all know can be a very powerful source of intervention.

According to the Georgetown Health Policy Institute, about 1 in 5 persons living in the community with a need for assistance from others has unmet needs, endangering their health and demeaning their quality of life. So, obviously the status quo is not an option.

So I hope we can find a bipartisan consensus on these initiatives, and I very much look forward to working with the Chair and the members of the committee to try to do that.

Now, let me just very quickly ask you here, nearly all of you have cited in your testimony the additional opportunities that were made available to the States through the State plan amendment provision in the Deficit Reduction Act. We also know, as I said, that only Iowa has done this.

Do you agree with the feedback that we have received from State administrators, advocates, and providers that that option has been too narrowly restricted based on income eligibility, as well as the range of services that States are allowed to provide? Mr. Flood, I see you smiling.

Mr. FLOOD. Yes, yes, and yes.

Senator KERRY. Yes and yes.

Mr. FLOOD. Those are the two biggest problems with it: it only covers people up to 150 percent of poverty. The reality is, we all know in this room, that long-term care is a middle-class issue. The whole middle class needs to rely on Medicaid at some point, not just people up to 150 percent of poverty. Second of all, personal care is absolutely crucial. We need other options, or people really cannot remain in their homes.

Senator KERRY. Anybody disagree?

[No response.]

Senator KERRY. Do you agree that there ought to be some level of quality assurance that is associated with services via State plan amendment? In other words, CMS and the States have made progress in recent years ensuring quality management within the home- and community-based services. I guess that is via the 1915 waivers. But there are almost no requirements for quality assurance under the State plan amendment. So, go ahead.

Mr. FLOOD. It is one of my favorite questions about quality and home care. First of all, it is a red herring that, if people are living in the community in their own homes, quality is more at risk. It is simply not true. People are happier, they are healthier. They have their families around them, they have their support system around them. They are much better off than in an institution, number one.

Number two, though, of course you should have some kind of quality assurance program for any home- and community-based service system, but I plead with everybody not to model it on the nursing home system, which is far too bureaucratic. [Applause.] Just let me say, quickly, we can in fact have a consumer-based quality assurance system that works. [Applause.]

Senator KERRY. How do you see the chronic shortage of long-term care workers, especially those working directly with consumers, affecting the ability of States to be able to expand the Medicaid long-term care services? Mr. Concannon?

Mr. CONCANNON. Senator, that is a major challenge, even in urban areas, but particularly so in the rural areas. But, first, there are two opportunities that I am mindful of that I think may have some effect on mitigating that shortage issue. One is, for example, the Consumer Choices option that we have in our State, and I think now at least 18 States have, where individuals can hire directly that caregiver. They need not go through an agency. They may if they so choose. But I think that makes a huge difference, but it also includes, they may be able to hire relatives.

I have had examples of people, and I am sure other people here have as well, of family members coming in saying, I would leave my job to care for this person, but we have to pay our mortgage, we have to pay the heating bill, et cetera. Most of our programs prohibit that. But the Community Choice option, which has a center now, by the way, at Boston College, a national center, provides that opportunity. So that is part one.

The other phenomenon that I am mindful of, and it is occurring in our State and in others, is organized labor has entered into, and has a very demonstrated interest in, the workers who provide that care. Historically, they have not had benefits, they have not had pay. They have been involuntarily pressed into meeting the Nation's needs. At least now, I think, there is more attention and more interest in trying to provide some of the basic supports that many of us enjoy in other work.

Senator KERRY. Well, it is going to be a huge issue and a huge challenge.

Mr. Flood, I admire what Vermont has done, and I think Senator Baucus asked the question. So I am just going to ask Mr. LaPlante one thing if I can, and then we will wrap up.

You mention in your testimony that many States do not have the vision or wherewithal to rebalance the long-term support and services system, and it is evidenced by the 20 States that are not participating in the Money Follows the Person program. So, obviously many States need to do more. We all agree to that. But—here is the but—are you aware of the illogical ways in which CMS is conducting that application process?

That is, States like Massachusetts, which did not apply during the initial round of applications, are being told they are not eligible for the second round of applications. The reason is, they are limiting second round funding to only those States that applied and did not receive the first round funding, punishing States that were taking their time to make sure that their application was effective and sensible and sustainable.

So it just seems like this is one of those "gotcha" crazy bureaucratic catch-22s that has no relationship to the capacity of a State to do what we want them to do.

Mr. LAPLANTE. Well, I think there is bureaucratic entanglement or bureaucratic messes with incrementalism, such as the Deficit Reduction Act's State plan amendment approach is based on. The statistics are that, depending on what State you live in, looking at the rate of people who get personal care services under Medicaid per 10,000 State population, it ranges from 3 people in the lowest States to 84 people in the highest States. That is a ratio of 28:1.

I think that speaks volumes about the unevenness of the access to these services that everybody here is talking about, and Senator Harkin is responding to. So my feeling is, the Choice Act is a little bit misunderstood in Congress and people have not been paying attention to it because of the large woodwork effect issue and its cost. So, first of all, I applaud Chairman Baucus for asking for a new CBO score, and I think that is going to be very helpful.

But another thing the Choice Act does is, it rewards States that respond within the first 5 years of providing services. I think that is something obviously that Money Follows the Person is not doing. It is punishing States. So there should be a larger window that is available to the States to respond to the DRA initiative.

Senator KERRY. Well, we need to obviously try to get those bureaucratic entanglements out of the way and move this. It is hard enough to do this without having the agencies that are set up to make it work get in the way.

Mr. Flood?

Mr. FLOOD. Senator, I would like to just say one thing. I have been in the State of Massachusetts twice, talking to your people there about what we do in Vermont. I know that they very much would have liked to do the same thing that we are doing. The trouble is, we are pecking away at this problem instead of just dealing with it head on. Money Follows the Person is a great idea, except, you know what? You have to go to a nursing home first so that you can get out. It makes no sense.

The DRA provision around personal care is a good start for some States, but it is pecking away at the problem. I think what the Congress absolutely needs to do is seize the opportunity and the momentum now and, if nothing else, give every State the opportunity to do what we do. It could be done with the stroke of a pen.

Senator KERRY. Do you think the bias on the nursing homes is a sort of stereotyped, old view that that is the only way to have accountability for the flow of the money?

Mr. FLOOD. I think people are all wrapped up in that, absolutely. There are many, many models all over this country where it has been shown to work, not just Vermont, but Oregon and Washington have been doing this for 20 years.

Senator KERRY. Yes.

Mr. FLOOD. The experiments are over.

Senator KERRY. I completely agree with you. But I think it is that old hang-up. That, and some powerful lobbying. [Applause.] But what I see, all this orange I see in front of me, is its own powerful lobbying today. So, thanks for being here. [Applause.]

Thank you very, very much. Important testimony. It is a very important topic, and obviously the committee is going to continue to do its due diligence.

Mr. Liston, I apologize. You wanted to say something?

Mr. LISTON. Senator, if I could, everybody from New York has been thanked here, but I think it is important for you and the record to note that we have a lot of folks from Philadelphia, Delaware, Maryland, Kansas, from all over the country who have come to support this bill. [Applause.]

Senator KERRY. Well, that is great.

Mr. LISTON. I am sure that Senator Baucus will do everything he can. I hope this committee does everything it can to get this passed out of committee and onto the floor.

Senator KERRY. I will make sure that I educate Senator Schumer. Shame on Senator Schumer for hogging all of the spotlight like that. [Laughter.]

Thank you all, from all over the country. We love it. I appreciate it. Take care.

We stand adjourned. [Applause.]

[Whereupon, at 12:05 p.m., the hearing was concluded.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

Statement of Senator Jim Bunning
Senate Finance Committee Hearing
"Home and Community Based Care: Expanding Options for Long Term Care"

Mr. Chairman, I appreciate that the Senate Finance Committee has taken the time to conduct this hearing on Home and Community Based Care. I would also like to thank the witnesses here for taking time out of their schedules to come to Washington and help us work on this issue.

We all know that America is getting older. We all know that the baby boomer generation is entering retirement. In 1950, 8.1% of residents were age 65 or older. By 2000, this share reached 12.4% in 2000, and it is estimated to reach 20.6% in 2050.

We also all know that this seismic demographic change means that the health support systems set up for older Americans, namely Medicare and Medicaid, will come under significant strain.

This year, the Medicare trustees report projected that under assumptions, the Medicare hospital insurance trust fund will become insolvent in 2019. As for Medicaid, according to baseline projections from 2006, it will more than double over ten years, moving from $181 billion in 2006 to $392 billion in 2016.

We must find a way to continue to offer the support to seniors that they deserve while also maintaining the health of the programs themselves.

By far, the largest spender on long term care services is Medicaid. Of the $194.3 billion spent on long term care in 2004, 49.3% of that amount was paid by Medicaid. In 2006, long term care spending made up one-third of all Medicaid spending. It is clear that Medicaid and long term care are strongly linked.

However, I think that there are some opportunities to strengthen the Medicaid program within long term care and perhaps even provide better services for seniors. I believe the best of these opportunities may be in home and community based care.

It costs a lot of money to keep someone in a nursing home. However, maybe we do not need to spend these huge sums of money. I am hoping that perhaps during this hearing we can discuss some ways to give seniors more options and find ways to save the resources of the programs that our seniors depend and rely on.

Again, I thank the witnesses that have agreed to appear before this committee to help us with this task. I look forward to their testimony and I am optimistic that we can find some solutions to our problems.

Testimony Before
U.S. Senate Finance Committee
Dirksen Senate Office Building
Washington, D.C.
September 25, 2007

by

Kevin W. Concannon
Director
Iowa Department of Human Services
Des Moines, Iowa

Senator Baucus, Senator Grassley, and members of the Finance Committee. My name is Kevin W. Concannon and I appear before you today as the Director of the Iowa Department of Human Services. The Iowa Department of Human Services has the lead state responsibility for operating the Medicaid and SCHIP programs, TANF, Child Care Assistance, Child Welfare, Child Support Recovery, Mental Health and Mental Retardation Services, Food Stamps, and Emergency Services. Iowa DHS operates nine (9) state institutions, four psychiatric hospitals, two resource centers for people with mental retardation, two state institutions for juvenile offenders, and a special treatment center for chronic sexual offenders. We also maintain field offices in each of Iowa's 99 counties and, over the course of a year, directly provide services to 997,000 Iowans on an unduplicated basis, approximately one third of our population.

I am pleased to be here today to offer testimony regarding Iowa's myriad efforts and initiatives developed over a period of years to provide alternatives to institutional care. Currently Iowa operates seven (7) Home and Community-Based Waiver services focused on the following categories or conditions: AIDS/HIV waiver, Traumatic Brain Injury waiver, Elderly Services waiver, Ill and Handicapped waiver, services to people with mental retardation, physical disability services, and a Children's Mental Health waiver. The waivers for Elderly, Ill and Handicapped, and Mental Retardation serve the largest number of people (approximately 18,000 of the 23,000 people served in Iowa's HCBS waivers.)

The number of Iowans served has grown over the years from 1984 to the present with intermittent state efforts to reduce or eliminate waiting lists. No waiting list exists in the Elderly Services waiver, a small waiting list in Mental Retardation, and new appropriations represent specific effort to reduce waiting in our Children's Mental Health waiver.

Enrollment has grown by 10%-12% annually since 2003 and expenditures have grown from $176 million in 2003 to $348 million in 2007, or approximately 15% annually. As allowed by CMS, Iowa has enrollment and expenditure caps in the waiver programs. The caps are largely due to state budget constraints. However, enrollment, utilization, and expenditures have grown steadily demonstrating Iowans overwhelming choice to live in the community and the state's commitment to providing and promoting these options.

Iowa is also committed to innovative approaches that promote independence. Iowa implemented a "self direction" option called "The Consumer Choices Option." This allows Medicaid waiver consumers, who choose to do so, to manage their own services and providers. Members are given a budget equal to their need from which to purchase services that most fit their needs and choices. The budget is managed by a fiscal agent, Iowa's largest credit union is providing services statewide. There is an Independent

Support Broker who provides direct assistance. Among its many features, Consumer Choices may allow relatives to be reimbursed for care.

I would like to draw the Committee's attention to our most recent Iowa developments in this HCBS sphere. 1) The introduction of the Iowa Consumer Choices Option, initiated statewide on July 1, 2007, and a choice to any person enrolling in any of Iowa's six HCBS waivers; 2) The implementation of the Iowa Children's Mental Health waiver which allows parents who previously needed to relinquish custody in order to qualify for mental health care to now access such publicly supported care; 3) Iowa's award of a CMS grant in the category of "Money Follows the Person" to provide non-institutional choices to current residents of ICF/MRs over a five year period and; 4) Iowa's utilization of the Deficit Reduction Act provision which allows states to implement a Medicaid State Plan Amendment targeted at replacing "Adult Rehabilitation Services" with a State Plan Amendment entitled "Habilitation Services". This provision better suits the population previously served under Adult Rehabilitation without the requirement of being at risk of institutional level of care in order to qualify.

I. We are very enthusiastic about our Iowa Consumer Choices option available to all Home and Community-Based Services' waiver enrollees. "Cash and Counseling" is often the shorthand characterization of this option to set aside Medicaid funds in a financial institution (Iowa Credit Union) to provide Financial Management Services alongside the services of an Independent Support Broker which allows the consumer to directly contract with individual providers or organizations for care. Consumer choice, autonomy, appropriate service responsiveness, are all enhanced by this choice. As of this date, some 250 Iowans are taking this option which is expected to grow to match the percentages seen in other states which pioneered this option. It is about choice, quality, and autonomy and also may lend itself to more rural areas where health workforce shortages exist in the health workforce.

II. Children's Mental Health – Iowa sought this waiver in combination with proposed changes in our law to help parents secure mental health care for their children without the anguish and terrible dilemma of "custody relinquishment" still required in one-half of the states in the United States when parents are either not poor enough to qualify for Medicaid or SCHIP and who do not have adequate mental health private insurance. Iowa implemented in July 2006 and this current year will double the number of children and families so served.

III. Iowa's "Money Follows the Person Grant" from CMS is focused on our population with Mental Retardation who reside in Intermediate Care Facilities (ICF/MR) for people with mental retardation, both public and private. Iowa currently has the sixth or seventh highest rate of ICF/MR usage. Over five years we will be utilizing these enhanced dollar resources to provide and expand community choices for current ICF/MR residents in keeping with the Olmstead Supreme Court Decision.

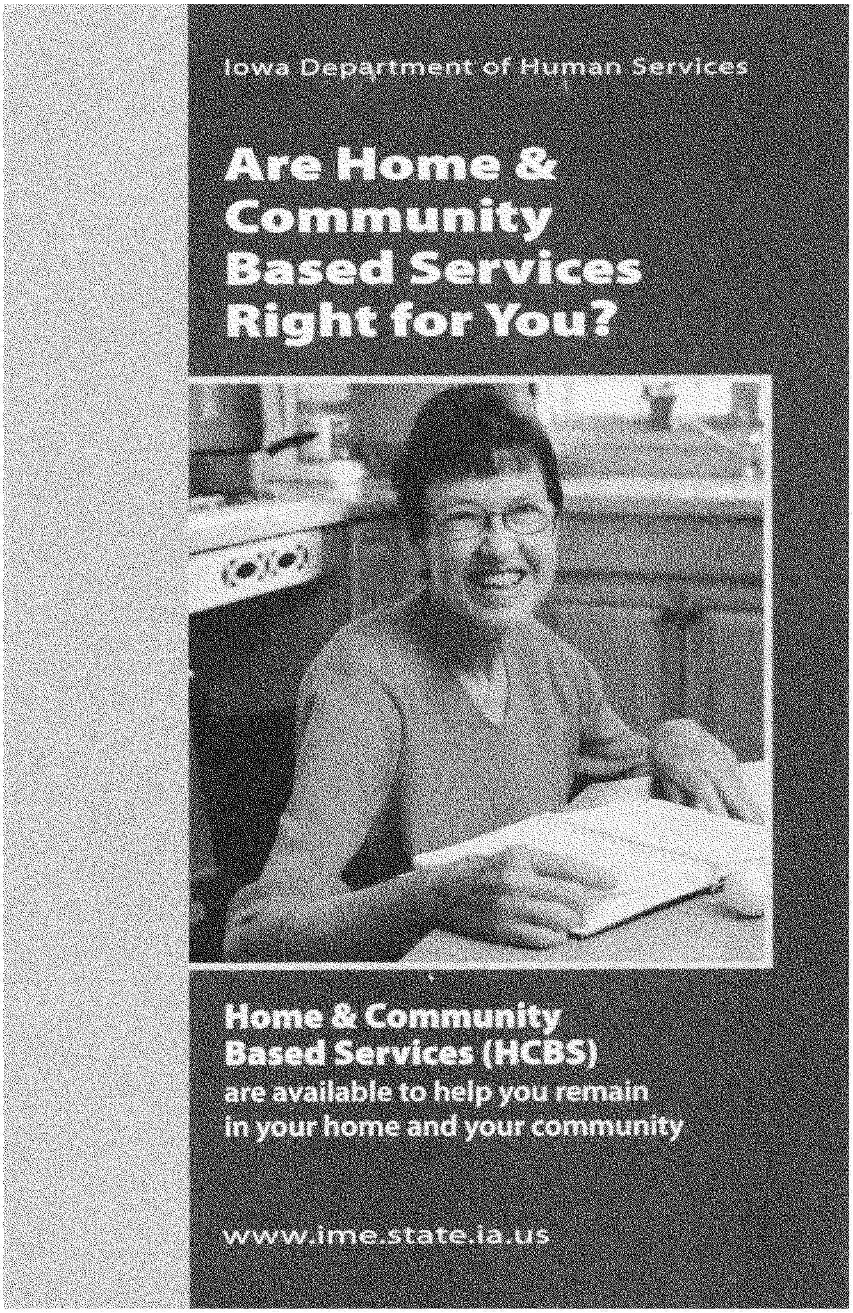
IV. Deficit Reduction Act. Iowa Habilitation Services. Beginning in 2001, and previous to DRA, Iowa operated the Adult Rehabilitation Option (ARO) to attempt to address the needs of the Chronically Mentally Ill in the community. Iowa was one of the first states to have its ARO program audited by the Office of Inspector General (OIG). The audit found some services provided were not rehabilitative, which resulted in a six million dollar payback. The key problem for Iowa and many other states was that there wasn't a way under Medicaid to meet the long-term habilitative needs of the Chronically Mentally Ill, as there are for other populations under the HCBS waivers. This is because in order to be eligible for HCBS waiver services, the member must meet an 'institutional level of care' (meaning nursing facility, ICF/MR or hospital). Most of the time, the CMI population does not meet this level of care, but still has a very real need for the type of community services provided under the waivers. Section 6086 of the DRA gave states, for the first time, the opportunity to provide long-term 'habilitative' community services. The key difference between the DRA and the HCBS waivers is that home and community based services can now be provided to individuals based on their meeting functional or needs based criteria -- without needing to meet an institutional level of care.

Iowa redesigned the former ARO program and replaced it with a 'Remedial Services Program', which uses a medical model that also fits with CMS proposed regulations, and the new Habilitation Services program under the DRA. Iowa developed our needs based eligibility criteria in collaboration with CMS. Habilitative services are available to any Medicaid recipient who demonstrates 'risk factors' and a need for services that are typically associated with a chronic mental illness. Services include home-based habilitation, day habilitation, pre-vocational services and supported employment.

V. Finally, I wish to point out Iowa's efforts to assure quality in Home and Community Based Services (HCBS) programs. We have been strengthening the program(s) and Iowa's systemic ability to assure quality, especially so over the past three years. Iowa has redesigned our Quality Assurance/Quality Improvement system for the HCBS, and Habilitation Services in ways that integrate all aspects of CMS's Quality Framework. Our plan is called Inclusion through Quality (IQ). CMS has approved the new system submitted in section H of the waiver application and has worked with Iowa to assure the implementation is occurring.

Thank you for the opportunity to brief you on some of the activities and initiatives in Iowa's Medicaid system. I would be pleased to answer questions from the Committee.

Kevin W. Concannon
Director
Iowa Department of Human Services



Iowa Department of Human Services

Are Home & Community Based Services Right for You?

Home & Community Based Services (HCBS) are available to help you remain in your home and your community

www.ime.state.ia.us

Home & Community Based Services Waivers

The **Iowa Home & Community Based Services (HCBS)** waivers are Medicaid Programs from the federal government which have rules set aside or "waived". This gives you more choice about how and where you receive services. It is available to people with disabilities and older Iowans who need services and supports; which may allow them to stay in their homes. You must be eligible for Medicaid and also meet the requirements for each waiver.

Iowa currently has seven Medicaid HCBS waivers. This brochure may help you decide if HCBS waivers are right for you. For more information or to apply, contact your local Department of Human Services office.

What to expect...

All waivers include some common service elements. These common elements are described below:

SERVICE COORDINATION

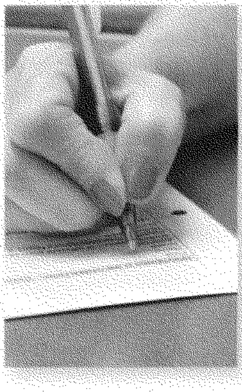
Your case manager/service worker is there to help you plan for and get the services and supports you need.

INDIVIDUAL PLANNING

All individuals who receive waiver services and supports have an **Individual Service Plan**. Your plan should include important information about you, your goals, and the steps you and your **Support Team** need to take to get there. Usually, the people on your team include yourself, your case manager/service worker, and other people whom you choose.

QUALITY ASSURANCE

It is important to make sure that you are satisfied with the services and supports that you receive, and that those supports are helping you move toward the goals that are in your **Individual Service Plan**. Iowa must also assure that HCBS waiver funds are used appropriately and in a fashion that meets federal and state requirements. You may be asked about your services and supports. These questions help ensure that waiver services help you lead a **full, satisfying, and safe life**.



Waiver services are designed to support you!

EASY ACCESS

You should be able to find and get the supports you need. Just contact your local Iowa Department of Human Services office or visit the Iowa Medicaid Enterprise (IME) website: **www.ime.state.ia.us**

FLEXIBLE SUPPORTS

You should receive supports that are creative and effective so that your individual needs are met in the most efficient way possible.

PERSON CENTERED APPROACH

You should feel you are respected, valued, and an equal partner in the design and delivery of the supports that are provided to you. Your team is there to support you in making decisions. You have the responsibility of letting your team know your service needs.

HEALTH & SAFETY

The Iowa Department of Human Services requires providers to supply high quality supports. These supports will help you stay healthy and safe while allowing you to make informed choices, try new experiences, take reasonable risks, and assume new challenges and responsibilities in your life.

Waiver descriptions...

HCBS AIDS/HIV Waiver

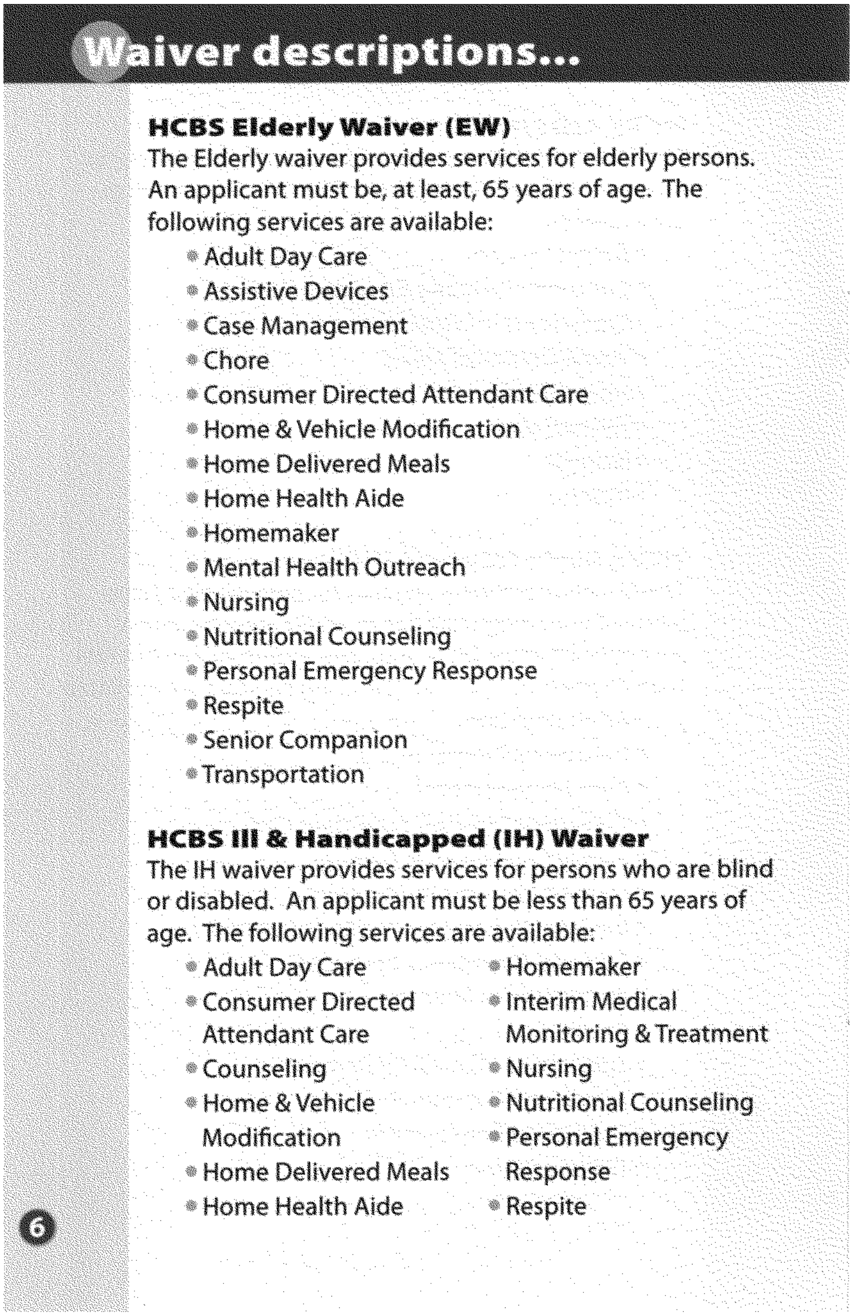
The AIDS/HIV waiver provides services for persons who have an AIDS or HIV diagnosis. The following services are available:

- Adult Day Care
- Consumer Directed Attendant Care
- Counseling Services
- Home Delivered Meals
- Home Health Aide
- Homemaker
- Nursing
- Respite

HCBS Brain Injury (BI) Waiver

The BI waiver provides services for persons who have a brain injury diagnosis due to an accident or illness. An applicant must be at least one month of age but less than 65 years of age. The following services are available:

- Adult Day Care
- Behavioral Programming
- Case Management
- Consumer Directed Attendant Care
- Family Counseling & Training
- Home & Vehicle Modification
- Interim Medical Monitoring & Treatment
- Personal Emergency Response
- Prevocational Services
- Respite
- Specialized Medical Equipment
- Supported Community Living
- Supported Employment
- Transportation



Waiver descriptions...

HCBS Elderly Waiver (EW)

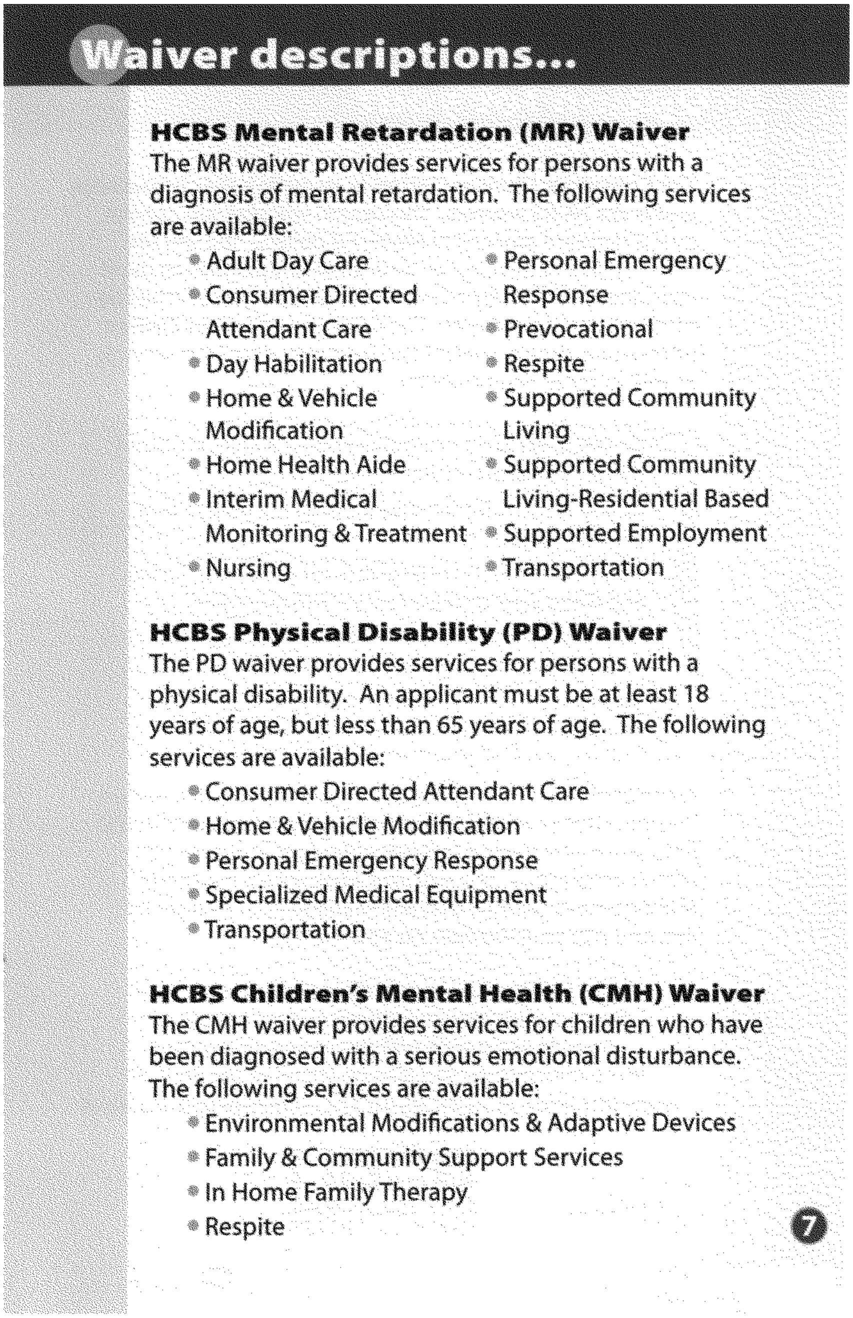
The Elderly waiver provides services for elderly persons. An applicant must be, at least, 65 years of age. The following services are available:

- Adult Day Care
- Assistive Devices
- Case Management
- Chore
- Consumer Directed Attendant Care
- Home & Vehicle Modification
- Home Delivered Meals
- Home Health Aide
- Homemaker
- Mental Health Outreach
- Nursing
- Nutritional Counseling
- Personal Emergency Response
- Respite
- Senior Companion
- Transportation

HCBS Ill & Handicapped (IH) Waiver

The IH waiver provides services for persons who are blind or disabled. An applicant must be less than 65 years of age. The following services are available:

- Adult Day Care
- Consumer Directed Attendant Care
- Counseling
- Home & Vehicle Modification
- Home Delivered Meals
- Home Health Aide
- Homemaker
- Interim Medical Monitoring & Treatment
- Nursing
- Nutritional Counseling
- Personal Emergency Response
- Respite



Waiver descriptions...

HCBS Mental Retardation (MR) Waiver

The MR waiver provides services for persons with a diagnosis of mental retardation. The following services are available:

- Adult Day Care
- Consumer Directed Attendant Care
- Day Habilitation
- Home & Vehicle Modification
- Home Health Aide
- Interim Medical Monitoring & Treatment
- Nursing
- Personal Emergency Response
- Prevocational
- Respite
- Supported Community Living
- Supported Community Living-Residential Based
- Supported Employment
- Transportation

HCBS Physical Disability (PD) Waiver

The PD waiver provides services for persons with a physical disability. An applicant must be at least 18 years of age, but less than 65 years of age. The following services are available:

- Consumer Directed Attendant Care
- Home & Vehicle Modification
- Personal Emergency Response
- Specialized Medical Equipment
- Transportation

HCBS Children's Mental Health (CMH) Waiver

The CMH waiver provides services for children who have been diagnosed with a serious emotional disturbance. The following services are available:

- Environmental Modifications & Adaptive Devices
- Family & Community Support Services
- In Home Family Therapy
- Respite

⑦

Is the Consumer Choices Option for you?

The Consumer Choices Option is an option that is available under the HCBS waivers. This option will give you control over a targeted amount of Medicaid dollars. You will use these dollars to develop an individual budget plan to meet your needs by directly hiring employees and/or purchasing other goods and services. The **Consumer Choices Option** offers more choice, control and flexibility over your services as well as more responsibility.

- **Do you want more control over how waiver Medicaid dollars are spent on your needs?**
- **Do you want to be the employer of the people that provide support to you?**
- **Do you want to be responsible for recruiting, hiring and firing your workers and service providers?**
- **Do you want to be responsible for training, managing and supervising your workers and service providers?**
- **Do you want the flexibility to be able to purchase goods or services in order to meet your needs?**

Additional assistance is available if you choose this option. You will choose an **Independent Support Broker** who will help you develop your individual budget and help you recruit employees. You will also work with a **Financial Management Service** that will manage your budget for you and pay your workers on your behalf.

If you feel the **Consumer Choices Option** is right for you, your case manager/services worker can provide assistance with accessing this option.
More information can also be found at the website:
www.ime.state.ia.us/HCBS/HCBSConsumerOptions.html

CONSUMER
CHOICES OPTION

TESTIMONY TO SENATE FINANCE COMMITTEE

PATRICK FLOOD, DEPUTY SECRETARY
VERMONT AGENCY OF HUMAN SERVICES

SEPTEMBER 25, 2007

I am here today to tell you about a better way to provide long term care services in this country. For far too long we have relied on expensive nursing home care, care that elders and people with disabilities don't even want. As the population ages, we will not be able to afford the current institutional model.

Fortunately, there is a better way. It is not a theory. It is succeeding today in Vermont, and be duplicated in any state. It can save the Medicaid program billions of dollars nationwide that can be re-directed to meet the growing need long term care, especially as the population ages.

In Vermont we have developed a long term care model that provides more people with the kind of services they want, services that allow them to remain in their own homes and communities, surrounded by family and friends. Even better, this model is cheaper than nursing home care, and allows us to care for more people than we ever could with the institutional model.

How often these days can we find a public policy that gives people what they prefer and saves money? This is one of those rare opportunities: a win for people, a win for states, a win for the federal government.

Let's examine the current system for a minute. Under current Medicaid law, nursing home care is an entitlement. That is, if you are eligible and want to go to a nursing home, the state, and federal government, must pay. On the other hand, the service that people prefer, staying at home or in a less institutional setting, is not an entitlement. Instead, you have to wait in line, even though these services, on average, are cheaper than nursing home care.

It doesn't make any sense. The more expensive service that people don't want is an entitlement, but the cheaper, more desirable service is capped and you have to wait in line for it.

Some will argue that home based care is not cheaper. However, in Vermont we conducted a comprehensive study in 2002 to compare nursing home costs to home based care. We collected all the Medicaid costs for individuals in nursing homes and people on our Waiver program. These cost included nursing home services and home health costs, but also hospital care, physician care, prescription drugs, therapies, transportation and all other services covered by Medicaid. For people living at home we also collected other state and federal benefits such as food stamps, fuel assistance, etc. When all the expenses were collected and compared, the average cost for keeping an elder at home on the Waiver was 2/3 the cost of average nursing home care. For adults with physical disabilities, the average cost was about the same.

So, to us, if for no other reason than economics, it only made sense to expand home based care and reduce our reliance on nursing homes.

Of course, it is also the right thing to do for the elders and adults with disabilities who need care.

We had been able to make significant progress over the years in reducing nursing home use. However, the nursing home entitlement posed a significant barrier. We continued to have a nursing home entitlement but a cap on our home based waiver. Why? Because policy makers, budget staff and legislators were worried that if we expanded home based care too much, we would have a "woodwork" effect, and have an uncontrollable home based care system. So, instead people would end up in more expensive nursing home care because they could not stand to wait on the home based care waiting list any longer.

My staff and I were frustrated by this one-sided entitlement, and did not believe that expanding home care would be a problem, but no state is going to create another open ended entitlement in these times.

So we applied to CMS for an 1115 Waiver that would let us re-design our long term care system and create more flexibility. In its simplest terms, our Waiver provides an equal entitlement to either nursing home care or home based care, but in a way that lets us manage to the available funding. We want to thank and acknowledge the people at CMS who grasped what we were trying to do and gave us the chance to radically reform the system.

Our theory was that, given a choice, more people would choose home based care. Since that care, on average, is cheaper, we could serve more people for the same amount of money. We would use nursing home care less, and those savings would be transferred to cover more home based care for more people.

However, we also needed some mechanism for controlling costs if our projections were wrong and our home based costs were far more than anticipated. So we requested and CMS approved a process that permitted us to put the lightest care people on a waiting list if necessary. Keep in mind that we always had, and every state has, a waiting list. The problem is that the waiting list is only for home based care; there is no waiting list for nursing home care. That was neither fair nor logical. Under our system, the highest needs persons get served first, and can choose either option. Lighter care people may have to wait, for either option.

This is a key element to reforming the system. Armed with this new equal access to either nursing home care or home based care, yet with the ability to control over all costs, we implemented the program in October 2005.

So what happened? So far, the program is working just as it was designed. We are serving twice as many people at home as we could have under the old system. Nursing home use is down, and we are operating within our budget. We have had a small waiting list on and off, but today there is no waiting list.

Since the program started we have added 467 new people to either home based services or alternative residential settings such as Assisted Living. At the same time, the number of people in nursing homes has decreased from 2286 to 2038.

The program has worked almost exactly as planned. There has not been any uncontrollable "wood work effect". Even if there was, the ability to serve more people for the same amount of money means the state can absorb a degree of "wood work effect".

There other elements of our program that have been important for our success and that we would recommend to any state.

The first is to have a portfolio of services. We offer not only personal care and case management, but respite, residential care, adult day, adaptive equipment and home modification. We also offer a very flexible "cash and counseling" option. It is important to have person centered, flexible options because every person's needs are different.

Another key option is consumer direction. Consumers, whether elders or adults with physical disabilities, know best what will meet their needs. For years we have offered a consumer directed option that permits consumers to hire their own care givers instead of relying on agency services. This is very effective and positive for several reasons. First it gives consumers control of their services, and results in much higher consumer satisfaction. Second, by letting consumers hire family members and friends, it supports the natural supports that people have. Third, it is a far more cost effective option than agency services. In Vermont, the consumer directed option costs the state about $13 per hour, while agency services cost $26 per hour. Lastly, this option brings thousands of family members and friends into the care giving system that would never work for an agency, and thus helps address the shortage of caregivers.

One constant concern raised is about what happens to nursing homes. Some suggest we will need all of our nursing homes as the boomers age. Not so. We need new and different options, and the kind of alternative settings that the boomers will demand. Not to mention the boomers will not need nursing home level of care for another 15 to 20 years at least, by which time most of our current nursing homes will be obsolete. Some argue that nursing homes need to be kept open because they are major employer. Not so. In a reformed system there will be just as many if not more jobs in the home based care system. It is possible to manage the downsizing of our nursing home system. The kind of change we are engaged in does not result in mass closings of nursing homes. The change can be managed in an orderly manner. Some nursing homes will close; they already are. Others can be helped to become smaller more efficient facilities, and change their environments and how they operate.

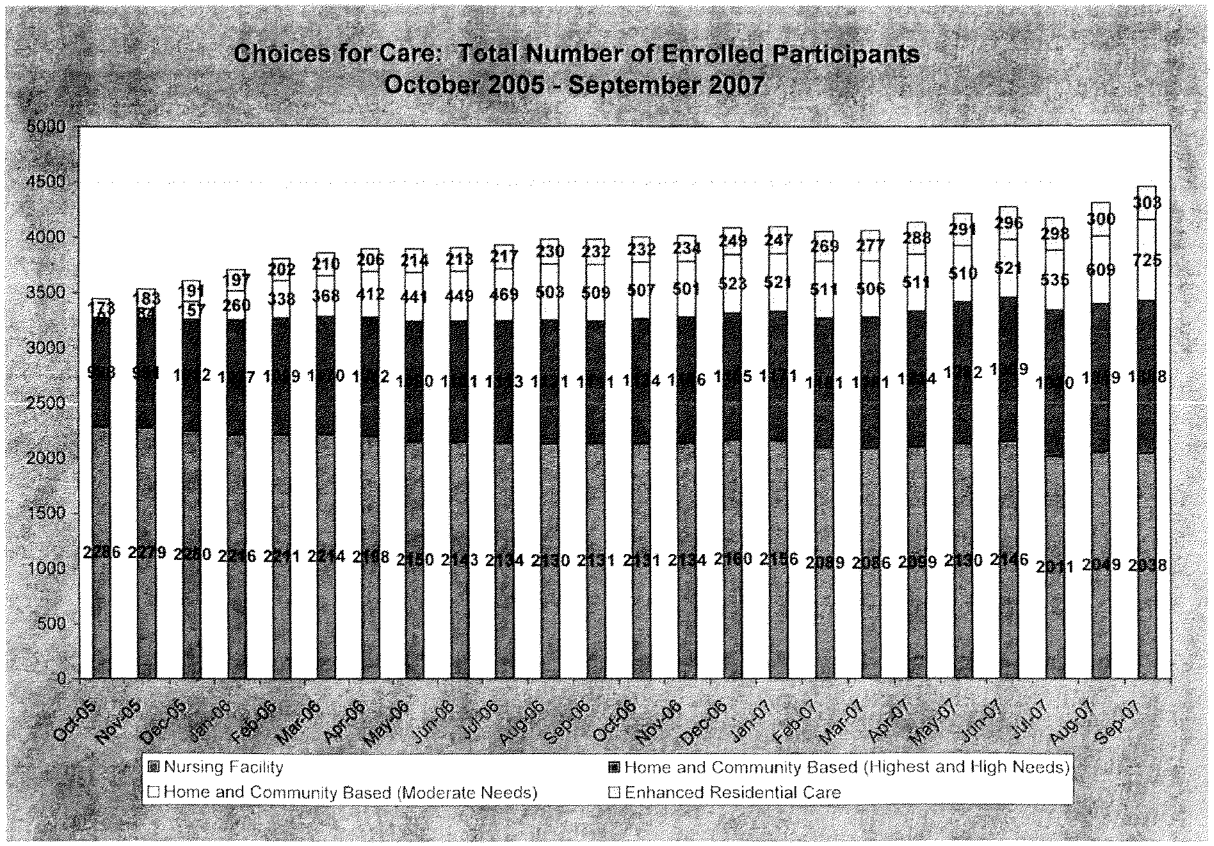
Any state can do what we have done. Yes, it is easier to make progress faster in a small state like Vermont, but the principles are the same. In fact, many states are adopting some of the same approaches.

However, other states cannot adopt the same model as Vermont until the Congress and federal Government give them the same opportunity to re-design their long term care systems that we have. They need the same permission to provide equal access to either home based care or nursing home care, with the ability to control expenditures. This is the key to reforming long term care and being ready for the aging of America.

CMS and Congress have taken some steps in this direction, promoting Cash and Counseling, and passing some helpful provisions in the DRA. But these are tentative steps that will only result in incremental change. A larger change is needed and needed now. Even with a fundamental change in federal law, it will take states years to completely re-design their systems to fully reinvent themselves. We need to change the law now.

Fortunately, the solution is clear. We can do this and it can work.

The State of Vermont stands ready to help Congress, CMS or any state design and develop a system that truly serves people.


Choices for Care: Total Number of Enrolled Participants
October 2005 - September 2007

VERMONT

Choices for Care

Quarterly Data Report
July 2007

This report documents the status and progress of Choices for Care, Vermont's long term care service system. This report is intended to provide useful information regarding enrollment, service, and expenditure trends in Choices for Care. A brief explanation accompanies each graph, chart or table.

The primary data sources are SAMS Choices for Care enrollment and service authorization data maintained by the Division of Disability and Aging Services, Medicaid claims data maintained by EDS, and nursing home census data from the Division of Ratesetting.

We welcome your comments, questions and suggestions.

Bard Hill, Director
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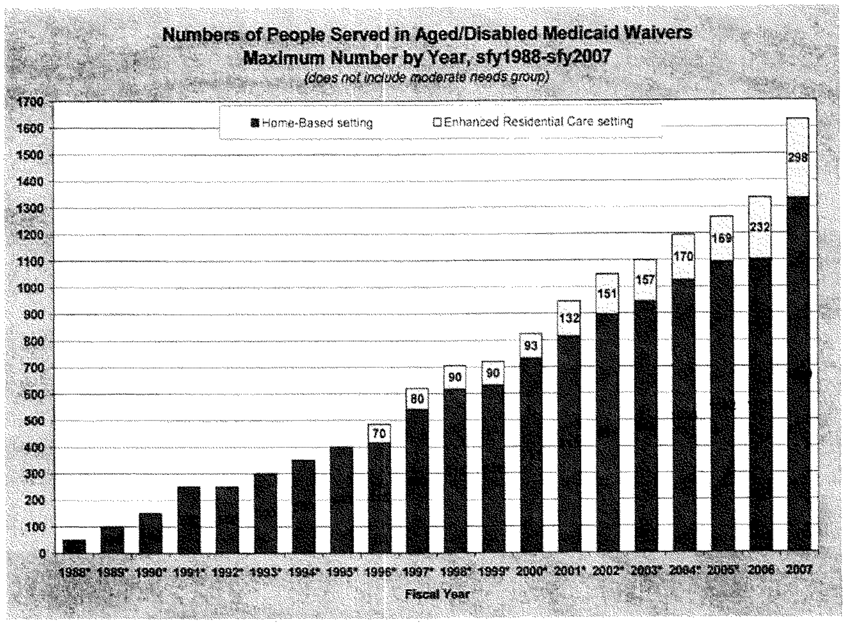
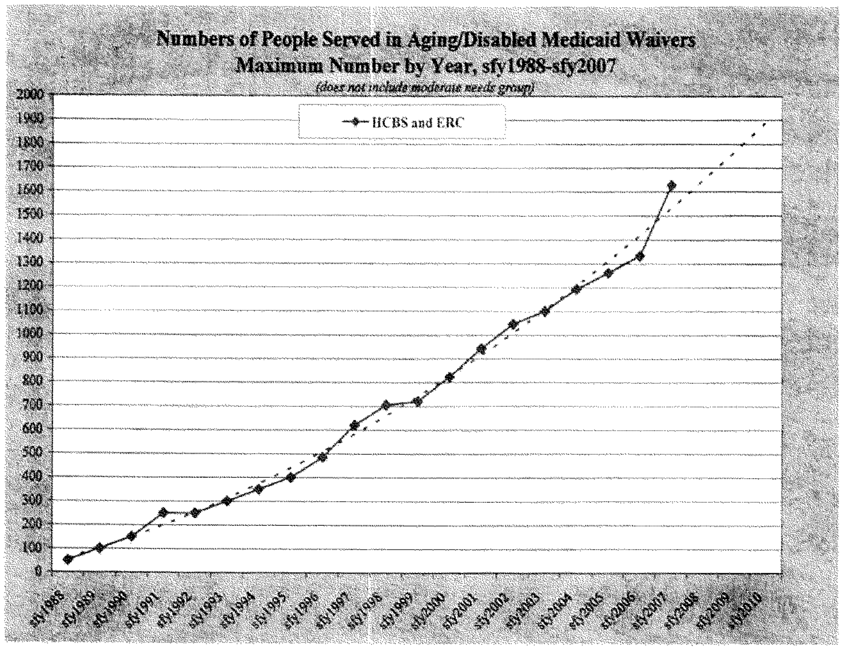


Data source: DAIL/DDAS databases
* years preceding Choices for Care, with limited funding and enrollment

This graph illustrates the growth in home and community based services in Vermont for people over age 60 and people with physical disabilities since sfy1988.

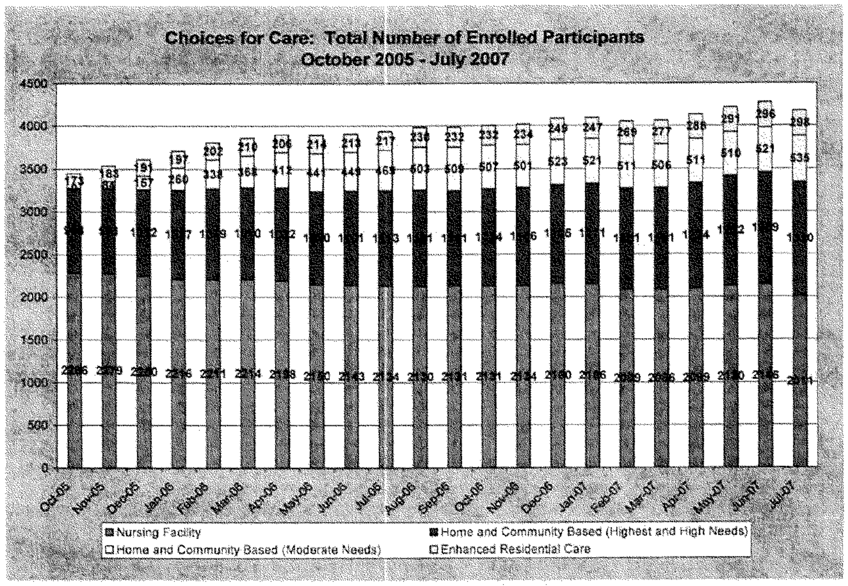
Prior to the implementation of Choices for Care in sfy2006, growth was fairly steady, but limited by the funding available within each state fiscal year. During these years all eligible Vermonters were entitled to receive nursing home care under Medicaid, but were not entitled to receive alternative community-based long term care services. Some people who applied for home and community based services were placed on waiting lists, and had to wait for funding to become available.

In sfy2007, the number of people enrolled in home and community based settings increased by nearly 300, the largest increase ever. This represents an increase of more than 20% over the previous year.



Data source: DAIL/DDAS databases

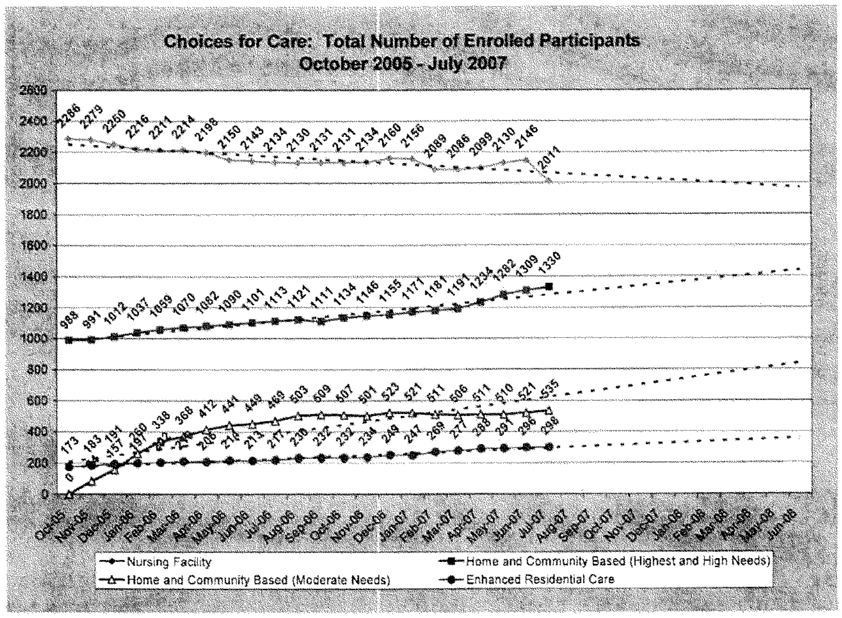
This graph combines HCBS and ERC enrollment data, and projects the historical enrollment trend through sfy2010.



Data source: DAIL/DDAS SAMS database.

This shows the changes in enrollment in Choices for Care settings since October 2005. The number of people served in nursing homes has continued to decrease, while the numbers of people served in the Home and Community Based and Enhanced Residential Care settings have continued to increase:

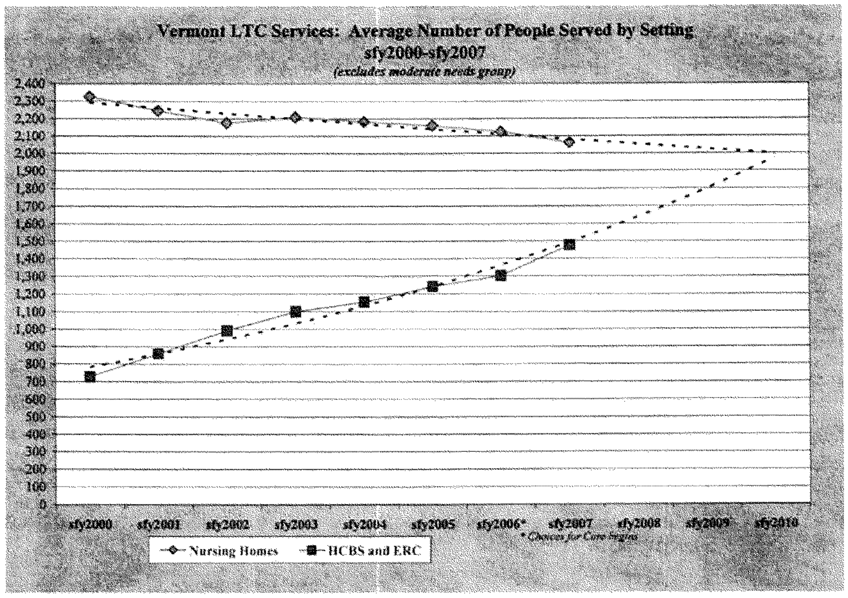
1. Nursing homes: the number of people in nursing homes decreased by 275 (from 2,286 to 2,011) between October 2005 and July 2007. The closing of the Morrisville Center nursing home in January 2007 contributed to this decrease.
2. Home and Community Based Services (Highest/High Needs Groups): the number of people increased by 342 (from 988 to 1,330) between October 2005 and July 2007. Substantial increases have occurred in the last four months.
3. Enhanced Residential Care: the number of people increased by 125 (from 173 to 298) between October 2005 and July 2007. Some people transitioned to ERC settings from the TBI Waiver and from the Morrisville Center nursing home, contributing to this increase.
4. HCBS Moderate Needs Group: the number of people in this 'expansion' group increased from 0 to 535 between October 2005 and July 2007.



Data sources: DAIL/DDAS SAMS database

This shows another view of Choices for Care enrollment since October 2005, with projections through sfy2008.

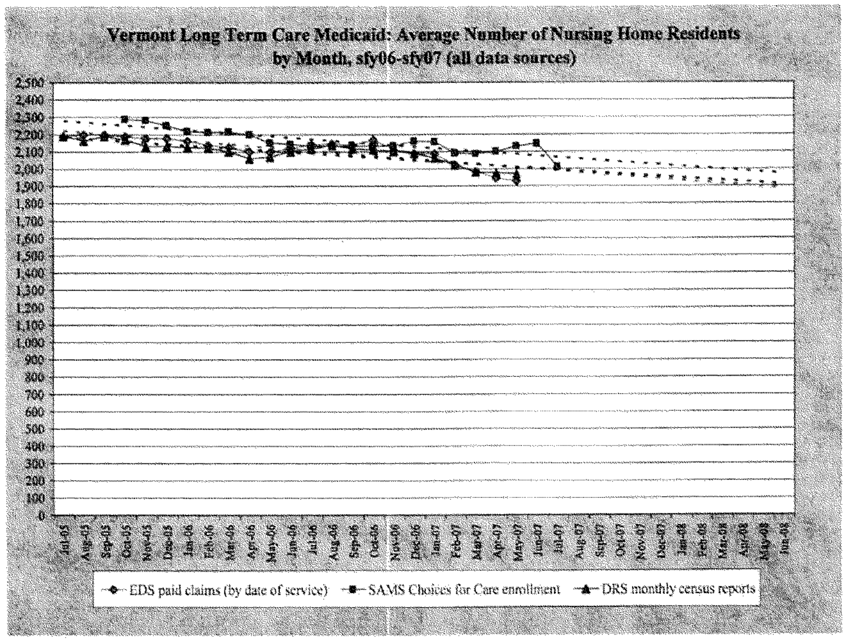
The number of people enrolled in the HCBS and ERC settings has increased by about 450, while the number of people enrolled in nursing home settings has decreased by about 250. The core hypothesis of Choices for Care appears to be supported: by offering an entitlement to community-based care, the number of people choosing community alternatives will increase, and the number of people choosing nursing homes will decrease…and that this will make funds available to serve more people in the community.



Data sources: DAIL/DDAS enrollment data; DAIL Monthly Monitoring Report; Division of Ratesetting

This graph compares trends in service settings since sfy2000, using a second data source for nursing home services ('days' reports submitted by nursing homes to the Division of Ratesetting).

The trends suggest that the number of people served in nursing homes will continue to decrease, and that the number of people served in alternative settings will continue to increase. If these trends continue, within three years the number of people served in alternative settings will be comparable to the number of people served in nursing homes.

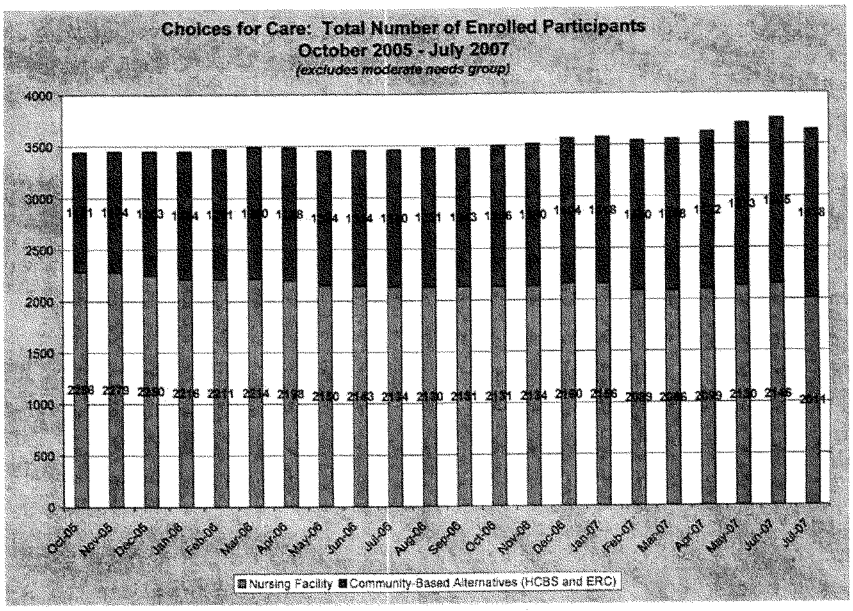

Vermont Long Term Care Medicaid: Average Number of Nursing Home Residents by Month, sfy06-sfy07 (all data sources)

Data sources: DAIL/DDAS SAMS database; EDS paid claims, by date of service; Division of Rate Setting.

This shows trends in the use of nursing homes under Medicaid using three different data sources:

1. EDS Medicaid paid claims. This represents services actually paid by Medicaid. This is the 'gold standard' of Medicaid service data, but is not acceptably accurate for 3-9 months after the date of service.
2. SAMS enrollment: This enrollment data is maintained by DAIL, and is used to track applications and eligibility.
3. Division of Ratesetting monthly census reports: This monthly 'days of service' data is submitted by nursing homes to the Division of Ratesetting (DRS), and includes all funding sources.

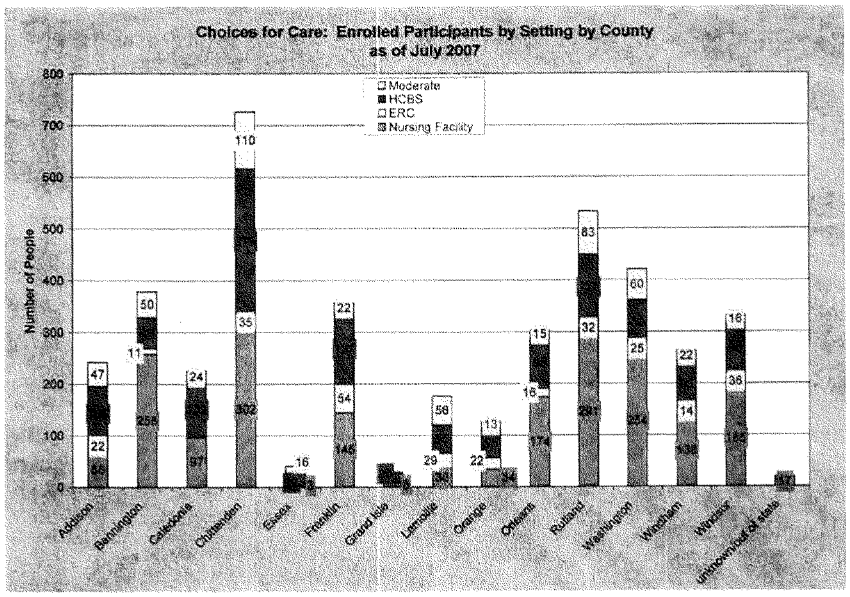
All three data sources show a nearly identical trend in the declining use of nursing homes. This increases confidence in the validity of the trend. On average, the DRS data is within 1% of the EDS paid claims data (ranging from 0.1% to 2.2%). On average, SAMS data is within 3% of the EDS paid claims data (ranging from 0.3% to 7.9%).



Data source: DAIL/DDAS SAMS database.

This shows trends in enrollment of people in the Highest Needs Group and the High Needs Group. All of these people meet traditional nursing home eligibility criteria.

The total number of people enrolled in these two groups has grown modestly. In 22 months, the total number enrolled has increased by about 190 people (about 3% per year). Prior to Choices for Care, the annual increase in the number of people enrolled in HCBS and ERC was also about 100. This suggests that initial concerns about a 'woodwork effect'- in which large numbers of people would enroll in Medicaid long term care services and cause unexpected increases in the total number served, and in total costs- were unfounded.

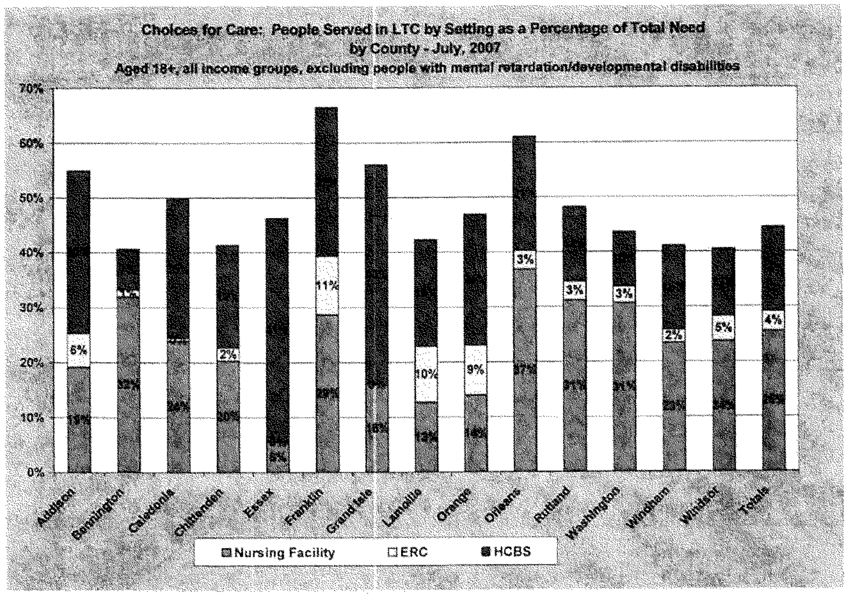


Data source: DAIL/DDAS SAMS database.

This shows the settings in which Choices for Care participants are served, by county. The graph can be used to compare the numbers of people served in each setting within each county, as well as the numbers of people served across all counties.

Chittenden County, with the largest population in Vermont, has the highest number of Choices for Care participants. Rutland County has the second largest population, and the second highest number of Choices for Care participants.

In Addison, Lamoille, and Orange Counties, a relatively large proportion of people in the Highest and High Needs Groups are served in the HCBS and ERC settings. In Bennington, Rutland, and Washington Counties, a relatively large proportion of people in the Highest and High Needs Groups are served in Nursing Facilities.

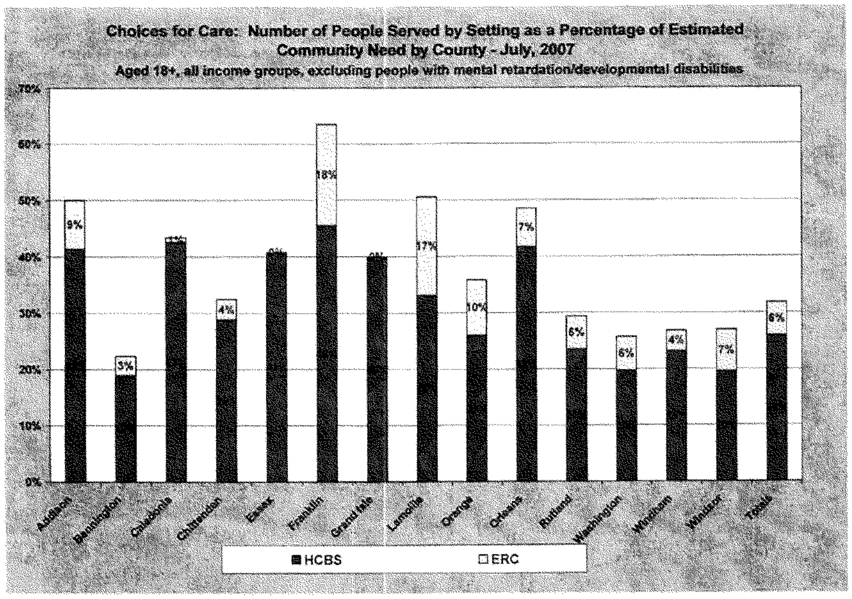


Data sources: DAIL/DDAS SAMS database; Shaping the Future of Long Term Care and Independent Living 2007.

This provides a demographic perspective on Choices for Care enrollment in each county, based on estimates of total demographic need. The data does not include the Moderate Needs Group.

The chart is based on Shaping the Future of Long Term Care and Independent Living by Julie Wasserman (May 2007), which includes two estimates of need: nursing homes and community settings. Estimates of the 2006 need in both settings were combined to produce an estimate of total need, including all people aged 18 and over with two or more ADL assistance needs, in all income groups. The total need was then compared to the number currently served, producing an estimate of the percentage of people in need who are actually served.

While it would not be reasonable or feasible to attempt to serve 100% of the estimated number of people who may need assistance, this graph does provide a perspective on the relative numbers of people served in each county.

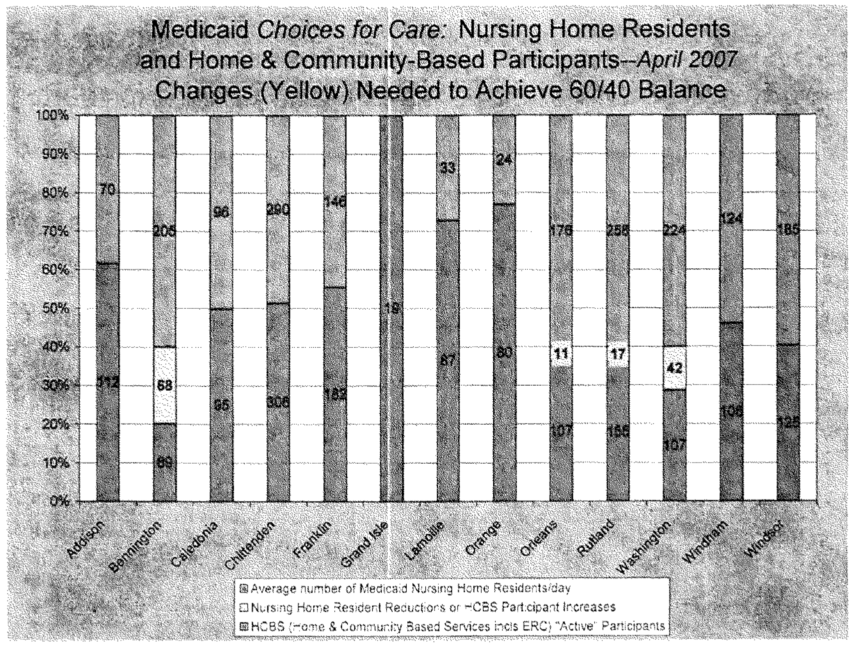


Data sources: DAIL/DDAS SAMS database; Shaping the Future of Long Term Care and Independent Living 2007.

This provides a slightly different demographic perspective on Choices for Care enrollment in each county, with a focus on alternative settings. The data does not include the Moderate Needs Group.

The graph is based on estimates of need for assistance in community settings only (*not* nursing home settings), as presented in Shaping the Future of Long Term Care and Independent Living, by Julie Wasserman (May 2007). The estimates of need include all people aged 18 and over with two or more ADL assistance needs, all income groups. The total community need was then compared to the number currently served in the community, producing an estimate of the percentage of people in need in the community who are actually served.

Again, it is neither reasonable nor feasible to attempt to serve 100% of the estimated number of people who need assistance. This graph does provide a perspective on the relative numbers of people served in community settings in each county.

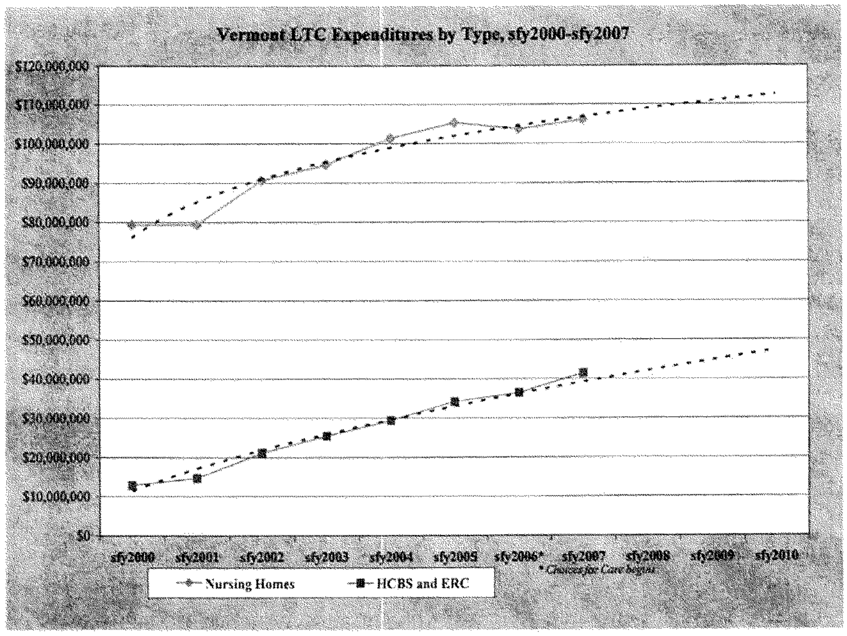


Data sources: DAIL/DDAS SAMS database; Division of Rate Setting.

One of the goals of Choices for Care is to serve a higher percentage of people using Medicaid-funded long term care in alternative community settings, and to reduce reliance on nursing homes. This graph illustrates our status in achieving this goal in each county as of April 2007.

The graph shows the number of Choices for Care participants who were served in nursing home settings (blue), the number served in alternative settings (red), and the number of participants who would have to move from a nursing home setting to an alternative setting to reach the benchmark of 40% in alternative settings (yellow).

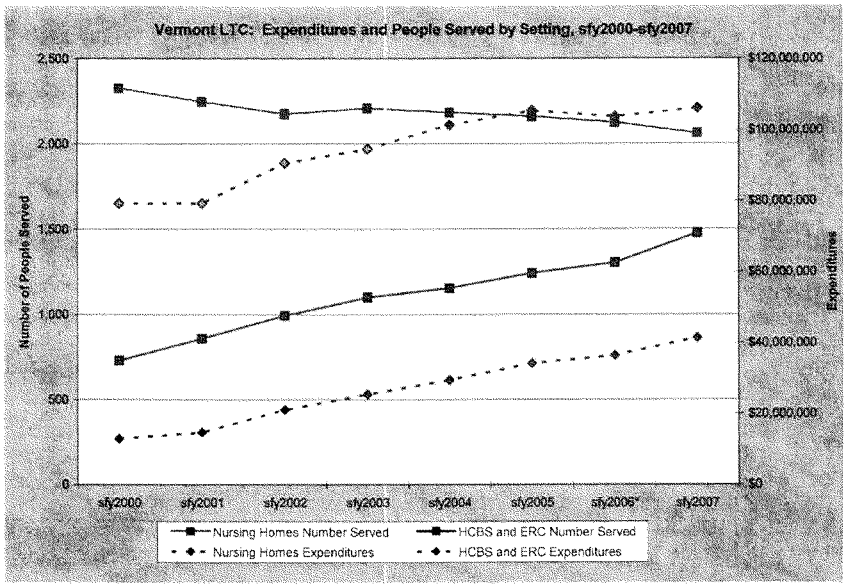
In Addison, Chittenden, Franklin, Grand Isle, Lamoille, and Orange Counties, more than 50% of Choices for Care participants are now served in alternative settings. In Caledonia, Windham and Windsor Counties, more than 40% of participants are served in alternative settings. People using Medicaid long term care in the remaining counties - Bennington, Orleans, Rutland, and Washington- remain more dependent on nursing homes, with less than 40% served in alternative settings.



Data source: DAIL Monthly Monitoring Report

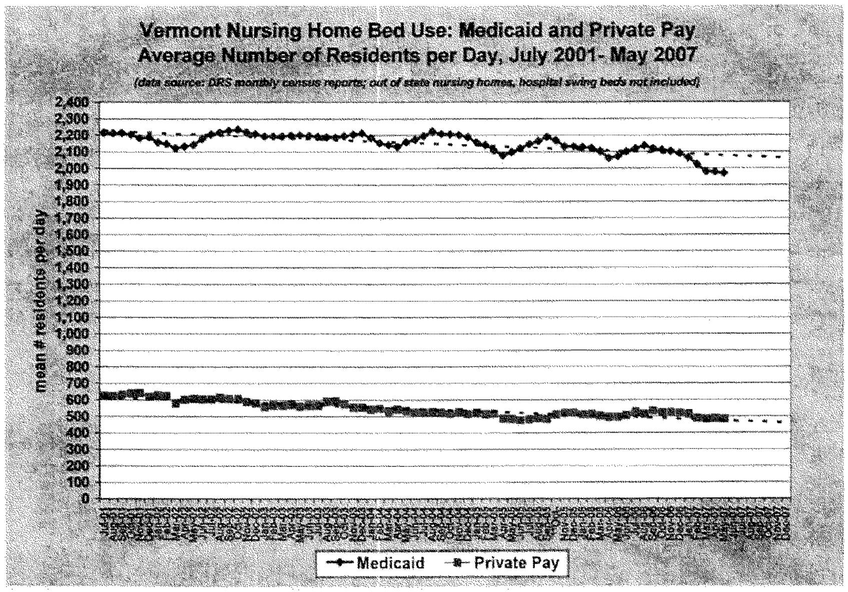
This graph shows direct Medicaid long term care expenditures by setting. Since sfy2000, annual Medicaid expenditures have increased about $30 million in both nursing homes and in alternative settings.

Note that other expenditures are also relevant. People in the HCBS setting tend to incur substantial expenditures for Medicare services, Medicaid services, and other support services (housing subsidies, transportation, food, utilities, etc.) People in nursing homes and enhanced residential care tend to incur fewer of these other expenditures.



Data sources: DAIL/DDAS SAMS database; DAIL Monthly Monitoring Report

This shows trends in both the average numbers of people served and total expenditures by setting. As noted, expenditures have increased by similar amounts in both settings. These increases are related to different patterns in the number of people served: the number of people served in nursing homes has decreased, while the number served in alternative settings has increased substantially.



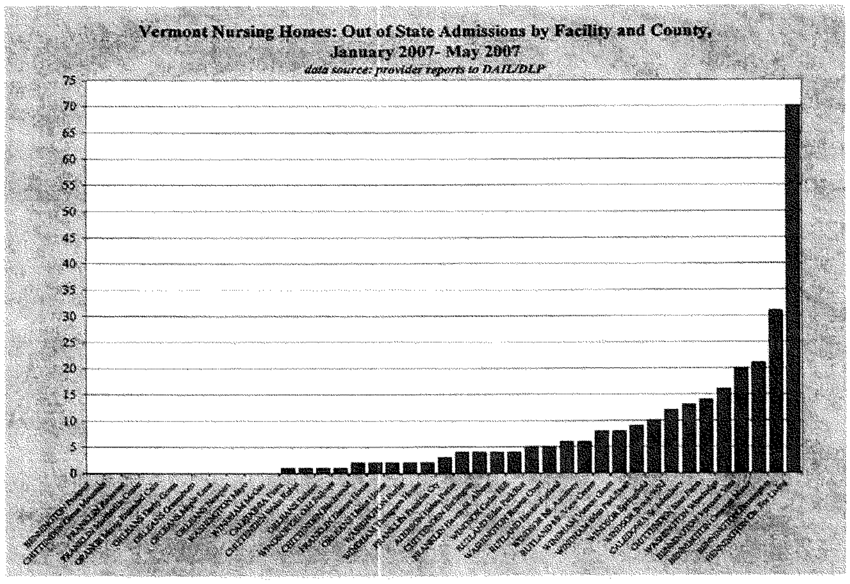
Oct-05: beginning of Choices for Care

Data source: Agency of Human Services Division of Rate Setting, reported resident days by month.

This shows trends in nursing home use over time for people whose primary payor was Medicaid, as well as for people who paid privately. These average occupancy figures are computed from monthly census figures reported by Vermont nursing homes to the Division of Rate Setting.

Consistent with other data sources, this data suggests that the number of Medicaid nursing home residents has decreased over time- about 200 people between October 2005 and May 2007. Note that nursing home closings and other reductions in the number of licensed beds have contributed to this decrease.

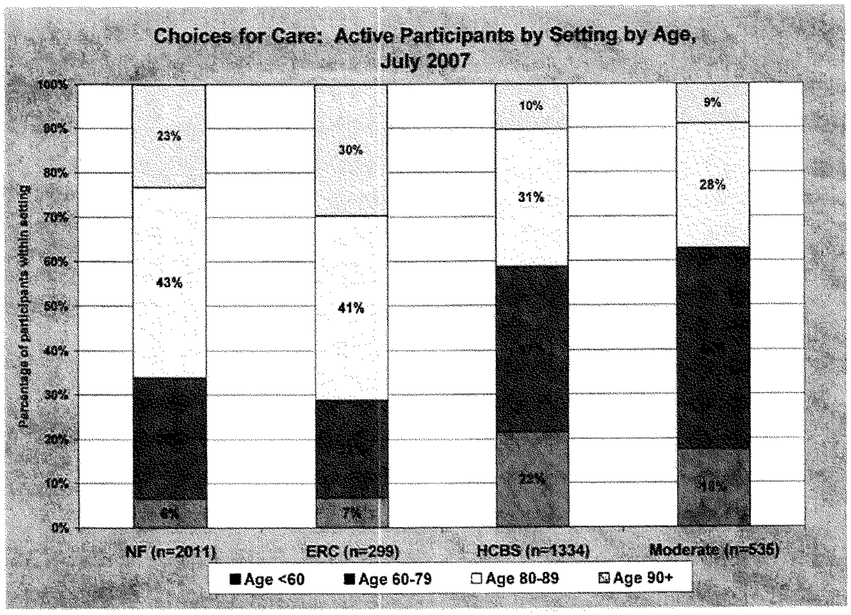
The number of private pay residents has decreased slightly since October 2005. Long term care Medicaid financial eligibility requirements have become more rigorous, which would tend to increase the number of nursing home residents who pay privately. However, more people may be paying privately for community-based services, which would tend to reduce the number of nursing home residents who pay privately.



Data source: DAIL Division of Licensing and Protection

Concerns are occasionally expressed about residents of other states who are admitted to Vermont nursing homes and subsequently become eligible for Vermont long term care Medicaid. This graph shows admissions of residents of other states to nursing homes in Vermont, as reported to the DAIL Division of Licensing and Protection. Note that citizens have the legal right to move freely within the United States, including the right to change state residency and to apply for Medicaid in the state in which they reside.

While thirty nursing homes admitted at least one person from another state, only nine nursing homes admitted more than ten people from other states. Just four nursing homes admitted twenty or more: Center for Living (70), Bennington Health and Rehabilitation Center (31), Crescent Manor (21), and Vermont Veteran's Home (20). These four Bennington County nursing homes represented nearly half of all admissions from other states. The number of these people who are (or will be) served under Choices for Care is currently unknown. Changes to the Choices for Care application form would allow more accurate tracking of the original residency of people who use Choices for Care services - both from other states and within Vermont.

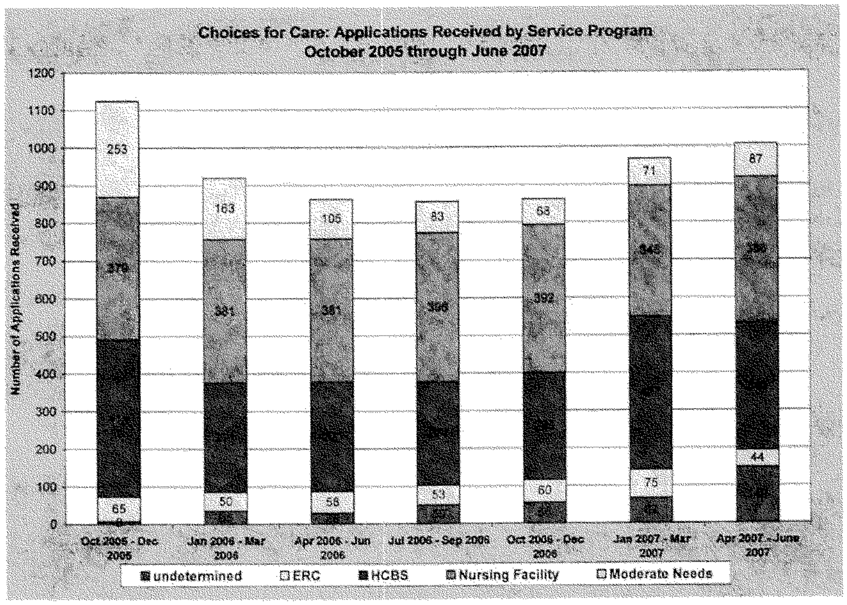


Data source: DAIL/DDAS SAMS database.

This graph shows the ages of participants within four groups of Choices for Care participants: Nursing Facility, Enhanced Residential Care, Home and Community Based Services, and the Moderate Needs Group.

The median age of people enrolled in the HCBS Highest/High Needs Groups is nearly 80. However, many younger people are also served in Choices for Care, including over 400 people under the age of 60.

Overall, more than half of the Choices for Care participants are aged 80 or older, and nearly 20% are aged 90 or over. The highest percentage of people aged 80 and over is found in the Enhanced Residential Care setting, followed by the Nursing Facility setting. The highest percentage of people under the age of 60 is found in the HCBS setting.

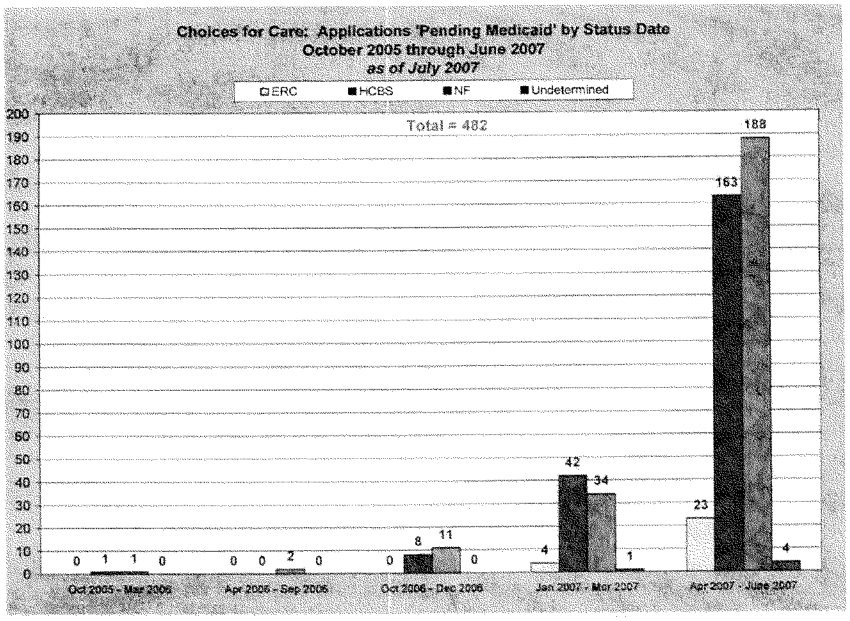


Data source: DAIL/DDAS SAMS database.

This graph shows the numbers of Choices for Care applications received over time. This data is useful in viewing changes in overall 'demand' over time, and in changes in demand among the different settings. It also provides a measure of staff workload in processing applications at DAIL and at the Department of Children and Families.

The preexisting waiting lists for HCBS and ERC services (241 people in September 2005) contributed to a large number of applications in October and November 2005. In subsequent months, the number of applications stabilized, but the number of applications has increased again in the last six months. DAIL/DDAS currently receives more than 300 applications each month.

About 40% of applications are for Nursing Facilities (including short-term and rehabilitation nursing home admissions.) About 40% are for Home and Community Based Services, about 8% for Moderate Needs Group, and about 8% for Enhanced Residential Care. The percentages of applications for Home and Community Based Services and for Enhanced Residential Care have increased slightly over time.



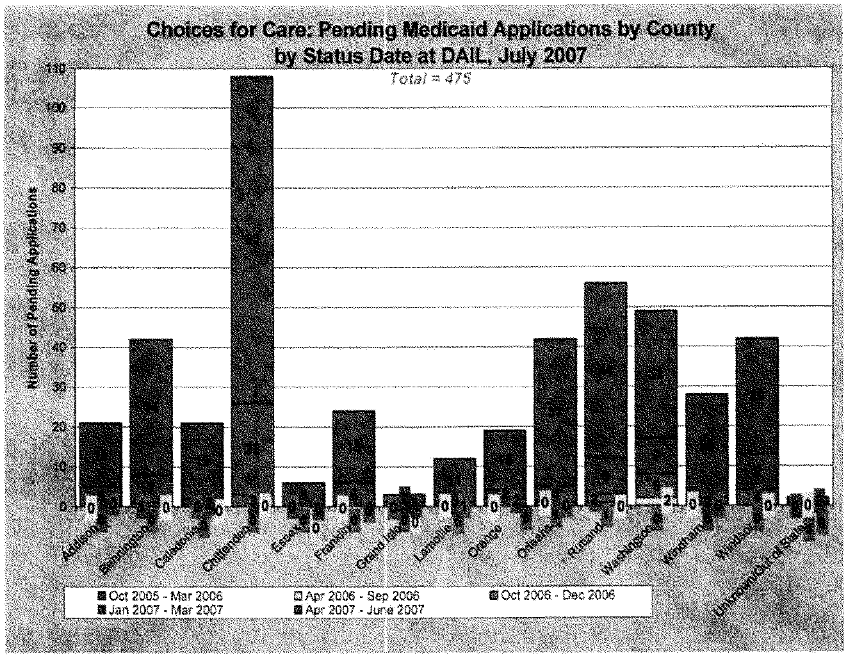
Data source: DAIL/DDAS SAMS database.

One of the goals of Choices for Care is to help Vermonters access long term care when they need it. An indicator of our success in achieving this goal is the time required to process individual applications.

Most applications are processed within eight weeks. Over 90% are processed within twelve weeks. A small percentage remain pending for many months due to delays in Medicaid eligibility. Causes for delays in Medicaid eligibility include:

1. Long-term care Medicaid applications are never submitted.
2. Long-term care Medicaid applications are delayed or incomplete.
3. Some applicants under the age of 60 (those not already eligible for SSI) are required to undergo a Disability Determination process, which routinely requires several months.
4. Some applications lead to complicated asset searches and/or legal review by the Department for Children and Families (DCF).

Staff from DAIL and DCF continue to work to find ways to process Choices for Care applications as accurately and as quickly as possible. Ongoing communication and collaboration between DAIL regional staff, DCF regional staff, and local case managers contributes to the timely processing of applications.

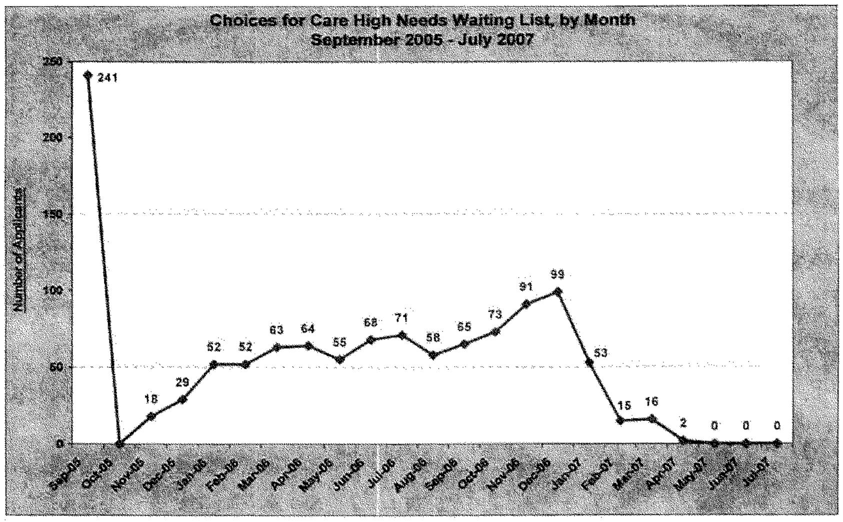


Data source: DAIL/DDAS SAMS database.

The number of 'old' pending applications can be used as an indicator of success in ensuring timely access to services across Vermont. This also provides a measure of DAIL and DCF staff workload within each county.

Orange, Washington and Windsor counties appear to have high percentages of 'old' applications. DAIL staff are working with DCF staff to ensure that this data is accurate, and to process applications.

The total number of pending applications is related to the size of the county's population, but this relationship is not entirely consistent across the state. Relative to estimates of long term care need, Bennington, Essex, Orleans, Orange and Chittenden counties have more pending applications than other counties.



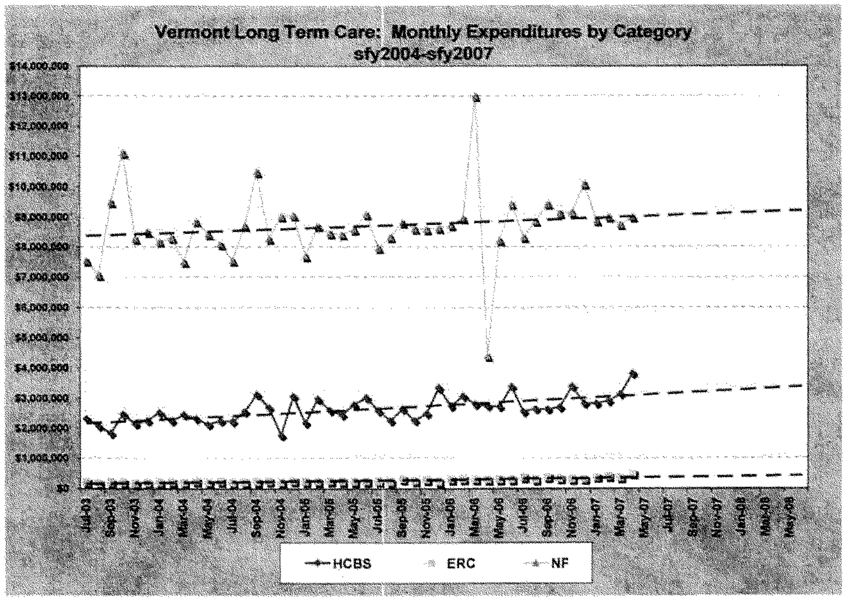
Data source: DAIL/DDAS SAMS database.

A goal of Choices for Care is to improve access to home and community based services. One measure of access is the number of people on waiting lists. Note that waiting lists for home and community based services are common across the United States. In some states, the number of people on waiting lists is unknown. In many states, the waiting lists are long, and getting longer:

> ***In 2005, 260,916 individuals were on waiting lists for 102 waivers in 30 states, up from 206,427 individuals in 2004. The average length of time an individual spends on a waiting list ranges from 13 months for aged/disabled waivers to 26 months for MR/DD waivers.***
> *Kaiser Commission on Medicaid and the Uninsured, Medicaid 1915(c) Home and Community-Based Service Programs: Data Update, December 2006*

Prior to Choices for Care, access to Home and Community Based Services and Enhanced Residential Care were limited by available funds, and Vermonters were often placed on waiting lists. The total number of people on waiting lists fell when Choices for Care was implemented in October 2005, when all applicants who met the Highest Needs Group eligibility criteria became entitled to services.

Beginning in October 2005, applicants who met the High Needs Group eligibility criteria were placed on a waiting list. The number of people on this waiting list slowly increased over time. Based on the availability of funds, small numbers of people from the waiting list were enrolled in Choices for Care during July 2006 and December 2006. Since January 2007, all High Needs Group applicants have been enrolled, and the waiting list has disappeared.

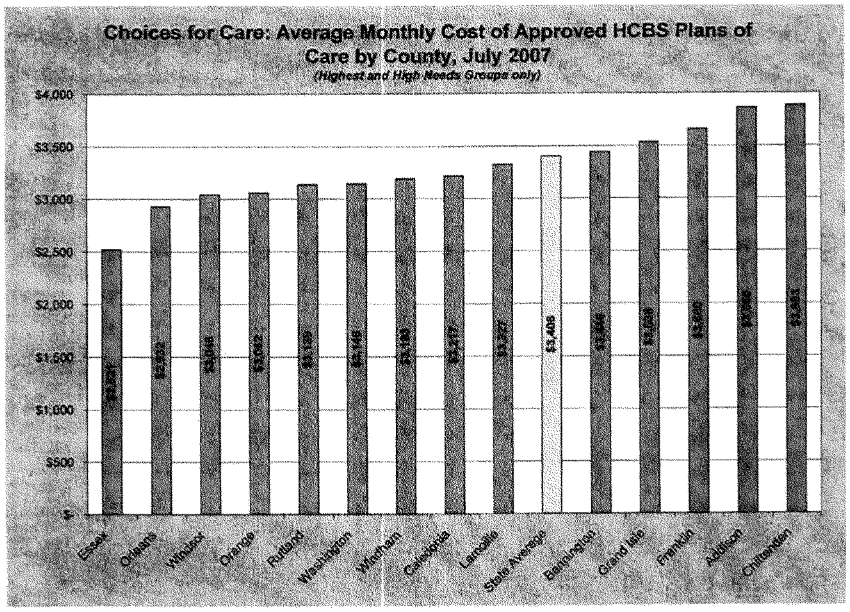


Data source: DAIL Monthly Monitoring Report.

This shows monthly Medicaid long term care payments by setting. These payment figures are adjusted to include third party payments and other cash adjustments, including estate recovery.

Nursing Facilities (NF) currently represent about 70% of current Choices for Care expenditures. Home and Community Based Services (HCBS) and Enhanced Residential Care expenditures represent about 30%. In comparison, about 55% of highest and high needs participants are served in Nursing Facilities, while about 45% of these participants are served in alternative settings.

Average monthly expenditures for Enhanced Residential Care have grown the most in recent years, increasing about 80% since the beginning of sfy2004. In the same time period, Home and Community Based Services expenditures have increased about 40%, and Nursing Facility expenditures have grown about 4%.

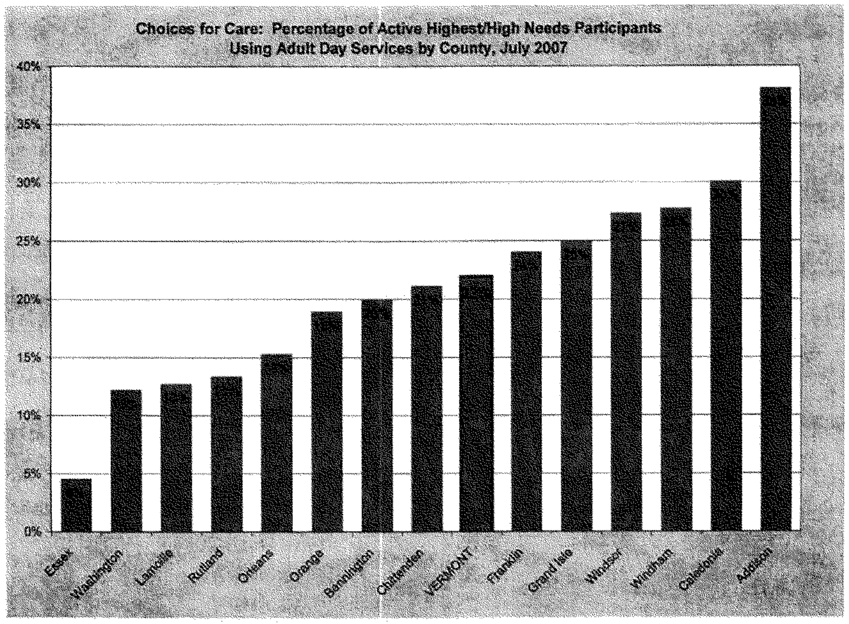


Data source: DAIL/DDAS SAMS database.

The average approved cost of HCBS Highest/High Needs Group Plans of Care was $3,406. The average costs in Chittenden, Addison, and Franklin Counties were well above the state average. The average cost in Essex and Orleans Counties was well below the state average.

Several factors can contribute to higher HCBS plan of care costs, including:

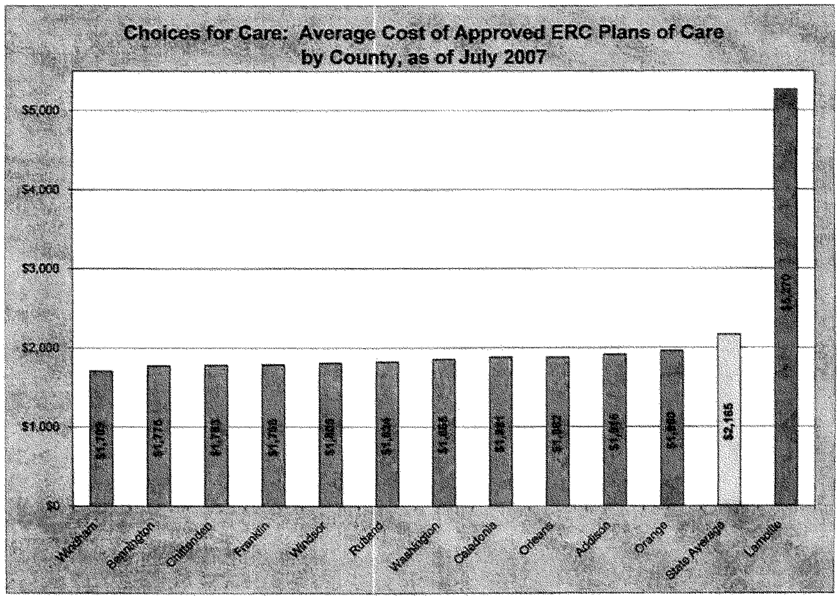
1. Higher use of Home Health Agency personal care services, at a higher reimbursement rate.
2. Higher number of hours of personal care services.
3. Higher use of adult day services.
4. Lower use of home health services (nursing and licensed nurse assistants) supported by Medicare or Medicaid.



Data source: DAIL/DDAS SAMS database.

This shows the percentage of active High Needs Group and Highest Needs Group participants who were approved to use adult day services in each county.

Statewide, just over 20% used adult day services. More than 25% used adult day services in Addison, Caledonia, Windham, and Windsor Counties. Less than 15% used adult day services in Essex, Washington, Lamoille, and Rutland Counties.



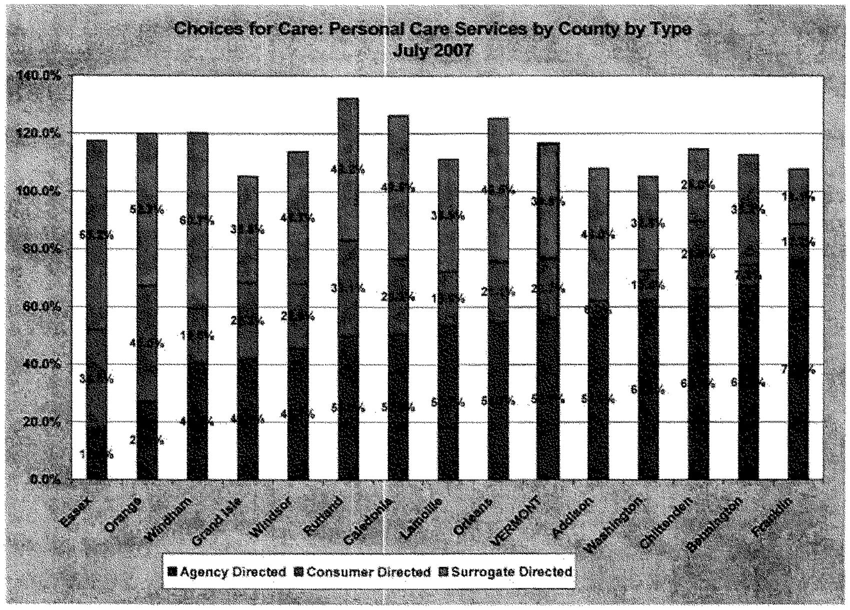
Data source: DAIL/DDAS SAMS database.

The average approved cost of ERC Highest/High Needs Group plans of care was $2,165. This is nearly 40% less than the average approved cost of HCBS plans of care.

The highest costs were found in Lamoille County. This results from special rates paid to Lamoille County providers to serve a small number of people who were discharged from Morrisville Center nursing home and from Traumatic Brain Injury services.

There is no consistent relationship between approved HCBS costs and approved ERC costs by county. Addison county had high ERC plan of care costs as well as high HCBS plan of care costs. Chittenden and Franklin counties had low ERC plan of care costs but high HCBS plan of care costs.

With the exception of 'special rates', the range of ERC plan of care costs is smaller because fewer factors contribute to the differences. ERC plans of care are based on three daily reimbursement 'tiers' which directly reflect the functional and cognitive status of ERC participants but do not represent a specific number of hours of personal care. ERC plans of care do not include adult day services, which contributes to higher HCBS plan of care costs.

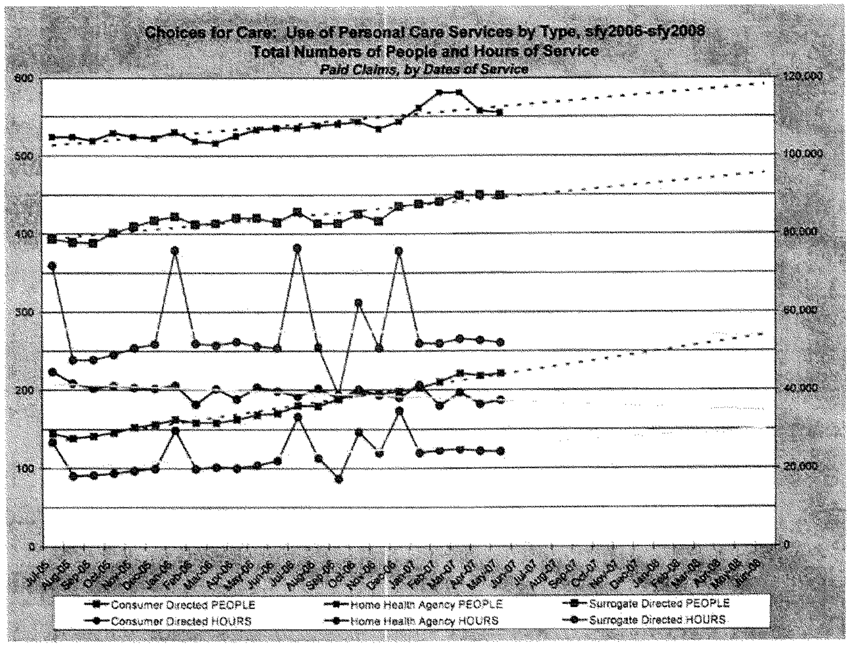


Data source: DAIL/DDAS SAMS database. Includes people who receive more than one type of personal care service.

This shows the percentage of people who were approved to use each type of personal care services in each county, using DAIL/DDAS SAMS data. Note that this reflects the services that people were approved to use, not what they actually did use.

Statewide, about 56% of people had service plans that included some home health services, and about 61% had plans that included consumer or surrogate directed services. About 17% of the people plan to combine home health agency services with consumer or surrogate-directed services. Because of this, the totals are higher than 100%.

In every county, significant numbers of people had plans with each type of service. However, there are significant variations among the counties. In Franklin, Bennington, Chittenden, and Washington counties, a high percentage of people had service plans with home health services. In Essex, Orange, Windham, and Grand Isle counties, a low percentage of percentage of people had service plans with home health services. In counties with lower use of home health services, people seem to have used both consumer and surrogate directed services as an alternative.

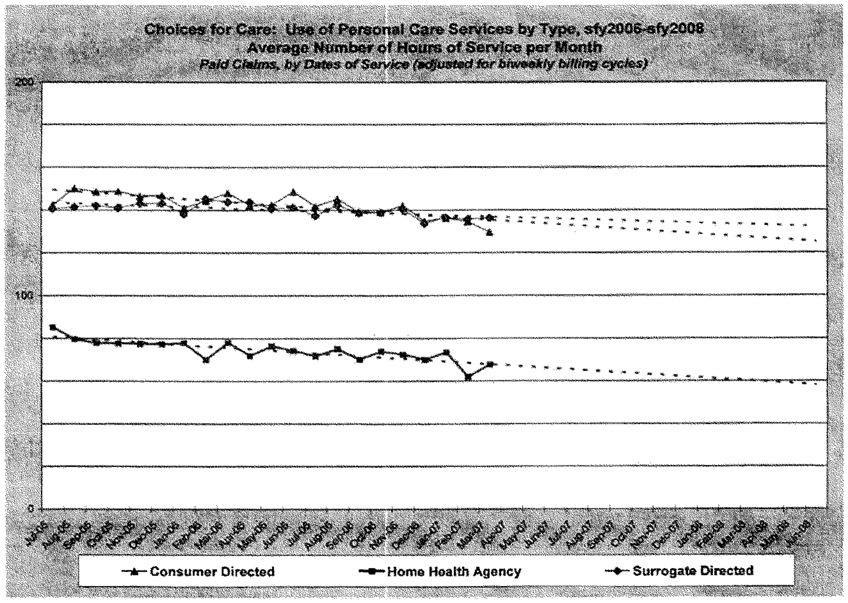


Data source: EDS paid claims, by date of service

This graph shows recent trends in paid Medicaid claims (by dates of service) for the three different Choices for Care personal care service options: home health agency, consumer-directed, and surrogate-directed.

The number of people using each type of personal care services has increased. The largest increase has been in the number of people using consumer-directed services. The numbers of people using home health services and surrogate-directed services have increased at a similar rate. The data for recent months suggests the following:

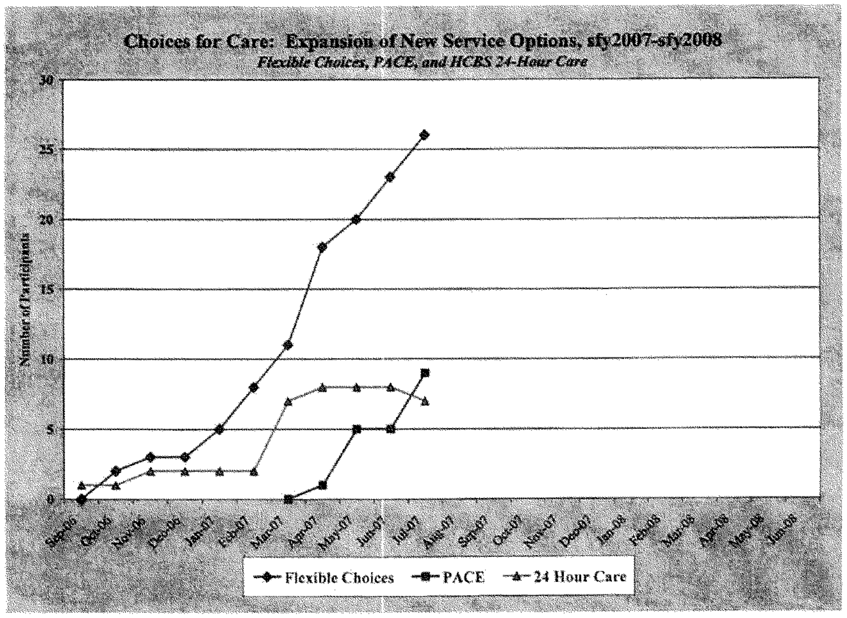
option	***% of people***	***% of hours***	***service volume***
Home health	50%	35%	slight decrease
Consumer directed	15%	20%	increase
Surrogate directed	40%	45%	the same



Data source: EDS paid claims, by date of service
Note: consumer and surrogate directed data adjusted to reflect equal numbers of payperiods in all months

This graph shows the trends in the average number of hours of service that people actually receive each month.

People using consumer and surrogate directed services receive an average of about 140 hours per month, or about 33 hours per week. People using home health agency services receive an average of about 75 hours per month, or about 17 hours per week. Because some people use a combination of services, the average number of hours of all personal care services is about 150 hours per month, or about 35 hours per week.



Data source: DAIL/DDAS SAMS database

One of the goals of Choices for Care is to expand the range of service options. This graph shows the initial growth in enrollment in three new service options: Flexible Choices, PACE, and HCBS 24-Hour Care.

In May 2007, Choices for Care implemented a policy allowing spouses to be paid to provide personal care, which represents a new service option. However, no process currently exists to track the number of people who use this option.

Testimony of Mitch LaPlante, Ph.D., Associate Professor, University of California, San Francisco.

Senate Finance Committee Hearing on "Home and Community Based Care: Expanding Options for Long Term Care" Tuesday Sept 25th, 2007 at 10am, Dirksen Office Building G-50

Chairman Baucus and members of the Committee, I am pleased to be able to speak today on expanding the options low-income people with disabilities have to choose between living in an institution and living in the community. In our nation's history, deinstitutionalization occurred first for persons with mental illness in the 1960-80 period, financed through general funds and block grants, with mixed results. As a result of the Medicaid waiver program, a second wave of deinstitutionalization occurred in the 1990s for persons with intellectual and developmental disorders. We appear to be entering a third wave of deinstitutionalization in which persons with physical disabilities and older persons will remain in the community instead of going to a nursing facility. As our population ages, we must find ways to provide home and community based services (HCBS) of sufficient quantity and quality so that individuals can choose where and how they will live.

The ADA protects the right of individuals to reside in the most socially integrated setting they desire and the Supreme Court Olmstead decision has reinforced this right. The goal of the Administration's New Freedom Initiative is to improve HCBS. Many people with significant disabilities, regardless of age, want to avoid institutions and to leave an institution if they are placed in one. According to CMS data, about 20 percent of nursing home residents wish to live in the community.

Medicaid, in its design, rules, and procedures favors placement in institutions over HCBS, what is known as the institutional bias. The key aspect is that states are required to provide institutional services under the Medicaid program while HCBS are optional. Some states use their options, but many states do not. The fraction of a state's population that is provided personal care services (PCS) or HCBS waivers ranges from a low of 1 person per 1,000 state residents in the lowest state to 13 persons in the highest state (Martin Kitchener, Ng, & Harrington, 2007). About 30 states use the PCS optional benefit which funds personal care services and attendants. In states that do not use the PCS option, PCS are only available if the state has a waiver that provides personal care. However, states that do not use the PCS option also rank low on waiver participants. Unlike the PCS benefit, the waivers are often restricted in who they will serve, and there are long waiting lists. This results in a continued significant bias towards institutions and individuals are not provided a choice. While additional HCBS opportunities can be created through the State Plan Amendments of the DRA of 2005, these too are optional.

There is evidence of unmet need for personal assistance among low-income persons. The fraction of persons who need help with 2 or more ADLs who have unmet need for personal assistance services and are in poverty was 31 percent among working ages and about 25 percent among those 65 and older in 1995-7. Unmet need is associated with a host of adverse consequences, such as injuries from falling, poor nutrition, and dehydration, which add significant costs to the system (LaPlante, Kaye, Kang, & Harrington, 2004).

The Community Choice Act (S. 799) is a proposal to help people with low incomes avoid institutions, allow them to choose community services, and reduce unmet need. By making HCBS a mandatory benefit it would greatly reduce the institutional bias. The CBO estimated in 1997, for an earlier version of the bill, that new federal expenditures would be $10-20 billion a year, if only a quarter of those who could be eligible obtained the benefit. I have to say frankly that estimate is inflated and erroneous. Based on research I and my colleagues have published (LaPlante, Kaye, & Harrington, 2007), we estimate a range from $1.4 to $3.7 billion depending on the rate of participation from 30 to 80 percent. Adjusting for inflation, it is about one-tenth the CBO estimate. The key difference between our estimate and the CBO estimate is the number of people who would be eligible. Measures of institutional need are typically based on two or more of the basic activities of daily living, which include bathing, dressing, transferring, toileting, and eating. The CBO estimate included people who need help with a much broader set of instrumental activities including shopping for groceries or getting places outside of walking distance. However, someone who only needs help shopping for groceries or getting around is not a candidate for an institution. Including these activities greatly inflated the CBO estimate.

There has been concern over a woodwork effect in that persons would obtain the benefit who otherwise would not have gone into an institution and their family members would have continued to help them without any cost to the government. Such individuals receive a tremendous amount of support from their families who often do everything they can to keep them out of an institution at their own personal expense, including giving up work and careers. The CCA will not generate a large woodwork effect because it restricts the benefit to people with an institutional level of need. We estimate that 600,000 persons would be eligible, not several million.

I am concerned that the institutional need criteria are not specific. We know that some states use loose criteria, such as a physician's letter, while others use strict criteria, such as 3 or more ADL for determining institutional need (Tonner & Harrington, 2003; Tonner, LeBlanc, & Harrington, 2001). Institutional need criteria should be specified in the CCA, such as 2 or more ADLs, so that this does not become an Achilles' heel for the CCA.

While it is often claimed that HCBS are cheaper, the argument is rarely made that HCBS cost any more than institutional services. One study concludes that Medicaid saves $44,000 by providing HCBS instead of a nursing home stay (M. Kitchener, Ng, Miller, & Harrington, 2006). Our ongoing research shows that 9 states that have greatly expanded their HCBS programs in the 1990s have been able to reduce their institutional expenditures within 5 years. States that have established HCBS are ahead of the curve and controlling their costs. States that are reluctant to explore their options are behind the curve and experiencing increasing costs (Kaye, LaPlante, & Harrington, 2007).

States do not like Medicaid mandates, but given ample options, many states apparently do not have the vision or wherewithal to rebalance their LTSS system. Twenty states are not participating in Money Follows the Person two years after grants were first announced.

I have been able to touch on just a few points of a complex issue. I apologize if I have given some areas short shrift. However, it is my professional opinion that the CCA is fiscally responsible legislation. It would replace a safety net that varies depending on which state a person lives in with one that is more uniform for all persons with significant disabilities and it is likely to save money in the long run while improving people's lives. Given that the oldest baby boomers are 61 years old, there is not much time left to get rebalancing done. Until the institutional bias in Medicaid is remedied, choice will remain constrained.

Citations

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Responses to Questions for the Record From Mitchell P. LaPlante
September 25, 2007

Chairman Baucus:

Questions for Dr. LaPlante, Mr. Concannon and Mr. Flood:

1. How would The Community Choice Act affect existing services that are provided through waivers?

The Community Choice Act (CCA) would help the states with their obligation to support the right of low-income Americans with significant disabilities to choose to receive "services in the most integrated setting appropriate to the individual's needs" and thereby avoid unnecessary institutionalization of individuals. The right of an individual to choose services that are most appropriate to their needs flows from the provisions of the Americans with Disabilities Act and has been upheld by the Supreme Court Olmstead decision. However, this goal is not being realized as many individuals do not have the ability to choose to receive services in the most integrated setting even in states that provide services through waivers. The reason is that most waivers are not statewide, restrict the populations served, or have limits on the number of persons served.

The CCA is needed to redress the bias under the Medicaid program that favors institutional placement over home and community based services. This institutional bias is present in Medicaid's rules, procedures, and financing. The principal effect the CCA would have on services is to make personal assistance services and supports a universally available benefit as opposed to an option that a state may or may not offer through a waiver (or grant). It includes services that are provided in an individual's own home but includes other settings such as small group homes.

It is true that many states already offer some home and community based personal assistance services (PAS) through waivers and a few states are exemplars. However, waivers are typically restricted to certain populations within a state (such as elderly only, or persons with intellectual and developmental disabilities only) and in many states, there are long waiting lists where the supply falls short of the demand. While some states have utilized their existing authority extensively, most states fall quite short of addressing people's needs. The CCA would ensure that all persons with disabilities within a state would have a choice between home and community based PAS and institutional services. However, the CCA would not displace services provided through waivers. The CCA provides the incentive of an enhanced FMAP for states to provide services that are consumer-directed, and includes a maintenance of effort provision so that states would not reduce their level of effort on waiver services under sections 1905(a), 1915, and 1115.

2. Do we need The Community Choice Act if the states can receive waivers and grants?

Yes, because most states do not use their waiver and grant options fully and some states do not use waivers and grants at all. By Medicaid allowing PAS to be available *at a state's option*, people with disabilities living in states that do not fully use their waiver and grant options are not able to choose PAS in their homes and communities and are forced inappropriately into institutions, in contradiction to the Americans with Disabilities Act and the Supreme Court Olmstead decision. The optional nature of waivers and grants for PAS perpetuates the institutional bias under Medicaid for nursing homes and ICFs-MR, while most people want services in their homes and in their communities, not in institutions. AARP has written that 90 percent of older Americans want to remain in their own homes as they age. Older Americans do not want Medicaid administrators to dictate that they can only receive PAS in a nursing home.

It should be noted that a layer of bureaucracy has evolved to evaluate and administer waivers and grants. As Senator Kerry pointed out in the case of Massachusetts application under the Money Follows the Person grant program, even well-intentioned states are not always granted the opportunity to provide PAS because of administrative obstacles. I challenge anyone to defend to an elderly widow why she cannot get the services she needs at home because her state didn't apply for or get a waiver and now she must move into a nursing home. The CCA would also alleviate the bureaucratic entanglement in which states have to apply for waivers and grants to provide PAS and instead ensure that PAS are a standard Medicaid benefit available to all eligible persons with disabilities having an institutional level of need in all states, just as nursing homes and ICFs-MR are now a standard benefit. The CCA is necessary to ensure that home and community based PAS have parity with services provided in nursing facilities and ICFs-MR. A standard PAS benefit is necessary to address the institutional bias and ensure that low-income individuals with disabilities have the right to choose to live in the most integrated setting they wish to and is appropriate for them. That choice should not depend on whether a state has been given a waiver or grant.

Senator Smith:

Question for All Witnesses:

1. As you may know, my home State of Oregon is one of the few states that are almost even in terms of spending Medicaid funds on institutional versus community care. In fact, for physical disability funding, my state is one of just a few that spends less on institutional services than community services. As a former state Senator, I've not often been persuaded that mandates are the best policy – particularly when some states are putting to use the authorities already available.

Therefore, do you believe, using Oregon as an example, that there are other ways to encourage states to serve more people in their communities?

Oregon ranks highest of all the states in community spending under Medicaid with 72 percent of LTC Medicaid funds going to home and community based services in 2006 (Burwell, Sredl, & Eiken, 2007). New Mexico, Alaska, Minnesota Washington follow, all above 60 percent. These are states that are using their authorities, but most states are not. The average for the entire United States is just 39 percent. However, these statistics are heavily influenced by states using Medicaid waivers to enable people with IDD to live in the community. It is noteworthy that both Oregon and Alaska have eliminated ICF-MRs and spend all their Medicaid dollars on home and community services for persons with intellectual and developmental disabilities (IDD), either in their own homes or in small group homes integrated with their communities.

However, the track record for persons with physical disabilities and aged persons is not as good. When expenditures for IDD are taken out, nationally only 27 percent of Medicaid expenditures for non-IDD LTC are spent on home and community based services for persons with physical disabilities and aged persons. Again, Oregon ranks high at 54 percent (the state of Washington is equally high at 55 percent). Can Oregon do more for people with physical disabilities and aged persons? I believe Mr. Flood from Vermont would likely say "yes" based on Vermont's more recent experience with its 1115 waiver. It is not obvious what the optimal percentage should be since it is not likely that that nursing homes will be eliminated and thus the rate would not approach 100 percent as it has for IDD in Oregon. Nevertheless, it seems safe to say that Oregon still has work to do.

With the incentive of an enhanced FMAP, the Community Choice Act could help propel Oregon further while helping all the other states who are far behind. The aging population wave is now upon us, and Oregon is a state that appears to be among the most highly prepared to grant people their wish to age in place. Oregon is to be commended for its vision and initiative, unfortunately few other states have been able to achieve that vision. But the compelling issue is not so much about the best way to change the behavior of the states as it is about the need for states to comply with the Supreme Court Olmstead decision. My father, who is 87 years old, lives in Indiana, a state that spent only 7.5 percent of its non-IDD LTC budget on HCBS in 2006. My father does not want to go into a nursing home, and he lives with my sister in her home. We are doing our best to ensure he remains living at home as long as he wants to and is able to do so. My father would have more options if he lived in Oregon, but that is not a possibility. The CCA will help Indiana and the many states that are in a similar situation to follow the path of Oregon and better comply with Olmstead.

The Olmstead decision provides an urgency to correct the institutional bias under Medicaid. People can not exercise their right to choose to stay in their own homes in states that take little action to correct the institutional bias. As I mentioned in my testimony, the rate of PAS provided under Medicaid varies from 3 persons per 10,000 state residents in the lowest state to 84 per 10,000 in the highest state, a ratio of 28:1. Oregon ranks fourth by that statistic. Participants per 1,000 elderly persons range from 1 to 80, a ratio of 80:1. Oregon ranks first by that statistic. Oregon is a state that has shown that more persons can be served while keeping Medicaid LTC expenditures steady. It is clear that low-income persons with significant disabilities have better choices in Oregon. All people with significant disabilities living throughout America deserve the same degree of choice.

The ability to choose whether one lives in one's own home or an institution is a right upheld by the Supreme Court that should not depend on optional services. Personal assistance services are as basic and needed as institutional services and it is necessary to correct Medicaid's rules, procedures, and financing to make these services a standard benefit available to all Americans with disabilities who have an institutional level of need. That is what the Community Choice Act would achieve.

I do not believe that continuing to encourage states is the best strategy when the Supreme Court compels all states to a certain standard that has not been realized through voluntary state actions.

Questions for Dr. LaPlante:

In your testimony, you mention that CBOs' score is inaccurate because it assumes costs associated with persons who would only need help for activities such as shopping independently or getting to places beyond walking distance.

1. Since the bill never intended to provide assistance to persons at that level of need, do you believe CBO would change its assumption if informed of the clarification?

Yes, I believe the clarification that the eligibility for the CCA is based on having an institutional level of need will be useful for the CBO to consider in its assumptions.

2. To what degree and in what areas of spending do you feel that the federal government and states actually could save money in the long run if more people were served in their communities?

Although the Olmstead decision renders consideration of cost secondary to the right to choose, the issue of cost cannot be ignored. While it is often claimed that HCBS are cheaper, the argument is rarely made that HCBS cost any more than institutional services. The experience of the home and community based services waivers and grants programs under Medicaid shows that the states spend far more on institutional services per person served than for home and community based services, even though the waivers, by design, are restricted to persons who have a level of disability that is similar to persons in institutions. One study estimates that "in 2002, HCBS waivers produced a national average public expenditure saving of $43,947 per participant" compared to Medicaid spending on institutional services (Kitchener, Ng, Miller, & Harrington, 2006)

Providing personal assistance services to persons in their own homes offers a tremendous savings potential for the Medicaid program and the states. Savings can be obtained by helping persons to stay in their own homes or communities longer before they have to go into a nursing home or by avoiding nursing homes entirely. States that are not offering sufficient home and community services run the risk of forcing residents into institutions unnecessarily and paying a higher price as a result.

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Hearing of the Senate Finance Committee

Home and Community Based Care: Expanding Options for Long Term Care

September 25, 2007

Testimony of Robert D. Liston
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Chairman Baucus, Ranking Member Grassley, and Members of the Senate Finance Committee:

Thank you for the opportunity to testify today on assuring that home and community-based care is at least an equal option as we move forward to reform our broken long-term care system.

My name is Bob Liston, and I am both proud to be a person with a disability, and proud to be from Montana, The Last Best Place. In Montana, I have the honor of serving as the Executive Director of Montana Fair Housing; the President of the Board of Directors for the Montana Advocacy Program; I'm a member of Missoula People First; a member of the Missoula Coalition for Disability Rights; a member of Montana ADAPT; and a recently retired member of Montana's State Independent Living Council. In my younger years, I helped to establish Montana's first Center for Independent Living. In addition, I spent ten years in the state of Michigan in the 1980s and 1990s where I worked in both the Independent Living and Developmental Disability arenas.

I am testifying today as an individual who has lived with disability for 37 years. I am part of a disability community that according to Census 2000 includes 17% of the nation's population.

I am also testifying as one of the legion of baby boomers beginning to knock on the doors of the nation's public and private long-term care service systems. In all my 53 years on the planet, I have never met anyone of any age or any disability who said they WANT to live in a nursing home, an ICF-MR facility, or any other kind of institution.

And finally, I am testifying as a professional who has worked and volunteered over the course of a lifetime to assist people with even the most significant disabilities to move out of nursing homes and other institutional settings, and to live in their own homes in their own communities with the necessary services and supports. My expertise is not academic, or as a researcher or in the bureaucracy that administers various programs. Both my personal and professional lives have been lived, with intention, "in the trenches" partnering with one person at a time to help them live the life of quality and dignity they want, surrounded by their families and friends, in their own communities. Because they have allowed me into their lives to partner with them, I have learned more than I ever could have imagined about supporting people to live in the community. I can say with complete confidence that I KNOW what's possible.

And, while doing this work, and demonstrating not only what's possible, but, in fact, practically do-able, I have tried to lead by example so that as I age, and as my disability further affects my functioning, there will be in place "a level playing field" when I need it. I want to know that neither my age nor my disability will sentence me to an institutional situation like a nursing home. I want that "level playing field" so I have a choice in where I live and from whom I purchase my long-term care services and supports when I need them. Right now there is an entitlement to nursing homes, and a defacto entitlement to ICF-MR services, but community services are optional. With the limited long term care dollars we have today, this means people like me rarely have a real choice of community services without a LONG wait for those services.

When I was an "invulnerable" 16 year old track competitor, I rolled down a mountain in a pick-up truck on the outskirts of Helena, Montana. Montana being a rural and frontier state, trauma centers were few and far between back then, as they still are today. I was taken to a hospital nearly two hours away from home and after spending three months there immobilized in a Stryker frame, the doctor came into my room on the last day, casually told me, "Oh, by the way, you'll never walk again," and then signed the order sending me to a nursing home.

Upon arrival at the nursing home, even in my shock and grief at hearing the doctor's final words to me, it took me about 30 seconds to realize, "this is where people come to die." And during the four months I spent there, they *were* dying…all around me. I know first hand what being sentenced to a nursing home is like, so I'm sure you won't be surprised when I tell you that I'd rather die than ever have to go back to a nursing home again.

In many ways I represent the "Everyman" and "Everywoman" in this country. Nobody of any age wants to be institutionalized.

I am not a man of means. I work full-time and then some for a small Montana non-profit that exists to insure that no Montanan experiences discrimination in housing. I work very hard, but Montana Fair Housing runs on a shoestring- a shoestring that doesn't include either health insurance or a retirement or other long-term care program. My wife and I save for our eventual retirement, but it's unlikely that, no matter how much we scrimp and do without now, we'll be able to cover all our long-term care costs out of our own pockets. And I was surprised to learn that Medicare doesn't cover ANY ongoing, community-based long-term care services. That means that it's highly likely that at some point in our lives, we may have to rely on Medicaid-funded long-term care services. This is the situation of many aging baby boomers. And, as you all know better than most, more and more baby boomers are aging.

Right now, according to CMS, nearly 70% of Medicaid long term care dollars go to support nursing homes and other institutional settings, and just over 30% of our Medicaid long term care dollars go to support home and community-based services. And as I understand it, that 30% serves more people per dollar than the 70% does. This ratio has me gravely concerned for my own future because it means that I don't have even a 50-50 chance of being able to choose to stay in my own home as I age and become increasingly disabled. The current institutional bias in the nation's Medicaid program gives me two to one odds of being forced into a nursing home. The Community Choice Act would level the playing field and give people a real choice.

This current ratio also means that a creative state like Montana doesn't have the flexibility to stretch precious federal and state dollars in a way that is most efficient, cost effective, and in keeping with needs and desires of its citizens. We are the fourth largest state in geography with one of the smallest populations in the country. There is an average of 6 persons per square mile across the state. In a rural, frontier and tribal state like ours, or Alaska or Wyoming or North and South Dakota or a number of other states, offering people only the choice of a distant institutional setting is not a choice at all, and it's cruel to the individual, and cruel to our families and friends. Real choice would not only serve us better and more cost effectively overall, but it would give the state the tools it needs to be good stewards of public money while being responsive to its citizens. The Community Choice Act would give the states, as well as individuals and families, real choices in providing long term services and supports.

There are so many people I wish could have had the opportunity I have today to testify before this august body. Since that isn't possible, I would like to be the vehicle for just a couple of them to share their stories. They are people that my wife and I know, and they represent just some of the reasons why this country desperately needs the Community Choice Act.

When I was sitting on the Montana State Independent Living Council, one of the other members hailed from the Fort Peck reservation in the far northeast corner of the state. His community was an 8 hour drive to and from Helena where most of our meetings were held. When his sister came to need more assistance and support than his family was able to provide, she had to move to a nursing home nearly five hours away from her community because that's the closest facility that had a place for her. Five hours away from her home, her family and friends and her culture. If the Community Choice Act had been in place, she could have the choice to stay in her own home, receive culturally appropriate care, and continued to be a valued part of her family and community.

Instead she was completely separated from everything she knew and everyone who loved her, and placed in the closest available setting, which then meant her family had to make an expensive ten-hour round trip just to visit her, and check on her well being. This is an everyday reality for those of us in rural, frontier, and tribal America, and those of us who live in rural, frontier, and tribal America are treated unfairly under the current long-term care system. This is only one example of countless thousands of families who everyday experience hardship, and heartache, and loss when family members are forced into distant institutional settings, deprived of any choice by the current long-term care funding system.

Sometimes people are forced to live far from family because their home state doesn't support people with various disabilities in the community. Our friend Mark moved from a North Dakota nursing home all the way to Missoula so he could live in the community like anyone else because North Dakota doesn't fund community supports for people who use ventilators. Mark just started classes at the University of Montana where he is majoring in journalism. In a few years, armed with his degree, and with the aid of some assistive technology, he will be a working journalist, who contributes to the community with both his writing skill and his tax dollars. That would never have been possible if he had remained in the North Dakota nursing home. The Community Choice Act will allow people to stay in their home states, and pursue the lives they choose. Or if their family moves, or they need to move for work, they will no longer risk losing all their services by moving to a state with less to offer.

I am told that the average cost of a nursing home in America is approximately $42,000/year, and in the average nursing home, according to data collected by CMS, a resident can expect to receive an average of 3 hours a day of actual contact with a staff person. On the other hand, the average cost of home and community-based consumer-directed personal assistance services is about $15,800/year. In Montana, for someone who receives funding for the maximum time allowed of 40 hours/week of personal care, and pays their attendant $9/hour, the yearly cost would be about $18,800. Even if you add in another $1000/month for food and shelter, the total is only 73% of what our public dollars currently pay for a nursing home, and the person receives almost twice as much contact each day with a care provider. Plus that care is delivered in a setting where family and friends can monitor the care and supplement it with additional unpaid support.

The average per person cost differential is even more striking when we look at developmental disability institutional costs. According to the "Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006," published last month (August 2007) by University of Minnesota's Research and Training Center on Community Living Institute on Community Integration/UCEDD; in Montana the MR/DD institutional dollars served just over 70 people at over $167,000/person/year for a total of almost $13 million dollars, while the community dollars for the same population served over 2000 recipients at a fraction of the cost per person, $31,000/person/year, for a total of nearly $63 million.

Another person I bring with me today is my friend Gail. Gail is now about 40 years old, and has significant cerebral palsy. She uses an electric wheelchair, an assistive device for communication, and she needs hands-on help to get up, dress, eat, bathe, and use the toilet. Gail graduated from high school with my wife's younger son, Steve. After school Steve would jog to the locker room for football practice or baseball practice depending on the season. Or maybe go home to prepare for a big dance or a concert, or go to his part time job. Gail, on the other hand, would be put on the little yellow bus that shuttled her 20 miles to the nursing home where she was forced to live when her mother could no longer care for Gail at home because her mother developed health problems of her own and also had to work to support herself and the rest of the family.

When my wife Marsha would visit Gail, regardless of the time of day, she would almost always find her lying in bed waiting. Waiting for someone to help her into her wheelchair. Or waiting for someone to clean her up and change her bed linens because the staff didn't answer her bathroom call in time and she had been lying in her own waste for an hour or more. Or even worse, Marsha would often find Gail lying naked and uncovered with her door left wide open waiting for staff to return from some errand and dress her.

Gail is a bright, funny, warm, religious woman who worked hard to be awarded her regular high school diploma. But in the nursing home, she was just another body that had to be quickly dressed, bathed, fed and changed. Her electric wheelchair afforded her a great deal of independence when she was allowed to use it, but it was rare that she got to use it in the nursing home because it was more convenient for the staff to leave her lying in bed all day.

We fought hard to help Gail achieve her dream of her own apartment. The good news is that Gail did leave the nursing home, and she did move into her own apartment where she continues to direct her own staff. She schedules her staff so she can get up when she wants, eat what she wants when she wants it, use the bathroom when she needs to and avoid accidents, and finally, at long last, have a life. A life that includes all the things she was never allowed to do in the nursing home. All the things you may well take for granted, like going to the mall, voting, having dinner with friends, getting her hair done, and volunteering. If the Community Choice Act had existed when Gail was a young teen, her single mother could have had the assistance she needed to keep Gail at home, and Gail could have progressed much sooner from her mother's home, directly into her own home, and not have had precious years of her life wasted in the nursing home

During the time I spent in Michigan, I worked for five years at a local Arc, partnering with people with developmental disabilities and their families to move them out of state institutions (ICFs/MR), nursing homes and their family homes into their own homes in the community with the supports they needed and desired. I assisted one woman who was deaf and blind and cognitively disabled to buy her own home and find housemates and personal assistants. I also facilitated numerous person-centered plans and then worked with people on individual service budgets to actualize those plans. People didn't ask for the world…they didn't even ask for what they were entitled to. One woman who had cognitive and physical disabilities only wanted enough paid assistance to help her bathe and dress, and transfer from her wheelchair for a little while each day so she could sit on her new couch in her new apartment.

My friend Rayford lived in a state ICF/MR institution for many years, was moved to a nursing home for more years, and then was moved to a community ICF/MR group home before he finally got to move into his own apartment at the age of 40. Ray has very significant cerebral palsy, doesn't read or write or have assistive communication, is a brittle asthmatic, has numerous allergies, and due to swallowing problems uses a permanent feeding tube surgically placed into his stomach. He requires physical assistance for nearly every aspect of his daily life, yet he has lived comfortably, safely and successfully in his own apartment with appropriate assistance for over 15 years. He is a registered voter, a valued friend, and became a member of ADAPT because he was adamant that he would never return to a nursing home, and wanted to do everything he could to assure that he and others would always have a real choice to live in the community.

The one thing you can say about disability is that it's "equal opportunity". Disability can strike anyone at any time with no regard to age, race, gender, political affiliation or any other distinguishing characteristic. It may be acquired before or at birth or later, through accident, disease, medical condition, war, or simply through the normal aging process.

Add to that the prediction in an Alliance for Health Reform Issue Brief earlier this year that estimated when the last of us baby boomers reach retirement, the nation's population of those over the age of 65 is expected to double.

And when we also consider how much has changed in this country since the mid-60's, it's no wonder that the 40 year old Medicaid and Medicare long-term care systems are no longer a good fit for most of America.

If we are to efficiently and effectively serve the incredibly diverse population now and soon to be eligible for long-term care services, we must provide more than the current "one-size-fits-all" method of service delivery. We all know that something that is "one-size" never fits anyone properly. The Community Choice Act is a beginning to providing both individuals and states with the opportunity to "customize" services to fit each individual and each state, using the tools of choice and consumer control to craft respectful, responsive services for one person at a time.

Customization will require that:
- People have real choice in where they receive their long-term care services and supports;
- Eligibility for services must be based on functional need, not on a specific diagnosis, a person's age, or a discrete funding stream;
- Attendant services must be available in the community, 24 hours a day, seven days a week;
- Attendants must earn a livable wage and have benefits;
- Consumer control must be maximized at every step of the process, including flexible payment and management systems.

Fully balancing the nation's long-term care system to provide the level playing field that allows for this customization will take time, but there are immediate steps that each of you can take now to end the institutional bias in Medicaid. One of those steps is passing the Community Choice Act.

The Community Choice Act (CCA) (S. 799) gives people real choice in long-term care. It provides people eligible for Nursing Facility Services, or ICFs for people with cognitive and intellectual disabilities, with the opportunity to instead choose community-based services and supports. Nothing in the bill forces states to close nursing facilities or other institutions, and nothing in the bill prevents anyone from choosing a nursing home or other institution, if that is their wish. Rather than be forced into any type of institutional setting, people could choose to get assistance in their own homes. That assistance would include the basic activities of daily life that most people take for granted like meal preparation, eating, toileting, bathing, grooming, shopping, managing finances, and participating in the community.

The Community Choice act addresses the need for assistance with health-related functions, and implements other necessary reforms, like;
- **providing assistance** in a person's home and community, including at school, at work, or when participating in religious activities;
- **including systems** for securing back-up attendants;
- **offering options** for consumer control of services;
- **supporting essential**, often minor, one time expenses for things needed by people returning to the community, such as security deposits for housing, bedding, and kitchen supplies.

The Community Choice Act does not create a new, unfunded mandate.

We already pay for this assistance when people are forced into nursing homes and other institutions by the Medicaid institutional bias. The Community Choice Act simply makes the existing mandate more responsive to consumers, and in the aggregate will prove to be a more cost effective use of public dollars. It doesn't make more people eligible. It simply means that the people who are already eligible for services will have a real choice, a level playing field, with the Community Choice Act.

Every major national disability organization supports The Community Choice Act. In fact, 92 national organizations are Community Choice act supporters. An additional 255 state or regional organizations also support the bill, as well as 306 local groups. I have included the full list at the end of my testimony. As you look through the list, you will notice just how diverse the support is.

Supporting organizations represent people with all types of disabilities: people with cognitive disabilities, people with sensory disabilities, people with mental health labels, and people with physical disabilities…of all ages. The list of supporting organizations even represents people without disabilities!

Appended to my testimony you will also find a page that shows the minimum of how many people want out of nursing homes right now in the states of each of the Committee members. Nationally, the total has gone from under a quarter of a million two years ago to over 300,000 currently. We have every reason to expect that number to continue to increase.

An additional page contains the figures from Thompson/Medstat showing the ratio by state of Medicaid dollars spent on institutional settings for every Medicaid dollar spent on community services. There are ratio columns for both MR/DD funding streams and for Physical Disability (aka Aging and Disability) funding streams.

Also appended to my testimony is a DVD containing the testimony given by a number of other individuals at a national hearing held in Nashville, Tennessee, last year. They are the real experts on this issue. The hearing was attended by federal officials from Health and Human Services and the National Council on Disability, as well as representatives from national disability organizations. Each one of you, and in fact every Senator and Representative, received a copy of this DVD in early May of this year.

I urge you to pass S. 799 out of committee and on to the full Senate. The disability community has been waiting for over 15 years, and over that time so many of us have become Seniors with disabilities who are still waiting for Community Choice.

In closing, I would like to thank Senators Schumer and Salazar, for their co-sponsorship of the Community Choice Act. And thank you all again for providing me this opportunity to testify. I would be happy to answer any questions that you may have at this time.

APPENDIX A

Centers for Medicare and Medicaid MDS Q1a Information Reflecting the Number of Nursing Facility Residents Who Indicate They Want to Move Back to Their Community as of the Second Quarter of 2007

MDS Active Resident Information Report: Second Quarter 2007

Q1a: Resident Expresses/Indicates Preference to Return to the Community

	State	No	Yes	#Yes	State Total
Jon Kyl	Arizona *	68.7%	31.3%	**3648**	11,656
Blanche L. Lincoln	Arkansas *	81.7%	18.3%	**3292**	17,988
	California	75.3%	24.7%		100,590
Ken Salazar	Colorado *	76.7%	23.3%	**3742**	16,061
	Florida	73.2%	26.8%		69,627
Mike Crapo	Idaho *	73.2%	26.8%	**1181**	4,408
	Illinois	75.9%	24.1%		74,542
Charles Grassley	Iowa *	81.3%	18.7%	**4785**	25,586
Pat Roberts	Kansas *	81.7%	18.3%	**3494**	19,040
Jim Bunning	Kentucky *	80.7%	19.3%	**4396**	22,776
Olympia J. Snowe	Maine *	76.1%	23.9%	**1512**	6,326
John F. Kerry	Massachusetts *	79.1%	20.9%		42,298
Debbie Stabenow	Michigan *	73.1%	26.9%	**10,782**	40,083
Trent Lott	Mississippi *	88.4%	11.6%	**1846**	15,913
Max Baucus	Montana *	76.3%	23.7%	**1213**	5,117
John Ensign	Nevada *	71.1%	28.9%	**1293**	4,475
Jeff Bingaman	New Mexico *	72.6%	27.4%	**1691**	6,173
Charles E. Schumer	New York *	78.8%	21.2%	**23,208**	109,473
Kent Conrad	North Dakota *	84.3%	15.7%	**908**	5,783
	Ohio	74.8%	25.2%		77,490
Ron Wyden, Gordon Smith	Oregon *	67.3%	32.7%	**2555**	7,812
	Pennsylvania	80.3%	19.7%		77,025
	Texas	79.9%	20.1%		91,583
Orrin G. Hatch	Utah *	67.7%	32.3%	**1692**	5,238
Maria Cantwell	Washington *	70.6%	29.4%	**5507**	18,734
John D. Rockefeller IV	West Virginia *	79.2%	20.8%	**2039**	9,802
	NATIONAL TOTAL	78.1%	21.9%	**303,709**	1,386,797

http://www.cms.hhs.gov/MDSPubQIandResRep/06_q1areport.asp?qtr=11&isSubmitted=q1a2

APPENDIX B

Ratio, by State and Funding Stream, of Medicaid Dollars Going to Institutions vs. Medicaid Dollars Going to Community Services According to Information Available in 2007 from the States

Ratio, by State and Funding Stream, of Medicaid Dollars Going to Institutions vs. Medicaid Dollars Going to Community Services

Senate Finance Committee Member	State	MR/DD Funding Institution:Community	Physical Disability Funding Institution:Community
	Alabama	$.15 to $1	$7.94 to $1
	Alaska	$0 to $1	$.94 to $1
Jon Kyl	**Arizona**	**n/a ***	**$1.53 to $1**
Blanche L. Lincoln	**Arkansas**	**$1.42 to $1**	**$2.84 to $1**
	California	$.53 to $1	$1.07 to $1
Ken Salazar	**Colorado**	**$.19 to $1**	**$1.99 to $1**
	Connecticut	$.68 to $1	$4.02 to $1
	Delaware	$.34 to $1	$6.63 to $1
	D.C.	$4.51 to $1	$2.69 to $1
	Florida	$.40 to $1	$6.88 to $1
	Georgia	$.46 to $1	$5.16 to $1
	Hawaii	$.10 to $1	$4.89 to $1
Mike Crapo	**Idaho**	**$1.04 to $1**	**$1.48 to $1**
	Illinois	$1.06 to $1	$3.88 to $1
	Indiana	$1.50 to $1	$11.33 to $1
Charles Grassley	**Iowa**	**$1.05 to $1**	**$3.05 to $1**
Pat Roberts	**Kansas**	**$.28 to $1**	**$1.79 to $1**
Jim Bunning	**Kentucky**	**$.74 to $1**	**$4.18 to $1**
	Louisiana	$2.48 to $1	$4.75 to $1
Olympia J. Snowe	**Maine**	**$.27 to $1**	**$2.99 to $1**
	Maryland	$.13 to $1	$5.05 to $1
John F. Kerry	**Massachusetts**	**$.24 to $1**	**$3.08 to $1**
Debbie Stabenow	**Michigan**	**$.02 to $1**	**$5.27 to $1**
	Minnesota	$.19 to $1	$1.33 to $1
Trent Lott	**Mississippi**	**$253.60 to $1**	**$40.50 to $1**
	Missouri	$.74 to $1	$2.35 to $1
Max Baucus	**Montana**	**$.20 to $1**	**$2.47 to $1**
	Nebraska	$.43 to $1	$3.93 to $1
John Ensign	**Nevada**	**$.44 to $1**	**$2.10 to $1**
	New Hampshire	$.02 to $1	$6.47 to $1
	New Jersey	$.84 to $1	$3.87 to $1
Jeff Bingaman	**New Mexico**	**$.11 to $1**	**$.86 to $1**
Charles E. Schumer	**New York**	**$.74 to $1**	**$1.77 to $1**
	North Carolina	$1.30 to $1	$1.32 to $1
Kent Conrad	**North Dakota**	**$1 to $1**	**$16.60 to $1**
	Ohio	$1.11 to $1	$3.74 to $1

	Oklahoma	$51. to $1	$2.75 to $1
Ron Wyden **Gordon Smith**	**Oregon**	**$0 to $1**	**$.82 to $1**
	Pennsylvania	$.48 to $1	$7.31 to $1
	Rhode Island	$.04 to $1	$7.60 to $1
	South Carolina	$.84 to $1	$3.99 to $1
	South Dakota	$.27 to $1	$8.51 to $1
	Tennessee	$.66 to $1	$87.31 to $1
	Texas	$1.69 to $1	$1.19 to $1
Orrin G. Hatch	**Utah**	**$.50 to $1**	**$9.16 to $1**
	Vermont	n/a *	$2.68 to $1
	Virginia	$.74 to $1	$3.34 to $1
Maria Cantwell	**Washington**	**$.33 to $1**	**$.87 to $1**
John D. Rockefeller IV	**West Virginia**	**$.30 to $1**	**$3.50 to $1**
	Wisconsin	$.35 to $1	$2.30 to $1
	Wyoming	$.22 to $1	$4.03 to $1
	National	**$.65 to $1**	**$2.49 to $1**

Ratio of expenditures for institutional versus community; that is, how much in Medicaid funds were spent in institutions for each Medicaid dollar spent in the community

* [1] Arizona and Vermont show zero reported MR/DD expenditures because all long-term supports are provided in managed care programs.

Note: What the above figures don't reflect are the numbers of people served by each dollar. For example, according to the "Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006," published in August 2007 by University of Minnesota's Research and Training Center on Community Living Institute on Community Integration/UCEDD, in Montana the MR/DD institutional funds served about 70 people at over $167,000/person/year, while the community dollars for the same population served just over 2000 recipients at a fraction of the cost per person ($31,000/person/year).

This data was computed from the CMS Medicaid reports from each state based on actual expenditures. The data is compiled by Thompson/Medstat and extrapolated by Steve Gold, to whom we are very appreciative.

Appendix C

National, State and Local Organizations Supporting the Community Choice Act of 2007 (S. 799 and H.R. 1621)

National

ABLED Publications: ABLED Woman Magazine
ADAPT
ADA Watch
Ad Hoc Committee on Healthcare Reform & Disability
American Association of People with Disabilities
American Association on Mental Retardation
American Geriatrics Society
American Rehabilitation Counseling Association
Americans with Disabilities Vote
Assoc of Programs for Rural Independent Living - APRIL
Association for Persons in Supported Employment, APSE
Association for Protection of the Elderly Executive Advocacy Advisory Board
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 Community 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 Education 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 Magazine
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 Administrators
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 International/International Ventilators Users Network
Ragged Edge
Research & Training Center on IL at University of Kansas
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
Alaska Statewide Independent Living Council (State)
Alaska Division of Vocational Rehabilitation (State)
Alaska Governor's Commission on Employment & Rehabilitation of People with Disabilities (State)

State of Alaska Transition Initiative (State)
Assistive Technology of Alaska (State)
Disability Law Center of Alaska (State)
Governor's Council on Disabilities & Special Ed (State)
Kenai Peninsula Independent Living Center (Local)

Alabama
Birmingham Independent Living Center (Local)
Alabama Department of Mental Health/Mental Retardation (State)

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

Arizona
ABIL, A Bridge to Independent Living (Local)
DIRECT (Local)
Arizona Governor's Council on Developmental Disabilities (State)
Arizona Governor's Statewide Independent Living Council (State)
Arizona State Rehabilitation Advisory Council (State)

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

California Disability Alliance (State)
California Statewide Independent Living Council (State)
California Alliance for Inclusive Communities (State)
Jay Nolan Community Services (State)
People First of California (State)
The Oaks Group (State)

Colorado
Atlantis Community (Local)
Center for Independence (Local)
Center for People with Disabilities (Local)
Colorado Springs Independence Center (Local)
Connections for Independent Living (Local)
Disability Center for Independent Living (Local)
Disabled Resource Services (Local)
Rocky Mountain MS Center King Adult Day Enrichment Program (Local)
Southwest Center for Independence (Local)
Denver City Council (Local)
Association of Colorado Independent Living Centers (State)
Colorado Developmental Disability Planning Council (State)
Colorado Gov's Council for People with Disabilities (State)
Colorado Nurses Association (State)
Colorado Statewide Independent Living Council (State)
Colorado Democrats (State)
Lupus Foundation of Colorado (State)
PEAK Parent Center (State)
Speaking for Ourselves Colorado (State)
Colorado Cross-Disability Coalition (State)

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

Delaware
Freedom Center for Independent Living (Local)
Independent Resources Inc (Local)
DE Statewide Independent Living Council (State)
Delaware Maryland PVA (State)
Easter Seals Delaware & Maryland's Eastern Shore (State)
State Council for Persons with Disabilities (State)
University of Delaware Center for Disabilities Studies (State)

Florida
CIL of Broward (Local)
Leon Advocacy and Resource Center (Local)
West Coast Florida Multiple Chemical Sensitivity & Chemical Injury Support Group (Local)
Florida Independent Living Council (State)
Florida Spinal Cord Injury Research Center (State)
Paralyzed Veterans Assoc of Florida (State)

Georgia
Access Center for Independent Living (Local)
Arc Cobb (Local)
Bainbridge Advocacy Individual Network (Local)
Brain Injury Family Assistance Center (Local)
Disability Connection MGC Independent Living (Local)
disAbility LINK (Local)
LIFE Inc (Local)
Savannah-Chatman County Fair Housing Council, Inc (Local)
Walton Options for Independent Living Inc (Local)
Atlanta Alliance on Developmental Disabilities (State)
Coalition on Disabilities Education (C.O.D.E.) (State)
Demanding Equal Access for All (D.E.A.F.) (State)
Federation of Families for Children's Mental Health (State)
Georgia Developmental Disability Council (State)
Georgia Advocacy Office (State)
Georgia Parent Support Network (State)
Georgia State Independent Living Council (State)
Let's Get Together (State)
North Georgia Wheelers (State)
Osteogenesis Imperfecta Council of Georgia (State)
Roosevelt Warm Springs Institute for Rehabilitation (State)
People First of Georgia (State)

Hawaii
Environmental Illness Association of Hawaii (Local)
Disability Rights Hawaii (State)
Environmental Illness Assn of (State)
Hawaii Statewide Independent Living Council (State)

Iowa
Evert Conner Rights & Resources Center for Independent Living (Local)
South Central Iowa Center for Independent Living (Local)
Three Rivers Independent Living Center (Local)
Iowa Department of Human Rights Division of Persons with Disabilities (State)
Iowa Human Rights Commission (State)
Iowa Creative Employment Options (State)
Iowa Statewide Independent Living Council (State)
Iowans with Disabilities Exercising Advocacy Skills (State)
The Arc of Iowa (State)

Idaho
Disability Action Center - NW, Inc (Local)
Living Independently for Everyone, LIFE (Local)

Comprehensive Advocacy (State)
Idaho Statewide Independent Living Council (State)
Intermountain Fair Housing Council (State)

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

Indiana
Everybody Counts (Local)
Indianapolis Resource Center for Independent Living (Local)
League for the Blind & Disabled (Local)
SICIL (Local)
Indiana Institute on Disability & Culture – Indiana University (State)
Indiana Council on Independent Living (State)

Kansas
American Legion Post 400 SAL (Local)
Center for Independent Living of Southwest Kansas (Local)
Coalition for Independence (Local)
Community Accessibility Awareness Task Force (Local)
Developmental Services of Northwest Kansas (Local)
Grandmothers, Aunts, Mothers, Sisters & Supports (Local)
Head Injury Support Group (Local)

Independence Inc (Local)
LINK (Local)
Prairie Independent Living Resource Center (Local)
Professional Home Health Services (Local)
Resource Center for Independent Living (Local)
Self Help for the Hard of Hearing Western KS Grp (Local)
Southeast Kansas Independent Living (Local)
Three Rivers (Local)
Topeka IL Resource Center (Local)
Western KS Association on Concerns of the Disabled (Local)
Youth Advocacy (Local)
CLASS CTD (State)
Kansas Association of Centers for Independent Living (State)
Kansas Association of the Deaf (State)
Kansas Commission on Disability Concerns (State)
Kansas Disability Rights Action Coalition for Housing (State)
Kansas Nurses Association (State)
Kansas Council on Developmental Disabilities (State)
Kansas Statewide Independent Living Council (State)
Kansas State Chapter World Association of Persons with Disabilities (State)
Kansas TASH (State)

Kentucky
Innovative Solutions Inc (Local)
Access to the Arts (State)
Kentucky Developmental Disability Council (State)
Kentucky State Independent Living Council (State)

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

Massachusetts
Boston Center for Independent Living (Local)
Cape Organization for Rights of/the Disabled CORD (Local)
Center for Living and Working (Local)
Greater Boston Arc, Inc. (Local)
Independent Living Center - the North Shore & Cape Ann (Local)
JAM Specialists (Local)
Metrowest Center for Independent Living (Local)
North Shore Arc (Local)
Northeast Independent Living Program (Local)
Rights for Equality and Dignity for the Disabled (Local) I
Stavros Independent Living Center (Local)
Disability Law Center (State)

Massachusetts Arc (State)
Massachusetts Office on Disability (State)
Massachusetts Statewide Independent Living Council (State)
Massachusetts Statewide Personal Assistance Coalition (State)

Maryland

Baltimoreans Against disAbility Discrimination (Local)
Calvert County Commission for Individuals with Disabilities (Local)
Independence NOW (Local)
MCIL Resources for Independent Living (Local)
Montgomery Co Commission on People w Disabilities (Local)
Resources for Independence (Local)
Southern Maryland Center for LIFE (Local)
Southern Maryland Independent Living (Local)
The Freedom Center (Local)
Chemical Sensitivity Disorders Association (State)
Maryland Assoc. of Community Services (State)
Maryland Developmental Disabilities Council (State)
Maryland Disabilities Forum (State)
Maryland Statewide Independent Living Council (State)
The Arc of Maryland (State)

Maine

Alpha One (State)
Maine Disabilities Coalition (State)

Michigan

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

Minnesota

Advocating Change Together (Local)
Center for IL of Northeastern (Local)
Independent Lifestyles, Inc (Local)
Metropolitan Center for Independent Living (Local)
S.M.I.L.E.S. (Local)
Southwestern Center for Independent Living (Local)
Stillwater Human Rights (Local)

The Disability Institute (Local)
Minnesota Assoc. of Centers for Independent Living (State)
Minnesota Governor's Council on Developmental Disability (State)
Minnesota Statewide Independent Living Council (State)
Options IRCIL (State)
Out in the Valley (State)

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

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

Montana
Living Independently for Today & Tomorrow LIFTT (Local)
Montana Independent Living Project (Local)
Summit Independent Living Center, Inc (Local)
Coalition of Montanans Concerned with Disabilities (State)

Montana Statewide Independent Living Council (State)
Montana Advocacy Program (State)
Parents, Let's Unite for Kids PLUK (State)

Nebraska
The Arc of Lincoln/Lancaster County (Local)
League of Human Dignity (State)

Nebraska Advocacy Services (State)
Nebraska Statewide Independent Living Council (State)

New Hampshire
Governor's Commission on Disability in New Hampshire (State)
Granite State Independent Living Foundation (State)
Institute on Disability University Center, University of New Hampshire (State)
New Hampshire Developmental Disabilities Council (State)
New Hampshire Statewide Independent Living Council (State)
New Hampshire Homeless@egroups.com(State)

New Jersey
Alliance for Disabled in Action (Local)
Camden City Independent Living Council (Local)
Center for Independent Living of South Jersey (Local)
Disabled Advocates Working for Northwest DAWN (Local)
Personal Assistant Service Program (Local)
Progressive Center for Independent Living (Local)
Warren County Advisory Council on Disabilities (Local)
Monday Morning Project – New Jersey Developmental Disability Council (State)
New Jersey Developmental Disabilities Council (State)
New Jersey MiCASSA Advocacy Coalition (State)
New Jersey Statewide Independent Living Council (State)

New Mexico
Independent Living Resource Center Albuquerque (Local)
Independent Living Resources (Local)
San Juan Center for Independent Living (Local)
Gov's Commission on Concerns of the Handicapped (State)
New Mexico Developmental Disabilities Planning Council (State)
New Mexico Legislative Health & Human Services Committee (State)
New Mexico State Agency on Aging (State)
New Mexico Statewide Independent Living Council (State)
Zia Chapter of the Paralyzed Veterans of America (State)

New York
SABE, Self Advocates Becoming Empowered of New York (State)
504 Democratic Club (Local)
Access to Independence of Cortland County (Local)
Action for a Better Community (Local)
Americans Demanding Access of (Local)
ARISE (Local)
Bronx Independent Living Services (Local)
Brooklyn Center for Ind. of the Disabled (Local)
Capital District Center for Independence (Local)
Cent. NY Self Adv. Grassroots Reg Organizing Prog (Local)
Center for Disability Rights (Local)
Disabled in Action of Greater Syracuse (Local)
Disabled in Action of Metro (Local)
Family Empowerment Council (Local)
Finger Lakes Independence Center (Local)
Greater Rochester Spina Bifida Association (Local)

Lakretz Creative Support Services (Local)
League of Women Voters of the Rochester Metro Area (Local)
Long Island Advocacy Center (Local)
Massena ILC (Local)
Mental Health Association of the Southern Tier (Local)
Mental Health Association of Rochester/Monroe Counties (Local)
Metro Justice of Rochester (Local)
Niagara Frontier Center for Independent Living, Inc (Local)
North Country Center for Independence (Local)
Northern Regional Center for Independent Living (Local)
P-FLAG Parents Family & Friends of Gays, Lesbians, Bisexuals & Transgendered (Local)
Public Interest Law Office of Rochester (Local)
Queens Independent Living Center (Local)
Resource Center for Accessible Living (Local)
Resource Center for Independent Living (Local)
Rochester Center for Independent Living (Local)
Rochester Chapter of the National Spinal Cord Injury Association (Local)
Rockland City Commission on Human Rights (Local)
Saratoga County Options for Independent Living (Local)
Southern Tier Independence Center (Local)
Southwestern Independent Living Center (Local)
Staten Island Center for Independent Living (Local)
Staten Island Independent Living Association (Local)
Suffolk Independent Living Oranization SILO (Local)
Taconic Resources for Independent Living (Local)
The Arc of Monroe County (Local)
The Health Association (Local)
Tomorrow's Future Self Advocacy Group (Local)
Westchester Disabled on the Move, Inc (Local)
Access to Independence & Mobility (State)
Grassroots Regional Organizing Program (State)
Mental Patients Liberation Alliance of (State)
New York Statewide Independent Living Council (State)
New York State Developmental Disabilities Planning Council (State)
New York State Independent Living Council (State)
New York State Institute on Disability, Inc (State)
Self-Advocacy Association of New York State (State)

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

North Dakota
Dakota Center for Independent Living (Local)
Freedom Resource Center, Fargo (Local)
North Dakota Disabilities Advocacy Consortium (State)

Ohio
Ability Center of Greater Toledo (Local)

Access Center for Independent Living (Local)
Center for Independent Living Options (Local)
Hamilton County Early Intervention Collaborative (Local)
Independent Living Center of North Central Ohio (Local)
LEAP Center for Independent Living (Local)
Lorain County Coalition of Citizens with Disabilities (Local)
Mid-Ohio Board for Independent Living Environments MOBILE (Local)
Services for Independent Living, Inc (Local)
Society for Equal Access (Local)
the Inclusion Network (Local)
Tri-County Independent Living Center (Local)
Irene Ward & Associates (State)
Ohio Assoc. of Centers for Independent Living (State)
Ohio Developmental Disabilities Council (State)
Ohio Personal Assistance for Independent Living, OPAIL (State)
Ohio Personal Assistance Services Coalition (State)
Ohio Statewide Independent Living Council (State)
Ohio Disability Action Coalition (State)

Oklahoma
Ability Resources (Local)
Progressive Independence (Local)
National MS Society - Oklahoma Chapter (State)
Office of Handicapped Concerns (State)
Oklahoma Statewide Independent Living Council (State)
Oklahoma Conference of Churches Impact Committee (State)
Oklahoma Parent Network (State)
Oklahomans for Independent Living (State)

Oregon
Community Partnerships (Local)
Independent Living Resources (Local)
Oregon Statewide Independent Living Council (State)
Oregon Developmental Disabilities Coalition (State)
Oregon Disabilities Commission (State)

Pennsylvania
Abilities In Motion (Local)
Anthracite Regional Center for Independent Living (Local)
Area Agency on Aging Office of Human Services (Local)
Bucks County Area Agency on Aging (Local)
CARIE Center for Advocacy for the Rights and Interests of the Elderly (Local)
Center for Independent Living of Central (Local)
Center for Independent Living of North Central PA (Local)
Center for Independent Living of South Central (Local)
Citizens for Independence and Access (Local)
Consumer Connection (Local)
Disabled in Action of Philadelphia (Local)
Freedom Valley Disability Center (Local)
Lawrence County Commission on Disability (Local)
Lehigh Valley Center for Independent Living (Local)
Liberty Resources PA (Local)

LIFT Pennsylvania (Local)
Lupus Foundation of SE PA (Local)
National MS Society - Greater Delaware Valley Chapter (Local)
Northeast Pennsylvania Center for Independent Living (Local)
Partnership for Choice (Local)
Pittsburgh Area Brain Injury Alliance (Local)
Three Rivers Center for Independent Living PA Local
TRI County Patriots for Independent Living (TRIPIL) (Local)
United Cerebral Palsy of Philadelphia (Local)
United Cerebral Palsy of Pittsburgh (Local)
Voices for Independence (Local)
Disabilities Law Project (State)
Pennsylvania Action Coalition in Disability Rights in Housing (State)
Pennsylvania Association of Area Agencies on Aging (State)
Pennsylvania Coalition of Citizens with Disabilities (State)
Pennsylvania Council of the Blind (State)
Pennsylvania Council on Independent Living (State)
Pennsylvania Developmental Disabilities Council (State)
Pennsylvania Statewide Independent Living Council (State)
Speaking for Ourselves (State)
UCP of Pennsylvania State (State)
Interfaith Specialty Services (Local)

South Carolina
Access Resorts Inc. (Local)
Disability Resource Center (Local)
Pathways For the Future (Local)
South Carolina Statewide Independent Living Council (State)
South Carolina State Chapter World Association for People with Disabilities (State)

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

Texas
ABLE Area Base for Living Enrichment Center for Independent Living (Local)
Austin Mayor's Committee for People w Disabilities (Local)
Austin Resource Center for Independent Living (Local)
Brazoria County Center for Independent Living BCCIL (Local)
Central Texas Coalition on Aging & Developmental Disabilities (Local)
Central Texas Rehabilitation Association (Local)
Crockett Resource Center for Independent Living (Local)
GMSA Management Group (Local)
Greater Austin PVA (Local)

Houston Area Women's Center (Local)
Houston Center for Independent Living (Local)
Panhandle Independent Living Center (Local)
Parents as Case Managers (Local)
REACH Resource Centers on Independent Living (Local)
RISE (Local)
San Antonio Independent Living Services, SAILS (Local)
TATP (Local)
Volar Center for Independent Living (Local)
Advocacy Inc. (State)
Advocates for Texans with Brain Injuries (State)
Brain Injury Association of Texas (State)
Coalition of Texans with Disabilities (State)
Disability Policy Consortium (State)
Disability Services of the Southwest (State)
Mental Health Association in Texas (State)
National Association of Social Workers - Texas Chapter (State)
Texas Advocates (State)
Texas Advocates for Supporting Kids with Disabilities (State)
Texas Association of Centers for Independent Living (State)
Texas Mental Health Consumers (State)
Texas Nurses Association (State)
Texas Planning Council for Developmental Disabilities (State)
Texas Rehabilitation Commission (State)
Texas Civil Rights Project (State)
Texas Health and Human Services Commission (State)
Texas PVA (State)
Texas Statewide Independent Living Council (State)
Texas State Chapter World Association of Persons with Disabilities (State)
United Cerebral Palsy of Texas (State)
University Affiliated Program, University of Texas (State)

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

Virginia
Blue Ridge Independent Living Center (Local)
Brain Injury Services Inc (Local)
disAbility Resource Center of the Rappahannock Area (Local)
Endependence Center - Norfolk (Local)

Commonwealth Coalition for Community (State)
Virginia Statewide Independent Living Council (State)
Virginia TASH (State)
Virginia Association of People in Supported Employment (State)

Vermont
Vermont Center for Independent Living (State)
Vermont Coalition for Disability Rights (State)

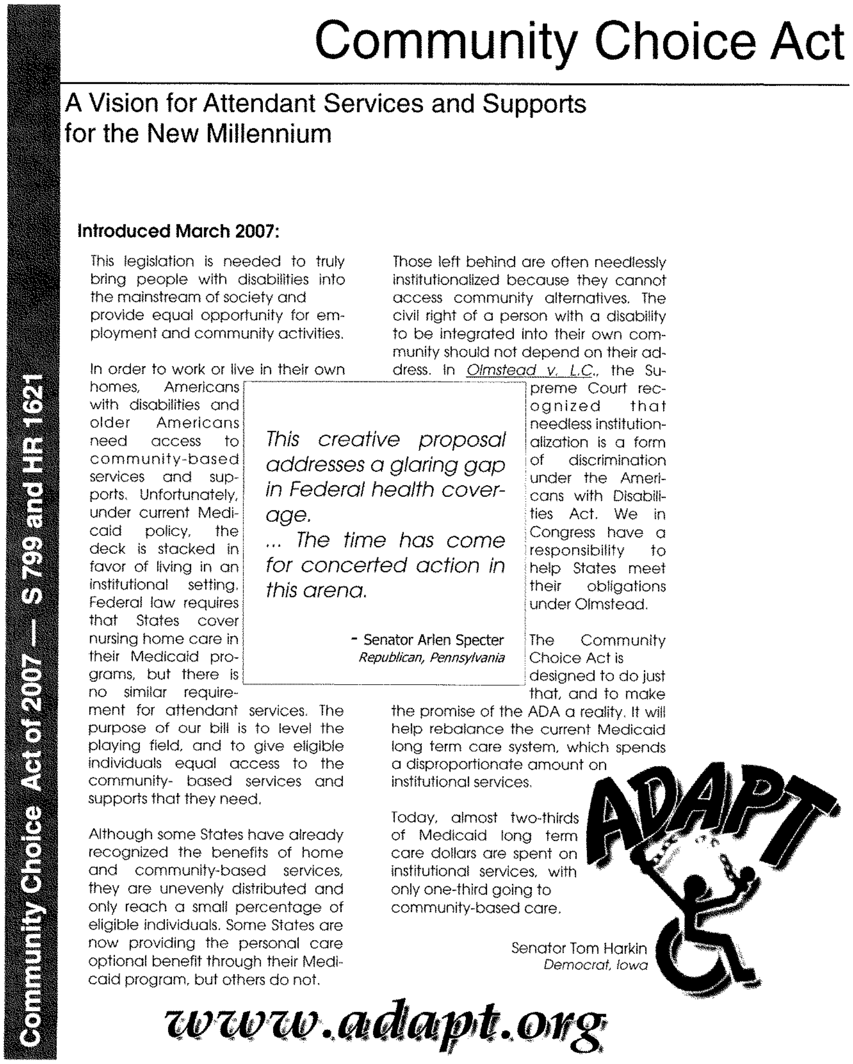
Washington
Coastal Community Advocates (Local)
CORD (Local)
disAbility Resource Center (Local)
Inclusion Daily Express (Local)
Tacoma Area Coalition of Individuals w Disabilities TACID (Local)
Alzheimers Society of Washington (State)
Arc of Washington State (State)
disAbility Resources of Southwest (State)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

Wisconsin
Access to Independence, Madison (Local)
ARC-Milwaukee (Local)
Aurora Community Services (Local)
Center for Independent Living for Western Wisconsin (Local)
Community Living Alliance (Local)
Disabled Womyn's Education Project (Local)
Easter Seals of SE Wisconsin (Local)
Employment Resources Inc. (Local)
Independence First (Local)
North Country Independent Living (Local)
Options for Independent Living (Local)
Pierce County Dept. of Human Services (Local)
Ranch Community Services (Local)
St. Clare Management, Inc (Local)
United Cerebral Palsy of Southeast Wisconsin (Local)
ARC - Wisconsin (State)
Aurora Residential Services (State)
Brain Injury Association of Wisconsin (State)
Client Assistance Program of Wisconsin (State)
National Multiple Sclerosis Society of Wisconsin (State)
Older Adult Service Provider's Consortium (State)
People First Wisconsin (State)
Rehabilitation for Wisconsin (State)
State Independent Living Council (State)
State Rehabilitation Planning & Advisory Council (State)
United Cerebral Palsy of (State)
Wisconsin Coalition for Advocacy - Milwaukee (State)

Wisconsin Coalition of Independent Living Centers (State)
Wisconsin Council on Developmental Disabilities (State)
Wisconsin Council on Physical Disabilities (State)
Wisconsin Governor's Commission for People with Disabilities (State)
Wisconsin Nurses Assoc (State)
Wisconsin Rehabilitation Assn. (State)
Wisconsin Statewide Independent Living Council (State)
Wisconsin Coalition for Advocacy - Madison (local)
Parents Education Project of (State)

West Virginia
Huntington West Virginia Grassroots Advocacy Project (Local)
Mountain State Centers for Independent Living - Huntington (Local)
Northern West Virginia Center for Independent Living (Local)
West Virginia Statewide Independent Living Council (State)

Wyoming
Wyoming Statewide Independent Living Council (State)



Community Choice Act of 2007 — S 799 and HR 1621

Community Choice Act

A Vision for Attendant Services and Supports for the New Millennium

Introduced March 2007:

This legislation is needed to truly bring people with disabilities into the mainstream of society and provide equal opportunity for employment and community activities.

In order to work or live in their own homes, Americans with disabilities and older Americans need access to community-based services and supports. Unfortunately, under current Medicaid policy, the deck is stacked in favor of living in an institutional setting. Federal law requires that States cover nursing home care in their Medicaid programs, but there is no similar requirement for attendant services. The purpose of our bill is to level the playing field, and to give eligible individuals equal access to the community- based services and supports that they need.

Although some States have already recognized the benefits of home and community-based services, they are unevenly distributed and only reach a small percentage of eligible individuals. Some States are now providing the personal care optional benefit through their Medicaid program, but others do not.

Those left behind are often needlessly institutionalized because they cannot access community alternatives. The civil right of a person with a disability to be integrated into their own community should not depend on their address. In Olmstead v. L.C., the Supreme Court recognized that needless institutionalization is a form of discrimination under the Americans with Disabilities Act. We in Congress have a responsibility to help States meet their obligations under Olmstead.

The Community Choice Act is designed to do just that, and to make the promise of the ADA a reality. It will help rebalance the current Medicaid long term care system, which spends a disproportionate amount on institutional services.

Today, almost two-thirds of Medicaid long term care dollars are spent on institutional services, with only one-third going to community-based care.

Senator Tom Harkin
Democrat, Iowa

> *This creative proposal addresses a glaring gap in Federal health coverage.*
> *... The time has come for concerted action in this arena.*
>
> - Senator Arlen Specter
> *Republican, Pennsylvania*

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The Community Choice Act gives people real choice in long term care options by reforming Title XIX of the Social Security Act (Medicaid) by ending the institutional bias. 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." The money follows the individual!

In addition, by providing an enhanced match and grants for the transition to Real Choice 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.

Specifically what does this bill do?

1) Provides **community-based attendant services and supports** ranging from 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.

2) Includes **hands-on** assistance, **supervision and cueing**, as well as **help to learn**, keep and enhance skills to accomplish such activities.

3) Requires services be provided in **THE MOST INTEGRATED SETTING** appropriate to the needs of the individual.

4) 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.

5) 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.

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

7) Allows **health-related functions or tasks to be assigned to, delegated** to, or performed by unlicensed personal attendants, according to state laws.

8) 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.

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

10) Provides for **quality assurance programs** which promote consumer control and satisfaction.

11) Provides **maintenance of effort requirement** so that states can not diminish more enriched programs already being provided.

12) Allows **enhanced match** (up to 90% Federal funding) for individuals whose costs exceed 150% of average nursing home costs.

13) Between 2007 and 2011, after which the services become permanent, **provides enhanced matches** (10% more federal funds each) for states which:
- begin planning activities for changing their long term care systems, and
- include Community-based Attendant Services and Supports in their State Plan.

SYSTEMS CHANGE

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

15) Calls for national 5 -10 year **demonstration project**, in 5 states, to enhance coordination of services for individuals **dually eligible for Medicaid AND Medicare.**

THE COMMUNITY CHOICE ACT HELPS FAMILIES OF CHILDREN WITH DISABILITIES

The Community Choice Act redirects the focus of the Medicaid long term services program from institutions to home and community services and supports, enabling families to make real choices. Given "REAL CHOICE" people overwhelmingly choose "HOME SWEET HOME."

Studies show that children currently living in America's institutions and nursing homes do not have more severe disabilities than those who live with their families at home and use attendant services and supports.

- Families DON'T want to place children with disabilities in institutions. Families want children to live at home where they can maintain family ties, go to school and grow as other children do.
- Families also want their children to have a secure future and real options for home and community services and supports when their families are no longer providing full-time care.

Some of the real reasons why children and young adults with disabilities go into institutions or nursing homes:

Parents can't hold down a job that supports their family AND provide full-time care to a child with disability.

- Parents may be able to provide much of the care that a young child needs, but may not be physically able to manage lifting and positioning as the child grows up.
- Waiting lists for community services are so long families get worn down while waiting, sometimes 10 years and longer!
- Parents fear that when their child is old enough to move out of the house, no independent living, community options will be available.
- People don't know that there are community alternatives to nursing homes and other institutions.
- Public policy supports institutions, NOT people with disabilities and their families.
- Young people with disabilities are not in institutions or foster care because of the amount of care they need. They are in because of the lack of attendant services and supports. Many, many children with significant disabilities DO live at home with their families.

Community Choice at a glance:

- CCA provides Medicaid funding for attendant services and supports for people of all ages.
- Services can be provided at home, in school, at work and at play.
- Assistance is available for a broad range for needs, such as bathing, dressing, meal preparation, money management and certain health-related tasks.
- CCA will be available to young adults when they move out of their parents' homes into the community.

Some Questions About the Community Choice Act.

1. What are the community-based attendant services and supports in the Community Choice Act?

In the Community Choice Act, the term community-based attendant services and supports means help with accomplishing activities of daily living (eating, toileting, grooming, dressing, bathing, and transferring) instrumental activities of daily living (meal preparation, managing finances, shopping, household chores, phoning, and participating in the community), and health-related functions (which can be delegated or assigned as allowed by state law). These services and supports can be done through hands-on assistance, supervision and/or cueing. They also include help with learning, keeping and enhancing skills to accomplish such activities.

These services and supports, which include back up, are designed and delivered under a plan that is based on a functional needs assessment and agreed to by the individual. In addition they are furnished by attendants who are selected, managed, and dismissed by the individual, and include voluntary training for the individual on supervising attendants.

The Community Choice Act specifically states that services should be delivered, "in the most integrated setting appropriate to the needs of the individual" in a home or community setting, which may include a school, workplace, or recreation or religious facility.

2. If someone can't manage their attendant services completely independently are they still eligible for the Community Choice Act services?

Yes! People who, due to a cognitive disability for example, have difficulty managing their services themselves can have assistance from a representative, like a parent, a family member, a guardian, an advocate, or other authorized person.

3. Do you have to be impoverished to be eligible for the Community Choice Act?

No. If you are eligible to go into a nursing home, an ICF-MR facility or an Institution for Mental Disease, IMD, (these are the technical names, not ones we would pick) you would be eligible for the Community Choice Act. Financial eligibility for nursing homes is up to 300% of the SSI level (roughly $1,800 per month for a single person). In addition, with the Ticket to Work and Work Incentives Improvement Act of 1999, TWWIIA, states can choose to have a sliding fee scale for people of higher incomes beyond the current Medicaid eligibility guidelines.

4. Is the Community Choice Act biased towards an agency delivery model?

No, the Community Choice Act assumes that one size does not fit all. It allows the maximum amount of control preferred by the individual with the disability. Options include: vouchers, direct cash payments or a fiscal agent, in addition to agency delivered services. In all these delivery models the individual has the ability to select, manage and control his/her attendant services and supports, as well as help develop his/her service plan. Choice and control are key concepts, regardless of who serves as the employer of record. All delivery models must comply with Federal and state labor laws.

5. Will the Community Choice Act replace existing community-based programs?

The Community Choice Act does not affect existing optional programs or waivers and includes a maintenance of effort clause to ensure these programs are not diminished. Waivers include a more enriched package of services for those individuals who need more services. With the Community Choice Act, people who are eligible for nursing homes, ICF-MR facilities or IMDs can choose community attendant services and supports as a unique service that is a cost-effective option. The money follows the individuals not the facility.

6. Is the Community Choice Act a new un-funded mandate?

No. The Community Choice Act is a way to make an existing mandate for nursing homes and virtual mandate for institutions for mentally retarded persons responsive to the needs and desires of the consumers of these services. The Community Choice Act says the people who are already eligible for these services will simply have a choice of where they receive services. The Community Choice Act would adjust the current system to focus on the recipients of service, instead of mandating funding for certain industries and facilities.

7. Why is the Community Choice Act needed?

Our current long term services system has a strong institutional bias. Sixty seven percent of Medicaid long term care dollars go to institutional services, leaving 33% to cover all the community based services. Every state that takes Medicaid funds must provide nursing home services while community based services are completely optional for the states. The Community Choice Act says, let's level the playing field, give the person, instead of government or industry, the real choice.

8. How does the Community Choice Act help states?

The Community Choice Act provides a five year transformation period for the states by providing both an enhanced match and grants for the transition to Real Choice before 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, and thereby helps with compliance with the Supreme Court's Olmstead decision as well.

9. Will the Community Choice Act bust the bank? What about the "woodwork" effect?

The Community Choice Act assures that a state need spend no more money in total for a fiscal year than would have been spent for people with disabilities who are eligible for institutional services and supports.

There is a lot of discussion that the people who are eligible for institutional services would never go into the institution but would jump at the chance to use the Community Choice Act. (This is called the woodwork effect.) The states of Oregon and Kansas have data to show that fear of the woodwork effect is blown way out of proportion. There may be some increase in the number of people who use the services and supports at first, but savings will be made on the less costly community based services and supports, as well as the decrease in the number of people going into institutions. Belief in the woodwork effect assumes caregivers are now delivering a lot of "free care". There is a real question whether this care is truly "free". Research on the loss to the economy of the "free" caregivers is beginning.

10. What are the transitional services?

Currently Medicaid does not cover some essential costs for people coming out of nursing homes or other institutions. These include deposits for rent and utilities, bedding, kitchen supplies and other things necessary to make the transition into the community. Covering these costs would be one of the services and supports covered by the Community Choice Act.

11. What about people who need more supports?

For people whose costs are higher than 150% of the average nursing home cost, the Community Choice Act will provide additional federal support to the states, so that people are not stuck in institutions because they need more services and supports.

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Continued on the next page ...

12. What about people who are dually eligible for both Medicaid and Medicare?

The Community Choice Act includes a national 5 to 10 year demonstration project in 5 states to enhance coordination of services for individuals dually eligible for Medicaid AND Medicare. These individuals often fall through the cracks now.

13. How is Quality Assurance addressed in the Community Choice Act?

States are required to develop quality assurance programs that set down guidelines for operating Community-based Attendant Services and Supports, and provide grievance and appeals procedures for consumers, as well as procedures for reporting abuse and neglect. These programs must maximize consumer independence and direction of services, measure consumer satisfaction through surveys and consumer monitoring. States must make results of the quality assurance program public as well as providing an on-going process of review. Last but not least sanctions must be developed and the Secretary of Health and Human Services must conduct quality reviews.

14 What is the purpose of the Real Choice Systems Change Initiatives section of the bill?

The Community Choice Act brings together on a consumer task force, the major stakeholders in the fight for community-based attendant services and supports. Representatives from DD Councils, IL Councils and Councils on Aging along with consumers and service providers would develop a plan to transition the current institutionally biased system into one that focuses on community-based attendant services. The people that have an investment in the final outcome, the consumers, must think through closing institutions, or at least closing bed spaces. The plan envisions ending the fragmentation that currently exists in our long term service system.

In addition, the bill sets up a framework and funding to help the states transition from their current institutionally dominated service model to more community-based services and supports. States will be able to apply for systems change grants for things like: assessing needs and gathering data, identifying ways to modify the institutional bias and over-medicalization of services and supports, coordinating between agencies, training and technical assistance, increasing public awareness of options, downsizing of large institutions, paying for transitional costs, covering consumer task force costs, demonstrating new approaches, and other activities which address related long term care issues.

OLDER AMERICANS AND THE COMMUNITY CHOICE ACT

The Community Choice Act redirects the focus of the Medicaid long term services program from institutions to home and community services and supports. It enables older people to make real choices. Given "REAL CHOICE" people overwhelmingly choose "HOME SWEET HOME."

Studies show that seniors currently living in America's institutions and nursing homes do not have more severe disabilities than those who are living in their own homes with attendant services and supports.

The Community Choice Act means REAL CHOICE!

- Older Americans generally prefer to be in their own homes. They do NOT want to live in nursing homes.
- Surveys show that most people who need long term services and supports prefer to remain in their homes and to "age in place." What do YOU want for yourself, for other family members? Tell your legislator!
- Home-based services DO work for older Americans.
- Although people in nursing homes do tend to be elderly (average age: 84 years) many older Americans are living in their own homes and communities with the help of community services and supports, but these programs are very limited.
- Some Americans diagnosed with Alzheimer's are cared for at home, but both the individual and the family members need appropriate supports, which the Community Choice Act could provide.
- Family members can't do it all, need help. The Community Choice Act is the answer!

Talking Points

1) The demographics of our country are changing. More and more people with disabilities are living, and could be thriving! Reasons for these changes include:

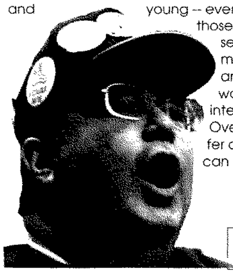
- a) the aging process, the graying of America,
- b) children born with disabilities are living,
- c) young adults, who previously would have died from accidents or illnesses, are living -- thanks to medical technology and other advances.

2) Our long-term service system must change. Created over forty years ago, it is funded mainly by Medicare and Medicaid dollars, medical dollars not originally meant to meet people's long-term care needs. We must think out of the box to empower people and allow REAL choices.

3) The money should follow the individual, not the facility or provider. A national long-term service policy should not favor any one setting over the other. It should let the users choose where services should be delivered. Our current system is not neutral, and it doesn't reflect people's choices.

4) The current system is needlessly expensive. We must explore cost-effective ways to meet people's needs.

5) People with disabilities -- both old and young -- even those with severe mental and/or physical disabilities want services in the most integrated setting possible. Overwhelmingly people prefer community services so they can stay in their own home.



Community services have been shown to be less expensive on average than institutional services, and better liked by individuals.

In FY 2005 67% of our total $94.5 billion long term care Medicaid dollars ($63.3 billion) are spent on nursing homes and other institutional services, leaving only 33% ($31.2 billion) for all community services (waivers, personal care, home health, etc.)

6) People with disabilities and their families want REAL choice, which means:

- a) equitable funding opportunities,
- b) no programmatic or rule disincentives to community services, and
- c) options for services delivery which include agency based services, vouchers, and fiscal intermediaries.

The Community Choice Act empowers people with disabilities and families.

7) Family values keep families together

- a) children belong in families
- b) Mom and dad together with the grandchildren
- c) communities take care of their own.

8) Money following the individual can eliminate overburdening government rules and regulations.

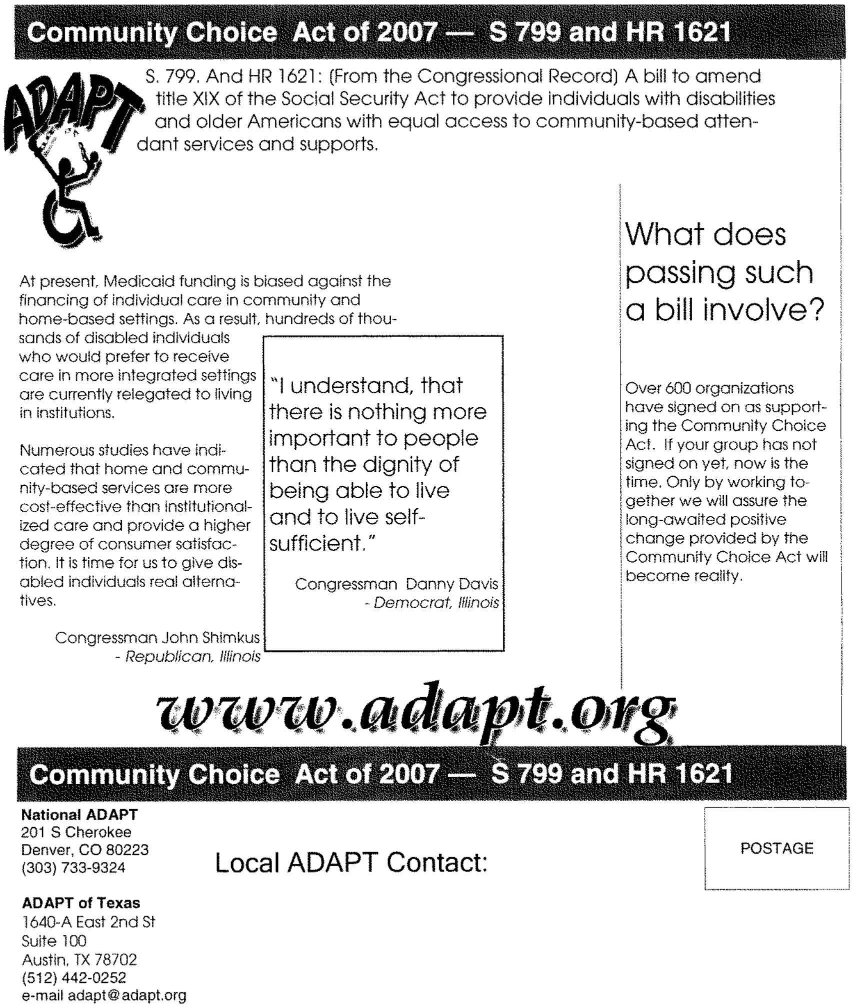
9) A functional system based on need instead of medical diagnosis could end FRAGMENTATION of the service delivery system.

10) Keeping people in the community allows the possibility for individuals with disabilities to train for work so they can become TAXPAYERS instead of TAX USERS.

11) The federal government needs to work in partnership with the states to create flexible delivery systems that give people REAL choice.

12) Change can cause fear of the unknown. Some long time providers of services and families believe REAL choice would threaten what they have. We cannot continue the system as it is today; it is expensive, fragmented, overly-medical and disliked by almost everyone.

There's No Place Like Home!



Community Choice Act of 2007 — S 799 and HR 1621

S. 799. And HR 1621: (From the Congressional Record) A bill to amend title XIX of the Social Security Act to provide individuals with disabilities and older Americans with equal access to community-based attendant services and supports.

At present, Medicaid funding is biased against the financing of individual care in community and home-based settings. As a result, hundreds of thousands of disabled individuals who would prefer to receive care in more integrated settings are currently relegated to living in institutions.

Numerous studies have indicated that home and community-based services are more cost-effective than institutionalized care and provide a higher degree of consumer satisfaction. It is time for us to give disabled individuals real alternatives.

Congressman John Shimkus
- *Republican, Illinois*

> "I understand, that there is nothing more important to people than the dignity of being able to live and to live self-sufficient."
>
> Congressman Danny Davis
> - *Democrat, Illinois*

What does passing such a bill involve?

Over 600 organizations have signed on as supporting the Community Choice Act. If your group has not signed on yet, now is the time. Only by working together we will assure the long-awaited positive change provided by the Community Choice Act will become reality.

www.adapt.org

Community Choice Act of 2007 — S 799 and HR 1621

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POSTAGE

Questions Submitted for the Record to Bob Liston

United States Senate Committee on Finance Public Hearing
"Home and Community Based Care: Expanding Options for Long Term Care"
September 25, 2007

From Senator Smith

Question: As you may know, my home State of Oregon is one of the few states that are almost even in terms of spending Medicaid funds on institutional versus community care. In fact, for physical disability funding, my state is one of just a few that spends less on institutional services than community services. As a former state Senator, I've not often been persuaded that mandates are the best policy – particularly when some states are putting to use the authorities already available. Therefore, do you believe, using Oregon as an example, that there are other ways to encourage states to serve more people in their communities?

Answer: The great state of Oregon is to be commended for its work in the area of community-based services and supports, especially when Oregon's progress has occurred by trying to find creative ways around the decades-old mandate for Medicaid to fund institutional services. I am convinced that Oregon has made the gains it has because the state listened to its citizens when they communicated repeatedly that they preferred to live in the community and receive needed services and supports in their own homes. Oregon has allowed its older and disabled citizens to have more choice in where they wanted to live, and as you so rightly pointed out, a growing majority of those citizens have firmly chosen their own homes and communities.

Oregon thus is a perfect example of why the Community Choice Act (CCA) is needed. The CCA would provide nationally what Oregon and a few other states have attempted to provide . . . *i.e.,* CHOICE in where to live and receive long-term care services and supports. Despite the "optional" efforts of Oregon and the other states, nationally a funding bias remains, with 67% of the Medicaid funding going to institutional settings, and only 33% going to the community. The Community Choice Act is one tool to "level the playing field" at the very least. As those of us in the baby-boom generation needing long-term care services and supports grow to tsunami size in the next 10-20 years, it would seem ill-advised economically to continue mandating funding for the most costly services, rather than allowing people to choose community if they so desire.

It seems to me that there are two main factors that can motivate states to serve more people in the community. The first is cost-effectiveness and efficient use of public dollars, or, in the vernacular, getting the "biggest bang for the buck." At the present time, because of the institutional bias in our nation's Medicaid program, the institutional service providers have a virtual monopoly on state funding and the federal dollars they leverage. And when states are under budget constraints, it is home and community services (and other services currently labeled as "optional") that can be limited, frozen or cut while the state is mandated to continue to fund the institutional services. For the same amount of money, a state can fund many more people in the community than it can in institutions. Since the whole system is already underfunded and Medicaid dollars are becoming more scarce, it only makes sense to fund what the vast majority of people want – home and community services.

The second motivating factor is the voice of the public. That voice is heard both in requests to the policymakers for community-based services and supports, and in the selection of community when people are given a choice about where they want to receive their long-term care services and supports. When states respond to the community-based preferences of their citizens, and share the responsibility for good stewardship of public dollars with those same citizens, the outcome is win-win, and avoids unnecessary legal remedies.

A few months ago, at Montana's yearly Senior Citizen's Association Conference, there was a survey taken by the Montana Home Choice Coalition that asked questions about affordable housing, universal design in housing, and also about where people wanted to live when they came to need assistance. 100% of the respondents said they wanted to remain living in their own homes, and they thought that Medicare and Medicaid should prioritize community-based care over institutionally based care. I suspect that the seniors in Oregon would give very similar answers.

Question: Your testimony about your friend Gail was very powerful. It certainly reinforces the possibility of unwanted institutionalization that can arise when persons are not given the choice to live in their communities. What steps did Gail and her family take to finally get to the point where she gained the needed supports to transition out of the nursing home?

Answer: Gail was and continues to be an amazing woman. My wife, Marsha, first met Gail in the early 1980s when she went to high school with Marsha's younger son Steve (Steve and Gail graduated together in 1985). At the time Marsha was working for an organization called the Association for Community Advocacy (ACA) in Ann Arbor, Michigan. ACA is a local Arc that serves people with all developmental disabilities. While Gail had a perfectly typical intelligence, her cerebral palsy, one of the developmental disabilities, qualified her for services from ACA and the developmental disability service system in Michigan.

Marsha was alerted to Gail's situation by a co-worker who was a school-based advocate for students with developmental disabilities. As Marsha and several of her co-workers began to visit Gail in the nursing home where she lived, they got to know her very well. Gail had limited ability to communicate verbally, but with the aid of a pencil, a narrow pad of paper, and enough time, she was quite capable of communicating her wants and needs and fears and hopes and dreams.

The repeated, wrenching sight of Gail uncovered and on display at the nursing home spurred Marsha and her co-workers to help Gail change her living situation and have the life she deserved. In addition, Gail herself communicated repeatedly that she hated the nursing home, and suffered many other indignities daily, as well as being put in many unsafe and hazardous situations. Clearly, things had to change, and so this tiny non-profit organization dove into the realm of nursing home emancipation . . . not because the staff knew what to do, but because it simply needed to be done.

By this time Gail was 18, and legally an adult. She didn't need her mother's permission to move, although her mother was immensely grateful when Gail was able to leave the nursing home.

Some of the steps that ACA took to assist Gail included first moving her into a group home they ran at the time. While that was not the most preferable outcome, in 1985 it was the one that could occur the most quickly, and still assure that Gail would have the assistance she required. Then, starting in 1985, as ACA divested itself of its group homes and began to assist people with even the most significant disabilities to move into their own apartments and houses, Gail was at the top of their list.

ACA staff helped Gail sign up for Section 8 housing assistance, took her to visit apartments until one that was accessible, affordable and on the bus line was located, and then planned for the transition. They partnered with Gail to list her needs for physical assistance and to establish an assistance schedule that worked for her. They helped her shop for furniture, and other items she needed to set up a household. ACA staff members also partnered with her to interview and hire her attendants, and then arranged to get everything moved into her new apartment.

I began to work at ACA after Gail had moved into her apartment, and I also became fast friends with her. On many occasions I met with Gail to help her problem-solve issues with her attendants, or assist her with the resources she needed to achieve her dreams. Gail continued on in school, attending the local community college. She has a boyfriend, regularly attends church and many community events, and spreads light and joy wherever she goes.

ACA has assisted many individuals who needed even 23-24 hours of support/assistance a day to live in their own homes with the services and supports they required. In some cases, where a parent might have been appointed as guardian, the move to community was facilitated by introducing the parent to the "disability-twin" of their son or daughter who was living in the community. When these loving, but frequently skeptical parents saw that someone with their child's disability (or even more disabled) was having a good, safe, meaningful and typical life in the community, they almost always chose community for their son or daughter.

In fact, one such set of parents even asked to be part of a video that ACA made to show how people with even very significant disabilities could live in the community with the services and supports they need. They wanted the opportunity to tell other parents that where they once refused to let their son Don live in the community, they now marvel at his life, and wish they had helped him make the move sooner.

These parents, and others like them, now have the peace of mind that their son is truly "connected" in the community . . . to friends, co-workers, neighbors and other people who are not paid to be in his life, including his siblings. These are the people who will continue to assure that Don has a good life when his parents are no longer around. The same can not be said for institutional (and sometimes even group home) settings where staff change, where the public never sees what goes on behind closed doors, and where only the illusion of safety is present.

Statement of Senator Gordon H. Smith
"Home and Community Based Care: Expanding Options for Long Term Care"
September 25, 2007

As a member of the Finance Committee and the Ranking Member of the Aging Committee, the quality and availability of long-term care has long been of great concern to me. My home State of Oregon has been a strong national leader in the provision of care in communities for persons with disabilities. I believe that it can be a good model for other states in providing quality care in a cost-effective way.

The Centers for Medicare and Medicaid Services estimate that national spending for long-term care was more than $190 billion in 2004, representing about 12 and a half percent of all personal health care expenditures. While those numbers are already staggering we also know that the need for long-term care is expected to grow significantly in coming decades. Almost two-thirds of people receiving long-term care are over age 65, with this number expected to double by 2030. We also know that the population over 85, those most likely to need long-term services and supports, is expected to increase more than 250 percent by 2040 from 4.3 million to 15.4 million.

Today, millions of Americans are receiving or are in need of long-term care services and supports. This population not only consists of the elderly-disabled – in fact, more than 40 percent of persons receiving long-term care are between the ages of 18 and 64. Some were born with disabilities; others came to be disabled through accident or illness. For those of us that are healthy, we cannot know when such accident or illness will strike. That is why we owe it to ourselves and our families to prepare.

I also strongly believe that the passage of Mental Health Parity legislation will help persons with mental illness to get the help that they need in their communities. This is such an important bill and I am so grateful to my Senate colleagues for passing this measure last week. I hope that we can quickly work out the differences with the House and send this to the President as soon as possible.

Ensuring that persons with disabilities are able to get back to work and are treated fairly in our welfare system also is of great importance to me. States currently face a conflict between the new federal TANF requirements and the nondiscrimination requirements of the Americans with Disabilities Act (ADA).

This year, I introduced S. 1730, the Pathways to Independence Act of 2007. My legislation encourages states to engage persons with disabilities in appropriate employment-focused activities without fear of facing federal penalties for not meeting their TANF work rate.

It also is important to me that low-income persons living in their communities can appropriately access necessary medications. Unfortunately, currently under the Medicare Drug Benefit, the financial assistance it provides to the most vulnerable beneficiaries is not available to all those who need it. That is why I filed the Home and Community Based (HCS) Copayment Equity Act.

As it stands, Medicare Part D waives the copays for some low income beneficiaries, but not others on the basis of where they choose to receive long-term care services. My bill corrects this inequity and further supports older Americans' right to choose the care environment that best meets their personal health needs.

Further, we know all too well that planning for the likelihood of disability in young or old age is not done as early or often as it should be. Too often, insurance is not purchased, funds are not saved and persons with disabilities are forced to rely on Medicaid for their daily care.

I introduced the Long-Term Care Trust Account Act of 2007 with Senator Lincoln this year to help individuals plan for their future by encouraging savings for long-term care services and long-term care insurance. I look forward to continuing to work with you all on these important issues. Senator Lincoln and I also introduced the Long-Term Care Quality and Modernization Act to ensure that persons who are in long-term care facilities receive the best care possible.

Thank you, Chairman Baucus and Ranking Member Grassley, for holding this hearing today to ensure persons with disabilities can remain independent and live healthy lives in their communities.

Senator Debbie Stabenow
Statement for the Record

United States Senate Committee on Finance

"Home and Community Based Care: Expanding Options for Long-Term Care"
September 24, 2007

Thank you, Chairman Baucus and Senator Grassley, for holding this important hearing on financing long-term care options. I first came into politics because of a long-term care issue in Lansing, Michigan. The issues surrounding long-term care have remained with me for the past thirty years.

Recently I met with a diverse range of groups—from community advocates to nursing home associations to health insurers—who are concerned not only about long-term care but about the financial stability of Medicaid, the largest funding source for long-term care services.

As our nation ages, long term care is going make a huge impact in how our health care system operates. Today, more than seven million people need long term care, but this is estimated to grow to more than 12 million older Americans who are expected to need long term care by 2020. The growth in long-term care needs is having a huge effect on our federal budget and on our families.

Part of our challenge must be educating people about planning for the future. According to Geneworth Financial, 65 percent of Americans admit to having made no long term plans for themselves or a spouse, and less than 10 percent of people nationwide have purchased long term care insurance. Many people fail to save for any potential long term care needs because they mistakenly believe that Medicare will cover these expenses.

Let me offer one example as to how Medicaid's long-term care services are helping a family in my home state. In 2001, Russell Faunce had an accident that left him disabled. His wife Irma became a round-the-clock caregiver, helping her husband with tasks such as personal care, getting meals, managing medication, and overall supervision, despite facing her own health difficulties.

Through Michigan's Medicaid program, Irma can continue her care-giving duties by receiving 16 hours per month of respite in her home. Irma says, "It can be a challenge when he doesn't sleep well at night, but I am happy I can help my husband be in his own home."

Meeting this challenge to help more families like the Faunces is not going to be easy, but together we can strengthen Medicaid to help all families and create the needed long-term care services for the future.

COMMUNICATIONS

Senator Max Baucus
Chair, Finance Committee
U.S. Senate

September 21, 2007

Dear Senator Baucus,

I am writing to you regarding Senate Bill 799, the Community Choice Act.

I am the Youth Leadership Coordinator for Access Living, the Center for Independent Living for metropolitan Chicago. I strongly support the Community Choice Act because it will provide non-institutional options for many of the disabled young people that I work with, who are all between 16 and 25 years old. Post-high school, they and their parents are waging and LOSING bureacratic wars to keep them out of institutions, because they have no access to community supports. Imagine spending some twenty years fighting to keep your child at home, then losing all you fought for because there is no support option outside of institutionalization. The day these kids graduate high school is the day their lives are taken away. It's just a matter of time and bad circumstance.

10.7 million people with disabilities need assistance with the activities of daily living (http://www.census.gov/Press-Release/www/releases/archives/facts_for_features_special_editions/010102.html). We are seeing an increase particularly in younger people with disabilities who need this level of assistance. The Medicaid health care system is going to be completely overwhelmed and overspent if action is not taken now. Senator Baucus, you can provide more people with more options for less money by supporting the Community Choice Act.

Sincerely,
Amber Smock

Amber Smock
Youth Leadership Coordinator
Access Living of Metropolitan Chicago
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COMMENTS TO THE SENATE FINANCE COMMITTEE

"ENDING THE INSTITUTIONAL BIAS IN LONG TERM CARE FUNDING"

Tuesday, September 25, 2007

THE ADAPT COMMUNITY
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THE ADAPT COMMUNITY COMPREHENSIVE LONG TERM SERVICES AND SUPPORTS REFORM

REAL PEOPLE – REAL VOICES

No More Stolen Lives

A Proposal to Reform the Institutionally Biased Long Term Services and Supports System

- **Disability is a "normal" part of life (children, young adults, older folks);**
- **Demographics expanding at all age levels;**
- **Cure versus care debate;**
- **Current paradigm – Disabled people are broke - Society will fix us;**
- **Need to convert from "medical" to a "social" model of support services;**
- **Long term care system almost 40 years old – Social Security Act – Title XVIII and Title XIX (Medicare/Medicaid) passed in 1965;**
- **Fragmented – Based on disease categories instead of function;**
- **Services following the funding stream instead of needs of individuals;**
- **Inequitable – System creates winners and losers;**
- **Medically focused due to Medicare/Medicaid funding;**
- **Entitlement only to nursing home services and defacto entitlement to ICF-MR services;**
- **67% of Medicaid long term care funding go to institutional services leaving only 33% for all community based services.**

- **Barriers to change:**

1. **Support services versus program services mentality; Receive whole package of services to get the piece we need to be as independent as possible;**
2. **Political inertia – incremental vs. comprehensive reform strategies;**
3. **Industries have developed around the "caring for" disabled and older people with so many "special interests" that reform seems to be politically impossible; Disabled people have become a crop to be harvested for economic gain by professionals and providers;**
4. **Consumers/advocates fear of losing what we have; Win the rhetoric war but lose the $$$$$$;**
5. **Identity politics: Developmental Disabilities versus Aging versus Mental Health versus Physical Disability versus Sensory Disabilities; Circle the wagons mentality;**
6. **Health care liability – Little "risk management"- Dignity of risk - Choice**

Comprehensive Reform Strategies

1. **Community Choice Act – S.799, HR 1621**
2. **Implementation of National Money Follow the Person policy;**
3. **Implementation of Olmsted decision – President's Executive Order;**
4. **Comprehensive Medicare/Medicaid/Social Insurance Reform – Development of a National Social Model of Services and Supports;**
    a. **National Long Term Services and Supports program that includes heath maintenance services RATHER THAN health care program including long term services and supports.**

Short Term Steps to Comprehensive Reform:

1. **Level nursing home entitlement; Allow equitable choice for community services; Passage of S.799 H.1621 Allows people real choice!**
2. **Consumer direction and person centered planning in all community programs including all managed care proposals to integrate acute and long term services and supports;**
3. **Transition from categorical funding based on age and/or disability label to a functional system based on need;**
4. **Define health and safety that recognizes the dignity of risk and allows for negotiated risk;**
5. **Promotion of nurse delegation/assignment for health maintenance activities;**
6. **Aggressive outreach for community workers that are paid a livable wage and benefits;**
7. **Quality measurement based on consumer satisfaction and community integration evaluators;**
8. **Coordination of support services and accessible, affordable, integrated housing; (Access Across America) Funding of "Housing Coordinators".**

Long Term Comprehensive Reform

Long term services and supports need to be considered as a funded entity in of itself rather than as a component of only health care funding. Medicaid/Medicare funding has focused on acute/insurance services with long term services and supports considered as a stepchild. Specific and dedicated funding needs to be allocated to create a National Long Term Services and Supports Program (NLTSSP) by combining LTSS funds currently in Medicaid, Medicare, Older Americans Act along with a new individual contribution program.

Attachments: 2005 Medicaid Data; ADAPT Definition of Consumer Control;

The ADAPT Community
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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%***

##

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

ADAPT Definition of Consumer Direction

As it relates to program design for community attendant services and supports, consumer direction means the right of the consumer to select, manage and dismiss an attendant.

The consumer has this right regardless of who serves as the employer of record, and whether or not that individual needs assistance directing his or her services.

This includes but not limited to delivery systems that use:

Vouchers
Fiscal intermediaries
Agencies that allow choice (Agencies with Choice)

Concept included in Community Choice Act
S. 799 H 1621

Alliance
for Retired
Americans®

Testimony of the
Alliance for Retired Americans

Hearing on Home and Community Based Care:
Expanding Options for Long Term Care

Finance Committee
United States Senate
September 25, 2007

The Alliance for Retired Americans commends the Senate Finance Committee for holding a hearing on expanding options for home and community-based services in long-term care (LTC). Founded in 2001, the Alliance is a grassroots organization representing more than 3 million retirees and seniors nationwide. Headquartered in Washington, D.C., the Alliance's mission is to advance public policy that protects the health and economic security of older Americans by teaching seniors how to make a difference through activism.

Long-term care reform is not a new concept in Congress and particularly in the Senate. During the past several decades, advocates and policymakers have attempted to bring long-term care to the forefront of public awareness. In the 1970s, the Senate Special Committee on Aging Subcommittee on Long-Term Care conducted investigations and hearings on the quality of care in nursing homes and in the community. Later, the Long Term Care Campaign, a coalition of aging and disability organizations, succeeded in making long-term care an issue in the 1988 presidential primary campaigns and subsequent congressional elections. And 17 years ago this month, the bipartisan and bicameral Pepper Commission, named in honor of Congressman Claude Pepper, released a blueprint for long-term care reform.

On behalf of our members nationwide, the Alliance for Retired Americans hopes that today's hearing will finally result in action. Action is needed to assure that this nation's 10 million individuals with disabilities, chronic illnesses, or ongoing limitations in their daily activities will receive the range of medical, personal and social services they need to function independently and in the setting of their choice.

Public Support for LTC Improvements

The Alliance released a poll, conducted by Lake Research, earlier this month on issues important to voters age 65 and older in the upcoming election year. Over half (52%) of the respondents said that they were 'very or somewhat worried' that all of their savings would be wiped out on paying for their long-term care costs. When asked what Congress should do to address the range of health care needs—making long-term care more affordable ranked among the highest responses along with guaranteeing all Americans health care, and controlling rising health care costs.

The 1,200 delegates to the 2005 White House Conference on Aging (WHCoA) had two top resolutions and policy recommendations. First, the delegates recommended swift reauthorization of the Older Americans Act. Second, they recommended that the government develop a coordinated, comprehensive long-term care strategy that addresses financing, choice, quality, service delivery and the paid and unpaid workforce. The WHCoA delegates were able to recommend an additional twenty priority recommendations for LTC reform including: training for the health care workforce, promotion of innovative models of non-institutional LTC, a national strategy for supporting informal caregivers, and long-term care financing models.

In a poll conducted for the National Academy of Social Insurance, baby boomers and the generations before them say they are concerned about paying for LTC, and that the current system needs major improvements or an overhaul. Nearly three-quarters of Americans over age 40 are concerned either a 'great deal' (54%) or a 'fair amount' (18%) about paying for LTC. Over half (53%) say that addressing LTC costs should be a 'high priority' for the nation, including 34% who say it should be a 'very high priority.' [1]

The increasing numbers of Americans who will need LTC in the future, and the costs of such associated that increase, make it imperative that we raise the political and public profile of LTC to an immediate national priority. Currently our financing and care delivery model of LTC relies heavily on the Medicaid program, which has become the primary source of public funding for LTC. Ironically, many individuals do not realize that in order to qualify for government assistance through the Medicaid program, they must deplete their financial resources. Additionally, many see the significant expense of LTC insurance as unreliable and exorbitant. These issues add urgency to addressing LTC as a public policy issue. Consequently, the recent poll found that seven in ten baby boomers and seniors feel that the current system of paying for LTC expenses needs a complete overhaul (41%) or major improvements (30%). The same percentage believes government should do more to help people meet the costs of LTC.[2]

Who Needs Long-Term Care?

The need for LTC ranges from those who use occasional help to those who require intensive or round-the-clock care. Trends indicate that one in four persons over the age of 25, and 40% over age 65 will have at least one stay in a nursing home during their lifetime. One in five individuals requiring LTC do not receive the services they need, and nearly 20% of family caregivers say they need help with their caregiving responsibilities that they do not receive.[3] Although the probability of needing LTC increases with age, nearly four in ten (38%) of those who need LTC services are under age 65. Over 80% of those with long-term care needs live in the community.[4]

Who Provides Long-Term Care?

We know that the vast majority of LTC recipients reside in the community—the focus of today's hearing. Three out of four Americans age 50 and older prefer to remain in their own homes to receive services.[5] The human element of LTC is very important; most LTC is hands-on and low-tech. More than three-quarters (78%) of LTC recipients living in the community rely solely on family and friends to provide the assistance they need. Eight percent receive care exclusively from paid staff and 14% from both paid and unpaid care.[6]

Aging and Disability Resource Centers (ADRCs) serve as a single point of entry for accessing LTC services. These have been successful models for assisting individuals with finding the appropriate service. The Alliance supports expansion of ADRCs into every state as called for in the 2006 Older Americans Act (OAA) reauthorization.

Family and Informal Caregivers

Families play an incredible role in providing care. There are an estimated 44.4 million individuals—one in five adults— providing health care for adult family members and friends.[7] While the participation of men as family caregivers is higher today (39%) than in earlier studies (25%), the bulk of caregiving responsibilities still falls on women who spend more hours caregiving per week than men.[8] It is anticipated there will be fewer family caregivers in the future partially because the fertility rate of baby boomer women is lower than previous generations[9] and the number very old population needing LTC will increase faster than the population who would traditionally care for them. Between 2000 and 2025 the population age 85 and older will more than double while the traditional caregiving population—women age 20-54—is projected to increase by just 9%.[10] It is not realistic to continue to depend on family caregivers as the future anchor of caregiving. Their numbers are fewer and they do not receive sufficient support and respite.

Many family caregivers have no preparation or training for the work that is involved. Studies show that as individuals grow older, they count on having a family member as a caregiver, should they need it. However, significant proportions do not talk to their potential caregiver about the prospect. In one study of older women, four in ten cited their husband as a potential caregiver but one quarter had not spoken to their spouse about arrangements. One third listed daughters as a potential caregiver yet 19% had not discussed the matter with their daughter.[11] Only half of older parents with adult children have talked to their children about their future long-term care needs. Similarly, only half of older married couples have talked to each other about their own long-term care needs. The conversation between family caregivers does not regularly occur because: 47% of people believe that the conversation is not necessary as they expect to live independently for quite some time; and 23% said that their children have too many of their own responsibilities and not enough time nor money to help their parent.[12]

Consequences of Caregiving

Caregiving often takes a heavy toll on the caregiver. In one study of working caregivers, 56% have health problems of their own, a third lack health insurance, and three out of five are stressed by medical bills. One-third of employed caregivers miss more than one week of work during the year and employers may lose as much as $29 billion per year in productivity.[13]

The National Family Caregiver Support program, established by the 2000 OAA Amendments, is a federally-funded program that provides grants to states to make information and support services—such as counseling, support groups and training, and respite services--available for family caregivers. The 2006 reauthorization of the OAA expanded the program to include caregivers of adult children with disabilities, caregivers of persons with dementia of any age, and grandparents age 55 and older caring for grandchildren. Increased funding was also authorized. However, funding for the program is still insufficient to bring the services to the thousands of caregivers who need it.

The National Family Caregiver Support program must have expanded funding in order to provide authentic respite. The Alliance for Retired Americans endorses national enactment of financial and other supports for family caregivers, including but not limited to, affordable health insurance, adequate provisions for respite, expansion of family and medical leave options, and guaranteed retirement security for those who leave the workforce for a loved one.

Formal Caregivers

Home health aides, personal care aides, and nursing home aides are the front line workers in delivering LTC. Yet, LTC workers have few protections in the health field themselves—over half have no health insurance or pension coverage. Workplace injuries or illnesses for these workers are twice that of workers in all private workplaces (10.1 versus 5.0 per 100 workers). Ninety percent of these workers are women, half are non-white, and one in three are unmarried with children. Most intentionally choose direct care work because of a desire to help people and an interest in working in health care.[14]

The National Governors Association (NGA) acknowledges that these direct-service workers face poor working conditions, earn low wages (the wages for personal and home health aides average between $8.05 and $8.75 per hour), receive few benefits and generally lack knowledge about public benefits.[15] As a result, staff turnover rates are high, and the vast majority of workers leave their jobs within the first few months of employment. Improvements in these areas are essential not only to the quality of life for the workers but also continuity and quality of care for the care receiver.

Identifying and Recruiting Future Formal Caregivers

Who will be the LTC caregivers in the future and where will they come from? A long-term care system that provides quality care requires a workforce that is well trained, compensated with adequate wages and benefits, and with opportunities for advancement. Aggressive measures must be undertaken to recruit and retain LTC workers, otherwise substantial shortages of home health aides and nursing aides will occur in the next several years. Between 2002 and 2012, the number of available paid caregiving jobs are projected to increase at a much higher rate than employment in the overall labor market—48% increase for home health aides, 25% for nursing home aides and 41% for personal aides in contrast to a 15% increase for all other occupations. Yet the number of workers who fill these jobs are expected to increase only slightly further exacerbating current shortages.[16]

There are steps Congress can take now to improve opportunities and the working conditions of caregivers. As an initial measure, the Alliance for Retired Americans supports "The Fair Home Health Care Act," S. 2061 and H.R. 3582, introduced by

Senator Tom Harkin and Representative Lynn Woolsey, respectively. This legislation will provide home health care workers at least the overtime and minimum wage protections under the Fair Labor Standards Act that other domestic workers have. In addition, the Alliance supports an employer of record for home health care workers in order to ensure proper training and delivery of quality care.

Paying For Long Term Care

LTC expenditures may be minimal to costly, depending on the setting and extent of care. Some observers have suggested that it is more affordable to live permanently on a cruse ship than in a nursing home. According to a 2006 survey, the national average cost of a private room in a nursing home is about $70,900 a year. Four hours daily of home health aide services would total about $36,500 annually.[17] National expenditures, including unpaid caregiving and out-of-pocket spending by care receivers and their families, amounted to over $207 billion in 2005. If donated care as well as out-of-pocket spending are taken into account, then recipients and their caregivers "pay for" 57% of LTC.[18]

Excluding donated care, which is typically community-based or in the home, about two-thirds of expenditures are for institutional – or "formal"- long term care. Public programs such as Medicaid and Medicare pay for over two-thirds of this institutional formal long-term care. Medicaid alone pays for nearly half. As a jointly funded federal-state program, Medicaid was identified as the major source of nursing home payments and increasingly the major source for home and community-based services (HCBS) for low-income individuals or those who become eligible after exhausting their financial resources.

Although the majority of Medicaid spending is for nursing home care, Medicaid expenditures for home and community-based services are increasing through HCBS waivers, which the Alliance supports. Non-institutional care accounted for 37% of Medicaid's LTC spending in fiscal year 2005, compared with 19% 10 years earlier.[19] According to the National Academy of Social Insurance, 75% of HCBS spending is for individuals with mental retardation or developmental disabilities with the remaining 25% for aged or disabled individuals.[20]

Medicaid, however, is not an efficient, compassionate, or comprehensive strategy for LTC services. Recipients must spend down all their assets to qualify, making them permanently dependant on the system. Additionally, the National Governors Association emphasizes that states are struggling to bear the primary public role of financing LTC services and stresses Medicaid cannot continue as the primary funding mechanism.[21] Finally, Medicaid funding also faces annual budget uncertainty in Congress.

The Medicare program covers limited nursing home care; up to 100 days following three days of hospitalization, or days at home for those requiring part-time skilled nursing or therapy services. Medicare's services are designed to help beneficiaries recover from acute illness rather than provide LTC.

LTC insurance is still not a major source of funding for LTC services. Currently only about 6.5 million policies are in effect. Availability and affordability are major shortcomings of LTC insurance. For example, it is not available to older, as well as younger, people who already have LTC needs. All policies currently sold exclude those with pre-existing conditions; overall about one in 5 applications. Nearly 60% of individuals over 80 who apply are declined coverage.[22] The average annual premiums for a 65-year-old are $2,862, making insurance beyond reach for 80-90% of seniors.[23] Despite tax incentives and the limited benefits, public demand for LTC insurance is very low. The CBO projects that the proportion of LTC spending that private insurance will pay will rise to only 17% in 2020 from 3% of total LTC expenditures in 2004.[24]

Alliance for Retired Americans Position on Long-Term Care

In the future, LTC costs must be distributed more equitably than they are currently. Care recipients and their caregivers should not shoulder most of the burden out of pocket, forcing families to become impoverished to care for each other. Therefore, the Alliance for Retired Americans supports a social insurance model for a long-term care system that incorporates the following principles:

- A range of quality care services including but not limited to the following services and settings that enhance the physical and mental well-being of recipients and their caregivers:
  - Skilled nursing care
  - Rehabilitative services
  - Respite care
  - Personal assistance with activities of daily living
  - Congregate living arrangements
  - Adult day care services
  - Home care
  - Hospice care
- Affordable care based on health and physical needs, not income levels;
- An individual's right to choice of provider and care environment, including one's own home;
- Enforcement of quality assurance measures;
- Educational efforts to promote informed decision-making by individuals and families including an examination of available options for types of care and settings, as well as financing options and eligibility criteria;
- Recognition of the essential role of front line long-term care workers in ensuring quality care through improvements in nursing home staffing ratios, staff and management training, fair pay, health, pension and other benefits, career advancement and other incentives, and safety protections for all health care workers; and
- The right for all long-term care workers to organize, bargain collectively for better pay, health and retirement benefits, and training with provision for effective enforcement.

The Alliance for Retired Americans supports many of the provisions in the Community Living Assistance Services and Supports Act (CLASS Act) of 2007 (S.1758, H.R. 3001). The CLASS Act creates a national insurance system for providing a cash benefit to eligible individuals to purchase the LTC services they need after they have contributed to the system through payroll deductions for a minimum of 60 months or five years. However, even if enacted tomorrow, the CLASS Act will not help those who currently need LTC assistance. Also, it excludes those with disabilities unable to establish a 5-year work history, and it does not ensure benefits and protections for LTC workers.

Additionally, the Alliance encourages its state and local affiliate organizations to participate in the development of state long-term care policies that incorporate the Alliance's principles above where possible. The Alliance rejects proposals that would divert development of a comprehensive long-term care system by substituting expensive federal tax credits and tax deductions for private long-term care insurance.

Conclusion

Access to appropriate and affordable long-term care is a right of all individuals. Many stakeholders are invested in the current long-term care "system" in place: federal, state and local governments, employers, private programs, and individuals and their families. However, this has resulted in a fractured system. Any LTC policy should focus on helping caregivers and those who are not obtaining LTC assistance to ensure that services are available and affordable wherever one lives. A social insurance approach best addresses all of these concerns.

The time for action by Congress is now. As individuals face the growing daily struggle of finding affordable services they need, or coordinating care for a loved one, the public demand for support and action will grow. The Alliance for Retired Americans, and our affiliates and advocates throughout the country, will work to make long-term care a critical national issue by raising it before Congress, in the states, and during the coming election campaigns.

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[20] National Academy of Social Insurance. November 2005.

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[24] Congressional Budget Office. April 27, 2005.

aahsa
creating the future of aging services

Written Testimony to the
Senate Committee on Finance
Home and Community-based Care: Expanding Options for Long term Care

Peter Notarstefano, Director of Home and Community Based Services
American Association of Homes and Services for the Aging
September 25, 2007

On behalf of our members, their residents they serve and their families, the American Association of Homes and Services for the Aging (AAHSA), appreciates the opportunity to submit written testimony for the Senate Committee on Finance hearing on Home and Community-based Care: Expanding Options for Long-term Care. The members of the American Association of Homes and Services for the Aging help millions of individuals and their families every day through mission-driven, not-for-profit organizations dedicated to providing the services that people need, when they need them, in the place they call home. Our 5,700 member organizations, many of which have served their communities for generations, offer the continuum of aging services: adult day services, home health, community services, senior housing, assisted living residences, continuing care retirement communities and nursing homes. AAHSA's commitment is to create the future of aging services through quality people can trust.

Home and community based services include adult day care, home health care, hospice care, PACE, senior centers, transportation services and a variety of other community-based supportive services. Supporting seniors and the disabled in their homes through community-based care offers a cost-effective alternative to premature institutional care. These services make it possible for seniors to remain in their homes independently, or with the assistance of long-distance and working family caregivers.

The demand for these services far exceeds the availability. Most services are funded with federal dollars through Medicaid waivers and Medicaid state option plans, Older Americans Act programs, Social Services Block Grants, the Federal Transit Administration's Section 5310 and New Freedom programs. Medicaid waiver programs, which serve the frailest seniors, limit participation. Despite rising expenses associated with operations, most of the home and community-based services programs have been level funded, decreasing the amount of services available for seniors that need them.

The country is facing a demographic trend that we cannot afford to ignore. An estimated 83% of older Americans who have long-term care needs live in non-institutional, community settings. We know that 14% of the population is over the age of 65, and by the year 2030 this group will comprise 20% of the population and number 70 million people. Under increasing budgetary pressure brought on by long-term care costs, the federal and state governments have committed to "rebalancing" the long-term care system in order to promote and support home and community-based options over nursing home placement where possible. Unfortunately the Administration has proposed cuts to the very programs that will make the home and community based services a workable alternative to institutional care.

Older Americans Act

The Administration on Aging provides the most systematic and accessible resource for community based services needs throughout the country through the local Area Agencies on Aging (AAAs). For years, Older American's Act funding has not kept up with inflation and the growing number of older adults using these services.

AAHSA urges members of Congress to take the following steps to assure that Older American's Act programs receive adequate funding:

- Support the Senate-proposed funding of $28 million allotted under Title II for the Choices for Independence programs that include the Nursing Home diversion program and Aging and Disability Resource Centers
- Support the House-proposed funding for Title IIIB Supportive Services and Centers, which would provide a 2% increase for in-home services, adult day programs, senior transportation, and senior centers.
- Support the Senate proposed funding levels for the Nutrition programs

Lifespan Respite Care Act

The Lifespan Respite Care Act provides planned and emergency respite care to assist family caregivers of adults and children and will promote development of state respite plans. An estimated 29 million caregivers currently provide $300 billion worth of unpaid care. AAHSA urges the Congress to provide funding for the Lifespan Respite Care Act for $10 million in FY2008.

Medicare and Medicaid coverage

Medicare and Medicaid fund services that enable seniors to remain independent in their own home. We applaud Congress for including provisions in the Deficit Reduction Act of 2005 to give Money Follows the Person Demonstration grant awards to thirty states and the District of Columbia to transition over 37,600 older adults and disabled from nursing homes to a community setting. We also commend the Congress for including the Rural P.A.C.E. provider grants in the Deficit Reduction Act. These grants promote the growth of the innovative Programs of All-Inclusive Care for the Elderly in hard to serve rural areas. P.A.C.E. has demonstrated that it manages chronic diseases and reduces hospitalizations for older adults and people with disabilities living in the community who require skilled nursing care. P.A.C.E. has demonstrated how quality care can be cost-effective.

Home health agencies and adult day services programs throughout the country are providing quality care despite low reimbursement. AAHSA would like to see some of the following Medicare/ Medicaid provisions in a Senate Medicare/Medicaid bill:

- Extend the Therapy caps exception for two years to require HHS to study alternative or refined system for therapy coverage.

- Allow adult day health services in the states of California, Texas, New York, New Jersey, New Hampshire, Maryland, Massachusetts and Washington to continue providing adult day health services under the Medicaid state option plan. Adult Day Health services in these states are an important cost effective service for older adults and disabled.
- Extend the authority for special needs plans for three years.

We are urging the Senate not to include in their legislation the House-passed provisions that would freeze Medicare payment rates for home health care providers, eliminating the payment updates that have been recommended by the Center for Medicare and Medicaid Services (CMS). The Centers for Medicare and Medicaid Services (CMS) have projected that the cost of the items and services that home health agencies must buy will increase by 2.9% over the next year. Since long-term care is a labor-intensive service, failure to provide the payment update CMS as proposed will have severe implications for providers' ability to recruit and retain the staff essential to meeting Medicare beneficiaries' needs. CMS's plan to impose payment reductions at the same time that a major overhaul is being undertaken in the case-mix system will be overwhelming for many home health agencies. Not for profit home health agencies are investing in innovative telehealth technologies and continuous quality initiatives that will reduce per episode cost and increase the time staff is available for older adults and disabled in a home setting.

Community Choice Act

AAHSA members are encouraging the passage of the Community Choice Act. This legislation provides personal care services through the Medicaid state plan for older adults and people with disabilities in every state. At this time, 20 states do not offer this care in a home setting. The legislation also provides enhanced federal matching funds to help states develop their long-term care infrastructure and grant funds to help states increase their ability to provide home and community-based services. Finally, this bill creates a demonstration project to evaluate service coordination and cost sharing approaches for those eligible for both Medicaid and Medicare services.

Again, AAHSA appreciates this opportunity to submit testimony regarding Home and Community-based Care as an important component of long-term care services for older Americans. Long term care will continue to be a challenge as Congress struggles to meet the needs of a growing senior population that is living longer. We encourage the Senate to take this opportunity to strengthen the existing community based programs that serve the elderly and persons with disabilities in their homes, without resorting to premature, costly institutional settings.

If you have questions regarding this testimony or the integral role that homes and community based services programs in our long term care system, please contact Peter Notarstefano at (202) 508-9406.

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September 21, 2007

The Honorable Tom Harkin
731 Senate Hart Office Building
Washington, DC 20005

Dear Senator ~~Harkin:~~ Tom

I am writing to you on behalf of the American Health Care Association (AHCA) and National Center for Assisted Living (NCAL), which represent nearly 11,000 non-profit and proprietary nursing facilities, assisted living residences, subacute centers and homes for individuals with mental retardation and developmental disabilities that provide professional, compassionate long term care for millions of Americans.

AHCA/NCAL appreciates your efforts to ensure that individuals, especially people with disabilities, have access to the care and services they need, in the most appropriate setting. Indeed, the intent of the *Community Choice Act of 2007* mirrors the first of several guiding principles that AHCA/NCAL developed in 2006 on Medicaid reform, which reads: *Publicly and privately financed long term supports and services must meet consumers' and families' needs and be responsive to their preferences.* A complete copy of our Medicaid reform principals is attached for your information. In this letter, we detail changes that we need in order to support this legislation.

AHCA/NCAL supports consumer choice, including the right to choose where an individual will receive necessary care and services – whether that care setting is within one's home, community, an assisted living facility, a nursing home, or other type of long term care facility. Our position that individuals should receive the most appropriate care in the most appropriate setting for his or her needs echoes the landmark Supreme Court Olmstead decision that states, "…nothing in the *Americans with Disabilities Act (ADA)* condones termination of institutional settings for persons unable to handle or benefit from community settings." The U.S. Department of Health and Human Services, which offered subsequent guidance to states regarding the Olmstead decision, emphasizes that, "individuals with disabilities and their families (be afforded) the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings."

AHCA/NCAL is concerned about three aspects of *The Community Choice Act of 2007*. First, we are concerned that the new, mandatory Medicaid entitlement for community-based personal attendant care, which this legislation would create, could divert critical funding away from optional Medicaid programs such as Medicaid 1915(c) Home and Community Based Services Waivers (HCBS), state plans for personal care services, intermediate care facilities for individuals with mental retardation or developmental disabilities (ICFs/MRDD), and away from mandatory programs such as nursing facility care. In 1997, the Congressional Budget Office (CBO) scored this kind of mandatory service **at $10 - $20 billion per year,** which we believe would cause budget constraints that would result in states shifting funds from other long term care programs to pay for the mandatory Medicaid benefit.

This prospect is especially troubling given evidence that HCBS programs generally increase state long term care (LTC) spending. To illustrate, Avalere Health recently conducted a study that demonstrates that most HCBS programs increase total LTC spending and are not cost effective for state LTC budgets. The study shows that cost-effectiveness is achieved only when states target HCBS to people who would have gone into a nursing home. However, evidence of such targeting was found in only a few states and programs. According to the Avalere study, HCBS expansion has not significantly reduced demand for Medicaid-financed services in any state; in fact, evidence indicates that the presence of HCBS increased demand.

In Minnesota, for example, HCBS recipients increased nearly 80 percent from 2000 to 2006, compared to a decrease of 21 percent among nursing facility recipients. Specifically during this period, the number of HCBS recipients increased from 26,798 to 48,108, while nursing home recipients decreased from 26,419 to 20,775. In terms of spending, this translates into a 149 percent increase in HCBS expenditures from 2000 to 2006, while nursing facility expenditures were flat with an increase of less than 1 percent during the period. The *Deficit Reduction Act of 2005 (DRA)* is now attempting to introduce controls on such growth by establishing an HCBS state plan option that allows states to limit enrollment and expenditures. Despite these controls, however, the CBO counted the option as a cost—indicating that it would increase Medicaid spending by $766 million between 2006 and 2010 and $2.6 billion between 2006 and 2015.

Second, although the legislation as written would apply to all Medicaid beneficiaries, it would seem more appropriately directed toward a smaller population, including higher-functioning people with disabilities. Much like the Supreme Court's Olmstead decision cautions against reading the *Americans with Disabilities Act* to mean that states should eliminate institutional-based care; the *Community Choice Act of 2007* should not imply that all people with disabilities are best served in home- and community-based settings. Many individuals with profound and severe mental retardation, for example, may prefer to receive care and services in ICFs/MR, which are homelike settings where 24-hour care as well as basic life skills training or "active treatment" is available. A brochure that explains both ICFs/MR and waiver group homes for persons with mental retardation is included for your information. Naturally, the needs and preferences of individuals with profound and severe mental retardation and their families must remain an important consideration in developing legislation that impacts this special population. Again, AHCA/NCAL is concerned that by broadly mandating community-based Medicaid services, funding essential to ICFs/MR and their clients could be effectively reduced.

Finally, the Supreme Court Olmstead decision stated that a state's responsibility, "once it provides community-based treatment to qualified persons with disabilities, is not boundless." Under the Court's decision, States are required to provide community-based services when the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others who are receiving State-supported disability services. Yet, the legislation, as written, includes the provision, "That the State will provide community-based attendant services and supports to an individual described in section 1902(a)(10)(D)(ii) without regard to the individual's age, type or nature of disability, severity of disability, or the form of community-based attendant services and supports that the individual requires in order to lead an independent life." This provision is in direct contradiction to the protection the Supreme Court afforded to states of limiting their responsibilities by reasonableness. In order to meet this proposed legislative provision, States may need to fundamentally alter the states' services and programs, contrary to the Olmstead decision.

Like you, Senator, we support beneficiary choice, and applaud that you recognize the importance of choice and that you have articulated in *The Community Choice Act.* **We respectfully request that you take into consideration the changes mentioned in this letter as we both have the same goal in mind.** We look forward to working with you and your staff, and in partnership with key stakeholders, to affect change that preserves consumer choice when selecting the most appropriate care setting to meet an individual's needs to include facility-based care when desired and/or needed. Thank you for your consideration of these comments and we look forward to helping people with disabilities receive care the most appropriate care, in the most appropriate settings.

Sincerely,

Bruce

Bruce Yarwood
President & CEO
American Health Care Association

cc: Steve Ackerson

Enclosures

Been too long

We should get together a chat about this & other things

BY

ahca®
American Health Care Association

ncal®
National Center For Assisted Living

Principles for Long Term Care Reform
Executive Summary

Preamble

Continued Medicaid cost growth and increasing numbers of long term care users are driving states and the federal government to fundamentally reform the Medicaid program. Because long term care costs drive much of Medicaid growth, long term care reform – primarily within Medicaid reform efforts – has become a top policy priority for the federal government and most states.

In order for AHCA/NCAL to best represent member interests, a cross-cutting member work group developed a set of broad long term care reform policy principles – or essential programmatic elements – to guide or serve as a framework for AHCA/NCAL long term care policy development and reaction to federal and state proposals. The long term care reform principles build upon current AHCA long term care and Medicaid policies and will guide future AHCA/NCAL activity. Additionally, the principles also support one or more of AHCA's long term care and/or Medicaid policy goals previously developed by AHCA's Finance Subcommittee.

The member work group determined that managed care warrants its own set of principles.

The Principles

Three key principles frame a long term care program(s) that will: (a) support consumer preferences and needs; (b) foster policy efforts aimed at creating a more sustainable array of long term care financing options; and (c) provide a viable operating environment for long term care providers. Each principle includes several key elements.

Principle I. Publicly and privately financed long term care and related supports and services must meet consumers' and families' needs and be responsive to their preferences.

- *Recognize that consumers are key stakeholders in long term care policy decision making and government must include them in development, oversight and monitoring.*

- *Provide that every eligible individual who needs long term care services receives them in a timely manner in an appropriate setting, taking into account individual preferences and clinical needs.*

- *Acknowledge the key role that family care givers play and provide family care giver supports.*

Principle II. Long term care policies should promote and integrate a comprehensive array of public and private long term care financing options.

- *Encourage individuals to plan for long term care and provide viable private long term care financing options.*
- *Ensure that individuals have the tools they need to manage their long term care services as beneficiaries assume more personal responsibility for services – publicly and privately financed.*
- *Recognize the impact of reimbursement changes on long term care providers.*
- *Ensure that efficient coordination of benefits reduce administrative burdens on beneficiaries and providers.*
- *Encourage individuals, providers and government payers to engage in a policy debate on balancing public and private financing of long term care.*
- *Encourage the design of tax policies that coordinate with long term care financing strategy alternatives.*

Principle III. Through sufficient federal and state governmental infrastructure, policies should ensure that long term care service delivery systems provide an adequate array of services and administered by knowledgeable and quality driven providers across the long term care spectrum.

- *Include a strategic plan for building needed infrastructure and ensure a sufficient supply of long term care providers that engage in a variety of services to meet the needs of the population.*
- *Ensure that beneficiaries may move seamlessly among services across the long term care spectrum.*
- *Foster and support quality and efficiency in Medicaid services, as well as provide operational flexibility.*
- *Managed care plans should recognize that long term care providers deliver services that are distinct from acute care providers.*

- *Funding is adequate and timely in order to provide stability and predictability to meet the needs of long term care recipients at the appropriate time, in the appropriate place, and at the appropriate cost.*

- *Encourage development and use of a standardized post-acute assessment and benefit package to facilitate determination of patient need and placement.*

Complete AHCA/NCAL Principles for Long Term Care Reform

Introduction

Patients and their families are increasingly interested in sources of care and sites of services that are non-facility based, including home- and community-based settings (HCBS). Local communities, states, and the federal government are responsive, particularly since they believe that HCBS will be less costly and therefore save money. Because of consumer preferences and related federal and state policy changes, the proportion of long term care services delivered in facility-based settings is smaller than in the past. Medicaid reform has become the major vehicle for these and other long term care reform efforts at both the state and federal levels.

To date, many long term care reform proposals focus on delaying or preventing facility-based placement while encouraging use of personal long term care planning and expanding HCBS availability. The culminating outcome likely will be decreasing use of nursing homes and intermediate care facilities for persons with mental retardation (ICFs/MR).

This is not to suggest that the need for facility-based services will disappear. Rather, facility-based services are likely to play a relatively smaller role at least in the next ten to fifteen years. In the longer term, it is less clear how long term care will be delivered. Short term pressures and out-year ambiguity suggest that AHCA – the largest formal long-term care provider group in the country – adopt a forward-looking, leadership-based approach to shape long term care policies and ensure that there is a sustainable array of long term care services – and related privately and publicly financing options – for all Americans.

In late January, AHCA and NCAL members began the process of developing a set of guiding Medicaid reform principles. Principles were developed and assessed against the following dimensions:

- *Will the principles foster policy efforts aimed at creating a more sustainable long term care financing model?*

- *Do the principles support consumer preferences and needs?*

- *Will the principles foster a viable operating environment for long term care service providers?*

The principles were drafted to encapsulate existing AHCA/NCAL policy and provide a more succinct tool for sharing AHCA/NCAL positions as well as to frame proactive policy initiatives. The principles build on past policies by condensing concepts that are highly interrelated, promoting policies that are viable in the current political and budgetary environment, and providing a proactive positive framework for representing AHCA/NCAL interests. The principles also directly relate to AHCA long term care and Medicaid policy goals developed by the AHCA Finance Subcommittee.

The Principles

Three key principles frame a long term care program(s) that will: (a) support consumer preferences and needs; (b) foster policy efforts aimed at creating a more sustainable array of long term care financing options; and (c) provide a viable operating environment for long term care providers. Each principle includes several key elements and also supports one or more of AHCA's long term care and/or Medicaid Policy goals previously developed by AHCA's Finance Subcommittee.

> **Principle I. Publicly and privately financed long term care supports and services must meet consumers' and families' needs and be responsive to their preferences.** Unlike acute and primary health care services, long term care services are not discrete events (i.e., a sore throat, broken leg, etc.) that require specific medical interventions. Instead, receipt of long term care services becomes a lifestyle for both the person receiving services and his or her family. Long term care services are integrated into virtually every aspect of an individual's life and make the experience of long term care highly personal. To that end, long term care policies must:
>
> - *Recognize that consumers are key stakeholders in long term care policy decision making and government must include them in development, oversight and monitoring.* State Medicaid agencies are required to provide public notice and time for comment when changes to the Medicaid program are proposed. They also are required to respond to stakeholder concerns. The federal government should require documentation that these requirements have been met.
>
> - *Provide that every eligible individual who needs long term care services receives them in a timely manner in an appropriate setting, taking into account individual preferences and clinical needs.* Policies must recognize the individual – to the extent possible – as the key decision-maker regarding their supports and care. For privately financed options, policies also must ensure that these options – particularly insurance products – recognize the importance of consumer preference.
>
> - *Acknowledge the key role that family care givers play and provide family care giver supports.* Family care givers are a critical – but often unrecognized – segment of the long term care spectrum. State and federal programs must provide incentives and assistance for family care giving such as income tax deductions, availability of respite and day programming, and family counseling services.

Principle II. Long term care policies must promote and integrate a comprehensive array of public and private long term care financing options. As the proportion of our population age 65 or older increases and the number of younger persons with disabilities increases, the federal government and states must take steps to increase use of private long term care options. Increasing the use of private options will improve the sustainability of a publicly financed long term care program, currently Medicaid. And, reimbursement policies must recognize the potentially interrelated impacts of payment policy changes to ensure a stable long term care provider marketplace. A stable array of long term care providers will be better positioned to meet consumers' needs and preferences. To increase use of the array of long term care financing options, policies must:

- *Encourage individuals to plan for long term care and provide viable private long term care financing options.* The federal government should promote the development of innovative programs, such as incentives for families to purchase long term care insurance, save money for long term care or otherwise plan for private long term care needs. State and federal government also should fund programs to raise awareness of long term care planning needs and help individuals and families make the best long term care financing decisions.

- *Ensure that individuals have the tools they need to manage their long term care service as beneficiaries assume more personal responsibility for services – publicly and privately financed.* Long term care reform proposals include a wide range of elements that give beneficiaries more control over services and service dollars. Examples include HCBS Individualized Budgeting models, Money Follows the Individual and Cash and Counseling programs. In addition to increased control and responsibility, government also should provide adequate supports to beneficiaries on how to direct their own services and wisely allocate service dollars. Government should have safeguards and oversights in place to ensure that these services are appropriate and effective in achieving the care planning goals of the beneficiary.

- *Recognize the impact of reimbursement changes on long term care providers.* Long term care providers receive payments from private sources, Medicaid, and Medicare for post acute care stays. Policy changes that decrease or otherwise affect revenue streams should be evaluated in the broader context of the array of financing sources, e.g., the impact of changes to Medicare payments when providers experience shortfalls under Medicaid.

- *Ensure that efficient coordination of benefits reduce administrative burdens on beneficiaries and providers.* Beneficiaries should be able to move seamlessly among services across the long term care spectrum without limitation due to burdensome administrative requirements that are commonly placed on providers and beneficiaries. Attention to streamlining coordination of benefits will result in better care as needs change.

- *Encourage individuals, providers and government payers to engage in a policy debate on balancing public and private financing of long term care.* The increasing long term care population and accompanying growing costs results in a need for all stakeholders to be engaged in discussions on how best to finance this expanding population's care. This discussion should examine and weigh both public and private financing options.

- *Encourage the design of tax policies that coordinate with long term care financing strategy alternatives.* Identification of financing strategy alternatives is valuable only to the extent that such alternatives are implemented. Incentives, such as tax policies, will aid implementation efforts.

Principle III. Through sufficient federal and state governmental infrastructure, policies must ensure that long term care service delivery systems provide an adequate array of services and service providers across the long term care spectrum. Long term care reforms are being proposed and implemented at a rapid pace. Changes in service delivery systems, such as significant increases in HCBS use, must be accompanied by adequate increases in state administrative infrastructure including quality assurance and improvement, payment systems, data collection, and consumer and family information and referral services. To ensure market driven long term care system change at an appropriate pace, policies must:

- *Include a strategic plan for building needed infrastructure and ensuring an adequate array of long term care providers.* For publicly financed programs, government should require a reasonable plan for phasing-in changes that require substantial build ups in provider capacity and state infrastructure development. Government also should require that milestones or markers be met before additional changes or expansion. Government should encourage the notion that beneficiaries who need long term care services receive them at the needed intensity level (including facility-based services) as well as an adequate array of care management supports that do not place undue hardship on the individual or family caregivers.

- *Ensure that beneficiaries may move seamlessly among services across the long term care spectrum.* Long term care systems and providers are highly insular. For many beneficiaries, the result is typically a fragmented service system that is confusing and produces questionable outcomes. Government must ensure that long term care providers have the capacity to develop service arrays, partnerships, and business arrangements that foster a seamless service experience.

- *Foster and support quality and efficiency in long term care services, as well as provide operational flexibility.* Long term care providers face significant operational costs including purchasing or upgrading health information technology systems, capital improvements to existing facilities, and financing innovative services that could support specialty populations. Government regulation should not impede long term care service innovations among long term care providers that follow consumer preferences in a cost effective manner.

- *Managed care plans should recognize that long term care providers deliver services that are distinct from acute care providers.* A key long term care reform component is managed care – particularly for Medicaid-financed long term care. Experiences in states like Arizona show both positive outcomes and concerns for long term care providers. As managed care for Medicaid beneficiaries who are elderly, blind and have disabilities is expanded, federal and state officials should avail themselves of the long term care professionals' policy, operational, and clinical expertise as these arrangements unfold.

- *Funding is adequate and timely in order to provide stability and predictability to meet the needs of long term care recipients at the appropriate time, in the appropriate place, and at the appropriate cost.* Government should recognize that demand for long term care services and financial pressure on providers – as well as increased risk bearing at the plan, provider and consumer levels – make additional investment in provider capacity, service quality and efficiency a necessity. Government payment rates at all levels of the long term care spectrum should be sufficient to provide quality services and cover the cost of operating, as well as needed capital improvements.

- *Encourage development and use of a standardized post-acute assessment and benefit package to facilitate determination of patient need and placement.* As opportunities to receive services are expanded, the need for uniformity in assessment becomes increasingly important.

Framework for Moving Forward

Since the inception of the Medicaid program, responsibility for long term care financing and delivery gradually has migrated away from the beneficiary and the family to the public sector. Increasing reliance on Medicaid for long term care services raises serious questions about programmatic sustainability. Additionally, demography, care delivery challenges (such as worker shortages), marketplace demands, financing, legal and regulatory, and industry trends, create an unprecedented need for the long term care professionals to help shape its future.

In partnership with consumer groups, long term care providers, including HCBS providers and facility-based, will lead the effort toward development of an integrated, flexible long term care array that responsibly informs and educates Americans about their long term care responsibilities and options, but also delivers Medicaid-financed services in a cost-effective, customized manner. In order to achieve these goals, AHCA/NCAL will partner with other long term care organizations based on its long term care policy principles to address the challenges and opportunities associated with building a sustainable long term care system.

AHCA/NCAL Managed Care Principles

At the AHCA/NCAL long term care reform work group meeting held on January 26, 2006, participants decided that managed care warrants its own set of principles. Staff were assigned the responsibility of drafting such principles for discussion at the March meeting.

Work group participants asked that additional attention be paid to managed care because of growth in:

1. ***Managed care for Medicaid-only Beneficiaries Who Are Aged, Blind or have Disabilities.*** The effects on long term care systems will be: a) increasing pressure to use less costly services including earlier hospital discharges into sub-acute facilities or temporary placement in nursing homes; b) limited use of nursing home services until all less costly options have been explored; c) increased competition among nursing homes based on managed care organizations' (MCO) focus on best price; d) additional bureaucratic layer, which results in the redirection of a significant portion of available dollars from the bedside into administration; e)increased potential for duplication (among and between MCO's) in both quality assurance and regulatory intervention, which is both costly and cumbersome; and f) increased flexibility and opportunity for innovation.

2. ***Managed Medicare and Medicaid Integration Programs.*** The Medicare Modernization Act of 2003 Special Needs Plan (SNP) authority could lead to increased state interest in managed care arrangements that integrate or better coordinate the Medicare and Medicaid programs. Commercial interest has been considerably greater than expected; to date, 296 SNP products are available.[1] Additionally, the 2007 Medicare Advantage plan application includes an expanded SNP section for Medicare and Medicaid integration options. And, Dr. McClellan has made integration one of his top policy priorities. A significant number of states are exploring managed care arrangements that would capitate both Medicare and Medicaid payments to managed care plans. In turn, providers would be reimbursed with rates based on the Medicare and Medicaid capitation payments to plans. While integrated care may be helpful from a continuity of care perspective, Medicare and Medicaid Integration programs will negatively impact provider reimbursement as it will be considerably lower than traditional Medicare

3. ***Managed Care Delivery of Preventive Care (i.e., disease management (DM), care coordination, and wellness initiatives).*** DM, care coordination and disability management programs hold the promise of reducing disability acuity and the impact of chronic illnesses. In turn, such outcomes also result in lower costs and reduce financial strain on the health care system. Many Section 1115 Medicaid waivers include wellness incentive programs for beneficiaries. States also are heavily leveraging Medicaid managed care plans and/or integrated Medicare/Medicaid managed care plans to deliver such services.

Managed Care Principles

Managed care policies should recognize that long term and post acute care providers deliver services that are distinct from acute care providers. A key long term care reform component is managed care. Experiences in states like Arizona show both positive outcomes and concerns for long term care providers. As managed care for Medicaid-only beneficiaries who are elderly, blind and have disabilities or for dually eligible individuals is expanded, federal and state officials should avail themselves of the long term and post acute care professionals' policy,

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[1] Presentation by Jennifer Podulka, MEDPAC staff person using CMS data, at the MEDPAC meeting. January 11, 2006

operational, and clinical expertise as these arrangements unfold. Five key managed care elements should be considered with the managed care principle:

- *Enhanced Flexibility in a More Competitive Operating Environment.* Long term care providers should have the freedom to take on a wide array of roles in the coordination and provision of individuals' long term and post acute care. Policies should allow providers to take on various roles, alone or in partnership, in the delivery of long term and post acute care services including risk contracting, administrative organizations roles, information and referral, care coordination of an individual's clinical needs, as well as care management and disease management.

- *Inclusion in Managed Care Program Development and Operational Decision Making.* Long term care providers should be meaningfully included and engaged in managed care program design. Specific points of engagement should include: (1) ongoing participation in capitation payment methodology and rate development and refinement; (2) agreement on, development and testing of a uniform assessment tool that identifies service needs and will ensure a reasonable and adequate payment by site of service; (3) plan contracting requirements – specifically, plan profit requirements (ensuring that plan profits and overhead costs are not excessive), development of provider rates and processes for reconciliation; (4) ensuring a level playing field, including decisions on "any willing provider" requirements; (5) prompt payment; and (6) coverage, prior authorization and utilization management processes.

- *Special Consideration As Capitation Rates, Risk Adjusters, and Subsequent Provider Rates Are Developed.* Long term and post acute care providers must have the resources to deliver services, meet capital costs associated with facility or unit maintenance, and meet both state and federal licensure and operating requirements. First, MCO contracts and state oversight must ensure that plan capitations payments – including any frailty adjuster – associated with individuals using long term care be fully available for that purpose. Second, in Medicare and Medicaid integration arrangements, states must ensure that rates including or based on Medicare capitation payments to plans and providers also be actuarially sound (currently a Medicaid requirement for managed care capitation payment rates). Third, the long term care provider marketplace faces significant capital costs to maintain aging facilities, upgrade existing facilities, and/or develop new service settings – such as small congregate settings or single occupancy capacity. Payment rates must include a margin that will support critical capital maintenance and development and ensure provider financial viability and sustainability.

- *All long term and post acute care settings should have quality measures tailored to the type of service setting and long term or post acute care populations.* Acute care quality measures and measurement tools are inappropriate for long term care settings and, in some instances, long term care populations. States and plans must work with long term and post care providers to: identify a quality measurement system that is (a) targeted to long term care or post acute care service outcomes; and (b) based on current clinical or social supports best practices. Finally, all willing providers with the capacity to implement and collect data on the quality measures in a managed care coverage region should have the opportunity to participate in the provider network.

- *Managed care plan coverage determination processes (i.e., medical necessity definitions and related procedural guidance) must reflect the difference between acute care service outcomes and long term care service outcomes.* Because of the unique needs of the long term care population and the nature of long term and/or post acute care settings, coverage determinations on access to care should emphasize maintenance of functioning and specialized healthcare needs. Additionally, coverage determinations should reflect that long term care consumers' physical and psychosocial support needs are ongoing and must be tailored to individual preferences to the degree possible.

- *Development and use of a standardized post-acute assessment and benefit package to facilitate determination of patient need and placement.* As opportunities to receive services are expanded, the need for uniformity in assessment becomes increasingly important.

Conclusion

The long term care system is under considerable pressure driven by payer and consumer preferences to shift from facility-based care to consumer-directed home- and community-based or more home-like services, along with tighter reimbursement, and difficult to manage Medicare and Medicaid operating requirements. Considerable attention must be given to the potential impact of managed care on the stability of the long term care provider marketplace to ensure erosion of capacity is not accelerated. The principles and key elements above should be used by policymakers, providers and others to help craft policies, including a long term care provider bill of rights to address issues arising from the expansion of managed care for long term care populations.

American Health Care Association

Working to Ensure that Choice is Provided

Services and Supports Options

For Individuals with Developmental Disabilities

The Keys: Client Needs, Abilities and Preferences

Intermediate care facilities for individuals with mental retardation and developmental disabilities (ICFs/MR/DD), Medicaid home- and community-based (HCB) program group homes and home care provide settings to accommodate the needs, functional abilities and preferences of individuals with developmental disabilities (DD). The real advantage of today's residential alternatives is that, collectively, they offer real choice to clients and families.

Fast Fact

The federal government defines any facility with four or more beds an "institution"

Each of today's residential choices offers advantages based on the best interest, capabilities and needs of the client. That choice may be an institution, albeit a small one as the federal government considers a facility to be an "institution" if it has four or more beds. According to the U. S. Supreme Court's *Olmstead v. L.C.* decision "nothing in the Americans With Disabilities Act (ADA) or its implementing regulations condones termination of institutional settings for individuals unable to handle or benefit from community settings... Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." Thus, today's imperative is to provide access to services and supports in a full array of settings to accommodate a broad range of disabilities, and this includes individuals with developmental disabilities.

Consider these facts about ICFs/MRDD facilities:

- The median number of clients in an ICF/MRDD is six (*CMS*).
- A group home can be part of an ICF/MRDD that operates several small residences under one license.
- ICFs/MRDD sometimes have fewer beds than HCB group homes.
- ICFs/MRDD can be private or public; profit or not-for-profit.
- ICFs/MRDD provide 24-hour staffing.

While the needs, functional abilities and preferences should be the main criteria in selecting a living arrangement for MR/DD clients, there are major differences between the settings in terms of the supervision, services and supports provided.

ICFs/MRDD—Serving the Most Vulnerable

ICFs/MRDD generally serve individuals with profound and multiple disabilities, thus they are staffed accordingly and offer an array of supports and services to clients with DD and their families. Larger facilities often serve clients with the most severe and multiple handicaps as they offer a wider array of in-house or contract services. Supports and services offered by ICFs/MRDD add to the quality of life of clients and motivate and guide them in learning practical life skills. The goal for a client with DD is to enable travel, recreation, and potential employment and to graduate to a more independent housing option. ICFs/MRDD provide:

Health Care Services
Includes a comprehensive medical care plan; physician services; annual physical exams; dental and pharmacy services; and drug administration.

Active Treatment
Incorporates a team approach to teach skills and socially responsible behavior to attain maximum independence and minimize regression.

Respect
Ensures and protects client rights even outside the facility.

Positive Social Behavior
Uses positive techniques to teach socially responsible behavior.

ICFs/MRDD Staff and Client Outcomes

Staff training is continuous on topics such as: infection control; detection of abuse and neglect; client rights; disaster preparedness, etc. Staffing level, which must conform to government standards, is based on client age and level of ability.

Fast Fact*: Estimated Medicaid spending on ICFs/MRDD in 2006 totaled $13.1B[1]

A notable distinction between ICFs/MRDD and HCB group homes is the level of involvement from federal and state agencies. Through a process known as "surveying," conducted annually, or as needed, a team of specialists examines staff performance in achieving client goals.

HCB Group Homes, Home Care

Since 1981 states can make HCB services available to Medicaid recipients who are eligible for nursing facilities, ICFs/MRDD or hospitals. This allows for care at home or at a group home while receiving Medicaid payments.

Fast Fact*

Trend in Total Spending for HCB Care, 1990-2006

FY 1990	*FY 2001*	*FY 2006*	*Percentage Increase*
$3.9B	$22.7B	$39.1B	902%

States need to apply to the federal government for a "waiver" of Medicaid rules to offer an HCB program. With a waiver a state may cover, at its discretion, non-medical and social services and supports that allow individuals to stay at home or in the community. An HCB program may provide: case management and services, such as homemaker; home health aide; personal care; adult day care; habilitation; and respite care. States may also offer other, non- medical services, such as transportation, in-home support services, special communication services, minor home modifications and adult day care.

Fast Facts*

- **Currently, there are approximately 287 waivers in place serving more than 922,000 individuals;**
- **Every state has at least one waiver;**
- **Currently waivers represent 12% of Medicaid long term care expenditures.**

HCB group homes receive only cursory federal and state monitoring of care and services, are not required to provide individualized training for clients and staffing may be minimal and sometimes only part time.

Olmstead and the New Freedom Initiative

The "New Freedom Initiative" (NFI) is the government's effort to help states implement the U S. Supreme Court's Olmstead decision (*Olmstead v L.C)*. In Olmstead the Court held that some individuals with disabilities in institutions might have suffered discrimination under the Americans with Disabilities Act (ADA) by being deprived of an opportunity to live in the community. The Court also held that the ADA does not mandate deinstitutionalization, stating "nothing in the ADA condones termination of institutional settings for individuals unable to handle or benefit from community settings." NFI provides a framework for giving elders and individuals with disabilities a choice regarding housing arrangements for as long as possible prior to needing a more secure environment. Under the NFI the federal government provides funding for demonstration programs that support HCB services as well as technical assistance to states.

AHCA is Committed to these Principles

- Individuals should receive proper supports and services in the most appropriate setting, according to their needs and preferences;
- Barriers to community placement should be removed;
- Adequate funding must be provided for the spectrum of facility and HCB services; and

- Quality assurance systems must be built into all services and supports programs and consumer protections enforced through appropriate government regulation.

Fast Fact

ICFs/MRDD and HCB programs are optional benefits of a state's Medicaid program. They are not entitlements.

Key Determinants

The needs, functional abilities and the preferences of the client with DD (and his or her family) should be the criteria in choosing a setting where services and supports are provided, not what the setting is called. Individuals and their families need choices and ICFs/MRDD, group homes and home care each offer advantages to them. Each setting can meet the criteria set down in Olmstead to offer clients the most integrated, least restrictive, and safe setting based on their abilities. These options can provide a person with independence and dignity but their needs, functional abilities, and preferences should be considered when deciding on a residential setting.

The American Health Care Association (AHCA) is committed to quality and performance excellence in the long term care profession and actively supports Quality First, a covenant for healthy, affordable, and ethical long term care, and adherence to its principles and goals. Nationwide, AHCA represents more than 10,000 non-profit and for-profit facilities that are dedicated to professional and compassionate care for more than one million elderly and disabled individuals daily in nursing facilities, assisted living residences, subacute centers and homes for individuals with developmental disabilities. For more information contact:

The American Health Care Association
1201 L St. NW
Washington, DC 20005
202-898-842-4444

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[*] The State Long-Term Health Care Sector 2005: Characteristics, Utilization and Government Funding, American Health Care Association, August 29, 2006. http://www.ahca.org/research/statestatsrpt_20060823_final.pdf

CAREtenders®

November 8, 2007

THE HONORABLE Max Baucus, Chairman
THE HONORABLE Charles Grassley, Ranking Member

PLEASE TAKE THE TIME TO CONSIDER *REJECTING* THE MARKET BASKET HOME HEALTH FREEZE INCLUDED IN H.R. 3162.

AND TAKE ACTION TO:

***ELIMINATE* THE HOME HEALTH "CASE MIX CREEP" ADJUSTMENT AS PART OF THE FINAL HOME HEALTH PROSPECTIVE PAYMENT SYSTEM (HHPPS) REGULATION.**

****

I AM WRITING ON BEHALF OF THE ELDERLY WHO WILL BE THE ULTIMATE VICTIMS OF THE CUTBACKS. WHEN AGENCIES CAN'T SURVIVE MANY, IF NOT ALL WILL HAVE TO CLOSE SHOP LEAVING THE ELDERLY WITH ONLY THE HOSPITALS AND NURSING HOMES FOR ASSISTANCE. THAT IS, IF THEY QUALIFY.

HOME HEALTH AND HOSPICE HAVE PROVEN TO BE COST-EFFECTIVE ALTERNATIVES IN DELIVERY HEALTH CARE TO MEDICARE AND DISABLED AND TERMINAL CITIZENS, ENABLING THEM TO REMAIN IN THEIR OWN HOMES FOR LONG PERIODS OF TIME.

Please read the message from the National Home Health and Hospice Association and the enclosed letters. Please also pay attention to the customer satisfaction surveys conveying patients' feelings and appreciation for the assistance Home Health provided for them.

We very much appreciate your time and consideration and strongly urge you to consider the implications reaching way beyond the home health agencies themselves.

Thank you for your time and for your efforts to protect the care and assistance that our elderly need. This need, I need not tell you, will only increase every year as we baby boomers reach age and find little to no help available.

Respectfully Submitted,
Juliana L. Nicholas RN

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HOMECARE & HOSPICE

Elaine D. Stephens, RN, MPH NATIONAL ASSOCIATION FOR HOME CARE & HOSPICE Val J. Halamandaris, JD

[illegible]

*NATIONAL ASSOCIATION FOR HOME HEALTH & HOSPICE

OPPOSE CUTS TO MEDICARE HOME HEALTH SERVICES

ISSUE: Legislative and regulatory provisions propose to reduce the Medicare home health services rates by $8.63 billion over the next five years (fiscal years 2008-2012). The legislative provision, part of H.R. 3162, The Children's Health and Medicare Protection Act of 2007, reduces Medicare home health services payment rates through a one-year freeze in the market basket inflation update for calendar year 2008. Over five years, this provision would reduce outlays for home health by $2.6 billion. The Centers for Medicare & Medicaid Services (CMS) administratively has proposed a 2.75% across-the-board rate reduction for home health services for 2008, 2009, and 2010, as well as a 2.71% reduction for 2011(10.96% total rate reduction). Over five years, this provision would reduce outlays for home health by $6.03 billion. This reduction is based on an unfounded allegation by CMS that case mix weights have increased without attendant changes in patient characteristics, referred to by CMS as "case mix creep."

***RECOMMENDATION:** Congress should: 1.) Reject the home health market basket freeze included in H.R. 3162; and 2.) Take action to eliminate the home health "case-mix creep" adjustment as part of the final home health prospective payment system (HHPPS) regulation.

***RATIONALE:**

- H.R. 3162, which freezes for one year the home health market basket index for 2008, coupled with the CMS "case mix creep" proposal to reduce base payment rates by 2.75% for 2008, 2009 and 2010, and 2.71 % for 2011(10.96% total rate reduction) would result in cuts that exceed $8.63 billion over five years from a benefit that is less than $15 billion per year and under control in terms of expenditure growth (see chart below). H.R. 3162 does, however, offer a 5% rural add-on for 2008 and 2009, at a value of $300 million.

- The market basket freeze proposal was recommended by the Medicare Payment Advisory Commission (MedPAC), justified by claims that home health agencies are making excessive profit margins on Medicare services. MedPACs financial analysis of Medicare home health agencies (HHA), alleging a 16% margin, is unreliable. First, it does not include any consideration of the 1,723 agencies (21%) that are part of a hospital or skilled nursing facility. In some states, hospital-based HHAs make up the majority of the providers (MT 63.2%; ND 65.4%; SD 60.5%; OR 58.3%). Facility-based HHAs have an average Medicare profit margin of negative 5.3%. Second, the MedPAC analysis uses a weighted average, combining all HHAs into a single unit, rather than recognizing the individual existence and local nature of each provider. Third, MedPAC margin data fails to recognize many agency costs, including the cost of telehealth equipment, increasing costs for labor, emergency and bioterrorism preparedness, and system changes to adapt to the new home health payment changes. When all agencies' margins are included and given equal weight, the true margin would be closer to 3%. MedPAC fails to evaluate the impact on care access that occurs with the current wide ranging financial outcomes of HHAs. Instead, it sees a single national profit margin as representative of over 8,000 very diverse HHAs.

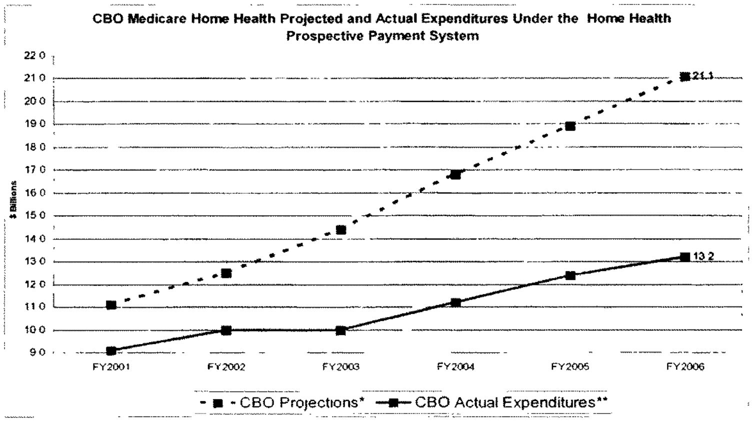
- Home health agencies are already in financial jeopardy as a result of Medicaid cuts and inadequate Medicare Advantage and private pay rates. Ongoing study of home health cost reports by the National Association for Home Care & Hospice indicates that the overall financial strength of Medicare home health agencies is weak, and expected to diminish further. In 2002, the average all-payor profit margin for freestanding HHAs was 2.53%. A more recent cost report data analysis indicates that the average all-payor profit margin for 2004 dropped to 1.55%.

- MedPAC's recommendation for a one-year freeze in the home health market basket inflation update was made without knowledge or consideration that CMS would propose a "case mix creep" adjustment.

- Using MedPAC calculation methodology, the National Association for Home Care & Hospice projects that the CMS "case mix creep" adjustment, combined with enactment of H.R. 3162, will lead to 51.8% of the nation's agencies' Medicare margins dropping below zero by 2011.

- The "case mix creep" adjustment ignores increases in patient acuity, particularly a significant increase in orthopedic and neurologically impaired patients requiring restorative therapy. These changes in patient characteristics are documented in a report from the Lewin Group and directly correlate with changes in case mix weights.

- CMS alleges that the entire change in the average case mix weights between 1999 and 2005 is the result of provider upcoding or factors unrelated to changes in patient characteristics. If this had occurred one would expect to see a big increase in Medicare home health expenditures. In fact, as the chart below indicates, Medicare home health expenditures are far lower than the Congressional Budget Office (CBO) had expected under the new Home Health Prospective Payment System.



CBO Medicare Home Health Projected and Actual Expenditures Under the Home Health Prospective Payment System

CBO Medicare Home Health Expenditure Projections and Actual Expenditures

	CBO Projections*	CBO Actual Expenditures**
FY2001	11.1	9.1
FY2002	12.5	10.0
FY2003	14.4	10.0
FY2004	16.8	11.2
FY2005	18.9	12.4
FY2006	21.1	13.2

*Source Congressional Budget Office (CBO) projections, March, 2000 (These projections were made just prior to the implementation of the Prospective Payment System in October, 2000, as anticipated expenditures for home health care under the new payment system)

**Source CBO, March 2002-2007 reports of actual expenditures under the new Medicare Home Health payment system

For more information, please contact the National Association for Home Care & Hospice
Government Affairs Department, 202-547-7424 (8/30/07)

The Honorable Max Baucus, Chairman
The Honorable Charles Grassley, Ranking Member
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Chairman Baucus and Ranking Member Grassley:

Home health and hospice have become increasingly important parts of our health care system. The kinds of highly skilled and often technically complex services that our nation's home health and hospice agencies provide have enabled millions of our most frail and vulnerable seniors and disabled citizens avoid hospitals and nursing homes. By preventing such institutional care, home health and hospice services save Medicare millions of dollars each year.
Most importantly, they enable individuals to stay just where they want to be – in the comfort and security of their own homes. We therefore urge you to ensure that Medicare beneficiaries continue to have access to important home health and hospice services by supporting full market basket inflation adjustments, as provided under current law, and opposing any cuts in payment rates through administrative actions.

The Administration's FY 2008 budget includes a legislative proposal to cut Medicare home health payments by $9.7 billion and hospice payments by more than $1.1 billion over five years. It also includes additional administrative cuts in payment rates. The Medicare home health benefit has already taken a larger hit in spending reductions over the past ten years than any other Medicare benefit. In fact, home health as a share of Medicare spending has dropped from 8.7 percent in 1997 to 3.2 percent today, and is projected to decline to 2.6 percent of Medicare spending by 2015. This downward spiral in home health spending began with provisions in the Balanced Budget Act of 1997 (BBA), which resulted in a 50 percent cut in Medicare home health spending by 2001 – far more than the Congress intended or the Congressional Budget Office (CBO) projected.

We believe that further reductions in home health and hospice payments would be counterproductive to controlling overall health care costs. Home health and hospice care have been demonstrated to be a cost-effective alternative to institutional care in both the Medicare and Medicaid programs. In fact, the Medicare Payment Advisory Commission (MedPAC) has noted the results of a 2002 RAND study which showed "in terms of Part A costs, episodes in an inpatient rehabilitation facility or skilled nursing facility are much more costly for Medicare than episodes of care among patients going home." (MedPAC's June 2005 Report to Congress).

Further reducing Medicare home health expenditures would also be in direct conflict with the Administration's desire to prioritize health care in the home as a cost-effective alternative to institutional care. During the World Health Congress in February of 2005, Secretary of Health and Human Services Michael Leavitt said: "Providing the care that lets people live at home if they want is less expensive than providing nursing home care. It frees up resources that can help

other people. And obviously, many people are happier living at home."

Reducing Medicare home health and hospice payments would place the quality of home health care and hospice and the home care delivery system at significant risk. Several factors have contributed to the increased cost of providing care in the home over the past few years, including:

- The cost of travel by clinicians to patients' homes;
- The use of technology, like telehealth monitors, which is not covered by Medicare;
- The need to pay significantly higher salaries for nurses, therapists, and home health aides to attract these individuals from the scarce supply of clinicians nationwide.

Many home health providers currently do not have a sufficient number of clinical staff to accept patient referrals from physicians and hospitals. As a consequence, hospital discharge planners have reported that they are finding it more difficult to refer patients for home health care. Additional cuts to the home health benefit could leave home health providers no alternative but to reduce the number of visits and/or patient admissions, which would ultimately affect access to care and clinical outcomes. In addition to these costs, hospices are also experiencing rising costs for pain management pharmaceuticals, and they are also finding that patients with shorter lengths of stay are requiring more intensive services.

In order to ensure that home health care and hospice remain a viable option for Medicare patients, we urge you to support full market basket updates for home health and hospice, as provided under current law, and to oppose any cuts in payment rates through administrative action. Thank you for your consideration of this important matter.

Sincerely,

Juliana Nicholas RN BS.
Director of Professional Services
Caretenders of Kentuckiana

Please Read

P.S. I have enclosed some customer comments from their satisfaction surveys to emphasize the significance of the care they receive from their perspective.

Thank you
Julie

Please please please remove these cuts for the sake of citizens who are the end result of eliminating services they vitally need.

CAREtenders

LOCATION CODE
0 1 2 3 4 5 6 7 8 9
0 1 2 3 4 5 6 7 8 9
0 1 2 3 4 5 6 7 8 9

31
DEPT. CODE
0 1 2 3 4 5 6 7 8 9
0 1 2 3 4 5 6 7 8 9

Please check the services you are receiving:

☐ Homemaker/Home Health Aide	☐ Nursing	☐ Social Worker
☒ Physical, Speech, Occupational Therapies	☐ Personal Care	☐ Waiver Services

145 31

Have you found our employees to be:
Caring ☒ Yes ☐ No Timely ☒ Yes ☐ No Knowledgeable ☒ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☒ Yes ☐ No
Did our employees address your pain needs effectively? ☒ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☒ Yes ☐ No
Would you recommend us to others? ☒ Yes ☐ No

Comments The therapy I received was exceptional. Due to my situation the in-home care I received was perfect for me.

Name [redacted] (Optional) Patient Name ______ (Optional)

4/06 VS-600-CTD

CAREtenders

145
LOCATION CODE
0 1 2 3 4 5 6 7 8 9
0 1 2 3 4 5 6 7 8 9
0 1 2 3 4 5 6 7 8 9

31
DEPT. CODE
0 1 2 3 4 5 6 7 8 9
0 1 2 3 4 5 6 7 8 9

Please check the services you are receiving:

☑ Homemaker/Home Health Aide	☐ Nursing	☑ Social Worker
☐ Physical, Speech, Occupational Therapies	☑ Personal Care	☐ Waiver Services

14531

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments I do not know of anything more to say' she is very good to me and I like her very much.

Name [redacted] (Optional) Patient Name ______ (Optional)

4/06 VS-600-CTD

CAREtenders

LOCATION CODE ○○○○○○○○○○ 0 1 2 3 4 5 6 7 8 9 (three rows)
DEPT. CODE ○○○○○○○○○○ 0 1 2 3 4 5 6 7 8 9 (two rows)

Please check the services you are receiving:
- ☐ Homemaker/Home Health Aide Not sure if without
- ☑ Nursing
- ☑ Social Worker
- ☑ Physical, Speech, Occupational Therapies
- ☑ Personal Care
- ☐ Waiver Services ?? Don't know what it is

we received + but no longer are receiving

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☐ Yes ☐ No didn't have any medication questions per
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments Everyone was super nice and worked with Mother very well.

Name [redacted] (Optional) Patient Name [redacted] (Optional)

4/06 VS-600-CT

CAREtenders

LOCATION CODE 145 ○○○○○○○○○○ 0 1 2 3 4 5 6 7 8 9 (three rows)
DEPT. CODE 31 ○○○○○○○○○○ 0 1 2 3 4 5 6 7 8 9 (two rows)

Please check the services you are receiving:
- ☐ Homemaker/Home Health Aide
- ☑ Nursing
- ☐ Social Worker
- ☐ Physical, Speech, Occupational Therapies
- ☐ Personal Care
- ☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments Thanks for all your help.

Name ______ (Optional) Patient Name [redacted] (Optional)

4/06 471504375 VS-600-CTD

CAREtenders

LOCATION CODE

DEPT. CODE

Please check the services you are receiving:

☐ Homemaker/Home Health Aide
☒ Physical, Speech, Occupational Therapies
☐ Nursing
☐ Personal Care
☐ Social Worker
☐ Waiver Services

Have you found our employees to be:
Caring ☒ Yes ☐ No Timely ☒ Yes ☐ No Knowledgeable ☒ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☐ Yes ☐ No
Did our employees address your pain needs effectively? ☐ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☒ Yes ☐ No
Would you recommend us to others? ☒ Yes ☐ No

Comments The girls who came to the house were very helpful & nice.

Name [redacted] (Optional) Patient Name [redacted] (Optional)

4/06 VS-600-CT

CAREtenders

LOCATION CODE 145

DEPT. CODE 31

Please check the services you are receiving:

☐ Homemaker/Home Health Aide
☑ Physical, Speech, Occupational Therapies
☑ Nursing
☐ Personal Care
☐ Social Worker
☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No 14531
Did our employees address your pain needs effectively? ☐ Yes ☐ No ☑ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments Very Caring & Helpful

Name [redacted] (Optional) Patient Name same (Optional)

4/06 VS-600-

CARE*tenders*

LOCATION CODE ○○○○○○○○○○ 0 1 2 3 4 5 6 7 8 9 ○○○○○○○○○○ 0 1 2 3 4 5 6 7 8 9 ○○○○○○○○○○ 0 1 2 3 4 5 6 7 8 9

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Please check the services you are receiving:

☐ Homemaker/Home Health Aide	☒ Nursing	☐ Social Worker
☐ Physical, Speech, Occupational Therapies	☐ Personal Care	☐ Waiver Services

Have you found our employees to be:
Caring ☒ Yes ☐ No Timely ☒ Yes ☐ No Knowledgeable ☒ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☒ Yes ☐ No
Did our employees address your pain needs effectively? ☒ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☒ Yes ☐ No
Would you recommend us to others? ☒ Yes ☐ No

145 31

Comments Brenda was my caretender and I can't say enough good things about her. Thank you Brenda

Name [redacted] (Optional) Patient Name (Optional)

4/06 VS-600-CTC

CARE*tenders*

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LOCATION CODE ○○○○○○○○○○ 0 1 2 3 4 5 6 7 8 9 ○○○○○○○○○○ 0 1 2 3 4 5 6 7 8 9 ○○○○○○○○○○ 0 1 2 3 4 5 6 7 8 9

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Please check the services you are receiving:

☐ Homemaker/Home Health Aide	☒ Nursing	☐ Social Worker
☒ Physical, Speech, Occupational Therapies	☐ Personal Care	☐ Waiver Services

Have you found our employees to be:
Caring ☒ Yes ☐ No Timely ☒ Yes ☐ No Knowledgeable ☒ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☒ Yes ☐ No
Did our employees address your pain needs effectively? ☒ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☒ Yes ☐ No
Would you recommend us to others? ☒ Yes ☐ No

Comments I found the nurses and [illegible] therapists to be extremely caring [illegible] individuals - courteous and friendly [illegible]

Name [redacted] (Optional) Patient Name (Optional)

4/06 VS-600-C

CAREtenders

LOCATION CODE
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DEPT. CODE
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Please check the services you are receiving:

☐ Homemaker/Home Health Aide	☑ Nursing	☐ Social Worker
☑ Physical, Speech, Occupational Therapies	☐ Personal Care	☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☐ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments Everyone has been wonderful and willing to work around our schedule

Name ______________ Patient Name [redacted]
(Optional) (Optional)

4/06 VS-600-CT

CAREtenders

LOCATION CODE 145
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Please check the services you are receiving:

☐ Homemaker/Home Health Aide	☐ Nursing	☐ Social Worker
☑ Physical, Speech, Occupational Therapies	☐ Personal Care	☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

145

Comments Very pleased with the service

Name [redacted] Patient Name ______________
(Optional) (Optional)

4/06 VS-600-C

CAREtenders

LOCATION CODE 145
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Please check the services you are receiving:
☐ Homemaker/Home Health Aide
☑ Physical, Speech, Occupational Therapies
☐ Nursing
☐ Personal Care
☐ Social Worker
☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments Tami Arbogast and Tony Anderson are very Caring people who take there jobs very responsible and are very repectful of there Patients and I would like at this time to say thank you for your Caring help

Name ________ (Optional) Patient Name [redacted] (Optional)

4/06 VS-600-C

CAREtenders

LOCATION CODE 145
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Please check the services you are receiving:
☐ Homemaker/Home Health Aide
☑ Physical, Speech, Occupational Therapies
☐ Nursing
☑ Personal Care
☐ Social Worker
☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments All of the nurses and therapists did an exceptional job. We appreciated all that they have done. Thanks for everything.

Name [redacted] (Optional) Patient Name [redacted] (Optional)

VS-600-CT

4/06

CAREtenders

LOCATION CODE　DEPT. CODE

Please check the services you are receiving:

☐ Homemaker/Home Health Aide　☑ Nursing　☐ Social Worker
☐ Physical, Speech, Occupational Therapies　☐ Personal Care　☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No　Timely ☑ Yes ☐ No　Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments when I needed Physical and other help the services were excellent. I recommed you to others often. Susan and Janice are great.

Name [redacted] (Optional)　Patient Name ______ (Optional)

4/06　VS-600-CTD

CAREtenders

LOCATION CODE 145　DEPT. CODE 31

Please check the services you ~~are~~ have been receiving:

☐ Homemaker/Home Health Aide　☑ Nursing　☑ Social Worker
☑ Physical, S~~peec~~h, Occupational Therapies　☐ Personal Care　☐ Waiver Services

ATTN: DisCharged 7-31-07
I Am Alot BETTER Now —

Have you found our employees to be:
Caring ● Yes ☐ No　Timely ● Yes ☐ No　Knowledgeable ● Yes ☐ No
Did our employees teach you about your medications and answer your questions? ● Yes ☐ No　1453
Did our employees address your pain needs effectively? ● Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ● Yes ☐ No
Would you recommend us to others? ● Yes ☐ No

I would have them again if I need them.

Comments Everyone who helped care for me were very nice. They made me feel like they cared for me as a preson, Not just a patient. Older people need this so bad espically if they are house bound. Just having someone to take time to answer their questions incourages them to try to get better. Life is our greatest gift here on earth, enjoy it even tho we hurt,

Name [redacted]　Patient Name ______ (Optional)

I Thank y'all —　[redacted]

4/06　VS-600-CTD

CAREtenders

LOCATION CODE
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○ ○ ○ ○ ○ ○ ○ ○ ○ ○
0 1 2 3 4 5 6 7 8 9

Please check the services you are receiving:

- ☐ Homemaker/Home Health Aide
- ☑ Physical, Speech, Occupational Therapies
- ☐ Nursing
- ☐ Personal Care
- ☐ Social Worker
- ☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments ____________________

Name [redacted] (Optional) Patient Name [redacted] (Optional)

4/06 VS-600-CT

CAREtenders

LOCATION CODE 145
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0 1 2 3 4 5 6 7 8 9

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○ ○ ○ ○ ○ ○ ○ ○ ○ ○
0 1 2 3 4 5 6 7 8 9

Please check the services you are receiving:

- ☐ Homemaker/Home Health Aide
- ☒ Physical, Speech, Occupational Therapies
- ☑ Nursing
- ☐ Personal Care
- ☐ Social Worker
- ☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments ____________________

Name [redacted] (Optional) Patient Name [redacted] (Optional)

4/06 VS-600-CTD

CAREtenders

LOCATION CODE ○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9 / ○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9 / ○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9

DEPT. CODE 31 ○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9 / ○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9

Please check the services you are receiving:

- ☐ Homemaker/Home Health Aide
- ☑ Physical, Speech, Occupational Therapies
- ☐ Nursing
- ☐ Personal Care
- ☐ Social Worker
- ☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☐ Yes ☐ No
Did our employees address your pain needs effectively? ☐ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments Great

Name ________ *(Optional)* Patient Name [redacted] *(Optional)*

4/06 VS-600-CTD

CAREtenders

LOCATION CODE 145 ○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9 / ○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9 / ○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9

DEPT. CODE 31 ○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9 / ○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9

Please check the services you are receiving:

- ☐ Homemaker/Home Health Aide
- ☐ Physical, Speech, Occupational Therapies
- ☑ Nursing
- ☐ Personal Care
- ☐ Social Worker
- ☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

(14531)

Comments Nurse is very kind + knowledgeable - helpful.

Name [redacted] *(Optional)* Patient Name ________ *(Optional)*

4/06 VS-600-CTD

CAREtenders

LOCATION CODE 145 DEPT. CODE 31

Please check the services you are receiving:
☒ Homemaker/Home Health Aide ☑ Nursing ☐ Social Worker
☐ Physical, Speech, Occupational Therapies ☐ Personal Care ☐ Waiver Services

14531

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments I found your nurses to be knowldgable caring a very helpful. I would recomend you to others.

Name [redacted] (Optional) Patient Name [redacted] (Optional)

4/06 VS-600-CTD

CAREtenders

LOCATION CODE 145 DEPT. CODE 31

Please check the services you are receiving: none now
☐ Homemaker/Home Health Aide ☐ Nursing ☐ Social Worker
☐ Physical, Speech, Occupational Therapies ☐ Personal Care ☐ Waiver Services

14531

Have you found our employees to be:
Caring ☑ Yes ☐ No Timely ☑ Yes ☐ No Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments I want to thank All who had a hand in helping me. Thru my sickness it was Gladly Appreciated May God Bless you All

Name [redacted] (Optional) Patient Name (Optional)

4/06 VS-600-CTD

CAREtenders

LOCATION CODE 173
○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9
○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9
○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9

DEPT. CODE 31
○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9
○0 ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9

Please check the services you are receiving:

- ☑ Homemaker/Home Health Aide
- ☑ Physical, Speech, Occupational Therapies
- ☑ Nursing
- ☑ Personal Care
- ☐ Social Worker
- ☐ Waiver Services

Have you found our employees to be:
Caring ☑ Yes ☐ No   Timely ☑ Yes ☐ No   Knowledgeable ☑ Yes ☐ No
Did our employees teach you about your medications and answer your questions? ☑ Yes ☐ No
Did our employees address your pain needs effectively? ☑ Yes ☐ No ☐ N/A
Has your overall experience with us been satisfactory? ☑ Yes ☐ No
Would you recommend us to others? ☑ Yes ☐ No

Comments Thank You So much for Your help You were Wonderful in taking care of our mother. thank You Tashia, mary, [illegible], Theresa and Liz

Name ______________ (Optional)   Patient Name [redacted] (Optional)

4/06   VS-600-CTD

The Honorable Max Baucus, Chairman
The Honorable Charles Grassley, Ranking Member
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Chairman Baucus and Ranking Member Grassley:

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Most importantly, they enable individuals to stay just where they want to be – in the comfort and security of their own homes. We therefore urge you to ensure that Medicare beneficiaries continue to have access to important home health and hospice services by supporting full market basket inflation adjustments, as provided under current law, and opposing any cuts in payment rates through administrative actions.

The Administration's FY 2008 budget includes a legislative proposal to cut Medicare home health payments by $9.7 billion and hospice payments by more than $1.1 billion over five years. It also includes additional administrative cuts in payment rates. The Medicare home health benefit has already taken a larger hit in spending reductions over the past ten years than any other Medicare benefit. In fact, home health as a share of Medicare spending has dropped from 8.7 percent in 1997 to 3.2 percent today, and is projected to decline to 2.6 percent of Medicare spending by 2015. This downward spiral in home health spending began with provisions in the Balanced Budget Act of 1997 (BBA), which resulted in a 50 percent cut in Medicare home health spending by 2001 – far more than the Congress intended or the Congressional Budget Office (CBO) projected.

We believe that further reductions in home health and hospice payments would be counterproductive to controlling overall health care costs. Home health and hospice care have been demonstrated to be a cost-effective alternative to institutional care in both the Medicare and Medicaid programs. In fact, the Medicare Payment Advisory Commission (MedPAC) has noted the results of a 2002 RAND study which showed "in terms of Part A costs, episodes in an inpatient rehabilitation facility or skilled nursing facility are much more costly for Medicare than episodes of care among patients going home." (MedPAC's June 2005 Report to Congress).

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- The cost of travel by clinicians to patients' homes;
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In order to ensure that home health care and hospice remain a viable option for Medicare patients, we urge you to support full market basket updates for home health and hospice, as provided under current law, and to oppose any cuts in payment rates through administrative action. Thank you for your consideration of this important matter.

Sincerely,

Kristy Hoyland RN

The Honorable Max Baucus, Chairman
The Honorable Charles Grassley, Ranking Member
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510

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Sincerely,

Katie Gardner RN

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The Honorable Charles Grassley, Ranking Member
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510

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Sincerely,

Sheryl A. Melton, PT

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The Honorable Charles Grassley, Ranking Member
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510

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Sincerely,

Tami Arbogast, PTA
1110 Woodland Trace
Memphis, IN 47143
1 (502) 387-9993 cell
1 (812) 294-3521 home

The Honorable Max Baucus, Chairman
The Honorable Charles Grassley, Ranking Member
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510

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Sincerely,

Laura L Mahoney, OTR
(Registered Occupational therapist)
2315 N. Liberty View Rd
Milltown, IN 47145

(812) 633-4203 home
(502) 299-4418 - cell

The Honorable Max Baucus, Chairman
The Honorable Charles Grassley, Ranking Member
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510

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Sincerely,

Betty Hobble PTA
812-267-0000

The Honorable Max Baucus, Chairman
The Honorable Charles Grassley, Ranking Member
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510

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[illegible], PT
5038 Wolf Pen Woods Drive
Prospect, KY 40059
502) 403-9712

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In order to ensure that home health care and hospice remain a viable option for Medicare patients, we urge you to support full market basket updates for home health and hospice, as provided under current law, and to oppose any cuts in payment rates through administrative action. Thank you for your consideration of this important matter.

Sincerely,

Barbara L [illegible] RN
CM

The Honorable Max Baucus, Chairman
The Honorable Charles Grassley, Ranking Member
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Chairman Baucus and Ranking Member Grassley:

Home health and hospice have become increasingly important parts of our health care system. The kinds of highly skilled and often technically complex services that our nation's home health and hospice agencies provide have enabled millions of our most frail and vulnerable seniors and disabled citizens avoid hospitals and nursing homes. By preventing such institutional care, home health and hospice services save Medicare millions of dollars each year.
Most importantly, they enable individuals to stay just where they want to be – in the comfort and security of their own homes. We therefore urge you to ensure that Medicare beneficiaries continue to have access to important home health and hospice services by supporting full market basket inflation adjustments, as provided under current law, and opposing any cuts in payment rates through administrative actions.

The Administration's FY 2008 budget includes a legislative proposal to cut Medicare home health payments by $9.7 billion and hospice payments by more than $1.1 billion over five years. It also includes additional administrative cuts in payment rates. The Medicare home health benefit has already taken a larger hit in spending reductions over the past ten years than any other Medicare benefit. In fact, home health as a share of Medicare spending has dropped from 8.7 percent in 1997 to 3.2 percent today, and is projected to decline to 2.6 percent of Medicare spending by 2015. This downward spiral in home health spending began with provisions in the Balanced Budget Act of 1997 (BBA), which resulted in a 50 percent cut in Medicare home health spending by 2001 – far more than the Congress intended or the Congressional Budget Office (CBO) projected.

We believe that further reductions in home health and hospice payments would be counterproductive to controlling overall health care costs. Home health and hospice care have been demonstrated to be a cost-effective alternative to institutional care in both the Medicare and Medicaid programs. In fact, the Medicare Payment Advisory Commission (MedPAC) has noted the results of a 2002 RAND study which showed "in terms of Part A costs, episodes in an inpatient rehabilitation facility or skilled nursing facility are much more costly for Medicare than episodes of care among patients going home." (MedPAC's June 2005 Report to Congress).

Further reducing Medicare home health expenditures would also be in direct conflict with the Administration's desire to prioritize health care in the home as a cost-effective alternative to institutional care. During the World Health Congress in February of 2005, Secretary of Health and Human Services Michael Leavitt said: "Providing the care that lets people live at home if they want is less expensive than providing nursing home care. It frees up resources that can help

other people. And obviously, many people are happier living at home."

Reducing Medicare home health and hospice payments would place the quality of home health care and hospice and the home care delivery system at significant risk. Several factors have contributed to the increased cost of providing care in the home over the past few years, including:

- The cost of travel by clinicians to patients' homes;
- The use of technology, like telehealth monitors, which is not covered by Medicare;
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Claudia Osborn PA

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Sincerely,

Donna Fields RN

INDEPENDENT LIVING, INC.
5 Washington Terrace
Newburgh, NY 12550
Phone: (845) 565-1162 • Fax: (845) 565-0567 • TTY: (845) 565-0337

Promoting Choice, Self-determination and Total Participation

September 24, 2007

Senator Max Baucus
Chairman Senate Finance Committee
Washington D.C. 20515

Re: **Community Choice Act – S. 799**

Dear Chairman Baucus:

Independent Living is an organization whose mission is to advocate for people with disabilities. I am asking you to show your support for the freedom of people with disabilities by supporting the Community Choice Act (S. 799), introduced by Senator Tom Harkin (D-IA). The Community Choice Act of 2007 will increase access to community-based services and other supports for Americans with disabilities and older Americans.

The Community Choice Act will also give individuals who are eligible for nursing home services or other institutional care equal access to community-based services and supports. This legislation provides enhanced federal matching funds to help states develop their long-term care infrastructure and grant funds to help states increase their ability to provide home and community-based services. Lastly, this bill creates a demonstration project to evaluate service coordination and cost sharing approaches for those eligible for both Medicaid and Medicare services.

Your leadership is vital for the passage of the Community Choice Act (CCA). I strongly urge you to pass this important piece of legislation out of your committee favorably. Citizens with disabilities are depending on you.

Very Truly Yours,

Damaris Ruiz

Independent Living, Inc.

September 24, 2007

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Babbi Satzman

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Jennifer E. Clum
Independent Living, Inc.

United States Senate
Committee on Finance

Honorable Max Baucus
Chairman

Testimony
In Support of
S.799
The Community Choice Act

Provided by

National Council on Independent Living

NOT JUST RESPONDING TO CHANGE, BUT LEADING IT!

United States Senate
Committee on Finance
Senator Max Baucus, Chairman
September 25, 2007
Community Choice Act of 2007 (S.799)

The National Council on Independent Living is writing today to express strong support for the passage of S. 799, the Community Choice Act.

There remains a tremendous institutional bias in the long term care services funded through Medicaid. Efforts by Congress, such as Medicaid Waiver provisions and "Money Follows the Person" in the Deficit Reduction Act of 2005, to shift this bias to less expensive more humane and dignified home and community-based services are sorely underutilized by most states in their Medicaid plans. Most states continue to allow their Medicaid programs to be held hostage to the nursing home industry. Unfortunately, this takes away from hundreds of thousands of elderly and disabled persons any choice to live in the community and in their own homes among family and friends. People with disabilities are being forced into institutions away from society, their families, their communities and friends because of the failure of Congress and the States to take definitive action to end the institutional bias in Medicaid funded long term care services. This failure to act not only imprisons hundreds of thousands of people with disabilities, but it also costs the Nation's taxpayers billions of dollars on an annual basis.

The National Council on Independent Living (NCIL) supports efforts to create effective home and community-based services (HCBS) to support people with disabilities in living independently and productively in their own homes and communities. These HCBS should be under the control and of the choice of the consumer of the services. We support efforts at social insurance reform such as the recently introduced 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.

More importantly, 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.

We want to thank Senator Baucus for holding a hearing on long term care and the Community Choice Act. This is a historic day for the disability community. The Community Choice Act has been introduced in the last few sessions of Congress and its prospective passage has always been hampered by a brief and inaccurate estimate of the cost contained in a letter from the Congressional Budget Office to Rep. Newt Gingrich in 1997. More recently, university based researchers having a much better knowledge and understanding of the issues involved than CBO, have estimated new expenditures for personal attendant services to be $1.4-$3.7 billion per year, depending on the rate of participation, for up to half a million new recipients, more than a third of whom would be ages 65 and older. (see Bibliography at the end of this testimony) These initial estimated expenditures are one tenth of those estimated by the CBO for implementing the previously introduced Medicaid Community-Based Attendant Services and Supports Act. Further, NCIL is confident that as the baby boomers age and acquire disabilities, that a strong mandatory system of HCBS will save the Nation billions of dollars in the Medicaid program over the current system and its inherent institutional bias.

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 organize 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.

There is a strong historical linkage between NCIL and the struggle for people with disabilities to live in their own homes and communities and not in institutions. In fact, the definition of a CIL found in federal law (Rehabilitation Act of 1973, as amended) is that a CIL must be non-residential (not located in an institution or long-term care facility) but instead must be in the community at large. Part of the life story of the first President of NCIL, Max Starkloff, includes his fight to move himself out of a nursing facility and back into the community where he developed a housing project for himself and others with disabilities. This was a rare victory at this time in history (early 1970s), but it sets a clear and shining example for all of us still today of the depth of passion people with disabilities feel regarding the desire to be free and independent if they so choose. NCIL still carries this passion into the future through its mission, activities and particularly, by strong advocacy for "Money Follows the Person" and "The Community Choice Act" (S. 799). NCIL's CIL members remain at the forefront of the de-institutional movement.

NCIL knows that access to HCBS can be a matter of civil rights. 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 more freedom in Colorado than in Tennessee. The happenstance of where you live should not determine your very ability to enjoy your home and community, yet this is absolutely the case today in America.

This direct involvement of CILs with the Medicaid personal attendant service programs has caused a major paradigm shift in the nature of these programs nationwide. This involvement has caused the federal and state agencies who oversee the programs to fundamentally change the way the program recipients, people with disabilities, are viewed. Recipients and independent living advocates are now much more involved in the planning, start-up and delivery of the services provided, including direct control and management of the day-to-day services. This increased involvement in all aspects has strengthened the services and improved the quality of outcomes of the program, including employment of the recipients and others with disabilities.

Now, more than ever, people who use personal attendant services are working and remaining at work. The rise in employment of people who receive home and community services, especially consumer controlled services, compared to the stark unemployment of people residing in institutions must be noted, emphasized, and nurtured in our nation's long term care policies.

The leadership provided by CILs in provision of, and advocacy for, consumer controlled personal attendant services has given NCIL a wealth of direct experience and observations to share. These experiences and observations range from the wondrous and appealing to the woeful and appalling.

The local CIL in Topeka, Kansas recently assisted Charmaine, a young woman of 38 years with moving from a nursing facility. She has her own apartment close to friends and family and has learned to ride the public transit system. She has hired and manages an attendant and is very happy volunteering with the CIL. She is now seeking employment through the local vocational rehabilitation agency. Lorraine, on the other hand, has a different and appalling story to tell. She is elderly, 72 years old. Four years ago, she had a routine hip replacement done. The surgery went well and she was discharged from the hospital to a nursing facility for a 90-day planned brief stay for additional rehabilitative therapy. Lorraine owned a home, ran her own business and had much loved family pets all waiting for her at home. Four years later, she has lost her pets and her business. Her house is in terrible shape because it has been closed for so long. Lorraine's "planned brief stay", as happens so many times, turned into an unplanned permanent stay because the nursing home wouldn't let her leave and she wasn't given information about home and community alternatives. The local CIL is helping her leave, getting her house made habitable again and assisting her with litigation for the harm she has suffered from being unnecessarily institutionalized against her wishes for so many years.

This kind of situation, all too common, must come to an end! Only passage of "The Community Choice Act of 2007" will fix the broken system that creates this kind of problem to begin with. Expertise has allowed NCIL members to produce basic materials useful on day-today basis which we have shared and have been replicated around the country. The experience, the knowledge and the tools are available and NCIL is committed to sharing them. The laws need to be changed so they can be put to effective use.

……

How do we identify people who want to leave an institution for home and community? How do we get information and assistance to those who may have an interest? The federal government, CMS, collects information from people who nursing facility operators feel have a potential for discharge back to the community. This information, collected annually, is contained in a document called the Multiple Data Set (MDS) and is readily available and would be fairly easy to use as a good place to start. According to this information, which we feel under-represents the need, over 19% of the people currently residing in nursing facilities have potential for discharge back into their homes and communities. Almost 300,000 people are being unnecessarily segregated and isolated in nursing facilities.

Approximately 5.4 million American adults living outside an institution require some assistance from another person with daily living tasks such as dressing, eating, toileting, housekeeping, remembering to take medications, balancing a checkbook, and other everyday activities. There are 2.7 million people needing such assistance have unmet needs.

While progress is slowly being made to change institutional bias, national long-term services policy remains firmly biased in favor of institutionalizing people who need such assistance rather than assisting them in their own homes and/or communities. This bias is reflected in the fact that 72% of the $82.13 billion spent on long term care services goes to institutional services, while only 28% funds community services and supports._

Analysis estimates of 2002 costs, HCBS waivers produced a national average public saving of $43,947 per participant when comparing expenditures between Medicaid HCBS waivers and institutional care._

In 2001, 'The New Freedom Initiative' (NFI) was announced as a cross-governmental policy and funding initiative to remove barriers to community living for people with disabilities and to support efforts to comply with the Americans with Disabilities Act

(ADA). Later in 2001, an Executive Order outlined the Federal Government's commitment to community-based alternatives to institutional care for all people with disabilities. Federal agencies were directed to work with states to ensure compliance with the ADA integration mandate that was reinforced by the Olmstead ruling.

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 has provided national training presentations on ending the institutional bias and home and community services since 2000. These training activities have continued to provide cutting edge, hands-on information in a "how-to" style to thousands of advocates and service providers from across the country since 1995. The commitment to end the institutional bias must include a well trained cadre of advocates, counselors and agency officials to carry out this important work; work that is not just a concept or a funding stream, but rather is a veritable life commitment to liberty of the thousands of CIL staff who carry out this important work on a daily basis; many of whom have the unfortunate, direct experience of existing in institutions as well as the liberating experience of leaving for home, community and employment. CILs employ thousands of people with every kind of disability. Many of these employees have direct experience with the institutional bias and because of this experience, a fundamental commitment to ending it.

……

Our experience has taught us that a very effective method of finding and assisting people who want to leave the institution and go back home, is to have knowledgeable, empathetic staff and volunteers, peers with disabilities wherever possible, go in to the facilities and talk with residents one-on-one and in small groups about programs, services, assistance and options. This builds rapport and trust. Over time, family, if any, can be met and the resident can venture out into the community, check things out, ride the bus, and look for housing and so on. This is the peer-to-peer independent living model that many CILs use to good effect.

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 does 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.

There must be no unfavorable differential federal match requirement relative to any other long-term service programs.

Any benefits, whether direct vouchers/cash or not, derived by personal assistance service users must not be treated as disposable income nor counted as income for the determination of eligibility for other statutory benefits/services.

Federal and state governments must clarify tax withholding and personal assistant benefit requirements for personal assistance service users and providers.

Long-term services insurance reform should be undertaken in conjunction with a national personal assistance service program which addresses standardized benefits packages and the elimination of pre-existing condition exclusions.

No one who receives personal assistance service benefits at the time of adoption of a national personal assistance service program must lose the benefits they are receiving.

NCIL believes that a national personal assistance service program must include a uniform appeal/grievance procedure independent of funders, providers, and assessors which has an expeditious time-line and which provides expenses for the use of advocates and/or legal counsel by personal assistance service applicants/users or their families.

The Community Choice Act would address most of NCIL's above concerns on HCBS. The Community Choice Act allows individuals eligible for Nursing Facility Services or Intermediate Care Facility Services for the Mentally Retarded (ICF-MR) the opportunity to choose instead a new alternative, "Community-based Attendant Services and Supports." The money follows the individual.

In addition, by providing an enhanced match and grants for the transition to Real Choice before October 2009 when the benefit becomes permanent, Community Choice Act offers states financial assistance to reform their long term service and support system to provide services in the most integrated setting.

Specifically what does this bill do?

1) Provides community-based attendant services and supports ranging from 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.

2) Includes hands-on assistance, supervision and/or cueing, as well as help to learn, keep and enhance skills to accomplish such activities.

3) Requires services be provided in the most integrated setting appropriate to the needs of the individual.

4) 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 that includes voluntary training on selecting, managing and dismissing attendants.

5) 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.

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

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

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

9) Serves individuals with incomes above the current institutional income limitation – if a state chooses to waive this limitation to enhance employment potential.

10) Provides for quality assurance programs that promote consumer control and satisfaction.

11) Provides maintenance of effort requirement so that states cannot diminish more enriched programs already being provided.

12) Allows enhanced match (up to 90% Federal funding) for individuals whose costs exceed 150% of average nursing home costs.

13) Between 2005 and 2009, after which the services become permanent, 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.

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

15) Calls for national 5 to 10 year demonstration project, in five states, to enhance coordination of services for non-elderly individuals dually eligible for Medicaid AND Medicare.

Reform of the long-term care system is a clearly needed antidote to a system that expresses the poison of bias against people with disabilities through institutional segregation of those that society is uncomfortable with having around. A federal "Community Choice" option is a solid, fairly easy step that should be taken immediately in this Congress. States must be directed to allow people, who so desire, to leave institutions and go back home to their community of choice. Fundamental reform such as the Community Choice Act, or something similar, is still needed and soon, to begin the process of truly eradicating the deep seated bias that exists in the Medicaid system. Passage of the Community Choice Act must follow swiftly on the heels of the already passed "Money Follows the Person."

We must begin to end the disability bias by eliminating the institutional bias. Simply put, we have to stop locking people away from home, friends and family just because they are disabled. Ending this bias will make a better and richer society because history has shown that ending bias and segregation against people, any and all people, is good for us all.

NCIL urges the Senate to move quickly in passing S. 799, "the Community Choice Act".

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By: Mitch LaPlante, Ph.D., H. Stephen Kaye, Ph.D., et. al.
Disability Statistics Center, University of California, San Francisco, Aug. 2002

Three Stories of Alaskans Who Transitioned out of Nursing Homes

One of these stories involves a gentleman from Kenny Lake, who was in a facility in Anchorage recovering from a stroke which paralyzed his left side. He and the nursing facility staff felt he no longer needed to be in the nursing facility and could live in the community with the proper supports. The fact that this gentleman lived on a homestead without running water didn't deter him from going home. Nursing Facility Transition grant funds were used to pay for transportation, PCA services and care coordination services for a trial visit to the homestead. Determination was made that it was possible for him to reside at home with community supports and services. He made a successful transition and has been home since 2003.

Another success story is a man from Kipnuk who had been in Anchorage either in the hospital or the nursing facility for a year. He had a motherless sixteen-year-old son at home and desperately wanted to be there for his son. Nursing Facility Transition grant funds paid for transportation, room and board for a caregiver from the village to receive training in Anchorage in his care and to escort him home. The caregiver reported that the man was met by many friends and relatives who carried him off the plane, loaded him onto an ATV, took him home and carried him into his home. He continues to thrive at home, and truthfully, probably has improved physical health due to mental stress and anguish having been eliminated.

A recent transition was for a 23 year old young woman who had been severely injured in an automobile accident in September of 2005. She was in a rehab facility in Seattle, and because the accident occurred in Seattle she was ordered by the court to stay there. Her mother from Alaska was appointed her legal guardian but could not move her without court approval. Either the mother or father was with her at all times living in a travel trailer on the grounds of the facility. Finally the family convinced the court to let them move her to a nursing facility in Anchorage. While there the mother felt she did not receive adequate care, and we were eventually able to convince the court to let us send her home on a trial basis. She is a quadriplegic and did not appear to comprehend anything, never focusing on anyone speaking to her. She was transitioned home March 5, 2007, and in August was sitting in her wheelchair next to her dad who was working a crossword puzzle. She reached over, took his pencil and wrote on his arm. He thought she was just scribbling, but had written "I'm fine", and she is still writing notes to her family members. I believe that her progress after two years was due to the nurturing care of her family in her home.

Rita Walker, Nursing Facility Transition Coordinator
State of Alaska

Written Testimony

S. 799 Community Choice Act of 2007

Senator Max Baucus
Finance Committee

Testimony from:
Renaye Sileo
4490 Virginia loop rd
Montgomery, AL 36116
(334) 284-4710
shedink@charter.net

Chairman Baucus, and honorable members of the Finance Committee, my name is Renaye Sileo and I am currently residing in Cedar Crest Nursing Home. I strongly support the Community Choice Act of 2007 S. 799 and I am asking for your support of S. 799. I have been residing in Cedar Crest a nursing home for the past 3 years because I was not able to receive the community base services I needed to stay in the community. I did not have the choice to choose between community base services or a nursing home.

Due to an automobile accident in 2001 that resulted in a spinal cord injury I have been depended on others to provide care for me. When I went through a divorce and my family was no longer able to provide care for me I had no other choice but to be put in a nursing home. I could not get the Community base services I needed to stay in the community with my three children ages 21, 18, and 10. It has been proven in the Alabama Medicaid Agency 2006 Annual Report that it would be more cost effective to provide me care in the community rather than in Cedar Crest Nursing Home.

I ask you to support this very important legislation. To give individuals like myself the ability to choose to receive their care in the community, rather than in an institutional setting. The Community Choice Act of 2007 is about individual choice, about keeping families together by providing care in the community. Give me my choice back and pass the Community Choice Act of 2007.

ILC
Independent Living Center

Promoting Independence Since 1980

www.birminghamilc.org

Now doing business as. . **Independent Living Resources of Greater Birmingham, Inc.**

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The Mission Continues . .
To Empower People with Disabilities to Fully Participate in the Community

S. 799 Community Choice Act of 2007

Senator Max Baucus
Finance Committee

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The Directors of Alabama's three Centers for Independent Living are writing this testimony jointly and in full support of the Community Choice Act of 2007.

The 2006 Alabama Medicaid Agency Annual Report contrasts the spending on nursing facility spending and waiver spending. Spending on nursing facilities reached $837,068,030 in 2006 during the same period of time the combined spending for the Homebound and Elderly and Disabled was only $73,492,510. When reporting on the Elderly and Disabled waiver the report states: *"During FY 2006, there were 8,601 recipients served by this waiver at an actual cost of $7,733 per recipient. Serving the same recipients in nursing facilities would have cost the state $29,878 per recipient.* ***This waiver saved the state $21,878 per recipient in FY 2006."***

United Way

The Alabama Minimum Data Set (MDS) report for the second quarter of 2006 indicates that there are 3,775 Alabama nursing facility residents who have indicated that they want to return to living in the community. The potential savings to Medicaid would be $83,597,375; the savings to the nursing facility resident – beyond value.

As it stands now, eligible individuals who require long term care services have immediate access to nursing facilities. The same individuals have no assurance that home and community based services would be available should they choose to remain in or transition to the community. The Community Choice Act of 2007 – S 799 would provide people with disabilities and seniors with community services and supports that would enable them to enjoy being a part of their communities, families and the American workforce. We urge you to support this legislation. We ask you to call for a Congressional Budget Office scoring of Community Choice Act.

To:
Senator Max Baucus
Finance Committee Chair

From:
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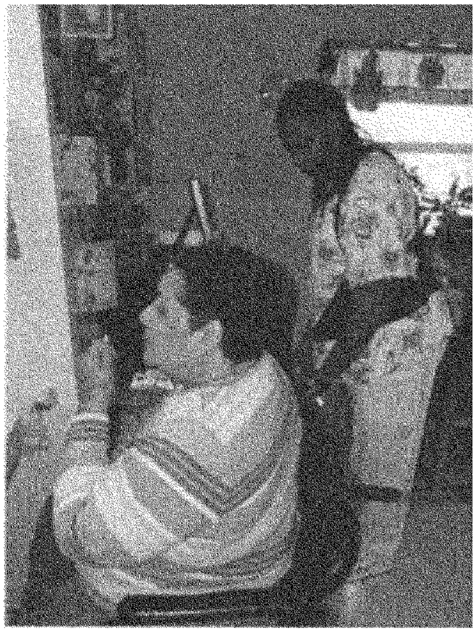

Regarding My Personal Position/Testimony
For Bill Number/Title:

S. 799 Community Choice Act

Monday, September 17, 2007

Senator Baucus:

My name is Florence R. Walker. I am a consumer and volunteer for the Independent Living Center of Mobile, which is an advocacy group for persons with disabilities. To date, I have lived in skilled nursing facilities for almost 3 years. Consequently, I am fervently in favor of the Community Choice Bill of 2007.

Currently, I am the survivor of a massive stroke that occurred on August 29, 2004. This brain attack left me right-side paralyzed and consequently dependent on the "care" of others. Since then, I have had a series of life-threatening complications that I have had to victoriously overcome. And yet, I still find myself occasionally disoriented, depressed, scared, and overwhelmingly uncertain as to what my future holds as a now disabled citizen of the United States of America.

At the time of my stroke, I was between jobs and with no health insurance. Ironically, this life altering experience occurred just seven days prior to starting my dream job working as a case manager for Goodwill Easter Seals. While trying to initially recover from my stroke… I literally battled for my life for six weeks, while intermittently in and out of intensive care units and acute rehabilitative therapy. However with God's grace, I survived many horrendous experiences.

And what has been my fate? ***On October 14, 2004, I found myself with no other options or alternatives, but to begin a life living in a "skilled nursing and rehabilitation facility", better known as a so-called nursing "home".*** Why, you might ask? Well, just like the other hundreds of thousands of Americans living in nursing homes today with limited financial resources, the answer lies in the simple law of economics and cultural convenience.

The long-term care (LTC) industry is big business and nursing homes enjoy a great, big slice of the American pie. I believe that this reality is primarily due to our consumer-driven, society's need for long-term care since our culture in general… no longer wants to be inconvenienced with personally taking "care" of the elderly or the disabled. Instead, we would rather an institution handle this burden of responsibility. Subsequently, Medicaid money allocation decisions regarding a person's quality of life… are not left to the suffering individual, but instead to the well-supported and powerful institutional systems that seem to stay deep in the pockets of it's own constituents, as well as accessing money from federal and state government programs.

Sadly, I only became Medicare eligible in February of this year (over 2 years after my stroke). This long awaited, added insurance benefit allowed me the opportunity to leave a designated "Medicaid bed" at an under-staffed nursing home and be admitted into a better facility.

But, I have still have not had **any** choice in selecting my own "at home" care plan. Nor have I have had control over what institutional standards were personally acceptable or where I ultimately live since I still require 24-hour care. So consequently, I have had to endure mediocre to fair long-term care institutions, where many nursing home employees simply see me more as a room number and a list of duties...not as a person with dwindling dreams, personal dignity, and actual feelings.

For me, it has been absolutely heart-breaking that after years of working hard and being a law-abiding, tax-paying citizen...my "living" choices have been forcefully removed from "my hands" and placed in the long ago, forgotten files of a booming healthcare industry and multi-layered, governmental bureaucracy.

Senator Baucus, my lack of living choices... is only because I had the misfortune of having a massive stroke at a time when our society would rather see people like me in a money-making, desensitized, skilled-nursing facility environment, rather than in the comforting surroundings of an actual home and within a community setting of "my own choosing". It currently costs Medicaid $117 dollars a day for me to live in my present skilled nursing facility. This nursing home revenue amounts to approximately $3,510 a month. As an American, why can't I have a say in how this Medicaid money would be better spent? **Why can't I have a choice to have it redirected to home healthcare? Why can't I choose to be surrounded by nurse attendants with more consistent, caring, and loving attitudes towards me?**

In closing, I can only pray that you will champion the Community Choice Act cause. I do not want to die in a nursing home. Please ***"be"*** my voice and help me re-gain my life and my dignity as a proud citizen of the United States of America. I desperately want to leave the confines of these four walls that seem to get smaller and smaller every day. I truly need my right to a community-based alternative to nursing homes...and to find the meaning of a real "home" again.

Respectfully yours,

Florence R. Walker
(251) 463-0497 /cellular phone
(251) 583-6136 / alternate phone

Senator Max Baucus
Finance Committee

Mark Jackson with S.A.I.L.S (Spa Area Independent Living Services)
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Bill: S. 799 Community Choice Act

I'm personally for the CCA as a person with a disability I've first hand knowledge of how much this bill can change lives.
In 1999 at age 34 I had a diving accident that left me paralyzed from the chest down and after going through rehab and not knowing about any available help I ended up in a nursing home at 34 years old which was devastating to me. I stayed there and after just 3 months ended up with a terrible pressure sore and dwindling weight and was on the verge of dying from multiple infections. Then one day a man named James Capps rolled in and asked me a simple question "Do you want to go home" and I was actually shocked because up until then no one had asked me this, I thought it wasn't possible. I didn't know they had programs that helped people in my condition and yes I wanted nothing more than to go home.
My life changed so fast when I moved home, my health started getting better, I was getting stronger, and I still had children and family that loved me and after getting my health back I started working again and got off of disability or SSDI.
My life has changed so much thanks to these Bills that are passed. I'm enjoying my life instead of wasting away in a nursing home and my health is great I have my family and children back and it saves money in the process not to mention I'm a tax payer again and an active voter.

I don't need any expert opinion on this, it's pretty simple, just let people use the money keeping them in nursing homes and let them use it to move home where you get better care and your health improves which saves a lot of money but most importantly you get your life back.

My most important point is, this is America, Home of the Free so let us go Home!

Sincerely,

Mark Jackson

PIRS

Placer Independent Resource Services

September 24, 2007

Senate Finance Committee
RE: Community Choice Act, S. 799

The Community Choice Act of 2007 gives individuals who are eligible for nursing home services or other institutional care equal access to community-based services and supports, like attendant services across the nation. The Community Choice Act is about individual CHOICE. It allows an individual to choose to receive their care in the community, rather than in an institutional setting.

We see examples of the need for this choice in our community everyday. This not only affects disabled people but also the elderly.

We have been working with a gentleman who has Multiple Sclerosis and has been in a skilled nursing facility (SNF) for over 10 years. He is currently 52 years old. He has had no quality of life as the SNF has such a high patient/staff ratio. This gentleman has all but given up and is currently in the state of waiting to die.

On numerous occasions we have tried to 'bust him out' but have been unsuccessful each time. Every time we think we have everything set up we hit another road block and have to start all over.

We urge you to support the Community Choice Act, S. 799.

Sincerely,

Leslie Brewer

Leslie Brewer
Director of Advocacy and Services

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COMMUNITY CHOICES NOW!

The following are a variety of personal testimonies from people in California who have been freed from institutions:

Butte County
September 21, 2007

My name is Thomas Franklin Smith and friends call me Frank, and I'm 56 years old and have cerebral palsy since birth. I bought my house in 1976 and became involved with (ILSNC) Independent Living Services of Northern California in '95 and was elected to the Board of Director of ILSNC in '96 and very involve in my community.

Little info about myself: Besides going to the Club three days a week I am very active in the community. I'm on the Board of Director of (ILSNC) Independent Living Services of Northern California and one other Board, and several committees. Also I'm in DOGFITE Chico Chapter, (DOGFITE) stand for Disability Organizing Group for Initiating Total Equality. A group of advocates, which I am and several times a year we go to Sacramento to rallies at the Capital etc.

I had been told by several people that I am a value member of the community, and lot of people expects me; that I am not aware of. If I did not have a provider come in to cook and clean I would not be able be involved in my community like I am.

So with that said, I am very much in support of Community Choice Act, CCA, (S.799). And! I urge all the members of this Committee to support Community Choice Act, CCA, (S.799).

Thomas Franklin Smith
976 California St.
Chico CA 95928
E-mail: tfsmith001@pacbell.net

Humboldt County
Aug 29, 2007

TR is a person w/ a disability who has successfully transitioned out of a nursing home twice. Here is a part of his story, as told by him.

All I did was sleep, and wake up to roommates hollering. Finally after awhile I realized that no matter how hard I tried I wasn't going to die, and I would have to live in a Skilled Nursing Facility forever. I felt trapped in the nursing home. I wanted to be up and around. When I got better I was able to get up and around I realized I should not have been there. I investigated and found out that I was there due to a Dr. Mistake (another story) I got really angry.

My experience with Skilled Nursing Facilities is both times I knew where I was and didn't want to be there. The 2nd time I was there for a year. I had another stroke and couldn't communicate for weeks. I just laid there in bed and for the 2nd time I was in a situation where I just gave up and thought that it was the end. When I was sent to a Skilled Nursing Facility I had a whole household of manuscripts and diaries and stories about my foster kids, cookbooks, my Seminary degree, all my things were lost. I was in the snf for more than 30 days so I lost my SSI and my apartment. Everything I had got scattered or thrown away. The only thing I had from my past was my bible. To lose everything was like a death sentence. To cope with being in a nursing home, to cope with the loss of my things, and to be told that I was going to die, well eventually I told myself nothing mattered anymore. I had tremendous feelings of hopelessness and loneliness. I felt like I was a nobody. Nobody knew who I was, who I had been in the community.

The days were boring, everyday was the same, you tried to keep track of the different nurses on the different shifts; some were quite nice, but some were abusive. And they always were violating the rules and then covering it up. They tried to move me from wheelchair to bed but I told them not to pick me up by my arms I had no strength they got really nasty and told me they knew more about it than I did. They tried to pick me up I slid down and fell on the floor. It should have been reported and written up but it wasn't'.

There was another times when they used a Hoyer lift to move me they obviously had no training. I had been using one for years told them the correct way. They got angry with me and wouldn't listen. I told them I would end up on the floor- they copped an attitude because I was sticking up for myself. I created a big scene and called for a head nurse. I told her their way would hurt me, I had been using one for a couple years. They got written up and then I dreaded when their shifts came, because if I needed personal care I would lay there in bed after I pushed the call light for four or five hours. They would ignore me. I developed a yeast infection. It was very painful they always said that they didn't have time or would come in to the room and answer somebody else's call "I will get to you in a few minutes can't you see I am busy?" We were 4 to a room. I lay in bed still as a stone for several days because I was afraid to move because of the pain. The nurses always had an attitude and were rough with me on purpose. I told an Ombudsman that they didn't have very good standards because they always dumped the urinals in the sink. That got reported and written up, but it only added to my rep as a troublemaker among the other staff. In conclusion, what I have to say is that the last time I was there in a nursing home long enough so that I saw people come in that were quite rational and so sweet and so nice and the place would break their spirit. It was designed to do that... Just like a prison where you are known as a number not a person. And in the snf you lose your personal identity. You give in and you become like a vegetable very quickly. You become acclimated to sit in your own urine. Or if you have fight in you and you rebel against some of their treatment to you, you end up with all kinds of humiliating things like restraints or they put you in walkers that you can't move in. I saw over and over people come in and within weeks they would change.

I have been out and in my own place a year and ½ and I remember everyday the residents that are still in there. I don't go back because I have survivor's guilt.

My life in my own apartment now is great because I am involved in my church and am a member of the IN Home Supportive service advisory board. My main problem now is that even though I have this wonderful wheelchair (which was not allowed in the snf) I can't be in my chair as much as I would like to do even more. But even if I am in bed, it's so much better I have my garden I have my computers and I can work when I want and listen to music when I want and I have direction and control each day over how I live my life. In spite of my health issues (almost blind and losing my hearing, being a complete quad) in spite of all that I have a young spirit and I am out there doing as much as I can and enjoying it and loving it. I have great care providers. I would rather die than go back to the nursing home.

Sonoma County
September 2007

I contracted Gillian Barr Syndrome in 1993, on my weekend off from North Coast Rehab where I was Head Orthopedic Nurse. This virus paralyzes you from your toes to the top of your head. Within a week I was paralyzed from my feet to my nose. I could still blink my eyes; the only way I could communicate for two years was with my eyes. After 3-4 months in ICU, I retuned to North Coast, only this time as a patient. I was on a ventilator and had a tracheotomy (14 years last April 16 with a trach).

After 2 moths in Rehab, I was sent to a hell hole in Vallejo, where the 2 year night mare began. Vallejo nearly killed me three times, my vent would pop off, the buzzer would sound and no one came. By the grace of God my best friend Forrest and my sister Sue found me *just* in the nick of time, it was fade to black.

The place was horrendous. I was sent to St. Luke's. I arrived with a blood clot in my lung, back to ICU, from there, things did get better, concerning the Trach but they dropped me head first out of the Hoyer lift. I made some upper body gains. Ninety percent of the aides spoke foreign tongue, they would talk over me, never including me, and I was treated like a side of beef, no face washing, no teeth brushed. They inserted a naso gastric tube, but I sweat so much I would watch the lines slid out because, no one was watching the tape holding it on, (when the lines get to a certain point, the fluid pours into your lungs.)

The coup de grace was when a Doctor whom I had never seen before came in an asked me a few yes questions, and then informed me he would call my family in, (just before Christmas) give me a large dose of valium and unplug me!! (I was still ventilator dependent at that time, so I would have died.) Again my best friend Forrest was there, and heard the whole thing, the Doctor was fired. So with my trach still in but now not ventilator dependent I was transferred back to Santa Rosa, to another hell. No hot food ever, finally gets asleep & at 5-6 am whoosh covers thrown off, side of beef time. When your turn for a shower you Were drug down the hall half naked with your bottom hanging out. The shower was pure hell, it was sprayed in your face, and it felt like being assaulted. Again never got my teeth brushed. PT got me to take a couple steps that was great, OT let my hands get stiff, (new OT didn't know squat). I went though the usual course of wrong meds, UTI's, poor care. I had friends and family come in daily, I was one of the lucky ones. Can you imagine the people that had no one?

So now 14 years later, I volunteered for 2 years and I have been working for 10 years; my trach will be closed Sept 12. Am I glad to be alive? You bet.

- **Senator Max Baucus**
  Finance Committee

- **My name is Teri Saltzman and I represent all persons with disabilities.**
  8503 Wakulla Dr. Tampa Fl. 33637
  813-375-3965 x104
  tsaltzma@tampabay.rr.com

- **S. 799 Community Choice Act**

- **I am writing in support of the Community Choice Act of 2007**
- **In order to protect persons with disabilities entering into nursing homes, The Community Choice Act of 2007 MUST be passed!**
- **I have a consumer, Kim who is 45 years old who acquired a brain injury during the birth of her second child. Because of the injury, Kim has suffered critical sensory impairments such as; sight, speech, and even the sense of touch. Her short term as well as her long term memory has been severely diminished to where she can not even remember her children. Her mother is the caretaker of both children, her frail husband, and she works to bring in the household income. Since Kim's brain injury, Kim has been in many different Nursing Homes. I have tried for 5 years now to get community based services so that Kim can moved back into her home and be with her children and her parents. Because Medicaid dollars are supporting nursing homes and not community based services. I can expect Kim to live in the nursing home for another 30 years.**
- **With the passage of S. 799, I can assist Kim out of the nursing home and into her own home and help her regain the life she deserves.**

- **Nursing Homes are using up %70 of all Medicaid dollars and %30 is only used for community based services. Based on the Supreme Court Decision; Olmstead vs. L.C and E.W, the court mandated that ALL states MUST provide the most integrated community based setting in order to prevent nursing home placement.**

Respectfully, Teri Saltzman

September 20, 2007

The Honorable Max Baucus
511 Hart Senate Office Bldg.
Washington, D.C. 20510

Re: SB 799 Community Choice Act

Dear Senator Max Baucus and Distinguished Members of the Finance Committee:

My name is Rebecca Ramage-Tuttle. I am president & CEO of a disability rights organization in Atlanta, Georgia – the Olmstead State. First and foremost, though, I am also a person who was born with a disability – spina bifida and have been a wheelchair user my entire life. I am writing to express my strong support for Senate Bill 799 – Community Choice Act. The reasons I support this bill and am subsequently requesting your support and passage are:

- ✓ As a disability rights leader in Georgia, which I referred to as, "the Olmstead State" above, I continue to see so many of my brothers and sisters with disabilities unnecessarily institutionalized. If these same people were provided with the community supports they require, they would have the opportunity to be meaningful contributing members to society, i.e. working, paying taxes, volunteering in their communities, etc., etc., etc.;
- ✓ The prime objective of this Bill is to provide individual choice.
- ✓ The Declaration of Independence states, "We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness." Believe me, there is no life, liberty and especially no evidence of happiness in nursing homes and other institutions; and
- ✓ Americans see nursing homes as a "rite of passage." As Americans age or acquire disabilities, nursing homes and institutions are seen as the only option for services. We must change this frame of thought. Persons with disabilities have so much to contribute and have throughout history contributed to our American society. I hope some will still remember that President Franklin Delano Roosevelt pulled our country out of a financial depression of the likes that has not been seen since and virtually saved the world from tyranny in World War II and he did this while serving from the Oval Office in a wheelchair. Where would we be today if he had been institutionalized?

I would like to thank you and the Committee for taking the time to consider this very important bill to **<u>ALL</u>** Americans – Because most of all, it's the right thing to do.

Sincerely,

<u>Rebecca Ramage-Tuttle</u>

I am responding to the request for testimony in support of the Community Choice Act. I cannot provide a "State Story", but only my personal experience working as a Disability Advocate at LINC, a Center for Independent Living in Boise, Idaho.

I have worked with two individuals, both with quadriplegia, who wished to transfer out of nursing facilities into an apartment or Certified Family Home in the community, and requested help from LINC.

Because of a lack of wheelchair accessible apartments, the inability to find people willing to work as attendants (and back-up attendants), insufficient "approved hours" from Medicaid, and lack of money for the transition, S.W. passed away in a nursing facility without accomplishing his goal of community living.

The other person, D.P., I am still working with, although after almost a year, we have still not found a Certified Family Home that he would be approved (by Medicaid) to move into, even though he has found providers who are willing. His health is getting worse because his needs are not being met in the facility, but he doesn't want to complain because he believes that his situation would get much worse if he did so. He believes that Medicaid makes it more difficult for people to find community living arrangements, that they use outdated and/or incorrect information about people (needs, abilities, personalities, etc.) to discourage potential providers, and that the requirements for providers and their homes are too stringent.

This is why I support the Community Choice Act-- so people have more options for long term care, and are not stuck in a place where they don't want to be.

Sincerely,

Todd Wilder
Disability Advocate
Living Independence Network Corporation (LINC)
2500 Kootenai St.
Boise, ID 83705
(208) 336-3335 ext. 27 (Voice/TTY)
(208) 384-5037 (Fax)

Topeka Independent Living Resource Center

785-233-4572 V/TTY • FAX 785-233-1561 • TOLL FREE 1-800-443-2207
501 SW Jackson Street • Suite 100 • Topeka, KS 66603-3300

United States Senate
Committee on Finance

Honorable Max Baucus
Chairman

Testimony
In Support of

S. 799
The Community Choice Act

Provided by
Mike Oxford, Executive Director

Topeka Independent Living Resource Center
501 SW Jackson
Topeka, Kansas 66603
(785-233-4572)
tilrc@tilrc.org

Advocacy and services provided by and for people with disabilities.

Dear Chairman Baucus and Committee members,

Topeka Independent Living Resource Center (TILRC) is pleased to offer testimony in support of S. 799, the Community Choice Act (CCA). TILRC has been actively involved with providing long term services and supports to people with disabilities of all ages who desire to live independently in their own homes for over 15 years. TILRC has also been assisting people with moving out of facilities into their own homes during this same time-frame. I have been personality involved in these activities for almost 25 years. The opportunity to provide input in support of S. 799, the CCA is very much appreciated. The need for S. 799, CCA, is perhaps best demonstrated by the amount of work and financial resources that have been expended from CMS, alone, to assist people with moving from facilities back to their own homes when the best and most efficient system would have ensured that appropriate home and community services and supports were provided in the beginning. It makes no sense for people to move into institutions against their best wishes only to move out later after a significant wait. There should be no argument that this is unnecessary; a waste of money and a waste of human dignity.

Topeka Independent Living Resource Center is a civil and human rights organization whose mission is to advocate for a fully integrated and accessible society. Topeka Independent Living (TILRC) is a 501(c) 3, not-for-profit, charitable corporation that is controlled, operated, managed and staffed by people with disabilities of all ages. TILRC provides all sorts of services for people with disabilities including housing assistance, life skills training, assistance with Social Security, help finding a job and so on. TILRC is also an award winning, nationally recognized policy advocate in the arena of home and community long term services and supports and the rights of people to live their own lives free of facilities and institutions, if they so choose. All of this experience backs up our support for the need to reform Medicaid long term care services and supports. The time has come for CCA.

One of TILRC's largest service areas is helping people to manage their personal attendant services. We assist people with locating, hiring and managing their attendants. TILRC acts as a fiscal intermediary paying taxes and other withholdings and cutting payroll checks on behalf of about 1000 people with disabilities per year who employ about 1,800 workers. We perform this function in partnership with the State of Kansas' HCBS Medicaid Waiver programs. Everyone we serve is otherwise eligible for a nursing facility or other institution. These people actually have to qualify for the facility or institution, but then choose the home and community option, if available. During years when the state budget is tight, many people cannot avail themselves of this choice and must wait on a list; sometimes for longer than a year. If their needs are too great or otherwise cannot be met, then they must enter a nursing facility and then fight to move out later when their name comes off of the waiting list. This is inefficient, unnecessary and violates ADA rights to an integrated setting. Even worse, many used to work and could work, but are now impoverished and unemployed. This was the only way to become eligible and receive the needed services.

TILRC assists people who choose to "self-direct" their attendant services (see attached). Self-direction is an important component of the needed reform promulgated under the CCA. Currently, self-direction is only an option that some states allow sometimes for limited populations. The paragraph below about Kansas paints the picture of the need for national reform:

> "The original HCBS program in Kansas allowed virtually no consumer input into the overall program, or the specific, individual services. Furthermore, oversight of the quality of services provided was ineffective. This ineffectiveness stemmed not only from the lack of any consumer input, but also from the lack of any type of complaint or evaluation process for the work being performed that included the consumer. After self-direction and consumer input into evaluation of services and consumer involvement with all aspects of programs and services was required by passage of the attached state law, complaints, including complaints about neglect, theft, poor quality and so on dropped dramatically while satisfaction increased to a very high level."

If it works in Kansas, it will work for the nation with CCA.

It should not be necessary to become poor and unemployed and then to have to qualify for a facility or institution to receive needed services. Other options need to be developed. This is why TILRC supports the Community Choice Act. When people feel in control of their lives and can be independent, they are happier. Issues, problems and solutions are best resolved when they can be shared and addressed immediately by those who are directly involved. The bottom line is that people need to have some "say-so" around what goes on in their own homes. This is why TILRC supports S. 799.

TILRC supports the Community Choice Act (S. 799 / H.R. 1621) for a very fundamental reason. It eliminates the institutional bias and levels the playing field in Medicaid long term care. The Community Choice Act (CCA) amends the Medicaid statute that currently requires nursing facility services as a priority and leaves home and community services as a secondary, lesser option. The CCA would require that home and community services also be provided at the same priority level as nursing facility and institutional services. Instead of a statutory priority for facilities, the priority would be for individuals to choose between facilities and home and community. With such market forces brought to bear, the system would reform itself and over time home and community services would predominate over the much more expensive facility based service system. Since, on average, home and community services are much less costly than the facilities, over time money would be saved through cost avoidance of the more expensive institutional services. The independence and liberty of people with disabilities will also be enhanced and respected once this important statutory reform is achieved by passage of CCA.

The CCA was drafted with broad based input from a range of stakeholders including representatives of aging, developmental disability, independent living, veterans, home care providers and organized labor. The bill as drafted already includes "must-haves" and compromises from the array of participants during the drafting process. It should be recognized that the bill is a "first step", basic "floor" in the community long term care edifice. It will not, and is not intended to, meet all of the nation's long term care needs. It is a bare bones, "Olmstead" compliance bill that says if you are eligible for mandatory institutional / facility based services, then you should be afforded a choice to receive the same level of assistance in your own home and community. It will only serve those who are already entitled, via state guidelines and authority, to enter a Medicaid funded facility.

The bill doesn't alter the basic structure of the state / federal partnership of Medicaid. States will still have final authority to determine eligibility for services, to monitor quality, and to control the need for licensure, training and other qualifications of providers. Most importantly of all, perhaps, states will still be able to maintain cost effectiveness of programs. No CCA program costs can exceed the cost that would have been incurred had beneficiaries exercised their entitlement to nursing facility / ICF MR placement.

States that have experience with CCA type programs and services, sometimes called "mature" states, report little or no problems with the woodwork effect and further demonstrate that the savings through cost avoidance is significant. Many of the service definitions and consumer control features are modeled after successful programs from Kansas, Pennsylvania and other states. All of these features in CCA have been tried and tested at the state level. It is simply time for our Nation to modernize long term services and supports. CCA simply codifies the philosophy and the Supreme Court "Olmstead" ruling that says if you are going to institutionalize a person, then an integrated home and community alternative should also be offered. The CCA home and community service alternative is a basic package of services and supports that could be used by an eligible person if the state determines they are needed and the program as a whole remains cost effective. CCA is a first step whose time is past due!

Please report S. 799 favorably and vote for passage of this important bill. It will be the most important disability law of the 21st century!

Feel free to contact me at your convenience.

Yours truly,

Mike Oxford
Executive Director

There are five separate statutes which address " attendant care" and "self direction" / licensure issues. These are: 1) KSA 65-5101 2) KSA 65-5102 3) KSA 65-1124 4) KSA 65-6201 5) KSA 39-7100

These bodies of law tell us three basic things:

1) What are attendant care services

2) Who can provide such services and under what conditions

3) What are the rights of consumers of such services

1) Attendant care services are defined as "basic and ancillary services which enable an individual in need of in-home care to live the in individual's home and community rather than an institution and to carry out functions of daily living, self-care and mobility."

2) In the statute "basic and ancillary services" are further defined. For purposes of this discussion, one of the types of ancillary service, "health maintenance activities", will be highlighted. Essentially, health maintenance activities are invasive, medical or quasi-medical procedures which normally must be provided and/or supervised by licensed professionals. Kansas law exempts the licensure requirement for "performance of attendant care services directed by or on behalf of an individual in need of in-home care".

3) "Recipients of attendant care services and the parents and guardians of individuals who are minors at least 16 years of age and who are in need if in-home care shall have the right to choose the option to make decisions about, direct the provisions of and control the attendant care services received by such individuals *including, but not limited to, selecting, training, managing, paying and dismissing of an attendant"* (Italics included here are for emphasis and are not found in the statute.)

The key terms here are the "right to choose..." and "including but not limited to...". HCBS eligible people in Kansas have a right to control their attendant services. Such control must include the five elements italicized above in order to meet the statutory requirement for self-direction. These five elements are not exhaustive, but they are necessary. If any of the five are missing, then the service cannot be considered "self-directed". Further, only "independent living agencies" and certain uncertified employees of home health agencies may administer self-directed attendant services. In the case of home health agency employees, they cannot be held out as "home health aides" and cannot be nurse supervised and the minimum five conditions described above must be met in order for "self-direction" to obtain. For both independent living agencies and home health agencies, the employer responsibilities are shared with the self-directed consumer and are limited to payroll and accounting type administrative functions.

Other related services may or may not be provided depending on the individual agency's program and the desires of the consumer. Examples include assistance with background checks, assistance with recruitment, providing additional training to consumers and so on.

Finally, self-direction is an option for people to choose. Not everyone is ready, or willing, to take on this responsibility. Traditional home health is critical for filling the gap for people who choose to remain in their own homes, but prefer professional assistance and intervention in the decision making surrounding their care.

Note: Medicare licensed providers probably cannot provide the self-directed option. Medicare requires licensure and certification and professional supervision of all workers and services which precludes self-direction. An additional concern is the number of hours which an attendant can work. An additional concern is the number of hours which an attendant can work. Attendants under the self-directed option are <u>not</u> independent contractors. Agencies need to be aware that hours worked in excess of forty per week are covered by wage and hour laws which mandate overtime. Allowing attendants to work more than forty hours without paying overtime exposes an agency to overtime back pay and any applicable penalties.

To: Senator Baucus, Chair, Senate Finance Committee

From: Chris Owens, Executive Director
Prairie Independent Living Resource Center

Date: September 25, 2007

RE: Support S.799, Community Choice Act

As early as 1965-66 with the passage of Medicare and Medicaid, our country began to talk about the cost of medical care and the coverage or lack of coverage of citizens within our country.

Rebalancing the Long Term Care system gives immediate health care reform.

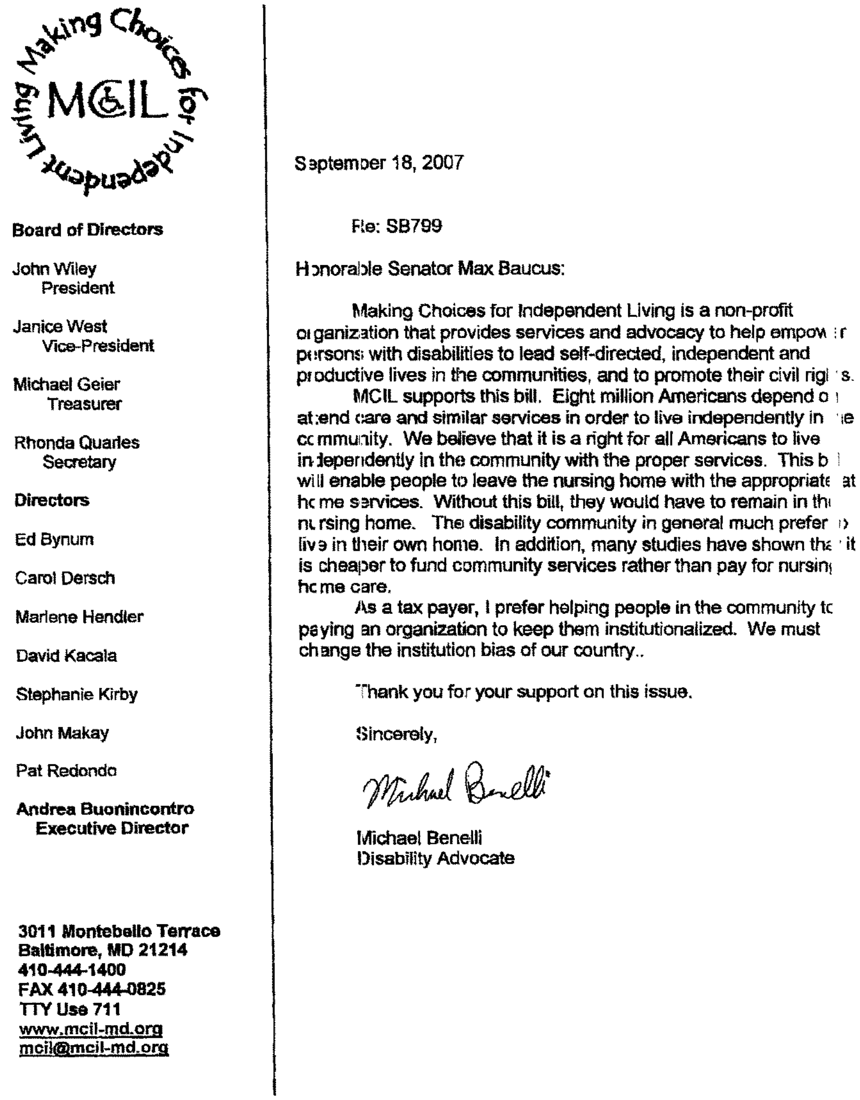
Rebalancing means putting all LTC services on equal footing; Home and Community based should be viewed on par with nursing home care. It means giving persons who need support services the opportunity for Choice and Independence. It means letting persons stay in their own homes and communities. For states, it means the opportunity of providing services to two persons in the community at the same cost of one person in a nursing home.

S. 799, the Community Choice Act, will assist not only individuals seeking long term care supports, but also offer much needed relief for State's Medicaid programs. Persons in need of services should not have to fit into a rigid and costly pattern of having to go to a nursing home.

Kansas advocates strongly support passage of S. 799. The Community Choice Act will offer flexibility and modernization of an antiquated system and long term care policies. This bill would offer a "consumer driven" system based on an individual's choice.

The attached Power Point presentation illustrates the heavy institutional bias in Kansas. While nursing home residency rates continue to drop dramatically, the institutional cost has increased 350%. In contrast, the utilization and cost of Home and Community Based services have increased uniformly, and at half the cost.

We urge all on the committee to act now and favorably pass the Community Choice Act.



Making Choices for Independent Living
MCIL

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September 18, 2007

Re: SB799

Honorable Senator Max Baucus:

Making Choices for Independent Living is a non-profit organization that provides services and advocacy to help empower persons with disabilities to lead self-directed, independent and productive lives in the communities, and to promote their civil rights.

MCIL supports this bill. Eight million Americans depend on attend care and similar services in order to live independently in the community. We believe that it is a right for all Americans to live independently in the community with the proper services. This bill will enable people to leave the nursing home with the appropriate at home services. Without this bill, they would have to remain in the nursing home. The disability community in general much prefer to live in their own home. In addition, many studies have shown that it is cheaper to fund community services rather than pay for nursing home care.

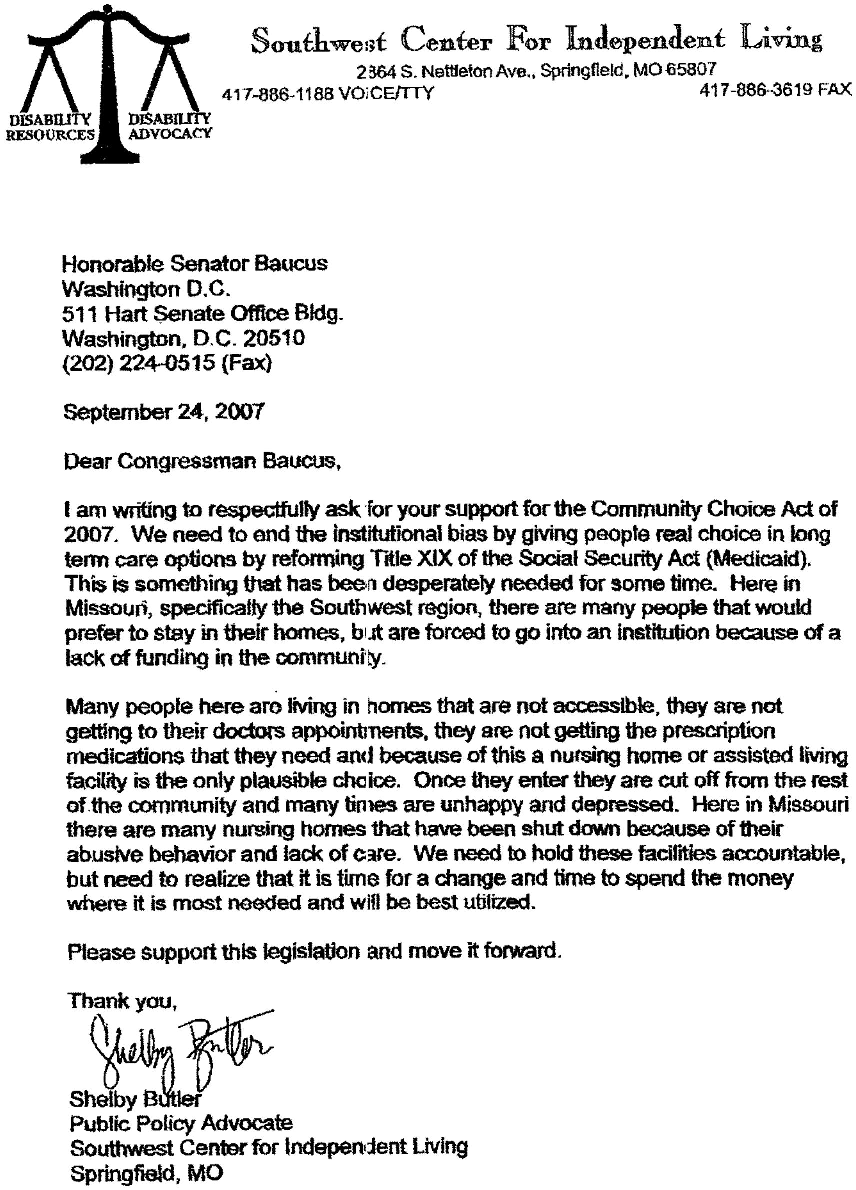
As a tax payer, I prefer helping people in the community to paying an organization to keep them institutionalized. We must change the institution bias of our country..

Thank you for your support on this issue.

Sincerely,

Michael Benelli

Michael Benelli
Disability Advocate



DISABILITY RESOURCES
DISABILITY ADVOCACY

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Honorable Senator Baucus
Washington D.C.
511 Hart Senate Office Bldg.
Washington, D.C. 20510
(202) 224-0515 (Fax)

September 24, 2007

Dear Congressman Baucus,

I am writing to respectfully ask for your support for the Community Choice Act of 2007. We need to end the institutional bias by giving people real choice in long term care options by reforming Title XIX of the Social Security Act (Medicaid). This is something that has been desperately needed for some time. Here in Missouri, specifically the Southwest region, there are many people that would prefer to stay in their homes, but are forced to go into an institution because of a lack of funding in the community.

Many people here are living in homes that are not accessible, they are not getting to their doctors appointments, they are not getting the prescription medications that they need and because of this a nursing home or assisted living facility is the only plausible choice. Once they enter they are cut off from the rest of the community and many times are unhappy and depressed. Here in Missouri there are many nursing homes that have been shut down because of their abusive behavior and lack of care. We need to hold these facilities accountable, but need to realize that it is time for a change and time to spend the money where it is most needed and will be best utilized.

Please support this legislation and move it forward.

Thank you,

Shelby Butler
Public Policy Advocate
Southwest Center for Independent Living
Springfield, MO

San Juan Center for Independence

3535 E. 30th Street, Suite 101 • Farmington, NM 87402 • Phone: 505-566-5827 • Fax: 505-566-5842

9/20/07

Dear, Senator Max Baucus; Senate Finance Committee,

My name is Patricia Ziegler. I am the Executive Director of San Juan Center for Independence in Farmington New Mexico. I am writing to you regarding S.799 the Community Choice Act. As a woman with a disability with a background in Gerontology I cannot stress to you enough the importance of passing this important piece of legislation. For far too long the Medicaid system has perpetuated an institutional bias by funneling individuals with disabilities as well as frail elders who rely on attendant care into nursing homes. We in the Independent Living Movement have demonstrated over and over again that individuals with disabilities can live in their communities with proper supports. In most cases this results in a 50% cost savings to Medicaid. In all cases community living offers individuals autonomy and dignity and choice, things that are insidiously stripped away from individuals forced to live in institutions.

Currently the fastest growing segment of the world population is represented by those individuals in the eighty-five year and older category. Statistics show that the incidence of disability increases as a consequence of the aging process. With these factors in mind we cannot as a country continue to have conversations about the increasing costs of Medicaid while ignoring the institutional bias and its increased cost both on the monetary side as well as the human side.

Aging and disabilities are equal opportunity issues. Statistics show that one in every five individuals will experience a disability in their lives. If an individual is lucky enough not to acquire a disability they most certainly will have a friend or loved one who does. I urge you to take steps toward providing meaningful choices with regard to providing care for those who need it by passing S.799.

I thank you for your time and consideration in this very important matter.

Sincerely;

Patricia D. Ziegler, Executive Director: San Juan Center for Independence.

New Vistas
1205 Parkway Drive, Suite A
Santa Fe, NM 87507-6201
505-471-1001, 800-737-0330
Fax 505-471-4427

Partnering with and supporting people with disabilities and families of children with special needs to enrich their quality of life in New Mexico.

Ronald I. Garcia, Executive Director

September 13, 2007

Senator Max Bacus
Senate Finance

Dear Senator Bacus;

My name is Sarah Grace, and I am the Chairperson of the Legislative Action Team for New Vistas, an independent living center in Santa Fe, NM, that has served the disability community in both Santa Fe and nine northern New Mexico communities for over a quarter of a century. I am writing on behalf of that committee and our entire organization regarding S799, the Community Choice Act.

We support this act most heartily and without reservation. Our organization, along with many other New Mexico organizations and stakeholder interest groups, has been working toward alternatives to nursing homes and other institutions for people who need long term care services.

Building on the Money Follows the Person concept, the Community Choice Act would enable two million Americans now living in nursing homes and other institutions to have a more compassionate option. It would establish a national program of community-based service, where a person could live out their life with dignity and hope.

Please know that when you support the Community Choice Act, you are holding out hope to many who are hopeless, and offering a brighter life choice to persons truly in need of that choice. Thank you for your consideration of this important Act.

Very truly yours,

Sarah Grace

Sarah Grace, LPAT
Chair, New Vistas Legislative Action Team
ZecilG@aol.com.

RE: Written testimony for the Senate Finance Committee for the hearing on September 25, 2007 of the Community Choice Act of 2007 (S799)

I am a resident of Santa Fe, New Mexico, and work for the State's Aging and Long Term Services Department as the Disability Liaison in the Elderly and Disability Services Division. I previously worked for NM's Governor's Commission on Disability. Prior to that, I worked as the Asset Manager for Atlantis Community, Inc., in Denver and as an ADAPT organizer. I have worked for two centers for independent living- in Las Cruces, NM and El Paso, Texas. I was a VISTA volunteer for the Coalition of Texans with Disabilities. I have been active in ADAPT since its inception in 1983 and in the disability rights movement since 1978. I worked as a newspaper reporter, photographer and columnist in Texas, as a person with a disability. I am also a member of AmeriGroup Corporation's new National Disability Advisory Board and a member of the National Council on Independent Living's Personal Assistance Services committee.

I was actively involved in the direct-action advocacy around the efforts to get all publically financed transit accessible through ADAPT's efforts and in the initial work and advocacy in bringing the life and death issue of home and community based services delivery to the attention of politicans and the nation as a whole.

ADAPT's efforts began with a demand for 25% of Medicaid spending on LTS being diverted to HCBS. Currently, the national average is over 30%, which is better, but not good enough. The Community Choice Act (S799), as sponsored by Senator Tom Harkin, one of the true disability-rights advocates in the U. S. Congress, will begin to break the historical grip of our country's institutional spending focus and provide all people with disabilities, young and old, needing LTS the choice of living in the community.

In terms of relating the CCA to New Mexico, our State, under strong leadership of elected and bureaucratic officials and disability-rights advocates, now provides almost 70% of Medicaid LTS dollars to HCBS. NM provides services, in the community, to some 12,000 recipients of the Medicaid Personal Care Option, about 3,000 people in the Disabled & Elderly Medicaid waiver and about 3,800 in the Developmental Disabilities Medicaid waiver and between 120 and 140 in the new Mi Via self-directed Medicaid waiver, which serves all of NM's waiver populations, if the recipient so chooses, and includes people with brain injury. NM provides the mandatory nursing home services to some 4,500 plus. New Mexico is a complete reversal of the Medicaid LTS spending national average, which is still heavily weighted toward NHs and institutions.

How is it that New Mexico and other states such as Oregon and Washington are so successful at providing the large majority of people receiving long term services the community option and the vast majority of other states are not? That is a multi-faceted question; but part of the answer is that NM, Oregon and Washington are committed to providing the services that people have demanded and that they want in the setting that people choose. On the whole, even with the highly skewed DD waiver per person average, the cost to the Medicaid LTS programs as a whole have consistantly shown the HCBS option to be more cost effective on a per person average, and, most importantly, what service recipients and family members want.

Finally, my question to the Senate Finance Committee is this: Why are the HCBS, which most people seem to prefer and want, not mandatory under Medicaid? Why are the more institutional services still the only mandatory "choice" for people with disabilities, both young and old, and their families, in all 50 states?

Respectfully submitted by:

Jim Parker
Aging and Long Term Services Department
Elderly and Disability Services Division
Toney Anaya Building
2550 Cerrillos Road
Santa Fe, NM 87505
(505) 476-4884
jim.parker@state.nm.us

September 7, 2007

Senator Max Baucus
Finance Committee

Clyde Terry, JD
Chief Executive Officer
Granite State Independent Living
21 Chenell Drive
Concord, NH 03301
1-800-826-3700
clyde.terry@gsil.org

S. 799, Community Choice Act of 2007

I submit this testimony in strong support of S. 799, the Community Choice Act of 2007.

Disability and aging are a natural part of life. For years, seniors and people with disabilities have wanted the choice of community-based services as an alternative to nursing home placement in order to meet their long term care needs.

New Hampshire citizens pride themselves on being independent and some might say a little stubborn. Given the alternative, most residents from the "Live Free or Die" state would choose services that allow them to live free in the community.

Community Choice would provide that alternative by making community-based attendant care services an option for Medicaid recipients who are "institutionally eligible."

Granite State Independent Living has been providing community-based attendant care services to a small population of New Hampshire residents since 1980. Year after year our consumers are extremely satisfied with this service delivery model as it affords a better quality of life and control over who, how, and when their attendant care is provided. These supports are also very cost effective as they receive the lowest reimbursement rate for this type of service in New Hampshire.

We know as the life expectancy of the American population continues to grow, so will the demand for long term care services. Community-based attendant care services allow individuals to live in their own homes and age in place. Unfortunately, states lack the infrastructure and incentive to provide these essential supports to their residents.

Under *Community Choice*, states would receive up to five years enhanced match rate (FMAP) for attendant care services and some administrative activities to enable states to develop their long-term care infrastructure. The bill also provides funds to support system change grants to help states increase their ability to provide home and community based services.

Community Choice requires States to work in collaboration with consumers, family members, and providers to develop and implement the program. States must maintain existing state funding levels for existing community-based care, in addition to the *Community Choice* funds that they receive. States are also required to put quality assurance systems into place to monitor and evaluate their community-based consumer choice services.

The Community Choice Act is about individual CHOICE. Choice between services that allow people to live free in the community, or to slowly die confined in a nursing home.
With your support, this Act will provide life changing assistance for seniors and people with disabilities in New Hampshire and across America.

Thank you for your consideration.

Written Testimony

Senator Max Baucus. Committee Chair
Senate Finance Committee

Testimony from:
Julia Sain, Executive Director, juliasain@disability-rights.org
Kevin Nale, Transition and Benefits Coordinator, kevinnale@disability-rights.org
Disability Rights & Resources
5801 Executive Center Drive Suite 101
Charlotte, NC 28212
704-537-0550

Re: **S. 799 Community Choice Act**

We are strongly in favor of the Community Choice Act.

Disability Rights & Resources is a Center for Independent Living covering four counties in the southern piedmont region of North Carolina. For five years we have been focusing efforts on assisting individuals who wish to transition from institutions back to their communities. Scrounging for dollars to assist these individuals has been time consuming and very difficult. In two of our counties, Mecklenburg and Gaston, we have been able locate money from private foundations and other grants and the statistics who we have had a small amount of success.

According to the 2006 MDS Medical Data, Q1A Report, Mecklenburg County had 511 individuals wanting to transition to the community, a number that decreased in 2007 to 480. By the same report in 2006 there were 135 individuals requesting a move to the community, down to 109 in 2007. However, in the two counties where private grants were not obtainable, the number of individuals requesting a transition rose. In Union County the number increased from 110 to 112. In Cabarrus County the number rose from 124 to 177. When money is available individuals are able to move into the community where they have the possibility of maintaining their independence, their dignity, and their ties to family and friends.

The Community Choice Act will finally allow agencies like CIL's to assist individuals in their goals of living integrated in their communities without having to spend valuable time and effort to chase private dollars. The institutional bias of the Medicaid System prevents individuals from living as they wish.

The Constitution of the United States guarantees Life, Liberty and the Pursuit of Happiness, but the Medicaid system requires an individual to give up their liberty and denies them the opportunity to be happy. The Community Choice Act supports the very essence of allowing an individual to choose where and how they live.

Senator Max Baucus

Finance Committee

Chris Stice
828 South Wheeling Ave
Apt. 105
Tulsa, Oklahoma 74104-3627
918-582-5790
C1Stice@cox.net

Re: S. 799 Community Choice Act

I support community-based alternatives to nursing home care for people with disabilities. For far too long state allocated Medicaid funds have restricted the lives of Oklahomans with disabilities and their families by offering too few options for home and community-based services. With no real alternatives, families struggle emotionally and financially to provide at-home care for their loved ones.

I am one of the 604,245[1] Oklahomans with disabilities that are not institutionalized, versus the 31,714[2] that are, and yet 73.33% of Medicaid dollars for care of persons with physical disabilities in Oklahoma goes for institutional services[3]. This is a disproportionate percentage considering that numerous independent studies have concluded it is more economical and preferred to provide services and supports in the community than in institutionalized settings.

Although I am not institutionalized, my disabling condition is of a severe nature, and I easily qualify for nursing home services. I have managed to stay out of a nursing home due in large part to the dedicated support of my family. I have seen how each of my family members has struggled. From traveling the 112 mile round-trip from their rural home to my accessible apartment in Tulsa, to the purchasing of my medical supplies, trying to maintain their own jobs and lives has been emotionally and financially stressful. My mother, stepfather, and two siblings would take three day rotations to care for me. My family and I could benefit from a national program of community-based attendant services and supports.

I support the S. 799 Community Choice Act. The per capita distribution of Medicaid funds in Oklahoma needs to adjust to the reality of the situation, that there are many more people with disabilities needing and wanting community-based alternatives to nursing home care.

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[1] 2005 U.S. Census Bureau

[2] Year 2000 Oklahoma Institutionalized Population

[3] Fiscal Year 2006 Medicaid Expenditures, Institutions versus Community-Based Services

From: Sharon E [mailto:seent@charter.net]
Sent: Sunday, September 23, 2007 5:44 PM
To: NCIL
Subject: Re: CCA hearing in 4 days!

Hello, I am not sure where to send the testimonies too. I am sending it to you with the hope you will forward. I have sent it on to others to but am not sure if it was heard or not since Oregon was not mentioned.

In approximately 1993, My daughter and I started receiving care from the Oregon Department of Health and Human Services. I was living in my own home but have disabilities that made my care and that of my daughter's eligible for service through SPD.

Megan, My daughter was born with a neuro-muscular disorder that was never identified in her seven years on this earth. She had seizures, brittle bones, cortical blindness, low muscle tone and many other problems that left her at a six month level of development. My disabilities in clued being considered legally blind at the age of nine months the eye was never correctly formed and this is different from my daughter. In her condition the brain would not send the picture back to the eye. Over my life time I developed back issues, knee problems and have had surgery 18 times. I have moved up in needs over the last 18 years to needing more services to stay in my home. I was a level 15 when I began needing services and have moved to a level 7. These levels come from OAR 411. I would not be able to stay in my home with out the on going support of the SPD office. I have had three in home workers who have worked with me over the time I became more disabled.

Just an example of my last year with getting approximately 100 hours a month, I still ended up in the hospital two times for breathing and vocal cord dysfunction/asthma combination, fallen twice this summer and continue to have on going back problems. If it was not for the Home Care Worker who was a CNA I would never have been able to stay out of the hospital even more or end up living outside my home.

Oregon is doing a good job of getting and keeping people out of institutions unless you talk about the younger disabled population. We then have falling numbers. Unfortunately the Oregon Budget just does not go far enough to care for the programs that have been in the front running through out the past twenty years. I have been very up to date on the last several sessions and Education, healthy children and other programs are being served first. We have had town halls and unfortunately the town hall lines just to get in the door are two to three hours long and then the ones who signed up first got to speak. These are the healthy, young folks who are for more help with education and the people who have trouble standing in line for that kind of time were not called on, you have it, these people where the seniors and people with disabilities.

After sitting on two Governor appointed positions and Physical Disabilities Advisory Committee I can honestly say there are many in my situation who need continued help to stay in there homes, this includes transportation, reasonable housing (including a way of maintaining our homes when we live on $624.50, 300 percent below poverty) and a way to work that would allow us to work when we can. This all is important in community services being available to people with disabilities and Seniors.

I ask that you please consider my testimony as a thank you for the services I have received and for the continued support to make a difference in seniors and people with disabilities. I am 44 years old and if it had not been for the companionship of others and the programs available to me I would never have been able to hold my daughter in my hands until she died at age seven and continue to live independently with a little help to maintain my home and way of life. I am able to be on boards, volunteer time to people less fortunate then myself and I would never be able to run a small business when my health allows it.

Thank you for giving me the opportunity to be as independent as I can and at times give back to the state and federal government through my taxes. Thank you.

Sharon Ely from Oregon

September 10, 2007

Senator Max Baucus
Finance Committee

Stanley Holbrook MBA, MPM
Chief Executive Officer
Three Rivers Center for Independent Living
900 Rebecca Ave.
Pittsburgh, PA. 15221
1-800-633-4588x133
sholbrook@trcil.org

S. 799, Community Choice Act of 2007

I submit this testimony in strong support of S. 799, the Community Choice Act of 2007.

Disability and aging are a natural part of life. For years, seniors and people with disabilities have wanted the choice of community-based services as an alternative to nursing home placement in order to meet their long term care needs.

Pennsylvania citizens pride themselves on being independent. Most consumers in our state would choose services that allow them to live free in the community.

Community Choice would provide that alternative by making community-based attendant care services an option for Medicaid recipients who are "institutionally eligible."

Three Rivers Center for Independent Living has been providing community-based attendant care services to a large population of Western Pennsylvanian residents since 1980. Year after year our consumers are extremely satisfied with this service delivery model as it affords a better quality of life and control over who, how, and when their attendant care is provided. These supports are also very cost effective as they receive the lowest reimbursement rate for this type of service in Pennsylvania.

Pennsylvania has the second largest aging population in the United States. We know as the life expectancy of the American population continues to grow, so will the demand for long term care services. Community-based attendant care services allow individuals to live in their own homes and age in place. Unfortunately, states lack the infrastructure and incentive to provide these essential level of supports to their residents.

Under *Community Choice*, states would receive up to five years enhanced match rate (FMAP) for attendant care services and some administrative activities to enable states to develop their long-term care infrastructure. The bill also provides funds to support system change grants to help states increase their ability to provide home and community based services.

Community Choice requires States to work in collaboration with consumers, family members, and providers to develop and implement the program. States must maintain existing state funding levels for existing community-based care, in addition to the *Community Choice* funds that they receive. States are also required to put quality assurance systems into place to monitor and evaluate their community-based consumer choice services.

The Community Choice Act is about individual CHOICE. Choice between services that allow people to live free in the community, or to slowly die confined in a nursing home. With your support, this Act will provide life changing assistance for seniors and people with disabilities in Pennsylvania and the nation.

Thank you for your consideration.

Stanley A. Holbrook
President and CEO
Three Rivers Center for Independent Living
900 Rebecca Ave.
Pittsburgh, PA. 15221
1-800-633-4588x133

Merry Adams
103 Richland Ave.
Smyrna, TN 37167
615-223-5386
adams5254@comcast.net

RE: S799 Community Choice Act of 2007

Dear Senator Baucus and the Senate Finance Committee:

I strongly support S799, the Community Choice Act of 2007.

The Community Choice Act of 2007 amends title XIX of the Social Security Act to make community based attendant care services an alternative for Medicaid recipients who are "institutionally eligible." Eliminating the institutional bias of long term care and making home and community based services (HCBS) a mandatory benefit is a win-win for individuals, for families, and for taxpayers.

The vast majority of Americans would rather receive long term care services in their homes or communities. However, families are torn apart, communities are losing valuable members and individuals are segregated into institutions because HCBS is not mandatory. Nursing homes are providing individuals long term care services that could easily be provided in their homes if home and community based supports were in place.

The Olmstead ruling by the Supreme Court in 1999 states individuals and families must be provided the option of community and home based services. Even so, many states still do not have adequate programs to allow consumer choice. Federal legislation in the form of S799, the Community Choice Act of 2007, making HCBS benefits mandatory, is necessary to ensure consumer choice in all states and end state sanctioned discrimination based on age and disability.

States with HCBS waiver programs have repeatedly shown an individual utilizing HCBS costs one-half to one-third that of nursing home services. This is a dramatic savings of tax dollars. Our national long term care crisis will only worsen as our older population doubles over the next 25 years if legislation is not passed to eliminate the institutional bias.

Please support S799, the Community Choice Act of 2007.

Thank you.

disABILITY Resource Center

September 19, 2007

Honorable Lamar Alexander
United States Senate
2 Dirksen Senate Office Building
Washington, DC 20510

Dear Senator Alexander:

The Community Choice Act (S.799/H.R. 1621) will be heard in Committee on **September 25, 2007,** a day earned though years of hard work and advocacy by people with disabilities. Having you as a co-sponsor will demonstrate for the Committee how critically important this legislation is for people with disabilities.

To provide you with an example, one of your constituents is a 68 year-old woman named Betty Canaday. Betty has been a paraplegic for 36 years, raised 4 children, and worked many years at the City/County Building in downtown Knoxville. Since May of 2005, she has been living in a nursing home after a stay in a hospital to have her right foot amputated exhausted her medical coverage. Under the current system, she cannot leave the nursing home even though she is healthy in all other respects because her health care coverage through Medicaid favors more costly institutionalization over home community-based services that will allow her to return home.

By co-sponsoring the Community Choice Act, you will help to end institutional bias as mandated by the U.S. Supreme Court in *Olmstead v. L.C.*, 138 F.3d.893. The *Olmstead* ruling held that unnecessary institutionalization of individuals with disabilities is a form of discrimination under the Americans with Disabilities Act.

As advocates and people with disabilities, I encourage you to act before the week's end to sign on as a co-sponsor of the Community Choice Act. Tennessean's need your leadership, and we hope to hear from your office that you have decided to support this legislation.

Respectfully,

Thomas Kahler Independent Living Specialist	Lillian Burch Executive Director

900 East Hill Avenue, Suite 120 Knoxville, Tennessee 37915 Phone: 865-637-3666 Fax: 865-637-5616

Lisa Buckland Testimony

- **Senator Max Baucus**
  Chairman U.S. Finance Committee

- **Lisa Buckland**
  13323 Maham Rd., Apt. 1404, Dallas, TX 75240

- **Re: S. 799 Community Choice Act**

- **I strongly support passage of the Community Choice Act**

- **I wish that the Community Choice Act was in place when I was injured in an accident so that I would not have had to go into a nursing home. At the time of my injury, there were no options for me accept going into a nursing home. I lived in a nursing home for 4 years, until the staff at the REACH of Dallas Resource Center on Independent Living assisted me in moving into my own apartment in the community.**

  As someone who had lived on my own and made my own decisions about how I lived my life, I was then forced into a nursing home and then told when and what I could eat, when I had to get up, when I could shower, etc. This loss of control took away my dignity, added unnecessary stress to my life, and impacted my feeling of self esteem.

- **I want Congress to pass the Community Choice Act this legislative session!**

TO: **Committee Chair**: Senator Max Baucus
Finance Committee

Northern West Virginia Center for Independent Living
Jan Derry, Executive Director
601-3 E. Brockway, Suite A and B
Morgantown, WV 26501
304-296-6091, Fax 304-292-5217
jderry@nwvcil.org

RE: S. 799 Community Choice Act

Introduction: We would like to take this opportunity to strongly state our support for the Community Choice Act (S.799).

According to the most recent Census, there are over 400,000 citizens with disabilities in West Virginia. This represents over 22.5% of our State's population. We have the most people with disabilities in any state in the Union. Current data collected on the Minimum Data Set from the Dept. of Health and Human Resources indicates that there are approximately 2,000 individuals currently trapped in nursing homes who wish to live in the home of their choice among their friends and family. In Fiscal Year 2005 West Virginia spent over $755,000 on long term care services. Only 40% of those service dollars were spent in the community. 60% ($391,460) was spent for institutional care.

West Virginia has a long history of supporting the deinstitutionalization and personal freedom of citizens with disabilities. Our State was one of the first to close its large DD institutions. The last one of these, Colin Anderson, was closed in 1994. However, the Olmstead decision presents us with new challenges. None of our current community support programs have the flexibility or consumer direction needed to meet the needs of those individuals requiring a nursing home level of care. Many individuals whom present difficult challenges have been locked away in nursing homes because our existing community service system cannot support them. Current data from the Disability Statistic Center in San Francisco indicates that 25.2% of those in nursing homes are individuals with mental illness. There are no services for people who require the use of ventilators in West Virginia. People are simply sent to neighboring states such as Ohio, Kentucky and Pennsylvania. Information provided by the Ohio Dept. of Health and Human Resources shows that there are 77 former WV residents who have been stripped of their citizenship and torn away from their friends and family simply because they need assistance breathing. The passage of the Community Choice Act would move West Virginia past the band aids and endless pilot projects to a fully integrated community based system which respects the rights of individuals.

The passage of S.799 would set forth the framework for a flexible consumer directed home and community based service system that would create the supports necessary for West Virginia citizens to have the opportunity to live full, productive lives in the homes of their choice and exercise the rights and freedoms afforded them by their citizenship.

VCIL
Vermont Center for
Independent Living

Citizens with disabilities working together for dignity, independence, and civil rights

Statewide and Central Vermont
11 East State Street
Montpelier,VT 05602
802-229-0501
(voice and tty)
800-639-1522
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vcil@vcil.org

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324 Main Street
Bennington,VT 05201
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(voice and tty)

Windham
28 Vernon Street
(Suite 401)
Brattleboro,VT 05301
802-254-6851
(voice and tty)

Chittenden
145 Pine Haven Shores
(Suite 1137A)
Shelburne,VT 05482
802-985-9841
(voice and tty)

United Way

To: National Council on Independent Living
From: Deborah Lisi-Baker, Vermont Center for Independent Living (VCIL)
Re: Community Choice Act of 2007
Date: September 21, 2007

I am writing to this letter to share why we feel this act is so important for Americans with disabilities and their families. We live in a state that has "shifted the balance" and made community services as real a choice as nursing homes. It wasn't always the case. For over 25 years VCIL has helped Vermonters move out of nursing homes (or avoid them all together). It took many years to build the understanding, the financing mechanisms, and the political will to give individuals the right to choose where and how they get long term care services. This is not a choice that only some Americans should have.

VCIL has worked with individuals who have been able to leave nursing home or stay in the community because of the availability of participant direct personal care, other home care services, and home modifications and assistive devices. Individuals with severe disabilities are in the workforce, living where they want to live, raising families, and contributing their skills to their communities because of many people's successful efforts to shift the balance.

The Community Choices Act honors the promise of the Americans with Disabilities Act and makes independent living viable, rather than telling these individuals that there is no place for them in America but in an institutions. "Money following the person" makes sense financially and socially and we hope that this bill becomes the law of the land. America will benefit. Thank you.

Senator Max Baucus
Finance Committee Chairman
U.S. Senate, Washington, D.C.

Dear Senator Baucus,

I write to you today representing our organization, Northwestern Illinois Center for Independent Living, in Rock Falls, Illinois, concerning S. 799 Community Choice Act. I am very much in favor and heartily support this act. I am the Personal Assistant Coordinator for our organization which has over 100 people who receive Department of Human Services "hours" to be able to pay their Personal Assistants to be able to live independently in the community of their choosing. What most people do NOT realize is how LESS the taxpayer spends in order for someone with a disability to live independently, versus the amount spent for them to live in a nursing facility! Not to mention the fact that people who live independently maintain their dignity! Please support this act. Thank you so much. I am,

Kay Arity
NICIL
229 First Ave, Suite 2
Rock Falls, IL 61071
kay@nicil.org

SEIUHealthcare.
United for Quality Care

ANDREW L. STERN
International President

ANNA BURGER
International Secretary-Treasurer

MARY KAY HENRY
Executive Vice President

GERRY HUDSON
Executive Vice President

ELISEO MEDINA
Executive Vice President

TOM WOODRUFF
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BYRON HOBBS
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KEITH KELLEHER
JANE MCALEVEY
DIAN PALMER
DAVE REGAN
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www.seiuhealthcare.org

Home and Community Based Care:
Expanding Options for Long Term Care

Statement of the Brad Boyer, Home Care Worker in Hamilton, Montana on Behalf of the Service Employees International Union To the United States Senate Committee on Finance

September 25, 2007

I have been a home care worker provider working with seniors and people with disabilities for two years. I was drawn to caregiving after taking care of my father for many years. I currently assist six people who direct me in providing services ranging from regular bathing and cooking to supervision of medication intake. Earlier this year, I became one of 425,000 home care workers in SEIU Healthcare and one of 500 members of SEIU Montana. Like many home care workers, I enjoy my job but low pay and lack of benefits make it tough to make ends meet. In-home caregivers like me work closely with clients to provide the key services that allow seniors and people with disabilities to live at home instead of an institution. But the choice to receive in-home care is restricted when long waiting lists or an unstable workforce strip consumers of the option to live an active life in the setting of their choice. That's why SEIU enthusiastically endorses the Community Choice Act of 2007 (S. 799) and believes that all Americans should have access to the quality long term care they need in the setting they choose. We support reform efforts that promote consumer choice in long term care and commend the chairman, Senator Baucus, for his years of leadership on this issue.

America faces a growing crisis over long term care services and supports. Medicaid is a cost-effective program that ensures access to comprehensive health care for millions of low-income individuals. But there are gaping holes in the program when it comes to long term care services and supports. We support the Community Choice Act because we believe that personal care and other home and community based services should be a mandatory part of any state Medicaid program.

Today, there is a fundamental misalignment between what most state Medicaid programs offer, what most people want, and what is in fact most cost-effective and appropriate, given consumer needs. According to the Kaiser Family Foundation, there are 260,000 people currently on state waiting lists for home and community based care. These are people that want to remain in the community; however, many will be forced into institutions not because they need to live in a medicalized setting but because the state offers them no choice. The Community Choice Act would right that imbalance, removing a tragic and costly bias in Title XIX and improving the quality of life and the quality of care for millions of Americans.

Today, a consumer's ability to receive Medicaid home and community based services depends not on health status, but on geography. The long waiting lists for HCBS services provided under section 1915 waivers are only one barrier. In other states, low wages and the lack of benefits have created work force shortages that make getting and keeping a home care worker very difficult. In states like Washington and Montana, where home care workers have joined together with one voice under collective bargaining, we are far more likely to see wages and benefits that allow a home care worker to sustain a family and enable a consumer to stay in the community. SEIU believes that partnering a consumer choice initiative with improvements in workforce conditions would create a better system for all long term care consumers by stabilizing the workforce and improving the continuity of care. To that end, SEIU supports the Fair Home Health Care Act (S. 2061) which would amend the Fair Labor Standard Act to provide minimum wage and overtime protections to home care workers.

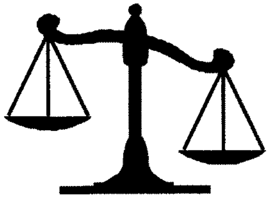
Underlying reforms in this bill is continued reliance on Medicaid to fund long term supports and services. Medicaid plays a vital role in providing health and long term care for 51 million Americans, but we must create new solutions for the growing problem of funding long term services to America's people with disabilities. Rebalancing state Medicaid programs and providing more home and community based services is the first step in improving our long term care system, but we must seize the political moment and broaden the health care debate to reform financing and coverage for long term supports and services.

America needs a new paradigm for considering long term care. We support shifting the financing of long term care from a state-based safety net model to a federal insurance model that will expand access, assure stable funding, prevent the impoverishment of countless disabled Americans, and ease state Medicaid budgets.

We should create a national insurance program for non-medical supports and services, funded by monthly payroll contributions, that would provide a cash benefit for adults should they become disabled. This would enable Americans to plan ahead for the services and supports needed to continue participating in educational, employment, and community activities should they become disabled.

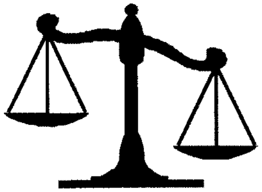
At the same time, we must make sure that the system is sufficiently funded to ensure adequate compensation for direct care workers. Unfortunately, that vision is far from the reality faced by most long term care workers today.

Whether you're young or old, one day you may need long term care—and the choice to live at home without spending down into poverty should be available to everyone in America. We need to expand the choices for this growing population that needs in-home care. Congress should take steps to ensure people have a range of options when it comes to community supports and services.



Reforming Kansas' Long-Term Care System

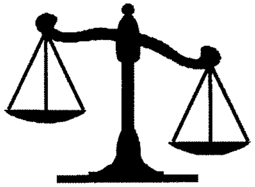
Presentation by:
Shannon M. Jones, Executive Director
Statewide Independent Living Council of Kansas



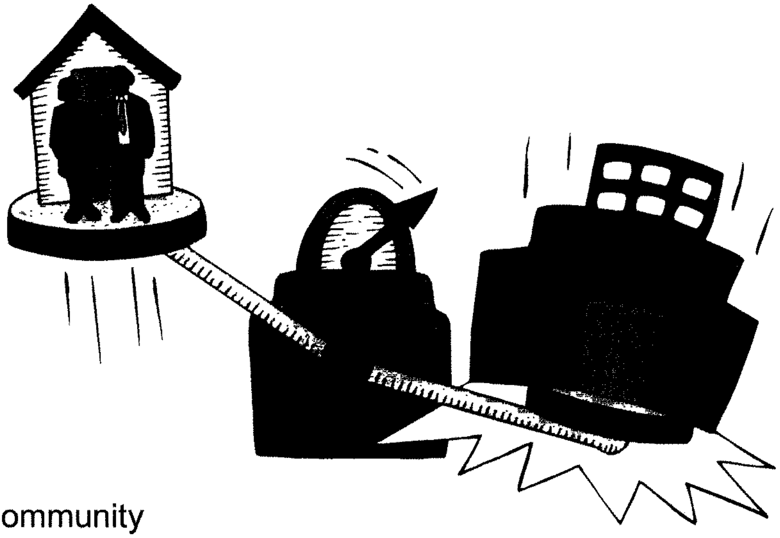
History of Kansas Expenditures for People in Nursing Homes (1986 – 2006)

- Expenditures by the State of Kansas for Nursing home costs
  - ✓ 1986 – approximately $90.2 million
  - ✓ 2006 – approximately $318.9 million
- Increase in nursing home cost
  - ✓ approximately 350%
- Decrease in nursing home residents
  - ✓ approximately 25%

What is Wrong with the Picture?

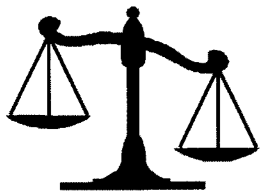


Medicaid Long-Term Care Funding



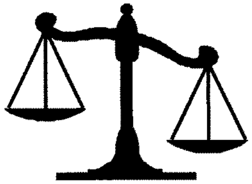
Home & Community
Based Services (HCBS)
Funding 31%

Nursing Facility Funding 69%



What Is Home and Community Based Services (HCBS)

- Medical and support services provided in the home and in the community.
- A variety of services, including but not limited to:
  - ✓ Personal care assistance
  - ✓ Assistive Services
  - ✓ Other
- HCBS emphasizes choice and independence
- Institutional care is minimized
- Providing people with long-term care options, is the **American Way!**



How Does HCBS Work?

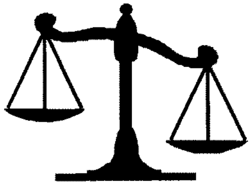
- Provides individual choice to receive the same Medicaid long-term care services in their own home, **if funding is available**
- PD/FE waiver Functional & Financial criteria is exactly the same criteria for people entering a nursing facility
- HCBS administrated through:
  - ✓Frail/Elderly (over age 65) - KDOA
  - ✓Physical Disability (ages 16 – 65) - SRS

Who Can Be Served By HCBS?

- 1980's Home & Community Based Services (HCBS) available in Kansas as an <u>OPTIONAL</u> program

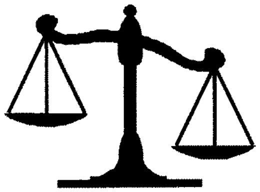
  ✓Some populations served

    ✓ People with Developmental Disabilities
    ✓ People with Traumatic Brain Injuries
    ✓ Children with Severe Emotional Disabilities
    ✓ People with Physical Disabilities
    ✓ Frail/Elderly

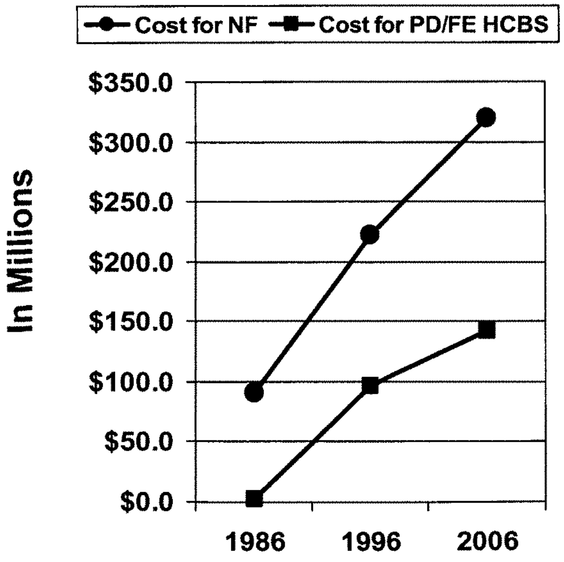


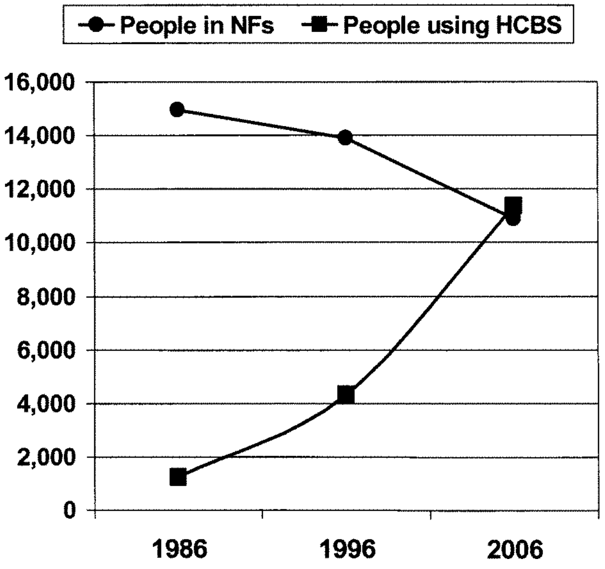
HCBS – The American Way

- Availability of HCBS allows people to stay in their homes with and near their families – Choice
- 1999 – Supreme Court Olmstead decision – services in the most integrated setting
- For every one person receiving nursing facility care, two people can receive services in the community



Cost & Numbers of Persons in Nursing Facilities vs. FE/PD HCBS



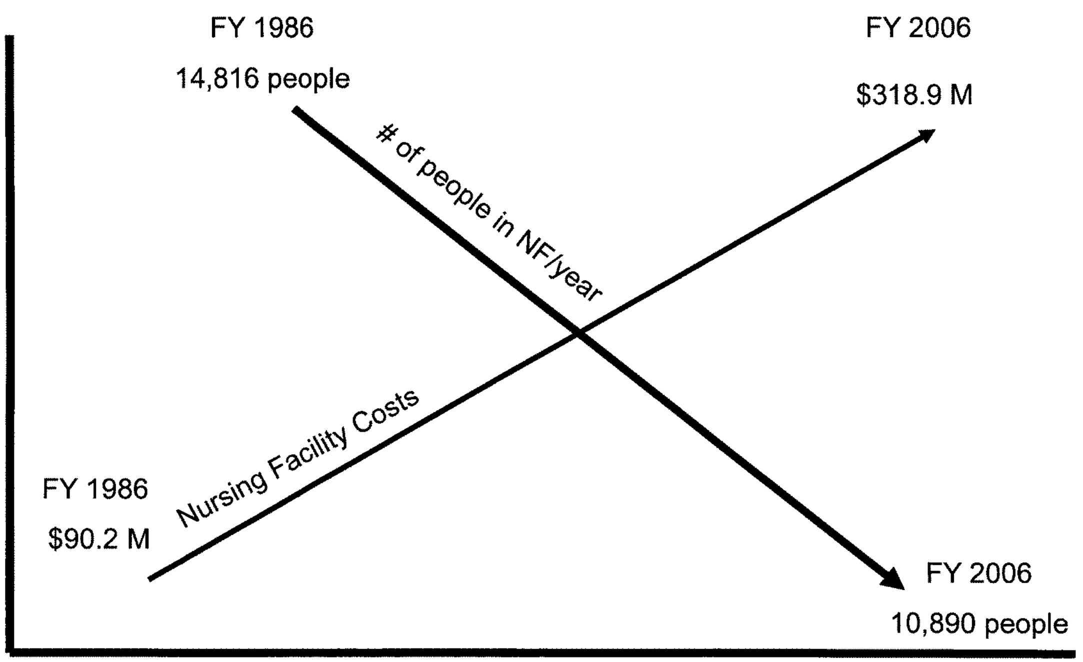


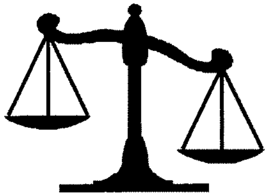
Kansas's FY 2006 Medicaid Long-Term Care Budget

- Kansas spent **$125.4** M SGF and **$318.9** M all funds for **10,890** people in nursing facilities.

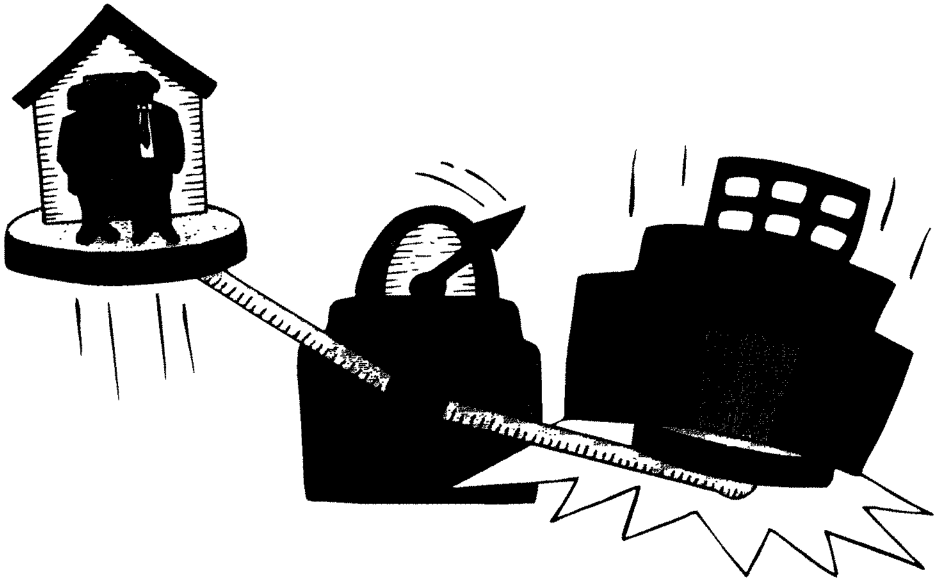
- Kansas spent **$56.1** M SGF and **$142.3** M all funds for **11,353** on the FE/PD HCBS waivers

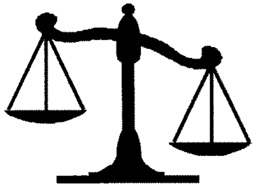
Rising Costs – Declining Occupancy





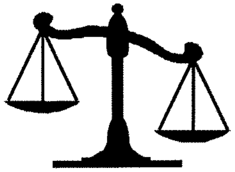
Health Care Reform = HCBS
HCBS = Rebalancing





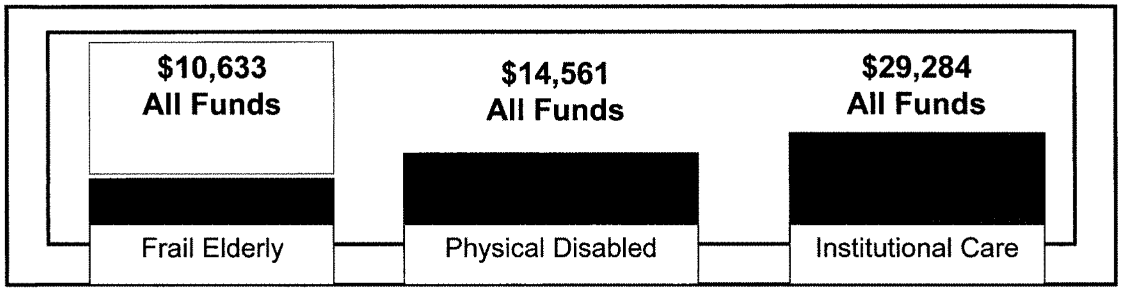
Health Care Reform

- There cannot be significant health care reform without giving attention to one of the costliest forces in the health care system – Institutional Care!
- Very few Kansans look forward to living out their lives in a nursing home!
- Look what's been done even without a formal policy making the option of HCBS equal to nursing home care.
- True Health Care Reform requires a public policy that makes HCBS equal to, and accessible as institutional care.



LTC costs per person per year

Long Term Care Cost /per person/ per year-FY2006

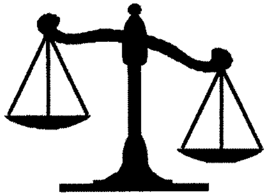


For FY'06 the Medicaid Long Term Care Budget

	All Funds	State General Funds	# Served
Nursing Facility	**$318.9 M**	**$125.4 M**	**10,890**
HCBS/FE & PD	**$142.3 M**	**$ 56.1 M**	**11,353**

Philosophy Necessary to Optimize Kansas' Long-Term Care System

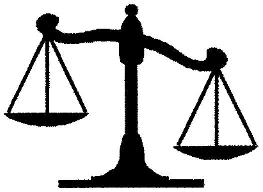
- A clear State vision that consumer choice should drive the system
- The belief that quality of life is as important as quality of care
- The belief that no one service is more important than another
- The belief that the most important service is the one the consumer needs and wants



Elements of a Reformed State Long-Term Care System

- A <u>single organizational unit</u> in State government to plan, develop, and operate the long-term care system

- A <u>single budget with flexibility and authority</u> to spend on a varied array of long-term care services to meet consumer needs and preferences

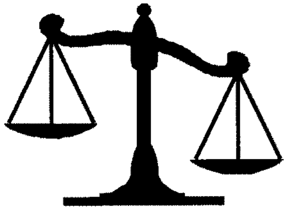


Elements of a Reformed State Long-Term Care System

- A fast, timely, and standardized way to assess financial and functional eligibility

- A case management system with capacity to provide assistance and oversight to consumers

- Fair rate setting and contract processing for providers



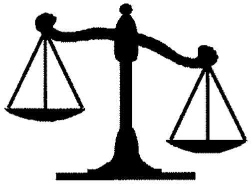
Elements of a Reformed State Long-Term Care System

- A process for assuring quality oversight throughout the system

- A well organized articulate, sophisticated group of consumers/families and providers who ***advocate*** for the long-term care system

Recommendations for Reforming Kansas' Long-Term Care System

- Higher visibility of HCBS
- Access to HCBS equivalent to access to a nursing home
- Actively pursue Money Follows the Person as state policy
- Improve diversion – Insuring all Kansans have the opportunity to make an <u>informed</u> choice
- Transition the 3,615 Kansans who want to move from nursing home to the community
  - ✓M D S data
  - ✓Data Utilization Agreement



Do the Math for Health Care Reform

2006 Nursing facility cost of the 3,615 people who would like to move out

$ 29,284

X 3,615

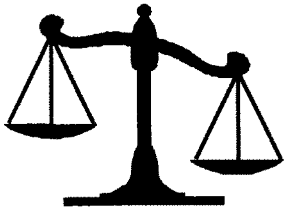
$105.9 M

The cost if these same people were receiving services through the PD HCBS

$ 14,561

X 3,615

$ 52.6 M



Savings for Kansas

$105,861,660	NF cost for 3,615 people
- $ 52,638,015	PD HCBS costs for 3,615 people
$ 53,223,645	Cost savings for Kansas

September 10, 2007

Senator Max Baucus
Finance Committee

Stanley Holbrook MBA, MPM
Chief Executive Officer
Three Rivers Center for Independent Living
900 Rebecca Ave.
Pittsburgh, PA. 15221
1-800-633-4588x133
sholbrook@trcil.org

S. 799, Community Choice Act of 2007

I submit this testimony in strong support of S. 799, the Community Choice Act of 2007.

Disability and aging are a natural part of life. For years, seniors and people with disabilities have wanted the choice of community-based services as an alternative to nursing home placement in order to meet their long term care needs.

Pennsylvania citizens pride themselves on being independent. Most consumers in our state would choose services that allow them to live free in the community.

Community Choice would provide that alternative by making community-based attendant care services an option for Medicaid recipients who are "institutionally eligible."

Three Rivers Center for Independent Living has been providing community-based attendant care services to a large population of Western Pennsylvanian residents since 1980. Year after year our consumers are extremely satisfied with this service delivery model as it affords a better quality of life and control over who, how, and when their attendant care is provided. These supports are also very cost effective as they receive the lowest reimbursement rate for this type of service in Pennsylvania.

Pennsylvania has the second largest aging population in the United States. We know as the life expectancy of the American population continues to grow, so will the demand for long term care services. Community-based attendant care services allow individuals to live in their own homes and age in place. Unfortunately, states lack the infrastructure and incentive to provide these essential level of supports to their residents.

Under *Community Choice*, states would receive up to five years enhanced match rate (FMAP) for attendant care services and some administrative activities to enable states to develop their long-term care infrastructure. The bill also provides funds to support system change grants to help states increase their ability to provide home and community based services.

Community Choice requires States to work in collaboration with consumers, family members, and providers to develop and implement the program. States must maintain existing state funding levels for existing community-based care, in addition to the *Community Choice* funds that they receive. States are also required to put quality assurance systems into place to monitor and evaluate their community-based consumer choice services.

The Community Choice Act is about individual CHOICE. Choice between services that allow people to live free in the community, or to slowly die confined in a nursing home. With your support, this Act will provide life changing assistance for seniors and people with disabilities in Pennsylvania and the nation.

Thank you for your consideration.

Stanley A. Holbrook
President and CEO
Three Rivers Center for Independent Living
900 Rebecca Ave.
Pittsburgh, PA. 15221
1-800-633-4588x133

www.wilc.org
WILC
Making a world of difference.
Westchester Independent Living Center, Inc.
200 Hamilton Avenue, 2nd Floor
White Plains, NY 10601
914-682-3926 (Voice)
914-682-0926 (TTY)
914-682-8518 (Fax)

September 24, 2007

TO: Senator Max Baucus
Chair, Senate Finance Committee
RE: S.799 Community Choice Act

Dear Senator Baucus:

I work as a systems advocate for the Westchester Independent Living Center (WILC) and for the Statewide Systems Advocacy Network. My work is to promote and ensure, through systems change, the full integration of persons with disabilities in every aspect of community life. I support the implementation of the Community Choice Act as one of the most strategic ways we can achieve this fundamental objective.

Thousands of New Yorkers with disabilities in need of long-term care support are currently segregated in nursing facilities and other institutions – not by their own choosing – but by policies that channel millions of tax dollars through Medicaid to warehouse them. Thousands more in our community are at risk of being forced into these profiteering institutions due to the lack of funding for community-based attendant services and supports. The Community Choice Act would allow us the dignity of choice to stay in our own homes, allowing us to maximize our independence through consumer-controlled, activities of daily living supports and related support programs.

WILC has successfully been utilizing the Traumatic Brain Injury (TBI) waiver for the past seven years to help individuals regain their independence through the assistance of independent living skills training services and other community support programs. We have over 170 consumers enrolled in the program and have provided resources to over 1,200 additional individuals, the overall majority of whom have reported experiencing a significant increase in their quality of life. The utilization of support systems have allowed our consumers in the TBI program to live in their own homes/apartments, to find employment and to actively participate in community activities.

The provisions within the Community Choice Act will allow the same options for individuals in need of long-term health care supports and services to exercise their basic human right to choose how and where they want to live.

Respectfully submitted,

Lisa Tarricone
Systems Advocacy Coordinator

Senator Max Bacus
Finance Committee

From: Joel Sheffel
Executiuve Director
West Suburban Access News Association (WSANA)
114 S. Humphrey #302
Oak Park, IL. 60302
708-383-6258

Bill S 799 Community Choice Act

I am in favor of this bill for the following reasons.

1. In 2001 I finally was able to leave a nursing home after being in it for over 18 months. I had no idea where to go for help, to get "my own place".

2.After finally getting into a HUD building and being at home, I founded WSANA and in 2003 our website www.wsana.org premiered. This is a website that today has over 200 pages solely with information for persons with disabilities and this year has been visited by over 35,000 persons seeking the information they feel they can not get anywhere else, as many of these visitors are persons who made a visit to our site and again and again returned to get more information that allows them to remain living in the community and independently. In addition we are constantly contacted by e-mail and phone by persons who feel they can turn to us to get the information so many agencies should be providing, so they can live in the community versus an institution.

3. It is a proven point that persons with disabilities if given the choice DO want to live in the community and not in an institution. But this also means that necessary services and programs need to be m ade available to them to allow them to live in the community.

FRor all of the above reasons I feel it necessary that the Community Choice Act - S.799 be passed

Joel H. Sheffel
Executive Director
WSANA.org
A non-profit organization with a website which provides information for persons with disabilities and their families.
P.O. Box 3221
Oak Park, IL. 60302
708-383-6258
Website:www.wsana.org
E-mail: info@wsana.org
Remember that disability does not mean inability We can live in the community and do okay

See attached testimony from two people with disabilities who recently moved out of a nursing home in Washington, DC. Please make these testimonies part of the official record of the hearing about the Community Choice Act.

Thank you,

Megan D. Boler, Law Clerk

Tiffani Nichole Johnson, JD
Advocate

University Legal Services
Protection and Advocacy Program
220 I Street NE
Suite 130
Washington, DC 20002
202-547-0198, ext. 101 (voice)
202-547-2662 (fax)
202-547-2657 (TTY)
1-877-221-4638 (toll free)
tjohnson@uls-dc.org

Testimonial of B.Q.

My name is B.Q. and I was a resident at Beverly Living Center from June 23, 2006 until June 29, 2007. Before entering the nursing home, I lived in a private residence.

Living in a nursing home was a drastic change in my life. Over time, I tried to address the problems on my own because nobody else was paying attention. For example, the nursing home was infested with roaches. I would often be out of my room for hours at a time for dialysis and the nursing staff would leave my meals uncovered and unattended. By the time I got back to my room, my food for the day was covered with roaches. I began to buy my own cleaning products, but that didn't help because they would still leave food in my room. I don't think anyone should have to live that way.

I feel very grateful to certain staff members at the nursing home who really did care about the residents. When I entered the nursing home, I felt like they would have pulled the plug on me, but the staff in the physical therapy department worked with me. Now, although I still use my wheelchair from time to time, I am able to walk on my own. This combined with the horrible things that I've seen and heard while in the nursing home are the reasons why community placement is so important. Nursing homes do have their problems, but they are there to serve a purpose. However, once that purpose has been served, people like me should be able to move back into the community. I'm enjoying my independence and often spend my days making friends in my neighborhood, sightseeing on the National Mall, and doing everything else that I couldn't do while in the nursing home. I'm 54 years old and I feel like I'm starting my life all over again.

Testimony of S.R.

My name is S.R. I moved into Beverly Living Center in the beginning of November 2006. I lived in a private residence until health issues arose, and it was necessary for my mother and me to relocate to a nursing home.

Although most of the staff would not intentionally harm the residents, I have either witnessed or been told of emotional and physical abuse at the hands of the nursing home staff. These instances range from malnutrition to poor hygiene. There had been several times when I would ask a nurse to clean my mother, and instead the nurse would intentionally ignore me and tend to my mother sometimes days later. Also, there have been times when I've asked a nurse why my medication was different, or asked for an explanation as to a drastic increase in dosage, and she would just tell me to take it. Out of fear for our health, my mother and I often refused.

Now that my mother and I are living back in the community, I have regained not only a sense of freedom, but also privacy and safety. We are enjoying the simple things in life, such as having our own bedrooms, walking downstairs to get the mail, and being able to lock our door at night. Our home health aides are very attentive and respectful. Once we completely settle into our new home, we look forward to getting involved in activities provided by the complex. We're both so grateful to have a home of our own.

Committee Chair: Senator Max Baucus
Committee: Finance Committee
Michele Almore
318 Palermo Dr. Slidell LA 70458
985 645-0795
MicheleAlmore@aol.com
S. 799 Community Choice Act

I support S. 799 Community Choice Act

It keep the participant as well as the community safe, by adding natural support to those that lack them.

I worked with a particiapant of the home and community based progam.
She had no family. This person had no understanding about how to function in the community. She did not know how to pay bills, shop for food, or the know how of how to get the resource that were availble to her. But with the help of a home and community based program, a person was hired to look after her well being. She is now able to shop for herself, live in a nice neigborhood, and have a good life. Without this person help, she would have been a victim of crime, homless are worst dead. These programs works to keep the community safe and the participant safe. Without home and community based programs, participants would not have a good life.

Attn: Senator Max Baucus
Finance Committee

From:
Craig Blackburn
119 Dogwood Drive
Luling, La 70070
craigblackburn@cox.net
Honorable Senator Baucus:

My name is Craig Blackburn and I am twenty-eight years old. I am a peer and self-advocate and I have Down syndrome. I am the Chairperson for Down Syndrome Association of Greater New Orleans. Although I have a disability my hopes and dreams are not unlike those of others my age. I have worked very hard my entire life to be all that I can be. One of my greates accomplishments to date is that I graduated from high school in 2000 with a regular high school diploma meeting the same and all requirements as my classmates. I never failed a grade nor a class.

Another goal that I have been working toward for many years is independent living and owning a home of my own. Bill S. 799 Community Choice will help me achieve this goal.

Unless you are impacted directly by a disability or have someone that is close to you with a disability, it is very difficult to understand how challenging every day can be for someone with a disabiity. I personally have always tried to be as independent as possible, however, I do understand that I need supports in place to be successful and live as "normal" a life a possible.

I have been employed by Winn Dixie in Luling for eight years and I work part time. I really want a full time job, however, I am restricted in my search for full time employment due to transportation limitations. There is no public nor private transportation in my Parish (St. Charles Parish, Lousiana). There is not even a cab service. Bill S. 700 Community Choice is necessary for others and myself to live happy and productive lives.

I am very excited as I became engaged to my girlfriend of five years in August. We want to begin our married life like any other newlyweds in a home of our own and not live with our parents. Please make our dreams come true and help us reach our goals, I request your approval of Bill S. 700 Community Choice.

Sincerely,
Craig Blackburn
Peer & Self-Advocate

Senator Max Baucus
Senate Finance Committee
S. 799 Community Choice Act

Dear Senator Baucus,

I support the passage of S.799 Community Choice Act.

I am writing to you on behalf of my granddaughter and every other disabled person who wants to remain in their home where they are surrounded by people who love them and who want to continue to care for them.
My granddaughter has autism and needs constant care.
She is happiest when she is at home. Our family is more than willing to take care of her in her home, but we realize that as she gets older, (she is 11 years old), we may need some help. We want any help the government can give to her to be given to her in her home and community. We know that this would be better for her and for our entire family, and I'm sure that it would amount to substantial savings for the government.

Thank you for your help in getting this bill out of the committee and onto the floor of the Senate for passage.

Sincerely,
Letha Brignac
P. O. Box 1406
Denham Springs, LA 70727

Outline for Written Testimony

- Name of Committee Chair: **Senator Max Baucus**
  Name of the Committee: **Finance Committee**

- My name: **Lisa Buckland**
  Name of the organization you represent (if any):
  My contact information: **13323 Maham Rd., Apt. 1404, Dallas, TX 75240**

- Bill title and number: **S. 799 Community Choice Act**

- **I strongly support passage of the Community Choice Act**

- **I wish that the Community Choice Act was in place when I was injured in an accident so that I would not have had to go into a nursing home. At the time of my injury, there were no options for me accept going into a nursing home. I lived in a nursing home for 4 years, until the staff at the REACH of Dallas Resource Center on Independent Living assisted me in moving into my own apartment in the community.**

  As someone who had lived on my own and made my own decisions about how I lived my life, I was then forced into a nursing home and then told when and what I could eat, when I had to get up, when I could shower, etc. This loss of control took away my dignity, added unnecessary stress to my life, and impacted my feeling of self esteem.

- **I want Congress to pass the Community Choice Act this legislative session!**

September 16, 2007

Committee On Finance
219 Dirksen Senate Office Building
Washington, DC 20510-6200

RE: Community Choice Act, CCA, (S 799)
Please ACT NOW!

Senate Finance Committee Members:

On behalf of myself and my family, I urge Committee Members to ACT NOW to pass Community Choice Act, CCA, (S 799)! In the year 2007, America remains segregated. People with disabilities are being incarcerated in nursing homes and other care facilities, as if having a disability is a crime. 2007 is the year to create a system of inclusion - to allow the money used to fund institutional care follow and support persons in the most integrated setting possible. It is time to support people, not institutions!

No doubt Committee Members have heard similar pleadings for home and community-based services. I have been actively pushing for the passage of a bill that embodied the philosophy of CCA (S 799) since I was nineteen years old, when I escaped a sentence in a nursing home. Twenty-nine years ago I was born with Cerebral Palsy, and I depend on personal assistance for all activities of daily living. I am wife to a wonderful supporter and care provider, mother of a three-year-old son and a two-year-old daughter, a college student, an Americorps*VISTA Leader Alumna and a disability rights activist.

My story as a wife and mother captures the need for CCA (S 799). In 2003, we began our family in Utah, where my husband was born and raised. Due to a lack of community-based services, and especially a lack of community-based consumer-directed services, my husband was unable to gain employment as he was left to provide much of my care and that of my children. We lived off of my Social Security Income($624) and Temporary Aid to Needy Families($370), racking up insurmountable debt just to “get by”. Agreeing that was no way to raise our children, we relocated to Colorado last year. I have adequate community-based services and supports now, my family-life is stable and flourishing, and my husband has achieved gainful employment.

Why am I concerned about passing CCA (S 799) if I have sufficient services in Colorado? We should have the right to choose the state we live in, and receive services reflective of our needs. My family should not have had to move for me to get the services that I require. Community-based services keep families together - in my case, community-based services enables two precious children to have their mother live at home and be a family. Until the passage of Community Choice Act, CCA, (S 799), I will live in fear of losing my services and being forced to return to an institution, which would be destructive to myself and my family. My story is anything but unique.

Support people! Support families! ACT NOW to pass Community Choice Act, CCA, (S 799)

Tammy Burton, MomOnWheelZ@aol.com
320 Martin Drive
Boulder, CO 80305
H: 720-304-8932
C: 303-815-6819

24 FEBRUARY 2007

I'M WRITING TO HOPEFULLY ILLUSTRATE TO YOU THE DIFFICULTY AND EXPENSE INVOLVED IN BEING IN A WHEELCHAIR. I'M A MANAGER IN PURCHASING AT BOEING IN ST. LOUIS, MISSOURI. I WORK WITH ELEVEN BUYERS IN THE WEAPONS DIVISION LOCATED IN ST. CHARLES, MISSOURI.

I WENT TO COLLEGE AT NORTHEAST MISSOURI STATE UNIVERSITY, NOW BETTER KNOWN AS TRUMAN STATE. I GRADUATED FROM COLLEGE IN DECEMBER OF 1979 WITH A BS IN BUSINESS ADMINISTRATION AND ACCEPTED A BUYER POSITION WITH MCDONNELL DOUGLAS IN FEBRUARY OF 1980. I GRADUALLY WORKED MY WAY UP THROUGH THE ORGANIZATION AND WAS PROMOTED TO GROUP MANAGER AT FAIRLY ACCELERATED RATE IN 1989. MY CAREER AND FUTURE SEEMED BRIGHT AND THINGS LOOKED GOOD. I HAD BOUGHT MY OWN HOUSE AFTER MY DIVORCE FROM MY WIFE AND LIVED BY MYSELF. ON DECEMBER 27, 1989, MY LIFE CHANGED FOREVER. MY CAR SLED OFF A SNOWY HIGHWAY AND I HIT A GUARD RAIL AROUND A CONCRETE PILLAR SUPPORTING AN OVERPASS. I HAD BROKEN MY NECK AND BECAME A C5-C6 QUADRIPLEGIC IN THE BLINK OF AN EYE. I SPENT FIVE MONTHS IN THE HOSPITAL. MY PARENTS, FAMILY, FRIENDS AND COWORKERS VISITED WITH ME AND HELPED ME THROUGH THIS TRYING TIME. MY PARENTS WANTED ME TO MOVE IN WITH THEM. I WAS 33 AT THE TIME, A LITTLE HARD HEADED AND ALL I WANTED WAS TO GO TO MY OWN HOUSE. I WAS FORTUNATE ENOUGH TO HAVE AN LPN AND A NURSE TECH FROM THE HOSPITAL OFFER TO ASSIST ME AT HOME AND MY OLDER BROTHER AGREED TO MOVE IN WITH ME TO HELP OUT.

WHILE I WAS IN THE HOSPITAL I HAD SIGNED UP ON A WAITING LIST WITH A PARAQUAD REPRESENTATIVE FOR ASSISTANCE ON THE NON-MEDICAID ELIGIBLE/PERSONAL ASSISTANCE (NME/PAS) PROGRAM. THINGS WERE QUICKLY OBVIOUSLY DIFFERENT AS I STRUGGLED TO MAKE ENDS MEET AFTER I WENT HOME. I REQUIRED MORE PEOPLE TO HELP ME GET SHOWERED & DRESSED IN THE MORNING AND TO COOK MY MEALS. I WAS CONTINUING THERAPY AT THE HOSPITAL GETTING TRANSPORTATION ON CALL-A-RIDE AFTER I CAME HOME. MY SAVINGS WERE DEPLETED QUICKLY AS I CONTINUED TO PAY MY NORMAL HOUSEHOLD EXPENSES ALONG WITH MOUNTING MEDICAL EXPENSES. I ENDED UP HAVING TO BORROW MONEY FROM MY PARENTS TO MAKE ENDS MEET.

A COUPLE THINGS OCCURRED AT PRETTY MUCH THE SAME TIME. I WAS MISSING THE SOCIAL INTERACTION AND INTELLECTUAL STIMULATION FROM WORK AND I COULDN'T LIVE ANYWHERE DECENT BASED UPON MY SOCIAL SECURITY PAYMENT. I WAS WELL LIKED BY THE VICE PRESIDENT WHO RAN THE PROGRAM I WAS ON BEFORE MY CAR ACCIDENT, AND I

CONTACTED HUMAN RESOURCES ABOUT RETURNING TO WORK. I RETURNED TO WORK AT MCDONNELL DOUGLAS IN OCTOBER 1, 1990. I KNEW OF NO OTHER PERSON IN A WHEELCHAIR, LET ALONE A QUADRIPELIGIC, WHO WORKED AT THE ST. LOUIS FACILITY. WE BOTH MADE IT WORK. THEY RAISED MY DESK AND TABLE WITH PIECES OF 4 X 4's TO ACCOMODATE MY WHEELCHAIR HEIGTH AND LET ME HAVE SOME SPACE TO SEE HOW I WOULD WORK OUT. MY ELECTRIC WHEELCHAIR WAS STORED AT WORK AND THE MORNING ATTENDANTS WOULD TRANSFER INTO THEIR CARS AND FINALLY INTO THE ELECTRIC WHEELCHAIR AT WORK. IT TURNED OUT AT WORK THAT MY BRAIN AND NEW TECHNIQUES ALLOWED ME TO DO MY JOB WELL.

MY EXPENSES TO PAY ATTENDANTS WAS COSTING ME THOUSANDS OF DOLLARS A YEAR AND I WAS FORTUNATE ENOUGH TO QUALIFY FOR A VAN THROUGH VOCATIONAL REHABILITATION BASED ON HOW LONG I WAS OUT OF WORK. KEEPING RESPONSIBLE ATTENDANTS WHO WOULD SHOW UP WHEN THEY WERE SCHEDULED MEANT YOU COULDN'T PAY MINIMUM WAGES. IF THEY DIDN'T SHOW UP & I COULDN'T FIND A BACK-UP, I DIDN'T GO TO WORK.

THEN MAGICALLY AFTER BEING ON THE WAITING LIST FOR **FIVE** YEARS, MY NAME CAME UP ON THE NME/PAS WAITING LIST. SUDDENLY I HAD HELP THANKS TO THE STATE OF MISSOURI AND PARAQUAD WITH MY EXPENSES. NOW MY CHECKBOOK ISN'T ALWAYS AT ZERO AND I CAN COVER THE UNPLANNED COSTS THAT ARISE IN EVERYONE'S LIFE. WHILE I MAKE A FAIRLY NICE INCOME, IN 2003 I SPENT OVER $14,000 IN MEDICAL EXPENSES. I WOULD URGE THE MEMBERS OF THE SENATE FINANCE COMMITTEE TO PASS THE COMMUNITY CHOICE ACT OF 2007. THESE KINDS OF SERVICES HELP OUR SELF ESTEEM BY ALLOWING US TO FUNCTION IN SOCIETY IN VARIOUS CAPACITIES. RATHER THAN DRAINING MISSOURI'S GENERAL FUNDS THESE PROGRAMS:

1. KEEP US PAYING TAXES BECAUSE WE HAVE JOBS,
2. KEEP US OUT OF NURSING HOMES AND OFF STATE WELFARE,
3. HELP OUR SELF ESTEEM.

PLEASE KEEP THESE COMMUNITY CHOICE PROGRAMS ALIVE AND PASS THE COMMUNITY CHOICE ACT OF 2007!

THANKS FOR YOUR VALUABLE TIME AND LET ME KNOW IF I CAN PROVIDE ANY FURTHER INFORMATION.

SINCERELY,

RICK CALDWELL

Committee Chair: Senator Max Baucus

Committee: Finance Committee

My Name: Barbara Cook

Contact Information: Marty & Barbara Cook

258 Ollie Caples Road

West Monroe, LA 71292

(318) 387-9356

bcook@caresolutions-inc.com

Bill Title & Number: S. 799 Community Choice Act

To Whom It May Concern:

I am in favor of S. 799 Community Choice Act. My name is Barbara Cook and I am the mother of a son who is deaf and autistic. His name is Scott and he is 35 years old. Scott has accomplished more than Marty & I could have ever dreamed possible. He attended the Louisiana School for the Deaf (LSD) and graduated in 1994. Scott learned sign language and began communicating with us while attending LSD. He has also proved himself as a hard worker and contributor to the community. Scott held down the same job for over two years working as a silver ware roller at El Chico in West Monroe.

Our next dream for Scott is for him to have his own home. We are currently renovating a small house for him. This process is slow and tedious because we are funding the project ourselves. This S. 799 Community Choice Act would provide the monetary funding needed to finish Scott's home.

We applied for help through the USDA Rural Development. We asked for $7,500 to complete the repairs to the house. Scott's application was rejected because he was under 65 and not a victim of Hurricane Katrina.

We applied for assistance through the Ouachita Citizens for Developmental Disabilities. They rejected Scott's request because he did not come out of an institution.

Marty & I have been good parents to Scott and have taught him to be as independent as possible. At times, I feel like we are being punished for being caring parents to our son and teaching him the independence that he craves. Scott is excited at the thought of living in his own home. But unfortunately this project is taking a long time because we are paying for all of the repairs ourselves.

I believe this bill will help parents like me and adults like Scott. The S. 799 Community Choice Act will provide funding so that people like Scott will be given the opportunity to live in the community with a sense of independence. He longs for the day of having his own home and this bill would make his dream come true.

Thank you,

Barbara Cook

Thanks,

Barbara

September 25th, 2007

RE: Community Choice Act (S. 799)

To the Members of the Senate Committee on Finance:

As you meet today to hear testimony on the Community Choice Act, a plea for freedom that has languished in our legislative system for 15 years now, I hope you will once again reason the facts, take to heart the justice inherent in our intent and act swiftly to bring about the fundamental change we seek for people with disabilities in this country.

As citizens who have chosen a life of service and as students of the history of our great country, you know that our direction has always been forward; not perfect, but always, inexorably, toward assuring freedom for all. When we recognize inequities, whether effecting individuals or classes of people, we use the force of law to make corrections. We have always sought to have all citizens stand as equals before the law.

I hope you will examine the larger meaning of this bill; that people with significant disabilities will no longer be forced to give up basic human and civil rights in order to access the public funds they require to live. I hope you will draw your thoughts inward and personalize the predicament millions of Americans now find themselves in—could the intent of public funding to support people with disabilities /ever/ have been to deprive them of the choice of where they live, and with whom? I hope you will recognize that the Community Choice Act (S. 799) is a responsible bill, in every sense of the word, and that your support is the right thing to do.

I have an adult son with a disability, aging parents and, as demographics show, will someday myself acquire a disability. So, I make the personal request of you that you consider this bill and then move it forward. We have waited a long time, but not as long as others. I would ask you to understand that our impatience is rooted in the reality of our lives. Time spent in loneliness and despair living in nursing homes or group homes, away from family and friends and a basic sense of self-directed destiny, only sharpens the urgency for change.

Thank you.

Sincerely,

Kristine Copeland
29020 Westfield
Livonia, MI 48150
734-427-2136

Personal Testimony in Support of the Community Choices Act

I am writing in support of the Community Choices Act. In doing so, I would like to emphasize that in my opinion, this is not an "anti-nursing home" bill. If someone chooses a nursing home or institutional setting, they are allowed to do so. If someone feels they need nursing home services or "care" they are free to apply for such services.

Rather, this is a free-market, freedom of choice bill. While no one should be prevented from entering a nursing home, neither should they be forced into one because of ingrained institutional biases, nursing home entitlement monopolies or decades-long waiting list for community services and attendant care. If I require assistance for my daily living needs, I should have the freedom to choose where I receive those services, so long as my choices don't increase overall existing costs. Put another way, if I qualify for a nursing home, the state and federal government are then prepared to give me a set amount of money with which I can purchase nursing home care. The Community Choice Act would allow me to take that funding and purchase attendant care that would come to my own home or apartment. Most often, my choices for community based attendant care would be much cheaper than the nursing home costs.

To me, this is a win-win-win piece of legislation. In empowering me to choose where I receive my services, I win. Generally speaking I will choose less expensive services than are being offered in the nursing home, in which case society wins. Under the bill I can't choose more expensive services, so society can't lose. In a free-market system where there is competition, providers of services have to offer quality services to compete. Therefore, those in nursing homes will win through enhanced services.

When my time comes to need services, if given any choice at all, I will choose attendant care services. I want to stay home, where I have made my surroundings comfortable, welcoming and most of all, mine. I want to be surrounded by friends, family, neighbors and church members, not strangers. I want to decide who will enter my home—my living space and when. If those who are paid begin to abuse, neglect or exploit me I want to fire them, no lodge a complaint with management. If I get hungry in the middle of the night I want to go to my kitchen for a snack, not wait until the kitchen is "open". If I have insomnia I want to be able to stay up all night watching reruns of old movies, not have a strict "lights out" policy. If I get the urge for Chinese at midnight, I want to go, not be restricted by set "activity hours".

As I said at the beginning of my testimony, what others choose when given a choice is not my affair. Let them choose nursing homes—I am not in the business of putting nursing homes out of business. But as for me, let me choose as I have always chosen—to live at home, to make thousands of my own daily personal choices that together make for my personal dignity, with friends and family. Do not make me a nursing home commodity—do not force me to a place less desirable than death to me simply so a business can keep their census up. Make the nursing homes compete for my choice if they want to stay in business.

Pass the Community Choice Act. Level the playing field of services for the elderly and persons with disabilities. Do so before it is too late, before I have no choice.

Jerry Costley

Senator Max Baucus: September 24, 2007
Finance Committee:

Jim Cronk

Community Choice Act S. 799

I support the Community Choice Act, S. 799! The bill will provide the disabled a choice in determining their long-term care destiny and will update our current antiquated long-term system, which is expensive and favors institutions over community services.

The demographics of our country are changing. New technology and medical advances have increased the lifespan of the elderly. Children born with disabilities and people who sustain them later in life are alive and living longer due to new advances. People with disabilities could be thriving if given a choice to determine their long-term care destination.

The current system for delivering long-term care was created over 40 years ago. It is funded with Medicare and Medicaid dollars which were not intended to meet long-term care needs. The current system needs to accommodate the country's changing demographics. Congress must implement a new system that allows funding of long-term care to follow the individual and not institutions.

Our current system is outdated and unnecessarily expensive! "In FY 2005, 67% of Medicaid's 94.5 billion long-term care dollars, $63.3 billion, were spent on nursing homes and other institutional services." (http://www.adapt.org/casa/talkingpts.html) This left only 33% of Medicaid dollars, $31.2 billion, for all community services -- home health, personal care, waivers, etc.--. (http://www.adapt.org/casa/talkingpts.html) The current system favors institutions over community services and does not accommodate long-term care choices. A national long-term service system should not favor one setting or another. It should provide services in the most integrated setting as required by the Olmsted decision. (http://www.nhpf.org/pdfs_bp/BP_Olmstead_3-03.pdf.)

Community services are less expensive on average than institutional services, and are preferred by the disabled and their families. According to the 2006 MetLife market survey, "the average cost of a semi private room in a nursing home in the United States is $183 per day." "The cost of a home health aide averaged $19 per hour nationally." Based on this figure, eight hours of home health care paid by Medicaid averages about 17% or $31 less per day than the cost of care in a facility. The average annual savings is $11,160 less than it costs to warehouse someone in a nursing home.

The Community Choice Act, S. 799, provides disabled people and their family's real choice in long-term care options by ending the institutional bias, which appropriates the majority of long-term care funds to facilities rather than community services. Community services are preferred by the disabled and are more cost-effective to provide.

The Community Choice Act will also help open the door for more people with disabilities to go to work. One of the biggest down falls for a person with a disability is being able to find and afford the homecare necessary to work. Going to work is a penalty when it comes to receiving home care. So please think of the contribution a disabled person can make to the community.

Senator Baucus, your support and efforts to bring this legislation to the Senate floor will be greatly appreciated.

Sincerely,

Jim Cronk
Advocacy /Outreach Coordinator
Space Coast Center for Independent Living
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321.633.6011

Testimony for the Finance Committee

Bill title and number S. 799 Community Choice Act

to the honorable: Senator Max Baucus, Committee Chair of the Finance Committee

David Doktor
10 Chestnut Street
Phelps, New York 14532
Email Chestnutforge@earthlink.net
Ontario Democratic Committee member from Village of Phelps , Member of ADAPT

I am in favor of the Community Choice Act Bill Number S.799.
I live in Phelps New York where many of our people want to live home with their families and not in in a NursingHome.
We are a Ageing Community and for many reasons one member of a family is placed in a care facility because the family can't change their house to accommodate a sick member families needs. In one case on my own street the
husband after a fall has been in a Nursing Home for a year. His wife of more that 50 years has to drive daily to visit her
husband. I believe if the Community Choice Act is passed, he could be returned home. In this case this would be a
saving to the people of our Village/ County because the changes to the house would be less that of one month of Nursing
Home stay. I believe that this what AMERICA needs to have its familys together.

Thank you, for addressing this Issue.
David Doktor

Senate Finance Committee:

I strongly urge you to consider voting for the Community Choice Act (S.799). I am the adoptive mother of 4 special needs children, 3 of whom lived in institutions before we adopted them. In my personal experience with my children, they have blossomed since coming to our home; Not because we have been so wonderful, but...because they get the stimulation from living in society. I would like to share one child's story with you.

Gabriel was born with a congenital myopathy. He is unable to use his hands, arms or respiratory muscles. He is ventilator dependent 24/7. He was born in California and after his release from the hospital he was admitted to an institution. He lived there until we were able to bring him home with us when he was 3 1/2 years.

Gabriel was considered to be moderately mentally delayed. When we finally were able to bring him home he could not talk, was combative and would not tolerate being outside. This child is now almost 8 years old, attending a regular first grade classroom and doing fine with the same schoolwork that the other children are doing. He talks all the time. He has gone camping, rode a roller coaster, loves to be outside, has gone snowmobiling. A couple of weeks ago when his judge read about Gabriel, she told the lawyer that this was not the same child, she had to call in Gabriels lawyer in to verify it was him. She could not believe it was Gabe as he sounded so "normal" This is what living in a family and in the community has done for him.

The institution Gabriel was living in did not want us to adopt him and fought the adoption for 2 years. In my experience, with Gabriel and with other institutionalized children we have either adopted or attempted to adopt, the institutions will fight the adoption. Institutions are business organizations and to stay in business they need clients. They advocate for keeping children in institutions. For example, there is a 13 year old boy in New York City living in an institution since infancy. He has been legally free since a very young age. Although DHS has posted his photo and write up on the New York State Adoption Photolisting website, the institution will not allow him to leave. We have been trying for 5 years to adopt him. What a moral crime to keep a child in an institution when there are alternatives.

I strongly urge you to listen at this hearing, do research, meet with persons that this Act will affect. You have the ability to change the lives of many people. Please consider what is best for the disabled people. You can improve the lives of thousands of people throughout the country. I encourage you to meet with individuals that are successfully living in community settings as well as those living within institutions. See for yourself the difference being within a community does for individuals.

Thank you for listening and I would be glad to invite any of you to my home if you would like to see how children are successfully living within a community setting.

Sincerely,

Nora Edgar
N 6545 H 33
Gould City, MI 49838
906-477-9027

To Whom It May Concern:

I am writing in favor of the passage of the Community Based Services for the Disabled. Having two friends who are quadriplegic, who have their own homes, I have seen first hand how well this can work. I have also seen both of these people in hospital settings and realize how much having control over their own affairs means to them. Both are long-time survivors who live almost "normal" lives in so many ways! I've come to believe that being maintained at home is the reason they have survived this long and are happy and can contribute to society.

Sincerely,

Cheryl Evans

9-23-07

Senate Finance Committee,

I support the Community Choice Act (799). Having a choice to pick my own living situation in society, has provided me with a wonderful and balanced life style. In return, I have much love and joy to give others.

Truly,

Debra Exum

Parent of a severely disabled child

I have an 18 year old daughter who is severely physically and mentally disabled. She has lived at home with us for most of her life except for a few years that we were forced to put her in a state institution because we did not have the resources to care for her in her own home.

After we were able to get her on a waiver program, we were able to bring her home again. Having her in the institution was some of the darkest days of my life. She became lifeless while in the institution and probably would not have thrived for long. We actually decided to bring her home before she got on the program because we were desperate to have her home for her well being and our own.

All individuals/family members should have a choice as to what is best for the person--institution or community care. I doubt many will choose the institutional route. I think it is a basic human right to be able to decide where you wish to receive your services.

Institutions are horrible places in my opinion and it certainly isn't where I want to be when I become elderly if my family is not able to care for me.

Please take this into consideration when you have your meeting.

Sincerely,
Ann Felts

Dear Senator Bingaman,

San Juan Center for Independence is in strong support for H.R. 1621 / S. 799, the Community Choice Act Bill. Our Center for Independent Living (CIL) as well as other CILs are proponents of "Choices and Consumer Direction." People with disabilities are often seen as weak people, but as I have seen within my work with my center, that is not the case. I am a person with a disability, but after having my last surgery on my left hip, I went and finished my college career and obtained my degree in Human Services. As I work with my consumers from my office, I see a lot of success, and this is by means of independence. Living in the community and being involved promotes happiness and progression for people with disabilities. In the state of New Mexico, we have some exceptional and unique Home/Community Based Service (HCBS) programs. Programs such as the Personal Care Option (PCO), Disabled and Elderly Waiver (D&E Waiver) and Mi Via Long Term Brain Injury keep people out of institutions, namely nursing facilities. They are able to get homemakers or attendants who help with their Activities of Daily Living (ADL), and that sustains them. New Mexico ranks number 2 in the U.S. with more money being spent on HCBS. We have come a long way since 5 years ago. Another positive outcome of HCBS is the economic factor, where homemakers are paid via Medicaid dollars from the state and that paycheck goes into the local economy. As you are aware, New Mexico is a very rural area and this is where this factor comes into play. I will attach a letter from an elderly Navajo woman who is proof that PCO is a success. I interviewed her for a report I made to our New Mexico Aging and Long Term Services Dept.

Douglas Holtsoi
Advocacy Peer/ Mentor Coordinator
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dholtsoi@sjci.org

MARY SIMPSON'S STORY

My name is Mary Simpson and I have a story to tell. I am a native of New Mexico, a Navajo Indian, 72 years of age. I am a person with dementia and severe osteoarthritis which get worse with age. Sometimes this nearly overwhelms me, but having the option to maintain my lifestyle with its many freedoms and dignity as a Navajo elder are the greatest joys of my life.

This is my story. The details below belong to me but there are many, many more of us scattered around the Reservation with similar stories to tell. Listen to us. We have lived long lives and we know many things. What you learn from us will help you understand and take care of others yet to come.

For the past six years I have been a consumer of San Juan Center for Independence (SJCI) in Farmington, New Mexico. SJCI is a Center for Independent Living serving the northwestern part of the state. SJCI is a provider for the Medicaid service delivery called the Personal Care Option (PCO), Consumer Directed Model. New Mexico is one of 32 states that provide this service to people with disabilities. Under this program I receive daily attendant services in my home and get assistance with my Activities of Daily Living (ADL). I have become an employer and now I am able to hire the attendant of my own "**CHOICE.**" I did this by speaking with a potential attendant and obtained information on her work ethic and experience working with elderly people like myself. I did not have to depend on SJCI or any other agency to send out one of their employees -- an attendant that I didn't know who would be a stranger in my home. I employed my niece, who has been working for me since I began the PCO program. I could not ask for anybody who would be more appropriate for my own situation. She is very compassionate and caring, not to mention reliable. It is also evident that she enjoys her work immensely. She helps me with my daily personal care, reminds me of medications, cooks my meals, washes my laundry and assists with my ambulation. She is also my companion, who talks to me and listens to my stories. Although caring for me is her job, she makes me feel important as a person.

Before hiring my attendant to care for me in my own home, I was institutionalized by my doctor in a nursing home. If it had it not been for the PCO, I would still be one of those institutionalized elders who have given up their freedoms and lifestyles they are accustomed to. During my stay in the nursing home, I was very lonely. No one had time to carry on a conversation with me. No one had time to fix my hair in its traditional style or maintain my traditional clothes. There was no privacy and I could not bear hearing the cries and shouting of the patients there during the day and throughout the nights.

"What kind of life is this?" I wondered. I felt a tremendous loss. All of my life I have been independent and chose what I wanted to do and when I wanted to do it. Mostly this was herding my sheep, eating my traditional foods with my many family members – especially the little ones. When I became suddenly limited in my physical activities due to my declining health, I was still able to make a lot of choices about what I ate, what clothes I want to wear daily and to make time to visit with my grandchildren. When I was diagnosed with dementia I did not have many resources to rely on to remain independent and live at home. I was not able to care for myself and I realized that. My doctor immediately wrote orders for me to be admitted into a nursing home. I did not know there were any other choices for me at that time and I felt that since he was the doctor that he would make the right decision for me. As you will find out in my story, this was not the case.

I felt very uncomfortable the day I was walked into the nursing facility. I also felt angry, thinking "why me?" I had heard many stories about nursing facilities and how people were put there to die. Looking around in the hallways and big room I could see them, nodding in their wheelchairs, some not even able to make known a need to drink or be covered with a shawl when they felt cold. I became very depressed and had crying spells. I wanted to be back in my home, sitting outside and looking at my flocks of sheep in my pastures. The staff got more medicines ordered for me because I cried and was depressed. These were not good. I could hardly even remember my home and my family then. But I didn't bother anybody so they thought I was better.

One of my family members visited me sometimes and we talked about the possibility of getting out of the nursing home and living back in my own home. Eventually she contacted SJCI and because she did that I am here telling you my story from my own home.

I have my life back now. Of course, it isn't the same life as I had when I was young, but it is a quality life of an elder woman with dignity living out the golden years with her family around. It is a good feeling to get up when I want to and to go to bed when I want as well. I can go visit family members when I choose and have them come over and visit me when they want to. My attendant prepares meals I am used to, the tasty foods of my culture. She takes me to the restroom when I ask instead of insisting I wear diapers because nobody was available when I needed them in the nursing home. I can have a bath when I want instead of on somebody's schedule. My attendant treats me with respect, like I am the most important person to her. This is valuable to me and something I missed in the nursing home, where the staff were always too busy and had too many people to take care of to pay much attention to me. In the nursing home, I felt my needs were considered very unimportant, sometimes like I was in the way of the staff.

I am very happy now. My mind works better since my medicines were reduced after coming home. No longer do I have to abide by institutional rules that dictate my life for the convenience of the staff caring for many, such as what food I will eat, when I will eat it, or to deal with people who were constantly stealing my clothes and other belongings. I have the privacy to sleep in my own bed when I want to and on clean sheets every night if I choose. I can sit outside, under the cottonwood tree and watch the kids play – the children of my children's children. I am overjoyed when they call out, "Hi Grandma!" Although my sheep are no longer around on my pastures because I cannot tend them any more, I can still sit outside at my brother's house and watch the descendants of my flock in the family pastures. I treasure those memories of my younger years and although I only watch in my older years, I can almost feel like I am running with the children and sheep through the hills like I did when I was young.

I hope you have learned something from my story about the quality of my life at home. In addition to this component, there is an economic advantage to the government for providing this type of home-based living. I have learned about this through my association with SJCI. I have even been involved in Santa Fe with advocating for the PCO program in the past when there was talk the PCO program may be one of the Medicaid cuts in New Mexico. I have learned that staying in the nursing home is far more expensive for the government than paying for PCO. So not only do I get quality care in my home but also Medicaid pays one-third to two-thirds less than it would pay to keep me institutionalized in a nursing facility. If cuts were made to the PCO program I would suffer a severe hardship and set back in the quality of my life. I do need the daily assistance from an attendant to maintain my independent lifestyle in my own home; if the PCO were not available there is the possibility of a nursing home again. I do not want to let that thought enter my mind. What kind of life would that be for this elder Navajo woman? No life at all.

San Juan Center for Independence is a progressive organization for people with disabilities and the elderly in our community. I am very thankful for their hard work and the way they approach each of us as individuals with wants and needs. The Center has certainly helped me maintain my dignity and integrity and independent lifestyle with their advocacy efforts.

Mary Simpson

Conversation translated June 2007 from Navajo
By Douglas Holtsoi, Disability Advocacy Coordinator
San Juan Center for Independence, Farmington NM

Senator Max Baucus
Finance Committee

Mark Jackson with S.A.I.L.S (Spa Area Independent Living Services)
339 Lamplighter Cr.
Haskell, Ar. 72015
501-778-7600
rollinon@hughes.net

Bill: S. 799 Community Choice Act

I'm personally for the CCA as a person with a disability I've first hand knowledge of how much this bill can change lives.
In 1999 at age 34 I had a diving accident that left me paralyzed from the chest down and after going through rehab and not knowing about any available help I ended up in a nursing home at 34 years old which was devastating to me. I stayed there and after just 3 months ended up with a terrible pressure sore and dwindling weight and was on the verge of dying from multiple infections. Then one day a man named James Capps rolled in and asked me a simple question "Do you want to go home" and I was actually shocked because up until then no one had asked me this, I thought it wasn't possible. I didn't know they had programs that helped people in my condition and yes I wanted nothing more than to go home.
My life changed so fast when I moved home, my health started getting better, I was getting stronger, and I still had children and family that loved me and after getting my health back I started working again and got off of disability or SSDI.
My life has changed so much thanks to these Bills that are passed. I'm enjoying my life instead of wasting away in a nursing home and my health is great I have my family and children back and it saves money in the process not to mention I'm a tax payer again and an active voter.

I don't need any expert opinion on this, it's pretty simple, just let people use the money keeping them in nursing homes and let them use it to move home where you get better care and your health improves which saves a lot of money but most importantly you get your life back.

My most important point is, this is America, Home of the Free so let us go Home!

Sincerely,

Mark Jackson

Senator Baucus:

I was an inmate at Warm Springs, the state psychiatric hospital for Montana. I was sent there for the worst 5 months of my life in 1989. It was a living hell.

I was sent to the hospital after a suicide attempt. I was placed in the "C" Ward, the Personality Disorders ward at Warm Springs. Unfortunately I was misdiagnosed with a Borderline Personality Disorder. Much to my dismay, all personality disorders were on the same ward, including antisocial personality disorders. These were people who had been in prison. They did things such as cutting their wrists or hurting themselves in other ways to get out of the state prison and into Warm Springs because it was an easier form of incarceration. They are able to have ground privileges, ward trips and the like. I was there with rapists, thieves and even murderers, you can get the picture.

The nicer one was the meaner one was treated by those people. And of course, I was extremely nice. And you know where that left me. I actually lived in fear of my life. My present therapist says that they did irreparable harm to me. (From both staff and patients)

The hospital no longer has a "C" ward. They found too many problems. The one thing that Warm Springs did teach me is that I never want to return. Fortunately, now I am doing very well living in the community of Missoula. I get good community support and services including personal care providers and a service dog. My life is a true blessing. I don't believe that anyone should be sent to Warm Springs. It is not in a community. It is so isolated and everyone is far from family and friends. That is why the Community Care Act is so important. If people can be treated in their community, then they could be around their already existing support systems and their families, if that is what they truly want.

Thank you for your consideration,

Brooke T. Jaqueth
1437 S. 1st Street West
Missoula, MT 59801
406.728.8093

To: Senator Max Baucus
Via Bob Liston, Community Choice Act hearing

My name is Sheila James. I live in Missoula, Montana. I am a former nursing home resident. I spent 10 years in a nursing home because of my inability to get anyone to take care of my personal needs. At the time Medicaid did not cover personal care services in a home. My only choice was to go live in a nursing home.

Today because of personal care services that are available to me, I am able to live independently, to work and do what I want to do. While I lived in the nursing home I was under the care of nurses 24 hours a day, 7days a week. Today I have nurses come to my home twice a month. It costs the government much less to have nursing services twice a month as compared to daily.

I ask that you support the Community Choice Act so that others can live as independently as I do.

Thank-you,

Sheila James
565Burton Apt.305
Missoula, MT 59802
406-728-5326

September 24, 2007

The United States Senate
Finance Committee Hearing on the Community Choice Act (S.799/H.R 1621)

Senator Baucus, the Chair of the Senate Finance Committee

Dear Senator Baucus:

Thank you for an opportunity to speak is support of the Community Choice Act. This legislation is necessary because many people with disabilities, including seniors, across our nation face very limited or no choices for long term care, other than a nursing home. In our community, in Syracuse, N.Y. younger people with disabilities face a great lack of affordable, accessible and integrated housing options, as well as limited or lack of support services. Also, seniors are expected by the Medicaid system to enter a nursing home at an older age, when they need more services. As a result many people end up residing in nursing homes, often against own will, and at a much higher cost than if they were living in own apartments, and receiving appropriate care at home.

We also have some limited day programs for those seniors who receive Medicaid and who speak English. However, for seniors who are too frail to be in an apartment by themselves for part of the time, who have difficulty being self-directive, and who do not speak English, there need to be other options in the community because they will not benefit from the existing adult day programs, or will not get accepted into the existing assistive living programs.

Therefore, I urge you to support the Community Choice Act. This legislation will increase much needed access to community-based services and other supports for Americans with disabilities and older Americans. It will allow people who are eligible for nursing homes or other Medicaid-funded institutional care to have the choice of living in the community through various services and supports. One of the programs that work extremely well in our community, that should be supported by the Community Choice Act, is the Consumer Directed Personal Assistant Program (CDPAP). It is very cost effective and it allows a person to stay in control of own home care, which is very important. Thank you for your support.

Sincerely,

Beata Karpinska-Prehn
635 James St.
Syracuse, NY 13203

To: Senator Max Baucus
Chair: Finance Committee

From: Richard A. Knechtges
1310 Cornell Street
Manistee, MI 49660

ph. 231-723-1162

email: rconnectus45@yahoo.com

Member, National Association of the Physically Handicapped

I'm writing in support of S. 799 Community Choice Act. I moved to my present community just over a year ago. I use crutches and a wheelchair. The only accessible public housing my wife and I could find was in low-income apartments. My income is higher than the limit allowed for residence. I am retired and have a pension plus SSDI. We were fortunate in finding a realtor who bought a home for us, completely remodeled it, and built a wheelchair ramp for me. We are currently renting this home, but will purchase it this year. There just is not enough accessible housing in this area.

When I get older, I want to make sure I can have care in my home. I do not want to have to move into a nursing home. I believe more choices should be available for those persons with a disability. Housing is just one. I believe there should be a national requirement that at least each new home built include a first-floor bedroom and full bath.

Adequate transportation must also be included. Also there should be caregivers available for those in need. I believe training should be done and employment opportunities made available through subsidies for medical care.

Please support this bill not only with your vote but with a very persuasive speech with your committee colleagues. You can really make a difference in someone's life this way. I want to see the bill passed so it make a difference in mine.

Thank you for your time and considerations.

Richard Knechtges

Dear Senator Baucus,

I am writing on behalf of my dear friend, Linda Westfall, and other quadriplegics and Americans with disabilities.

I urge you to vote for this important act so that Linda and others with disabilities have a stronger voice in making their own health care choices.

Thank you.

Sincerely,

Dixie Kuehn
211 S. 6th Street, #506
Cocoa Beach, FL 32931

September 24, 2007

To the Senate Finance Committee Members:

I'm writing to you in hopes that you and your colleagues will pass The Community Choice Act of 2007 to create and fund programs like the Non Medicaid Eligible/PAS (NME/PAS) program. This is a progressive and vital program that provides monies to pay for personal attendants that aid severely disabled people to stay in their own homes, stay out of nursing homes, gain employment and have control over their lives.

My name is Doug Landis, I'm a C 3-4 quadriplegic, paralyzed from the neck down after a 1975 high school wrestling accident at Kirkwood high school in St. Louis. After hospitalization, I returned to my high school to graduate with my class. I went on to graduate from Meramec Community College with a AA degree in Communications, then graduated from Webster University with a BA degree in Media Studies and finally, graduated from California Institute of the Arts with a MFA in Motion Graphics/Computer Graphics.

I worked as a freelance computer artist at home for Maritz Communications Company for a few short months after graduation. Once the project was completed for Maritz, I was let go. After a long and frustrating search for new employment with no luck, I went on to start my own wildlife art business MouthArt.com, marketing and selling wildlife art I draw by mouth.

I was very proud the day my wife and I saved enough money that I no longer qualified for SSI, but worried as well because I also didn't qualify for Medicaid. We couldn't afford the Missouri Health Insurance Pool. So for several years I didn't have any health insurance, but eventually I did qualify for SSDI and Medicare.

My wife and I were also very excited, because five years ago with our savings and help from family, we bought our first house and have been slowly renovating it.

The art business never really took off, and so five years ago, my wife and I began looking for work outside the home. I worked with St. Louis Vocational Rehabilitation and the Metropolitan Employment & Rehabilitation Services searching for a job. At the same time I also tried qualifying for the NME/PAS program, but was turned down.

There were several good paying job opportunities that I might have qualified for, but couldn't do the paperwork and I needed assistance in the mornings to prepare for work because of my disability of being paralyzed from the neck down. If I had an attendant that could have assisted me with bathing, dressing, transferring out of bed and the paperwork, I'm sure I would have had a fair chance of being hired.

With our savings nearly gone, little money coming in and no good job prospects on the horizon, my wife and I feared we would have to sell the house that we worked and saved so long for, but on January 4th 2002, my Vocational Rehabilitation Counselor called to tell me I qualified for the NME/PAS program. This was outstanding news and it opened up many new possibilities.

Shortly after I was given a slot in the NME/PAS program, I was granted a second interview with a local organization for a position I was turned down once before, because

I couldn't do the paperwork. As of May 28th 2002, I've been gainfully employed full-time as a Peer Consulting Coordinator. I qualified for this position because I have access to an attendant. This isn't just a minimum wage job, but a real career opportunity.

The NME/PAS program is a wonderful program that has truly helped me and others keep our independence, stay in our own homes, staying OUT of nursing homes and become productive tax paying members of society.

So, I implore you and your colleagues to PLEASE PASS The Community Choice Act of 2007. By passing this act you will be creating and funding programs like the Non Medicaid Eligible/PAS (NME/PAS) program and other home and community based care programs.

Thank you for your valuable time.

Sincerely,

Doug Landis
Ballwin, Missouri

Testimony in support of the Community Choice Act (S. 799)

I am writing in support of the Community Choice Act S. 799 because of the experiences my family has had in trying to get our dad back into our home. 4 years ago my dad had a severe stroke that left him paralyzed on the left side of his body and in need of full time nursing care. Because his care is paid for with Medicare and Medicaid he has been forced to live in a nursing home since his stroke. If he could choose how his health care money was spent he would chose to have it pay for home health aids. he would be much more independent and able to live with his family once again.

Please support the Community Choice Act (S. 799) and help me bring my dad and thousands of other people like him, back home.

Sincerely,

Steckley Lee
Gainesville, FL

Dear Senator Max Baucus, Finance Committee,

From: Gary T. Marshall
8720N 350W
Columbia City, IN., 46725
(260)799-9958
gthm41595@peoplepc.com

Regarding Bill title and number: S. 799 Community Choice Act

I would like to state that I am in favor of bill S. 799 Community Choice Act.

To have a choice in where children with disabilities, working-age adults with disabilities, and older Americans spend their days in need of care with the approval and assistance from Medicaid is an example of freedom for which this country stands. It brings dignity, comfort, and peace to these individuals thereby greatly increasing the quality of life for a voting population that deeply needs it. I believe this would also set a standard for other governments in countries around the world to follow. As the S. 799 Community Choice Act is implemented, I'm confident that other benefits, currently unforeseen, will begin to show the wisdom of this program.

I will restate that I am in favor of Bill S. 799 Community Choice Act. I am completely sure that it will greatly increase the dignity, comfort, and peace to all children with disabilities, working-age adults with disabilities, and older Americans.

Sincerely, Gary T. Marshall

COMMUNITY CHOICE NOW! WE ARE COUNTING ON YOU!!!

Dear Senator Max Baucus of the Finance Committee

I am Les Paul Morgan of 284 Wheeler Circle Warrenville SC 29851
Home 803-593-3523 Work 803-279-9611
Email: mycometpatrol@aol.com

Bill title and number S. 799 Community Choice Act

You could be just like me! I am a brain injury survivor I thought I was in perfect health.

I walked into my job where I was the senior operator in a factory at age 22 and in an instant with a powerful pain started shooing through my brain that felt just like an explosion!

I had to struggle and fight for my life, dignity, and a job for over 17 Years every inch of the way.

I can't even begin to tell you how very strongly I feel about helping people with disabilities to live the American dream because after a coma approximately 7 procedures which included removing a fist sized portion of my brain a porcelain plate and 15 permanent metal clips.

(Special Note) I recently received a very special and spectacular award for my work with our support group (Visit our web siteWeb site) www.csradreamcatchers.com and for helping with several community wide disability events by ABC Televisions Extreme make over home edition and Ford Motor Company.

I was awarded a beautiful 2007 Ford Edge for my work with Walton Options our support groups and brain and spinal cord injury prevention. I am telling you this because I would never ever have had such a wonderful thing like this happen in my life if not for my being able to work and live in the community even after the deaths of both my Mother and Brother in a 7 Month Period!

I now get to work in an Independent Living Center in North Augusta SC Walton Options for Independent Living as a peer supporter and my own mother who was a stoke survivor also benefited from a community based waver that allowed her to live at home with me instead of live in an institution even though the amount of time they were allowed to stay with her was not nearly enough.

I have seen great things happen when people get to chose their own destiny instead of having to live in a nursing home or work in a sheltered work shop.

I can testify and I am willing to do so if asked that I have worked with many and I mean a lot of people in my community that have greatly improved their lives by being able to live in the community be part of a support group and be a part of society!

I say even though we are at War and have budget short falls now more that ever is the time to stand up for what we believe is right and help people with disabilities reach their maximum potential and I believe very strongly that with out community based living that a large number of people would be at risk of loosing their dignity!

I have several friends who would suffer greatly if these programs were to be cut. It is my belief that funding for community based living programs need to be greatly expanded!

Community Choice Act

My husband and I strongly support the Community Choice Act. My niece was born with Cerebral Palsy. She depends on personal assistance for her every day activities. Due to lack of support in Utah, where her husband grew up, they had to move away from family, to Colorado. These services have kept her out of an institution, and home with her husband and two children.

Being disabled is not a crime. Disabled people should not be institutionalized. They have just as much to offer our community, as anyone else. My niece is a wife, mother, a college student, an Americorps*VISTA Leader Alumna and a disability rights activist. She is a wonderful example of the vitality and diversity disabled people bring to our community.

Please support Community Choice Act, CCA, (S 799).

Thank you,

Lillian Parsons
Assistant to Raj Kirpalani
Business Intelligence Director
Inkjet Supplies Business
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Senator Max Baucus
Finance Committee

RE: S. 799 Community Choice Act

I support S. 799 Community Choice Act.

I am writing on behalf of my son**, Anthony G. Dupre`**. Anthony is twenty two years old and is considered medically fragile, severely disabled, and quadriplegic, has cortical atrophy with a guarded prognosis, and brain stem apnea. He is unable to care for himself and is totally dependant; at times he requires stimulation as a reminder to breath. He receives numerous medications and has several machines to support his involuntary functions, not to mention he has gorgeous red hair, the longest eye lashes and beautiful big brown eyes you have ever seen.

My husband and I are both gainfully employed and work long hours; as a teacher I also attend after school meetings / in-services, I tutor, and I am an Early Steps Provider. The money we earn provide for our family's natural supports; which includes **his choice** of remaining at home with his family, in **his** room which we have equipped to better meet **his** personal and medical needs. **His quality of life** would be severely diminished as well as his dignity and security if his needs are not met in a way which supports **his needs** and continued **family interaction**.

Anthony graduated in May of 2007 and received a Certificate of Completion from his local high school, Acadiana High. He no longer has the same supports he has had in the past because of this, i.e. public school system. That is why the addition hours were necessary. I was told that 24 hour support would be granted if Anthony were not living in his parents home, and that natural supports as defined by OCDD means unpaid caretakers, be it a family member or friend. I see natural supports as much more. Having a paid worker here does not negate family time, it enables it.

Please help to keep this **Anthony's Choice**, and not that of predetermined policy. On behalf of Anthony and his entire family please support S. 799 Community Choice Act.

Sincerely,

Dawn Dupre` Paschal
Anthony G Dupre`

September 24, 2007

Senator Max Baucus

Finance Committee

Ginger Ratcliff
Advocate for disabled family member
129 Puckett Lake Road
West Monroe, LA 71292
318-366-3354
Ginger.ratcliff@centurytel.com

S. 799 Community Choice Act

I am in favor and support S.799 Community Choice Act. People with disabilities deserve to have a choice about how and where they choose to live. This is a basic freedom that May be taken for granted by some but has very serious consequences for the disabled.

This Act gives my family and I hope, not only for my brother's future but also others that are physically disabled. My brother is a C-4 quad as a result of a spinal cord injury. His accident occurred 27 years ago. He has a very strong spirit and has insisted on living in his own home. I would like to say "It Works"! Although, it has been a great challenge for my family and **more so** for my brother, but it is worth it, for his sanity and gives him a greater ***quality*** of life. He deserves to have a place of privacy for his friends to visit him and it allows him to have his own service dog. He enjoys watching his vegetable garden grow and relishes the tastes of healthy fresh foods he watches grow.

My family member is very intelligent and even though he cannot use his hands, he can give directions to a personal care attendant about how he chooses and prefers to be cared for in his own home.

Individuals with spinal cord injuries, such as my brother, are often sent straight from the hospital to a nursing home and not given an option about where they will live. They are very vulnerable at that time and do not understand that there are others living in their own home with greater freedom to make every day choices about such things as what and when they will eat, shower and when they will go to bed at night. My family member is fortunate to currently benefit from the Medicaid waiver. It has been a long, difficult road for him. He is living proof that caring for the disabled in the community will work.

As a taxpayer, I support the desire to fund services and supports that are "based on best practices and not on protecting any particular interest." Individualized supports provided in the community **have long demonstrated cost effectiveness and improved outcomes for recipients.**

Senator Max Baucus
Finance Committee

Testimony regarding S.799 Community Choice Act

As the parent of a child with Down syndrome and an active advocate in the disabilty community, I strongly support S. 799 Community Choice Act.

No one would presume to tell an adult without a disabilty where they have to live. How would any one of us feel if we knew we only needed minimal assistance to live at home, but were told the only way to get any assistance was to live in an institution? It would not be a choice any of us would make voluntarily. Yet we tell individuals with disabilities every day that they must live in institutions in order to get the support they need.

My son is 6 1/2 years old. I don't want an institution to be his only choice to live when we pass on. It costs way more than is necessary, is devastating to the individual, creates isolation, fosters fear among the community as if they are criminals, leaves our most vulnerable population virtually captive for abuse, and none of us would do it. We should not be asking our loved ones with disabilities to live in institutions. Community Supports for Community Choice is the right way-the only way.

Thank you.

Karen Scallan
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Destrehan, Louisiana 70047
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kscallan@cox.net

Senator Max Baucus
Ranking Member Chuck Grassley
U.S. Senate Finance Committee
September 25, 2008 Hearing
Home and Community Based Care: Expanding Options for Long-Term Care

Written Testimony by Harold Senechal
711 Jefferson Avenue
Utica, New York 13501
315.792-7732

Dear Senator Baucus and Grassley,

Thank you for this opportunity to provide testimony at this Hearing as you consider The Community Choice Act of 2007, S. 799 and to tell you a little bit about myself. I am 62 years old, have Cerebral Palsy and have been institutionalized all of my life. I am currently living in a group home but have been trying to move back into the community for the last 20 years or so. Because of the institutional bias of the Medicaid system, I have remained here. I want an apartment of my own and I would simply like to work like everyone else.

Because I am a brittle diabetic, the care that I need has not been able to be provided to me under the current Medicaid care systems structure to enable me to live on my own. I am unable to give myself the insulin injections I need to live because my hands are twisted. I am unable to walk and I use a power wheelchair to get around. I still have much to share and give though and want a chance to be independent. I secured an apartment 2 years ago with the help of advocates at my independent living center but because we were unable to secure appropriately trained staff that were available at the times needed for my care schedule, and in the geographic area needed, the whole plan fell apart and I was unable once again to achieve independence. To make matters worse, it is becoming even more difficult to find appropriately trained staff willing to work independently for disabled individuals like myself wanting to live in the community because no healthcare coverage is available for homecare workers like is available for those working in an institutional setting.

The Community Choice Act Bill is critical to help me finally be able to live on my own. I have waited for years and despite the fact that community based options are expanding, I am still trapped in an institution simply because I need help to live. This Bill would finally provide New York State with the means to create new programs specifically to help increase the stock of home and community based workers through skills enhancement, earnings increases, benefits provision, and career and future prospects incentives. Without a comprehensive approach to increasing the number of appropriately trained and competent home based workforce, thousands of New Yorkers like me will continue to be trapped in segregated facilities like the one I am in now. The other residents that I live with are also trapped by the current system that has little if no incentive to change. I've been in the system since I was a child and it has not changed.

Please work to pass this important Bill to ensure that I get the same right others without disabilities have to live, learn, and work in my community. Many of the residents that I live with have given up and have no hope left. I still do. Please help us.

Sincerely,
Harold Senechal
September 24, 2007

TO: Senator Max Baucus, Chair
Finance Committee

FROM: Brenda Smith
6000 Swede Ave
Midland, MI 48642
989-832-0060
swedebks@charter.net

S. 799 COMMUNITY CHOICE ACT

The hearing for the Community Choice Act, CCA, (S. 799) in the Senate Finance Committee is September 25th, that's THIS TUESDAY at 10:00 AM in the Dirksen Senate Office Building, Room G-50. Please attend this hearing and vote in favor of this bill. My husband, Jim, receives home health care aid from the Medicaid Waiver Program and from Medicare and must use an electric wheelchair for mobility. Right now he is on the verge of being sent to a nursing home against his will because he has incontinence issues due to his condition of hereditary spastic paraplegia. I am not able to keep him changed and dry myself due to a medical condition I have called osteogenesis imperfecta (brittle bones). If we had more care at home in the morning to change him, it would make all the difference. They are unable to give us more hours of care due to budget restrictions. However, it would cost a lot more to send him to a nursing home than give us a few extra hours at home per day. If this bill passes, people could have the same amount spent on their care at home instead of being sent to a nursing home. Please vote in favor of this bill so that many of our seniors and people with disabilities can have a choice on whether to stay at home or go to a nursing home. Thank you for your support of S799.

Brenda & Jim Smith
Midland, MI

Written Testimony

Honorable Senator Max Baucus
Chair
U.S. Finance Committee
Public Hearing on Community Choice Act Bill S.799
September 25, 2007
Testimony

Written by Gail Steen
52 Franklin Ave box 15
Clinton NY 13323
315-853-2705
gailwheels@adelphia.net

Dear Senator Baucus,

I am writing to you to tell you about myself and why the Community Choice Act Bill that the Finance Committee is holding hearings on is so important to me to be able to remain independent in my own home. I am in favor of this bill. I am a quadriplegic, paralyzed from the neck down and I do benefit from services in the community. I have lived alone for 8 years because of the services and supports that I get through the Medicaid Program to help with my personal care and my housekeeping and mobility needs. I feel by living alone, that I still have a say in how I live my life. I am able to get out, do my own shopping and go to college. If I were in a nursing home, I wouldn't be able to do any of these things.

I am also the mother of three wonderful children. They live in New Hampshire and I only get to visit with them on school vacations because I can't care for them myself. As a matter of fact, I had to relinquish custody of my children when they were babies because of my severe mobility impairments. This was the hardest thing I ever had to do in my life. I have no cognitive impairments, just am physically unable to do the "hands-on care" of child-rearing. Because of policies in place that do not allow the home-care attendants of persons with disabilities to assist parents with the "hands-on" aspects needed in child care and the fact that I did not have money to pay for assistance like other parents can do when they need help, I was forced to give them up. I cherish every minute that I now am able to have with them. They come to stay with me now that they're older and we go and do activities as a family. If there weren't services available for me to live independently, not only would I suffer but my kids would also suffer greatly.

This bill is essential to my well being. It is important that I remain in my home and be an active mother figure to my children. This bill would give states the opportunity to try new demonstrations and new approaches that could give severely disabled parents like myself the chance to by-pass narrowly focused policies that tear away basic rights to receive necessary assistance to raise their own children by limiting the scope of activities allowed for consumer-directed personal care aides. There should be exceptions that consider circumstances like mine that do not serve parents, children or society as a whole well. The bill contains provisions that would remedy disparities like this that represent huge gaps in services to classes of individuals with disabilities, like me and so many others, who are just trying to lead normal, happy lives with personal direction and meaning. We aren't asking for anything additional, just consideration to raise our families and engage in meaningful lives like everyone else. This includes the ability to raise children.

Thank you so much for allowing me the opportunity to speak on these important issues. Your decisions as a result of these hearings will impact me and thousands of others and we are depending upon you to assure that we have the same promise of the American Dream just like everyone else!

Thank you,
Gail Steen

Attention Senator Max Baucus and the Finance Committee,

My name is Gwendolyn Tezeno and my daughter Olivia has Cerebral Palsy. I am writing to you in reference to Bill S.799 / H.R 1621 , Community Choice Act. I support and I am in favor of this bill becoming law because people with disabilities should continue to have the right to have services in the community, live in their own homes, and make their own decisions. Not only will the person that is disabled benefit, but their families will benefit also. Many people with disabilities enjoy getting out and doing things in the community. Just because they have disabilities that doesn't mean they have to be isolated from the community. So I beg you to please support the Community Choice Act Bill S.799 / H.R 1621. Many families are very much in need, because 9 out of 10 people can't do it alone.

Thank you in advance,

Gwendolyn and Olivia Tezeno

Hi Chris:

I got your e-mail regarding The Community Choice Act Hearing and just wanted to put in my two cents. In my experience The community Choice Act would be beneficial to someone such as my self who lives in Ontario County because there are not a great deal of services available to individuals with disabilities in "rural" areas, such as affordable housing, and most importantly accessible transportation. It is my hope that you will take my testimony to the senate finance committee and they will act from their hearts and pass this very important legislation.

Regards,

Tom Turner

Senator Max Baucus:
Finance Committee:

September 22, 2007

Linda Joy Westfall

Community Choice Act S. 799

I support the Community Choice Act, S. 799! The bill will provide the disabled a choice in determining their long-term care destiny and will update our current antiquated long-term system, which is expensive and favors institutions over community services.

The demographics of our country are changing. New technology and medical advances have increased the lifespan of the elderly. Children born with disabilities and people who sustain them later in life are alive and living longer due to new advances. People with disabilities could be thriving if given a choice to determine their long-term care destination.

The current system for delivering long-term care was created over 40 years ago. It is funded with Medicare and Medicaid dollars which were not intended to meet long-term care needs. The current system needs to accommodate the country's changing demographics. Congress must implement a new system that allows funding of long-term care to follow the individual and not institutions.

Our current system is outdated and unnecessarily expensive! "In FY 2005, 67% of Medicaid's 94.5 billion long-term care dollars, $63.3 billion, were spent on nursing homes and other institutional services." (http://www.adapt.org/casa/talkingpts.html) This left only 33% of Medicaid dollars, $31.2 billion, for all community services -- home health, personal care, waivers, etc.--. (http://www.adapt.org/casa/talkingpts.html) The current system favors institutions over community services and does not accommodate long-term care choices. A national long-term service system should not favor one setting or another. It should provide services in the most integrated setting as required by the Olmsted decision. (http://www.nhpf.org/pdfs_bp/BP_Olmstead_3-03.pdf.)

Community services are less expensive on average than institutional services, and are preferred by the disabled and their families. According to the 2006 MetLife market survey, "the average cost of a semi private room in a nursing home in the United States is $183 per day." "The cost of a home health aide averaged $19 per hour nationally." Based on this figure, eight hours of home health care paid by Medicaid averages about 17% or $31 less per day than the cost of care in a facility. The average annual savings is $11,160 less than it costs to warehouse someone in a nursing home.

I have been a ventilator dependent quadriplegic for 23 years, though the average lifespan for a high level spinal cord injured patient is only eight years post injury. The individualized, quality care I have received via community services has enhanced my life significantly, and has afforded me a quality of life and HCI independence that is unavailable to patients in nursing homes. People with disabilities want services in the most integrated setting possible. I can testify, there is no place like home!

The Community Choice Act, S. 799, provides disabled people and their family's real choice in long-term care options by ending the institutional bias, which appropriates the majority of long-term care funds to facilities rather than community services. Community services are preferred by the disabled and are more cost-effective to provide.

Senator Baucus, your support and efforts to bring this legislation to the Senate floor will be greatly appreciated.

Sincerely,

Linda Westfall

ATTENTION: Senator Max Baucus
Director of Finance Committee

Dear Senator Baucus:

I am writing to you concerning S. 799 Community Choice Act, because I am in favor of this bill being passed.

I know from personal experience that it will benefit from being able to receive services in the community, from being able to live in their own homes and make their own decisions.

As you may know, the Institute of Medicine conducted a study concerning the quality of nursing home care, and their findings were not pretty. "The IOM's Study on Nursing Home Regulation (1986) and other studies reported widespread quality of care problems and recommended the strengthening of federal regulations for nursing homes (USGAO, 1987; US Senate, 1986; Zimmerman et al., 1985). The IOM Committee recommendations and the active efforts of many consumer advocates resulted in Congress passing Nursing Home Reform Legislation." (Harrington, Ph.D., Carrillo, M.S., LaCava, M.A.)

There have been several surveys that were also conducted on Nursing Home Care, and the worst feature that the surveys found was that 37.4% of the Nursing Homes surveyed found Food Sanitation to be a problem, and 15.8% said that the Nursing Homes were deficient in Dignity.
I think that these results among others are despicable, and I hope that you will support S.799 Community Choice Act.

Thank you,

Allison Wilber
RCAL Inc.
592 Ulster Avenue
Kingston, NY 12401
(845)331-6745

September 23, 2007

The Honorable Senator Max Baucus
Chair, Senate Finance Committee
Washington D.C.

Dear Senator Baucus

My husband and I are the parents of an adult son, 31 years old, who struggles daily with the affects of Asperger Syndrome, a developmental disability classified on the Autism spectrum. Fortunately he is diagnosed as being high functioning and has been able to earn a master's degree in library science and an ancillary certification as a school librarian. Upon completion of the initial degree he was immediately hired as a reference librarian at a public library in Louisiana. He lived successfully and independently, with a few minor exceptions, in an apartment near the library. He began making notable strides in confidence and verbal communications. The positive changes in his willingness to communicate were striking. However, within five months our hopes and dreams were dashed as our son met head on with the real world. He lost his job, primarily due to the lack of anyone knowing, including ourselves, he had Asperger's Syndrome. Therefore he did not receive any special accommodations that would have enhanced his chances for success. .A few months later he was once again employed and once again dismissed by employers who also failed to recognize the disability. We thought the first incident was a fluke, but after the second, decided to revisit an earlier childhood diagnosis.

In 1987, at age 12, he was diagnosed with Atypical Pervasive Developmental Disorder. Academically he had no problems, but socially he struggled, constantly unable to interact with his peers. The public school failed to acknowledge his disability, as did the private high school he attended. **HE RECEIVED NO EARLY INTERVENTION WHATSOEVER** during these years, causing him to endure constant teasing by peers and ridiculed by several teachers. In adulthood, this later transferred to employers and coworkers. It wasn't until he was diagnosed as an adult with Asperger's Syndrome that the pieces began to fit. He was then classified as handicapped by the Office of Citizens with Developmental Disabilities, **but received no benefits**. Many of the counselors from Louisiana Rehabilitative Services were unknowledgeable and indifferent concerning Asperger's Syndrome and therefore progress was questionable. Today, after 17 months he remains unemployed and living at home. His earlier sense of confidence is noticeably dwindling on a daily basis. Verbal communication is regressing.

My husband and I **strongly support S 799 Community Choice Act** because it would bring handicapped adult citizens shelter and help foster a feeling of independence at a time when they need it most. **Our greatest fear as parents is wondering what will happen when we are no longer available to provide <u>food</u>, <u>clothing</u>, and <u>SHELTER.</u>**

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