

FTS-HCFA

August 15, 2001
12:00 p.m. CDT

Coordinator	Thank you for holding, and welcome to this afternoon's teleconference. I would like to inform all participants that you will be able to listen only until the question and answer session. I would also like to inform all participants that this call is being recorded, and if you have any objections, please disconnect at this time. I would now like to turn the call over to today's first moderator, Ms. Robinsue Frohboese, Deputy Director, Office of Civil Rights. Thank you, ma'am, you may begin.
R. Frohboese	Thank you, and good afternoon and welcome to our many listeners and participants from around the country. My name is Robinsue Frohboese. I am the Acting Director of the Office for Civil Rights at the Department of Health and Human Services. I'm very pleased to be hosting this national teleconference, along with my colleague, Thomas Hamilton, from whom you'll hear a little later on in this teleconference. He is the Director of the Elderly and Disabled Health Programs Group within the Center for

Medicare and Medicaid Services at the Department of Health and Human Services.

We have a number of other federal agencies that are participating, and I will introduce representatives from these federal agencies in just a few minutes. I would like to let you know that this teleconference is being simultaneously Webcast with captioning on the HHS Website, and you can get to that at www.hhs.gov/newfreedom. This Webcast will be available until September 14th and you also can get an instant reply 24 hours a day until August 31st of this teleconference by calling 1-800-219-6389. These numbers and the Website for the simultaneous captioning will be provided to you again in just a couple of minutes, if you need those numbers again.

As all of you know, on June 18th of this year, President Bush signed Executive Order No. 13217 on Community-Based Alternatives for Individuals with Disabilities. This order underscores the administration's commitment to full implementation of the Americans With Disabilities Act and to break down barriers to community living. This executive order also directs the Department of Health and Human Services, as well as the Departments of Labor, Education, Housing and Urban Development, the

Social Security Administration, and the Department of Justice to undertake self-evaluations of their policies, programs, statutes and regulations, to determine whether any should be revised or modified to improve the availability of community-based services for individuals with disabilities. And although it was not part of the executive order, I'm pleased to report that the Small Business Administration, the Office of Personnel Management, the Department of Transportation and Veterans Affairs have also joined in this effort and will be undertaking agency self-evaluations and working with us to implement the executive order.

Our report on barriers and solutions to these barriers is due to President Bush by October 16th. A critical part of the executive order is ensuring that the federal agency reviews that each of these federal agencies is undertaking involves and takes into consideration the views of consumers, advocacy organizations, providers and relevant agency representatives. As Secretary Thompson said just a few weeks ago at a celebration of the 11th anniversary of the Americans With Disabilities Act here at HHS, "We can make real progress only if we first listen to the people who know the barriers better than anyone else could." And this is the purpose of this teleconference today.

I just briefly want to tell you that in addition to this teleconference, we have a number of other ways in which we are soliciting this public input. We have announced a period of public comment through August 27th of this year. You can either write to us or you can e-mail us, and you can write to us at the New Freedom Initiative Group, Department of Health and Human Services, Post Office Box 23271, Washington, DC 20036-3271.

We'll be giving you these numbers again a little bit later on in this teleconference, and you can get to the numbers, addresses and ways of public comment by going to our Website at www.hhs.gov/newfreedom. You can also e-mail us comments through August 27th at newfreedom@vms.hhs.gov. Again, all of these e-mail addresses and addresses where you can write to us are on our Website.

In addition to this teleconference that we are hosting today, we also are hosting a national listening session here in Washington, DC, at the Ronald Reagan Building at 1300 Pennsylvania Avenue NW, on September 5th. It will be a day-long national listening session in which Secretary Thompson and other cabinet members and high-level federal agency officials will be present to listen to your comments.

Before we get started, I want to allow maximum opportunity for all of you who are queued up and are going to give your comments this afternoon. I want to take just a few minutes to recognize my colleagues here at HHS, and from other federal agencies, all of whom have gathered today, to hear your comments on this teleconference to listen to you.

With me at HHS is Lance Leggett, who is the counselor to the Deputy Secretary of HHS, Claude Allen. Also as I mentioned, Thomas Hamilton, the Director of the Disabled and Elderly Health Programs Group with in the Centers for Medicare and Medicaid Services is hosting this teleconference and is representing Health and Human Services. We also have from the Office of Policy and Program Coordination at SAMHSA, Daryl Kade, the Associate Administration on behalf of Health and Human Services.

With me at HHS, we are being joined by Loretta King, who is the Deputy Assistant Attorney General for the Civil Rights Division at the Department of Justice. And Ms. King, if you could introduce other Department of Justice Staff and if you'd like to make a few brief remarks?

L. King

Thank you very much, Robinsue. Good afternoon, everyone. My name is Loretta King. I am a Deputy Assistant Attorney General for Civil Rights of the Department of Justice. With me today I'm joined by my colleagues, Mary Lou Mobley, who is an attorney in the Disability Rights section at Justice.

I've worked in the department for many years as an attorney in both the Civil Rights Division and the Civil Division. In 1994, I was appointed Deputy Assistant Attorney General by then-Assistant Attorney General ... Patrick. In my capacity, I have supervised the Special Litigation section, which handles the department's civil rights work on behalf of individuals with disabilities in state-run institutions; and I also supervised the Disability Rights section, which enforces the American Disabilities Act of 1990 or ADA.

The department enforces several laws that deal with the rights of individuals with disabilities. Title II and Title III of the ADA protect the rights of people with disabilities in a great variety of state and local government services, as well as services provided by private businesses that are open to the public. The department also enforces the Civil Rights of Institutionalized Persons Act or CRIPA. Under CRIPA, the department

has worked to identify Olmstead violations in a variety of institutions nationwide.

Finally, the department enforces the Fair Housing Act, along with the Department of Housing and Urban Development. The Fair Housing Act requires accessibility for individuals with disabilities in multi-family dwellings. We realize that in some cases, individuals with disabilities are kept in institutions, simply because of the lack of available accessible housing. We also work to protect group homes and other important housing alternatives.

On behalf of the Department of Justice, I welcome your input. We cannot solve problems and remove barriers without hearing from you. People with disabilities, people who advocate on behalf of others with disabilities, and those of you who work within state government and the healthcare system, I am here to listen. Together we can all play an important role in reuniting America's families and communities, while providing people with significant disabilities opportunities to development their dignity and independence, values that lie at the heart of this great nation. Thank you very much.

R. Frohboese Thank you, Ms. King, and I think it is significant that gathered in this room at HHS, we do have a number of federal agencies in addition to the Department of Justice. I would like to recognize Patricia Kinney, who is the Director of the Office of Work Life Programs at the Office of Personnel Management, who is here with us today; and as I mentioned earlier, the Office of Personnel Management has voluntarily joined in this effort to carry out the executive order on community living.

Also with us today at HHS is Paul Van de Water, the Acting Deputy Commissioner for Policy at the Social Security Administration, which is also a key partner, along with us in implementing the executive order.

Before introducing other federal agencies who are on the line, I would like to recognize that we are very honored to be joined this afternoon by Jennifer Sheehy, formerly with the President's Task Force on Employment of Adults with Disabilities and who most recently joined the Domestic Policy Council at the White House to represent the President on disability issues. And Ms. Sheehy, I believe that you had a few brief opening remarks that you'd like to make?

J. Sheehy Yes. Thanks, Robinsue, and I appreciate your putting this together. I want to thank the participants, the people who are speaking, telling their stories today. This is so important that we hear from you and I will be listening very carefully to the remarks. And I want to thank Robinsue and the Health and Human Services Department under the leadership of Secretary Thompson. It's amazing to me how hard that you all have been working on this, and it's a true testament to your commitment to this issue. And the final thing I want to say is that the President truly looks forward to receiving the report in October and is anxious to see the initial recommendations.

R. Frohboese Thank you, and we're very happy that you could join us today. We have the Department of Education also joining us to listen to your comments, and I'd like to introduce Beverly Stafford who is the Director of Planning, Policy and Evaluation at the Rehabilitation Services Administration of the Department of Education.

B. Stafford Thank you, Robinsue. I bring you greetings from Secretary Page and Assistant Secretary Robert Pasternak who are not here, but we're here in their stead. I'm in the Rehab Services Admin, which is housed under the Office of Special Education and Rehabilitative Services. Most of you

know that as OSERS. And with me today is Linda Emory, who is a Special Assistant to our newly appointed Assistant Secretary, Robert Pasternak in OSERS. I also have Ed Anthony who is the Director of Planning and Policy in OSERS and Troy Justesen from the Office of Special Education Programs where he's the policy analyst.

Most of you know our programs. they are programs under the Rehabilitation Act of 1973 as amended and also programs under the Individuals With Disabilities Education Act. We are also looking at other Department of Ed programs to ensure that there are no barriers to the swift implementation of the executive order, and we will be reporting on that. Once again as other folks have mentioned, we're here to listen to you, and we're anxious to get to the comments from our participants. Thank you, Robinsue.

R. Frohboese Thank you. And we also have the Department of Housing and Urban Development, Susan Sacco, a Senior Program Analyst from the Office of Policy Program and Legislative Initiatives within the Office of Public and Indian Housing. And Ms. Sacco, do you have a few remarks and individuals from HUD that you'd like to introduce?

S. Sacco

Yes, I do, Robinsue. Thanks very much. I am joined today by Deanna Ortiz, who is the Director of the Office of Enforcement in HUD's Office of Fair Housing and Equal Opportunity. And I'm also joined today by Milton Turner who is the Director of the Program Compliance and Disability Rights Division, also in HUD's Office of Fair Housing and Equal Opportunity.

I would like to make a few remarks. As a member of the Interagency Council on Community Living, HUD has a critical role in working to remove barriers to opportunities for people with disabilities. One of these barriers as everyone knows is affordable and accessible housing. HUD's Section 8 Housing Choice Voucher Program is one of our best tools for achieving the goal of opening the door to affordable housing opportunities for people with disabilities.

Just as an example for the Housing Choice Voucher Program, from fiscal year 1997 through fiscal year 2000, HUD distributed over 50,000 vouchers to housing authorities targeted specifically for persons with disabilities. 14,000 of these vouchers were distributed in the past year alone. Currently, approximately 25% of our voucher program dollars are used by families in which at least one member has a disability.

Another more recent project that HUD is working on is Project Access, and that is a program that will use these vouchers once again. But this time the use will be for people with disabilities coming out of nursing homes, in order to make their transition to the community possible by providing them affordable housing. HUD is in partnership with HHS on Project Access.

Regarding the issue of accessibility, HUD has recently issued notices and other guidance to recipients of HUD funds, to reemphasize their obligation to comply with laws such as the Fair Housing Act, the Americans With Disabilities Act and Section 504 of the Rehabilitation Act of 1973. HUD has also reminded grant recipients of the requirement to include persons with disabilities in the development of consolidated plans and annual action plans.

Another interesting point is that HUD has also set up a Section 504 Website, which can be accessed through HUD's Internet site. This Website provides the public with a variety of resources.

As the other speakers have said, we've begun also an internal evaluation of our programs and activities, to determine whether any barriers exist that

may be preventing Americans With Disabilities from fully taking advantage of our programs. In addition to evaluating the voucher program, we'll also be evaluating programs such as the Section 811 Supportive Housing Program and the Shelter Plus Care Program. We'll also be looking at the CDBG and Home Block Grant Programs where the funds from those two programs can be used by communities, to provide housing assistance to low-income persons with disabilities.

We are committed here at HUD to the successful implementation of the executive order, and will diligently work with the other federal agencies represented on this call today and with the states in tearing down the remaining barriers to equality for the millions of Americans with disabilities. Thank you very much.

R. Frohboese Thank you, and we look forward to working together with you. We also have the Department of Labor on the phone, Chris Button who is the Senior Policy Advisor at the President's Task Force on Employment of Adults with Disabilities. Do we in fact have the Department of Labor? Okay, we'll check on that.

And I do want to acknowledge that from the Department of Veterans Affairs, we have Jill Manske who is the Director of Social Work services. So in total we have eight federal agencies, high-level officials within those agencies, as well as a number of staff in the agencies who are here to listen to you.

Again, we want to allow maximum opportunity to hear your comments, and so we really will I think at this point, unless in checking, we can find the Department of Labor to open up that line. I would like to just move forward and to turn the program at this point over to Kathy Rama and our conference operator, Theresa, who will explain the ground rules about how we will proceed. Thank you.

K. Rama

This is Kathy Rama from CMS, and I want to welcome you as well and just wanted to repeat the 24-hour toll-free replay call number, and that is 800-219-6389. And also the Website if you wanted to view a captioned version of the call, it is www.hhs.gov/newfreedom. And the 24-hour replay will be available until August 31st, and the Website version will be available until September 14th.

To assure that as many participants as possible have the opportunity to provide input, each of our speakers will be allotted up to three minutes approximately. I just wanted to warn you that I will simply say, "You have 30 seconds remaining," at the appropriate time as an alert to you, so that you can begin closing your remarks. So I just wanted to warn you, when I say that, that's what it means. And I don't mean to be rude in interrupting you.

Our operator will give us instructions on how to key in to provide testimony, and we would like to as I said, to assure that as many people get the opportunity to participate as possible in speaking. We would like to keep things moving pretty well. So we do not plan to particularly answer any questions. That was not the intent of this particular call. It's more for us to listen to what you are able to identify as barriers to life in the community and to hear your recommendations on how these barriers can be overcome. So thank you again, and I'll turn it over to Theresa.

C. Button

Robinsue?

K. Rama

Yes, ma'am?

C. Button This is Chris Button. We were on before, and have a great gathering of folks here at Department of Labor –

K. Rama Terrific. We're so happy that you can join us, because as you can see, we have eight federal agencies and the White House –

C. Button It's really wonderful, showing this tremendous federal support for this initiative. We were muted and somehow couldn't get un-muted, so technology –

K. Rama I'm glad that now you can speak.

C. Button Yes, well, we are all – there's a great gathering of folks here at Labor and we're honored to be on this listening session on behalf of Secretary of Labor Elaine Chao, and also Deputy Secretary D. Karimen Finley. Secretary Chao recognizes that the choice to be able to work is really a very critical factor if increased access to the community is going to become a reality; and both in her role as Secretary of Labor and also in her role as Chairman of the Presidential Task Force of Employment and Disabilities, she is working to make sure that employment is an important part of that dialog.

We have here at Department of Labor Lisa Larriman, who is the Assistant to the Acting Assistant Secretary for the brand-new Office of Disability Employment Policy. We also have Paul Hippolytes who is from the new office. And we have Julie Clark and Mike Reardon who are policy staff with the Presidential Task Force, so we really do look forward to hearing the dialog today.

R. Frohboese Thank you. And with that, I will turn it now over to Theresa, who hopefully, has the first caller on the line.

Coordinator Thank you. At this time if you would like to make a remark, please press *1 on your touch-tone phone. Our first comment comes from Paul Marchand, and please state your organization. Excuse me, Mr. Marchand?

P. Marchand Hello. I'm sorry, I was also on mute. You wouldn't hear me. I'm Paul Marchand and I represent the ARC, which is the nation's largest organization that deals with people with mental retardation. I had no idea I had to go first. Let me begin by commending Robinsue and everybody in the Bush Administration for making these various inputs happen. It's a very, very good start to implementation of Olmstead and components of

the New Freedom Initiative. The rhetoric is right, the promise is right and let's hope you all can make it happen.

For us, the key to an awful lot of this is changes to policy in Medicaid. The new CMS and HHS has to do some very serious thinking about how it does business, and the Congress needs to do some very serious thinking about how Medicaid is structured. That is at the moment almost entirely working against what the promise and the rhetoric of Olmstead is, and I hope that that will be a very high priority for the working group.

I'd like to mention, though, one very large red flag in the executive order, and I'm quoting it a little bit out of context, but basically it says that the actions will be done consistent with this administration's budget. If that's the case, then the FY2002 Bush budget had better darned well have some serious money, so that these various promises can be met. More money must be found to make this real. Waiting lists are growing throughout the country in a number of types of disabilities for community services, and every day that people spend in institutions is a wasted day. And without more money, an awful lot of that promise won't be realized.

In the end, though, we will judge you by the concrete actions, not the rhetoric. I hope that the public involvement is not just phone calls, but somewhere being at the table, helping the federal government make decisions. That's real involvement.

Also I'd like to mention that tomorrow, the Bush Administration takes its first major step backward in implementing Olmstead, when it's going to announce the pulling back of the Medicaid Patient Protection Regulations. These regulations were carefully crafted with a lot of disability input over two years by the Clinton Administration, and instead of having been implemented, they're being pulled back, weakened. That is too bad. That is clearly the first black eye that this administration gets in regards to Olmstead implementation.

The executive order is fine, it's great, but the reality base needs to be the ultimate judgment. And I would hope that all of us will be working very closely together to make sure that the reality base means people leaving institutions or avoiding institutions in the first place. That's where the rubber is going to meet the road. Thanks a lot for the input time. Take care.

K. Rama Thank you, Mr. Marchand. Next speaker?

Coordinator Our next comment comes from Michael Maloney. Please state your organization.

M. Maloney I'm with KEY Consumer Organization. That's KEY, stands for Knowledge Empowers You. We are a mental health consumer and advocacy organization in Indiana. I also serve on the mental health subcommittee of a community integration action team for the Family and Social Services Administration in Indiana. Can you hear me?

K. Rama Yes, we can.

M. Maloney Okay. Again, I want to address the issue of money. I'm sure you were kind of expecting this. It's very important to show the Bush Administration's commitment to the Olmstead Decision, that there is enough financial resources to place individuals back into the community to a situation where they can receive better treatment. Statistics have shown that treatment in the community center is far more beneficial than in institutions.

The way I look at Olmstead's implementation is a stepping stone, people from institutions going into group homes, people from group homes going into SILP situations, people from SILP situations or cluster apartments going into private housing. One of the ways to make this happen is to fund assertive community treatment teams, so that people who are in group homes or cluster apartments at this time, can get into private and yet have 24-hour services available to them.

In Indiana, we were trying to get ACT teams implemented for all of our 30 community mental health centers. We could only get funding for three of the 30, and they are going to be under-funded because the only treatment they will provide are the same services that people were receiving in institutions. There will be no peer support services, no way to help them get back into the community, find jobs, to live a more independent lifestyle.

We also need to be sure that while we educate the consumers about reentering the community, we need to educate the community about the people that are coming from the institutions. People with mental illness and developmental disabilities are not the violent people that are shown in

the modern media; 98% of violent crime in this country is committed by people without mental illness. That is –

K. Rama Thirty seconds, please.

M. Maloney Again, I also want to thank you for this opportunity, not only for myself but for everybody around the country to put in their ideas. Thank you very much.

K. Rama Thanks very much, Mr. Maloney.

Coordinator Our next comment comes from Steven Eidelman. Please state your organization.

S. Eidelman I'm Steven Eidelman from the ARC of the United States; I'm in a different place physically today than Paul Marchand, so you got both of us, unbeknownst probably to either of us.

I just want to make two comments, and one of them echoes Paul's comments of commending the administration for coming right out of the box with very strong statements concerning the implementation of the

Olmstead Decision. We're very encouraged by that, and I think people all over the country are saying very positive things and feeling good about what could happen.

I have been in 15 states in the last two months, and in 14 of those states, I've heard significant complaints from advocates, both consumers and families; from professionals from legal services organizations about the state's willingness to significantly work on real public discussion about how Olmstead is going to be implemented. And in many places they are doubting the sincerity of state officials, thinking that in fact, there's going to be backpedaling on this issue. So I would just encourage the departments involved, especially CMS and the Department of Justice, to work diligently with the states, not to browbeat them, but to make certain that Olmstead is implemented as designed and consistent with the New Freedom Initiative. Again, thank you for the time.

K. Rama Thank you, Mr. Eidelman.

Coordinator Our next comments come from Dorothy Barron, and please state your organization.

D. Barron I'm speaking as a consumer. The greatest barrier is no true accountability. Without it, you lack parameters to determine program modifications and revisions. Briefly, some barriers faced with health and human services: Upon meeting policy requirements, were denied medically necessary services. My being denied resulted in my eating, sleeping, living and crawling on my floors for well over one year. Your healthcare plan changes without your being notified.

We're being forced to pay for medical transportation and prescriptions out of our pockets. I've had a prescription now for a week and can't have it filled because allegedly I have dual coverage – both 10 Care and Medicaid--yet neither will pay for the prescriptions. If I don't obtain relief soon, the lack of a \$10 prescription will most likely result in surgery. Bills that should have been paid by Medicare and Medicaid have resulted in a court judgment and debts on my credit report, further impeding my credit. Hearings are denied or put off for two or more years. Tennessee's 10 Care healthcare plan is costing its recipients in terms of both health and well-being.

Comments regarding our barriers, regarding community-based services barriers, two comments: The only means of my obtaining services after

being denied at the local level were to request and review program guidelines from the federal level and proceed downward. If government funding is placed in a general fund for various sectors, such as the disabled and elderly, the present ploy is to deny or dissuade a prospective recipient by stipulating the funds are predominantly or primarily used for the sector in which you are not.

Social Security: Perhaps the biggest disadvantage there is it does not reflect an individual's entire career history. I've written a Social Security plan to achieve self-support. After I met program enrollment requirements for Bethel College in Mackenzie, Tennessee, after arriving at the school on my electric scooter, shortly thereafter, my application was rejected. The school refrained from placing their verbal reject in writing. A written letter later reflected an entirely different reason than the verbal one.

I desire, have tailored and planned my path to be sure that I be successful, but I can't do it without your help. The program at Bethel begins in October and I'd like to be there.

Finally, the Department of Justice and Offices of Civil Rights, it's a sad commentary, but when complaints are filed, they, along with evidence are

concealed, misplaced and/or downplayed to the point that no assistance is forthcoming. Often retaliation now occurs in subtle forms, such as electrical and electromagnetic fields, frequencies and signals which are transmitted into the home, causing shock, pains and untold complications to the body. No assistance has and is forthcoming.

In closing, without accountability, you plan to fail. Nothing changes substantially and down here failure is more profitable because it's a surety that additional monies will be spent in an attempt to not solve, but re-solve the problems. Thank you for your time and attention.

K. Rama Thank you for your comments, Ms. Barron.

Coordinator Our next comment comes from Wally Dutcher and please state your organization.

W. Dutcher My name is Wally Dutcher and I've been a quadriplegic for 45 years, the result of a spinal cord injury incurred in service. I second or echo the comments of Paul Marchand and others as far as funding. My greatest—I've been in private business and I'm the Executive Director of the National Alliance of the Disabled, and I organized and served on the board

of a Center for Independent Living here in St. Petersburg. I'm also the Chair of the City of St. Petersburg's Committee to Advocate for Persons with Impairments.

After leaving the private sector and coming into the advocacy arena, one of the greatest things that I see is the fragmentation of federal programs. Obviously you're not the creators of that, but the recipients of that nightmare. And what I see is a lack of systemic solutions. We have all of these fragmented programs. We have waiting lists for affordable, accessible housing. You have problems with transportation. You have problems with obtaining healthcare services if you go into employment. Obviously Senate Bill 1298, just recently introduced will go somewhere to providing the community supports and services that are needed; however, it's still a poverty-by-eligibility program.

The solutions must eliminate the paternalistic view and medical model and look at what economic impact the programs will provide. My experience as a service-connected disabled veteran, the VA – the government has two programs, one of which doesn't work and one of which does. The one that does is the VA program, which offers healthcare services and provides financial support.

The result of that was that I was able to go into the private sector to buy my own housing, to go into the private sector to provide my own transportation and the personal attendant services which eliminates some of the under-the-table payments that are currently made and trying to obtain that, because simply the individual is not able to afford that.

As a result, I was able to create my own employment, plus the employment of others in a company that I owned, 165 employees. So there is a need to coordinate all of this and get a systemic solution, so that an individual doesn't have to go to so many different agencies to provide the benefits that are needed to get into an employable situation. The government spends a great deal of money on vocational services and rehabilitative services, and also to the –

K. Rama Thirty seconds, please.

W. Dutcher Thank you. – to the promotion of employment of the disabled. But unfortunately, those monies are often misspent or ill-spent and the individual is not able to make the goal of becoming employed. Thank you.

K. Rama Thank you, Mr. Dutcher, very much.

Coordinator Our next remarks come from Greg Kramer, and please state your organization.

G. Kramer Yes. I'm an independent living specialist with an independent living center in Dayton, Ohio. One of the major problems that we are facing in Ohio is getting the state to look at its plan in implementing Olmstead. What our governor has done is set out a group of people from his council and had nine different forums within the state. Out of those forums came what they call the Ohio Access Report. In that Access Report, the findings were that we didn't have enough access to housing and to personal care.

One of the big problems that we have is that all the money or a majority of the money goes into nursing homes, which the nursing homes are running at a 15% vacancy in the State of Ohio; yet the waiting list for the waiver services, at least for the Ohio Home Care waiver is at over 2,000 individuals. Those individuals are making a conscious decision to sit and wait for these services, as opposed to going into these institutions. So my question is, how can we as advocates force or help the state to stop putting

money into vacant beds and nursing homes and institutions, and give it to the people that are on these waiting lists, and get this implementation of the Olmstead Act passed and moving forward? Thank you for your time.

K. Rama Thank you, Mr. Kramer.

Coordinator Our next comments come from Donna Martinez, and please state your organization.

D. Martinez Good afternoon. I represent the National Coalition on Self Determination. We are the only national partnership of people with disabilities, parents and family members who work to promote federal policies that support the five principles of self-determination and the values of the community imperative. NCSD believes federal law regulations and policy can be a great facilitator to community living, as is demonstrated in the home and community-based services and programs. Our organization welcomes the opportunity to share our views.

It is a barrier when people with disabilities do not have the freedom to exercise the same rights as all citizens and to advocate for themselves. All people are entitled to live, work and play in the community, regardless of

the severity of their disability. NCSD believes people with disabilities should have the authority to control whatever sums of money are needed for one's own support. They must be afforded the opportunity to responsibly use public dollars as they organize their own resources.

One way to achieve these goals is to increase fiscal incentives to states to support self-determination and consumer-controlled initiatives. States are much more likely to fund programs during the budgetary process when they are tied to federal financial participation. Legislation must be crafted to attach the funding to the individual to offer true control.

One barrier to community living is reliance on the ICFMR Program, by which the HCBS is measured as a waived optional benefit. We believe that all the institutions should the waived service. In the meantime, we ask for an increase in federal oversight of the ICFMR Program. Best practices in the field of developmental disabilities emphasize people living in their own homes, controlling their own lives and being an integral part of their home community.

Several years ago, HCFA recognized that the ICFMR regulations and survey process needed to be updated. New regulations have been

developed and are currently being circulated through CMS for review.

NCSD believes that review should be expedited and published in the Federal Register for Public Comments and Suggestions for changes to the proposal.

Last year, HCFA awarded a \$3.5 million ICFMR Federal Monitoring and Oversight contract to the Council on Quality and Leadership and Support for People with Disabilities, to conduct, look behind surveys. As media reports continue to expose cover-ups, lax oversight and questionable state survey practices of public institutions, we believe the contract should be expanded to include other qualified contractors.

Also, additional CMSDD specialists should be hired to specialize on ICFMR surveys, specifically, state-operated facilities. This will help ensure their services truly assist people to achieve positive outcomes in rights, dignity, individual choice, control, relationships, community membership, personal goals, achievement, health and safety.

Our hopes are that you will carefully consider the barriers we have identified to community living for people with disabilities. Thank you again for allowing us to participate in this teleconference.

K. Rama Thank you, Ms. Martinez, for your participation.

Coordinator Our next comments come from Stuart Grabel, and please state your organization.

S. Grabel Hello, this is Stu Grabel from the Pima Council on Aging. And I'd like to reiterate a couple of things that have been said before and add another dimension. One of the things that we need to recognize is the need for elderly people or aging people to have these same freedoms. Placing people in an institution because home and community-based services are not available applies to the elderly, as well as to other types of people or individuals with disabilities, and I'd like to make sure that that's included in the President's directives.

In addition, to which the need for enough financing to cover these services is great. In Pima County, we also have waiting lists for home and community-based services, and we know we could keep people in their homes much longer if we had sufficient funds to cover these things.

Thank you, that's all for my comments.

K. Rama Thank you, Mr. Grabel. Thanks for bringing up the elderly population as well.

Coordinator Our next comments come from Jack Allison, and please state your organization.

J. Allison Hello, my name is Jack Allison. I'm with New Start Homes in Los Angeles. I'm a C-5 quadriplegic and a volunteer at New Start. I'd like to talk a bit about a way to save huge amounts of money.

We provide independence training to quadriplegics, and I'd like to comment that people with disabilities who hope to trade institutions for independent living are going to need proper independence training to live in the community. In all the discussions of Olmstead, I've heard nothing about offering these people training. I'm afraid they're going to trade a large institution for a smaller one.

In 1994, we started copying everything from negotiating my wheelchair around supermarkets to ordering my supplies. I went from 24-hour care a day to four hours' care a day. This training can save huge amounts in care costs and it could trade the large daily cost of nursing homes ... lesser cost

of an apartment and a caregiver. I know C-1 and -2 quadriplegics, paralyzed from the neck down who are living in their own homes with minimal care, thanks to a little training, once they left the nursing home.

That's about it. Good luck with the executive order and that we'll be out here watching.

K. Rama Thanks for taking time to participate, Mr. Allison.

Coordinator Our next comments come from Dierdre Whelan. You may make your comments and please state your organization.

D. Whelan Hello. My name is Dierdre Whelan, and I'm with the Massachusetts Developmental Disabilities Council. I want to commend the Bush Administration first of all, for this New Freedom initiative and also for the creating of the Interagency Coordinating Council on Community Living.

Above all changes, we believe that the culture of Medicaid must change. Now community services require a waiver. At present, community services are treated as an exception to the norm. Currently, institutions are the norm, which the Medicaid culture recognizes as the baseline for all

Medicaid recipients. The best thing the federal government can do we believe, is change the mentality of Medicaid. Make community services the norm. Require institutional services to apply for the waiver. This is the most powerful message we believe that you can send to the states.

Thank you.

K. Rama Thank you, Ms. Whelan.

Coordinator Our next comments are from Michael Hogan, and please state your organization.

M. Hogan Good afternoon. I'm with the State of Ohio, but representing the National Association of State Mental Health Program Directors. We applaud the New Freedom initiative, the President's executive order and this call. As the World Health Organization and Surgeon General have pointed out, mental illnesses are both prevalent and devastating. Depression alone causes more disability than any other illness. But what's even more tragic is that the costs of poor access to good care for people with mental illness are larger than the costs spent on care.

This is strikingly different from the pattern to other health conditions. For example, in Ohio, SSI and SSDI payments to individuals disabled by mental illness are about \$850 million annually, representing 40% of all SSI and SSDI payments to people in Ohio; and the cost of incarceration and prison mental health care for the 6,000-plus mentally ill inmates in our state prison system is about \$250 million a year. These are some of the hidden costs of limited care.

Many federal programs are a lifeline or should be a lifeline for people with mental illness, but it turns out these are mostly not mental health programs, per se; and the mental health component of each program is relatively small potatoes, and tends to get isolated and we think inadequate attention. For example, Medicaid is the largest federal mental health program, although depending on how you count mental health costs are only 5 to 10% of Medicaid.

Medicaid's approach to mental illness is deeply and specifically flawed. Most of the uninsured people needing mental health care in the states are not even eligible for Medicaid. The longstanding IMD exclusion means that neither institutional care nor more significantly, home and community-based waiver services are available to people with a mental

illness, despite the fact that these services are widely available to similarly situated people with a developmental disability.

Medicare is similarly flawed. It maintains unique burdens, patterns of discrimination against mentally ill persons and caregivers related to co-payment levels, limits on hospital care and other problems. In the absence of parity provisions in Medicare as the nation's largest health insurance program, set the tone for health coverage nationally and are at odds with the excellent and equitable health coverage available to federal employees.

We feel people with mental illness have fared poorly under changes in HUD recently. Levels of low income and disability housing production have plummeted. The numbers and levels of Section 8 vouchers have not nearly compensated for this. The movement toward elderly-only housing, conversion of low-income to market-rate housing and even consolidated planning have generally had a negative effect on people with mental illness.

Thus we're not surprised by the recent finding in a HUD report that the housing status of people with disabilities has worsened, while the housing

status of most low-income people has recently improved. We feel this is a major driver of criminalization.

Individuals with mental illness are the largest disability group getting VR services, yet nationally have the worst employment outcomes of any group of citizens with disabilities. VR's dominant service models are not consistent with those effective employment interventions for people with mental illness that have been validated in federal research.

K. Rama Thirty seconds remaining, please.

M. Hogan Thank you. In the education arena, we note that kids with mental disorders are at growing risk of school failure. Almost 60% of these children don't even graduate from high school, and we have the combination of zero tolerance policies and teaching to the tests with inadequate federal support for special ed that we think exacerbates this.

On a positive note, we do feel that recent changes in Social Security raise the bar and create models for other federal programs and this is perhaps because Social Security ends up paying a lion's share of the bill for inadequate treatment. The Ticket to Work and Medicaid Buy-In programs

are great examples of this, and we applaud these steps. We hope that the President's commitment to create a National Commission on Mental Health is an approach that allows us to look at all these programs in a more organized way and take some more of these steps to benefit people with mental illness. Thank you.

K. Rama Thank you, Mr. Hogan.

Coordinator Our next comment comes from Monica Smith, and please state your organization.

M. Smith Yes. My name is Monica Smith and I am a parent and also I serve on the Indiana Partners In Policymaking. My first concern is special education. It needs federal funding. States are struggling with dollars to get support our students need to succeed. Our students can be better educated if money was there. Right now, schools are cutting corners to keep up with the demand and cutting corners affects our kids. Schools are supposed to follow the ADA and federal laws. The school administrators are struggling, with no money to keep up with the demands to ensure that students get the supports and services they need.

My plea is to help with federal dollars, so our schools can give our kids what the law says they are entitled to.

My second concern is that the healthcare provider requirements need to be lifted. Some people don't need RN's or skilled nurses to care for their loved ones; they need people that are close to them, not strangers. Allow parents to choose or the disabled person to choose who they want to care for them. Allocate federal dollars to families for respite or have agencies there to monitor the dollars.

Most insurance companies don't pay for respite for autism. My insurance does. But the law says that companies must use a licensed home healthcare provider. The law needs to be amended. We need to have people who can do the same services for our loved ones, but they don't have to have the requirements to meet the state guidelines. These guidelines need some waivers for parents to sign, for us to be allowed to choose our own staff instead of staff from a home healthcare agency.

I feel parents know best for who is best to care for their loved ones. If aides make \$8.50 an hour, our insurance companies are being popped \$20 to \$60 an hour for these services for our loved ones and it makes more

sense, if you get a \$6,000 a year benefit, that this \$8.50 could be stretched to serve our children with disabilities, rather than paying for the overhead cost through a home healthcare agency.

I just think that this New Freedom executive order is wonderful; we're very much in favor. I can't express enough on what it's been like to be a parent of a child with a disability after having two normal kids. What it has taught me is that each and every one of us at any given time by giving birth, by an accident or cancer can be affected with a disability. So by keeping the train on the right track and in the new direction, positive change can and will make the quality of life to those with disabilities feel included. Thank you.

K. Rama Thank you very much, Ms. Smith, for taking time to speak to us today.

Coordinator Our next comment comes from Frank Bowe, and please state your organization.

W Hofster University.

K. Rama Mr. Bowe, are you there?

F. Bowe Yes. I am Frank Bowe. I'm representing the National Association of the Deaf. There are very large numbers of deaf people in institutions around the country, many of whom were misdiagnosed as mentally retarded or mentally ill, because they could not communicate. Some have been languishing in institutions for decades, some without any adequate communication and some with no meaningful consent for treatment. These people have to be identified and it is urgent that communications services, including interpreters, be made available to them in the community, so that they can be placed into the community and receive meaningful education and other services.

I want to concur with Paul Marchand who after 33 years on that job, certainly knows what he's talking about; that the budget is going to have to be reexamined in order to carry out these programs. Thank you very much on behalf of the National Association of the Deaf.

K. Rama Thank you, Mr. Bowe, very much for participating today.

Coordinator Our next comments come from Betsy Thompson. Please state your organization.

B. Thompson Yes. I'm Betsy Thompson, Director of Advocacy with the Autism Society of North Carolina and also a parent of an adult with autism and fragile ex mental retardation. And I wanted to of course applaud the New Freedom initiative and President Bush's executive order.

I wanted to particularly address the critical need for residential support for adults with the most severe developmental disabilities. We have recently done a statewide survey of families with autism in North Carolina, which shows the No. 1 need of families of children over 16 is residential support. We have found the Medicaid waiver to be tremendously beneficial to many of our individuals, particularly services such as supported employment and supported living have allowed many of our adults to live as independently as possible with the support of their families.

We would like to see a live-in caregiver option that's operable offered for the waiver. There is one currently in a few of the waivers that evidently nobody has been able to figure out how to make it work, because it would count as a resource against the Medicaid recipient. This would be very beneficial, because at some point these adults do not have the support of families and will need a live-in caregiver option.

So we would like to be sure that the Medicaid waiver would allow these most severely disabled to continue to live in their own place. We found the section rental vouchers for individuals to get apartments to be particularly beneficial as well. Our typical adult with autism, on SSI working in supported employment part time, thanks to the Medicaid waiver job code, just with supported employment, must begin at some point to consider moving to a licensed facility, because this is a barrier, the institutional bias, to special assistance funding available to people with disabilities who move to licensed facilities. Social Security, drawn on a deceased parent, doesn't count as a resource.

We would like to see this funding available in unlicensed facilities, such as the disabled individual's own home or apartment, so they can continue to be as independent as possible.

K. Rama Thank you, Ms. Thompson, for participating.

Coordinator Our next comments come from Sue Hetrick, and please state your organization.

S. Hetrick Hello. This is Sue Hetrick with the Ability Center of Greater Toledo. We're a center for independent living in Ohio and I'm the advocacy director. I'm joined by Shelly Pappenfuss, who's the Grants and Strategic Planning Administrator, and we, too, would like to applaud the President's initiative, the Olmstead outcomes and the most recent Mi Casa legislation that hopefully will go through.

Our concern has been expressed by previous callers in the enforcement and monitoring of these decisions and this kind of legislation. If there is no enforcement, if there is no monitoring, they're just worthless words and words on paper; and so we simply want to express that concern, as well as the infrastructure grants that are – well, the grant deadline has passed now, but were submitted – the nursing home transition grants. We were very concerned about Ohio's grant proposal. We felt that it was just same old, same old, and we're not clear in the RFP's how infrastructure change would be monitored and enforced.

S. Pappenfuss I think the issue that we want to see addressed is, does Medicaid restructuring at the federal level – states get those federal dollars from you, but I think that we are looking at a Medicaid restructuring. We need to make the shift from those dollars from nursing-care institutions to

community-based care. And I think the issue is, how are we going to make that shift? How are we going to restructure Medicaid so that will happen? And that's what we'll be watching.

S. Hetrick Thank you.

K. Rama Thank you both for participating. Two for one there. Next caller, please?

Coordinator Our next caller is Andrea Williamson, and please state your organization and your comment. Ms. Williamson? Thank you, ma'am, would you check your mute button, please.

K. Vall Okay, are you there, ma'am?

Coordinator Yes. Go ahead.

K. Vall Okay. My name is actually Kenton Vall. I work for the Independent Living Resource Center of Northeast Florida and my comment is, the communication or lack thereof of Medicaid, not only between Medicaid and the consumers, but also between Medicaid and the interdepartmental communication.

Here in Florida, Medicaid runs several different programs. Unfortunately, each program does not know what the other program has; and therefore the consumers are lacking the information to what is provided by Medicaid, and that is my only concern, is that the communication of Medicaid between consumer and inter-departments is lacking. There needs to be an improvement between communication of Medicaid and also the training of the staff, not on just a federal level but also on the local level. And that's my only comment.

K. Rama Thank you. We appreciate that comment. Next speaker, please?

Coordinator Thank you. Ronald Cohen, please state your comment and your organization.

R. Cohen Hello. I'm from United Cerebral Palsy of Los Angeles and Ventura County. It's my observation from a provider's perspective that the No. 1 barrier to the inclusion and integration of people with disabilities into our community is the ability of providers to pay a decent wage to direct-support, direct-care staff. As long as we're paying \$8.00, \$7.00, \$9.00, less than \$10.00 an hour, we can't attract nor can we retain a work force.

Regardless of where a person with a disability lives in our community, whether it be a group home, whether it be their own apartment, or whether it be their own home, if their support staff doesn't show up to get them out of bed, bathe them, dress them, toilet them, brush their teeth, they're in trouble. The entire provider community cannot – cannot – compete with McDonalds or Burger King. That seems to be in terms of my observation our No. 1 issue. We have to treat direct-care staff as professionals and be willing to pay them a decent wage.

Number two: Once we solve that problem, affordable housing. We have developed, UCP in Los Angeles has developed over two hundred 811 and 202 units. It's getting harder. It's taking five and six years to develop those units. There is no incentive anymore as a provider and a developer to develop those units when it takes six years, seven years to develop the homes, to develop the rental units, when just moving paperwork takes seven years. We need to speed up the process, make it an incentive to develop the rental units, the 811 units, the accessible units for people with disabilities, and once we have those units, we will then have a well-paid work force to come and support those folks. Thank you.

K. Rama

Thank you, Mr. Cohen.

Coordinator	Thank you. Randy Chaskin, please state your organization and your comment.
R. Chaskin	I'm with the Office of Disability Employment Policy. I'm here basically just to listen. We're kind of looking forward to implementing the employment piece. Frequently with the institutionalization of people with developmental disabilities and mental illness, there hasn't been a focus on employment. I think the Secretary of the Department of Labor and several others in Labor are going to be working hard on that piece of it, so I'm looking forward to working as a staffer on that. Thank you.
K. Rama	Are you a federal employee?
R. Chaskin	Yes, I am. I'm with the Office of Disability Employment Policy within the Department of Labor.
K. Rama	Okay, thanks very much. Just wanted to check if you were with the state or the federal government.
Coordinator	Thank you. Our next comment comes from James Secor, and sir, please state your organization.

J. Secor My name is James Secor, I work with The Whole Person, Incorporated, out of Kansas City, Missouri. We serve both Kansas and Missouri. To continue with the problem with payment for PCA services, I think part of the problem is that there is no support for PCA's, no training for PCA's, no benefits for PCA's. And I think all of this needs to be dealt with before we can keep and maintain our PCA's. I speak both as an advocate and as a consumer.

I think one of the problems may be that when cuts are made to healthcare services, particularly HCBS services, no cuts at all are made to the institutions that we get stuck in. And the nursing homes have to be I think cut just as we are, otherwise, there's going to be no possibility of a comparison to see whether home and community-based services actually are –

K. Rama Sorry, we can hear someone speaking. Please make sure you're on mute.

W I'm sorry, Mr. Secor.

J. Secor That's okay.

K. Rama Obviously we're all in a technological –

J. Secor Oh, we're all very anxious about this. If there is some way that a parallel situation can be arranged, so that not just home and community-based services are sliced when it comes to funding. But that the nursing home and the other institutions are also given the same treatment, then that money that comes away from them because they're not using it can be put over to the place where it is needed, so that an actual real comparison can be gotten hold of. Does that make sense?

M We understand, yes. Thank you.

J. Secor Okay, good. That's it. Thank you.

K. Rama Thank you.

Coordinator Thank you, and Ginger Ratcliff, your line is now open. Please state your comment and your organization.

G. Ratcliff I am calling as a consumer advocate. I have a brother that's a C-4 quad. He doesn't have any use of his hands. And the comments I would like to

make is just to reiterate what one of the previous speakers mentioned, that the overhead with the provider – the money that's spent, that goes to the provider, could be used for the consumer to have more choice about the person that's caring for them. And in the situation here in Louisiana, there's only one provider in the region where my brother lives and they terminated his services, his Medicaid waiver. In turn, his Medicaid was also terminated.

I would like to see the consumer to have more choices. This provider would not allow nighttime care for him. He had – their point was that they were running the program and that he didn't have any choice in that decision. I also agree with the previous speaker about the pay for the PCA's, that it's way too low. Let's see, what else did I want to say?

Also, the age of the disabled person, he was 23 when he had a motorcycle accident, and he was – he could have been cared for under the MRDD waiver, had he not had his accident after the age of 22. But he's in between the MRDD waiver and the Elderly waiver; there's a whole population of disabled people that are left out. And the largest number of hours that he had under his PCA waiver was five hours a day, which is

very minimal for someone in his disabled condition. And that's all I have to say. Thank you.

K. Rama Thank you, Ms. Ratcliff.

Coordinator Thank you, and our next comment comes from William Baggerman. Sir, your line is open. Please state your organization.

W. Baggerman My name is William Baggerman. I'm from Sarasota, Florida. I'm a member of the Citizens Advisory Commission, Division of Blind Services, the State of Florida. I am low-visioned, though I'm not actually blind. I can use a computer effectively. And I have no real complaints. I have a kind of a suggestion, but I'll go down the line a little bit here.

However I can easily operate a computer – I'm reading this, so I can be precise and short – with a large screen, I have the condition known as macular degeneration. I discovered this condition by accident some years ago. My comment is that some program could and should and would be probably a saving, to develop – and which I have the specifics worked out—where people, the public in general could be notified of major diseases and be put on guard to watch for certain conditions so that, like in

my case, if you have a condition developing, you're made aware of my case and you can effectively be treated.

My situation was I began to see lines that had a slight curve in them, and I just jokingly asked an ophthalmologist I happened to meet at a party, and the next thing I had was an appointment at his office and received a laser treatment. So my point is that there should be and I think I can suggest specifically, a program where people could be notified of, not only this condition that I have, but other major conditions, and put on guard to watch for it and therefore avoid becoming completely debilitated and cause the government a lot more expense than if they were able to receive early treatment and control the condition as I have.

And I won't attempt to go into the details, but possibly if Ms. Carma is interested, I could send her the specifics that I have worked out in this suggestion that I have. That is all I have to say.

K. Rama Thank you, Mr. Baggerman, for sharing with us today.

Coordinator Thank you. I show no other comments at this time. One moment. Meg King, your line is open. Please state your organization and your comment.

M. King Yes. I'm from the National Coalition on Self Determination and I would like to make a suggestion that HCFA also clarify perhaps in a letter, what things – make it more clear to the state and the people and the consumers what is available, so we can advocate more effectively. It seems to me if you're going to have true self-determination, you have to have a better source of information or more informed choices. I know a lot of people that I talk with, parents and self-advocates will say, "I've never heard of this." So if it could be more available. I know they have a primer out, etc.; however, people still don't understand what the waivers can do and should do. Thank you.

K. Rama Thank you, Ms. King.

Coordinator Thank you. Elizabeth Priaulx, please state your comment and your organization.

E. Priaulx Yes. I'm with the National Association of Protection Advocacy Systems, and I just want to comment. I was very encouraged by the five ... Medicaid Director letters that have come out from HHS regarding recommendations on how states should be implementing Olmstead. My concern is that now two years after the decision, we have not seen

significant numbers of people moving from institutional settings to the community.

When I've asked folks at HCFA or Center for Medicaid Services and Office of Civil Rights, they've told me that they can offer some examples of people who have moved out as a result of filing complaints with OCR. I think that it would be useful for OCR to make – not necessarily those names, but some statements about what has happened as a result of following up from these complaints, and if people have in fact been moving out in states. If there could be some way to provide that information to advocates, because it's very frustrating now two years out seeing some plan development, but very little movement. And we know that in most states there are existing lists of people, whose doctors have determined that it is appropriate, community placement is appropriate, so we know that people are ready and able to move at this point.

The other recommendation that I would make is that OCR and HHS have to move beyond the friendly, working together with states that they have been using for two years, and begin to establish time frames, made known to the states, for when they will be going in and looking at the plans and asking the states and discussing with the states how their plans are not in

compliance with the HHS recommended guidance in OCR Letter 2. We find that advocates are working hard out there to get the state to comply with HHS guidance, but we haven't actually received any indication from HHS that they, in fact, will be putting any kind of stick behind ensuring that the states comply with this guidance. Thank you.

K. Rama Thank you, Ms. Priaulx.

Coordinator Thank you. Rick Edwards, your line is open. Please state your comment and your organization.

R. Edwards I'm Rick Edwards and I'm with the ADA Steering Committee in Indiana. I have a couple of comments, primarily about the Americans With Disabilities Act. First of all, I also would like to commend President Bush on his Freedom initiative.

There are a couple of points about the ADA that I felt were important to ensure that the Presidential committee addresses, in terms of the transition plans and the self-evaluations that have been done by Title II entities. Those have been let go in terms of follow-up on the things that need to be done to ensure that those transition plans are actually addressed, the

barriers are actually removed. I'd encourage them to take a look at that section and that part of the ADA.

I'd also encourage the Committee to take a look at RSA and how they're implementing Technical Assistance Circular 9804, which is the rehabilitation agencies dealing with Title I reasonable accommodations, and I'd ensure that these state agencies are actually working with the employers to ensure that those reasonable accommodations are implemented.

I'd also like to ask the Committee to take a look at how federal officials who are responsible for monitoring the implementation of ADA are trained. We've had a number of situations where federal officials have come and done, for example, site evaluations and misquoted the ADA Accessibility Guidelines or not known exactly what is required in terms of accessibility.

And lastly as a person with a spinal cord injury for 31 years and a wheelchair user, I'd like to offer my support in the appointment of Mr. Sutton, who is interested in making sure that the ADA is implemented in the states correctly. Thank you very much.

K. Rama Thank you, Mr. Edwards, for participating today.

Coordinator Thank you. And Monica Smith, your line is open for your comment, and please state your organization.

M. Smith Yes, I spoke earlier today. I'm with the Indiana Governor's Partners in Policymaking here in Indiana, also a parent of a child with a disability. And I wanted to stress on a situation, since I relocated here from Oklahoma City, I was on the Medicaid waived service back in 1992. When I moved to Indiana, my services had stopped and I feel that the Medicaid waivers list should automatically be open to anybody that does qualify for these services. Nor should people who have waited on a waiting list in other states and received services and then moved and the services stopped, their services should follow the families instead of the services being stopped. They shouldn't have to re-sign up for services when they had them in another state.

And then I also wanted to emphasize the fact about the funding for staff and finding staff at \$7.00 and \$8.00 an hour. As everybody knows, finding staff these days has been tough. Imagine yourself, who would you like to come in and care for you? A stranger or someone you've never

met, or do you want somebody close to your family? Now, \$8.50 an hour or \$10.00 an hour would stretch further because the provider wouldn't be charging \$20.00 to \$60.00 an hour for services that were initially only \$8.00 to \$10.00 an hour, which actually the caregiver gets. Instead of the provider hiring the staff, let families have a choice who cares for their loved ones, and have insurance companies or state agencies reimburse families for services rendered. One would need to present a voucher or a time sheet for reimbursement.

I know some states offered this voucher with dollar amounts. Families use the dollars on who they want to care for their loved ones. By using these vouchers and letting families use who they know and trust, you cut a lot of overhead and the managed care collars. This way, families get the services they need and the money is being used on care, not paying the high overhead cost of agencies to pay their staff and their overhead.

Thank you.

K. Rama

Thanks for your additional comments, Ms. Smith.

Coordinator

Thank you. Toby Hale, your line is open. Please state your comment and your organization.

T. Hale I'm with the National Organization for Women, better known as NOW; and I would like to reiterate about the pay for PCA's. As we all know, most PCA's are women and women are notoriously underpaid. I think that getting a better pay schedule for these women and the few men that are doing this, too, is absolutely paramount. I also agree with the previous caller about families being able to take care of their own people.

Another point I'd like to bring out, especially as it deals with housing, is the concept of visit-ability; that housing that is being built, even for people who do not have disabilities, be accessible enough that we can visit their homes. I'm very limited where I can visit because I can't get in the doors or the living rooms of anyone's house. So I think that that concept of visit-ability should be added to the HUD funding and other housing authorities. Thank you.

K. Rama Thank you for your comments.

Coordinator Thank you. And Grace Burns, your line is open for your comment, and please state your organization.

G. Burns

My name is Grace Burns and I'm a parent of a child with multiple disabilities and I just moved from one state to the next. We had for my son, home and community-based waiver for my son, where I am getting paid to care for him directly. Now when I moved to another state, he is now totally out of the waiver. I can't get in the waiting list. For some reason, I'm having trouble accessing the community-based waiver. I find it very frustrating that now he's totally out of that community-based waiver, which was so hopeful for us, for me.

I was a single mom, my son incurred his multiple disabilities through abuse from his own father, so we have no help. I was a single mom all by myself in that county. And the home-based waiver tremendously helped me in nurturing his environment, so that he can be cared for and have – I focused on his nutrition and it helped us tremendously. That home-based waiver is so important in the lives of these children. He is blind; he doesn't walk; he doesn't talk; he doesn't reach out for a toy. I depend solely on Assistive Technologies, which is so important in his everyday needs, to eliminate, to reduce ulcers, bedsores. It's medically necessary that he be in that home-based waiver.

And now, I have no idea how to even get in that same system. I can't understand why he would lose it altogether, just from moving from one state to the next. Right now, I had to move because I got married; we have a family life. And I don't understand why having a family means losing the system that works for my son. And I just wanted to -- the positive input of this home-based waiver, how it changed my hopeless outlook to something that we were even -- that I even managed to get him into a normal community setting.

Now, right now he's in a school system. Like I said, he has total care. But that home-based waiver is so important in his care in his livelihood, and I can see there's so much hope for it. It has tremendous effect if the caregiver, a parent or a spouse, could have financial help to care for them, so that they don't have to be bogged down with responsibility having to find care, so that they can go out and provide a roof over their head.

And I just wanted to say that that is much more cost-effective, as far as dollars are concerned. My observation, briefly of -- my observation of this new state is that a lot of the funding from the government, from the federal government as it channels down into this state, my observation is that a lot

of these agencies put a building, maybe a letterhead, to get the funding; but no direct services go to the children.

To give you an example, I went to the county for the respite, and they said that there's a waiting list of three to five years, and the maximum you're going to get is \$3,000 or less. And yet, if I wanted somebody for respite, they gave me this number. I contacted the number, and they don't do the service directly; they train people, they educate people for advocacy.

It's like, I want service. I want direct service. I want somebody to come into the house and bathe him. I want somebody to come into the house to feed him, so that I can take some courses outside the home, so that I can stimulate my mind. But no, it appears that a lot of these agencies that I've looked, I've found on the Internet, like Agreeability, so I could get assistance for some kind of switches and sensors, so that my son could participate in the community. They say, "Oh, we don't fund that. We don't give you the resources. We just give you training."

I told them how I wanted these sensors to work. I have a background in electronics and design. I don't need training. I want the physical things that I need, the physical services, the direct care, the switches, the sensors.

But if the money goes directly to the parents or the caregiver, they can just go and buy it. They don't have to answer to someone who would just tell you how to do it the way it's been done in the long ways.

It appears that the money disappears in agencies to employ somebody that kind of just push papers, when in reality what's needed is the direct service, the direct care, the physical body that does the actual bathing of the person, the actual material that can help with the bathing, the actual sensors, the switches, the motors. These children are going to get heavier; the parents are going to get weaker. We don't need a whole bunch of lip service.

K. Rama We appreciate you taking the time to give us your comments today.
Thank you very much.

Coordinator Thank you. And Sara Thompson, your line is open for your comment and please state your organization.

S. Thompson Yes, I'm with the National Mental Health Association. I'd just like to make a few comments on community-based services. I think everyone knows, in order for Olmstead to be implemented, we need to have

housing. It's a huge stabilizing factor for persons with all disabilities, especially for people with psychiatric disabilities. We'd like to see a range of choices for housing, people being able to rent, people being able to buy, and the housing needs to be permanent, so that people are not moving from place to place to place.

In terms of other types of services, there needs to be a wide range of services, just like there needs to be a wide range of housing, ranging from self-help, peer support, employment, housing, integrated services and being able to work with persons who have co-occurring disorders of substance abuse and mental illness.

These services need to have an emphasis on a recovery philosophy, meaning that there is a belief by the agency that people with mental illness can and do get better. And that there's not an emphasis on kind of maintaining the individual, but making sure that they are growing as a person, so that they can lead a successful life in their community.

Lastly, in terms of employment, historically there really hasn't been a whole lot of incentives for providers to provide employment services and I'm glad to see through the Ticket to Work Act, that this is changing, and

that is the direction in which we should be going. So I want to thank you for letting me make this comments, and I'll turn it back to anyone else who wants to make comments.

K. Rama Thank you, Ms. Thompson.

Coordinator Thank you. One moment, please. Donna Martinez, your line is open.
Please state your comment and your organization.

D. Martinez Yes, thank you. I am calling as a parent of a child with Downs Syndrome, or a young man, 15 years old. I am also an advocate for all the parents in the State of Virginia. We are being trained to understand and comprehend the Medicaid waiver system that has developed within our state. As a result of this training then, we are encouraged to go out within our state to approach the other parents who are befuddled, misdirected, misguided or just simply not given the information that they should have in order to access the services that are due to them, that are their right and that are available to them.

Many of our services are being offered through, not only private organizations, but through the actual state agency. So there has

developed, or at least within our state, a problem of people playing both sides of the fence; and as a result, it is the consumer, the parent, the family who gets the short end of the stick. We have a state of affairs when there is a necessity by our volunteers to go and inform the families of what they can expect. It is now nothing more than a bureaucratic paper game with a sideline cheer that has been reduced to cries of appeal, apply, appeal, reapply, appeal, reapply one more time.

There needs to be a greater understanding of the individuals who receive the services, and a greater connect, nationally. As CMS develops the federal policies, the buy-in by the states needs to be consistent. Having moved from one state to another, the services are not the same. I have a dear friend who is even thinking of moving from his home state because that particular state does not offer what he needs to literally, physically survive. He must now move out of his home state, let alone go to an institution. This dire need must be addressed. Thank you.

K. Rama

Thank you, Ms. Martinez.

Coordinator

Thank you. And our next comment comes from Katsumi Kenaston and please state your organization.

K. Kenaston This is Katsumi Kenaston in Anchorage, Alaska. We were Alaska Mental Health, Consumer Web and Craft House. And we run the ... center for a consumer to come in and do what they want, what they need for seven days and seven nights with State of Alaska funding, thanks to the state. But I have been listening – please bear with my poor English because I am a Japanese immigrant; I cannot speak.

So anyway, I was so overwhelmed with all the consumer suggestions and opinions today, but not one person touched the racism and the discrimination. In Alaska, it's very much you go to the jail. It's the biggest mental health institution. And we have a mental health court, but we don't have community services, we don't have housing. Everybody is sleeping in the woods. So they need a bathroom. They need toilet paper. They need a lot of things. They don't have any basic human rights, which—we don't have a constitution, we didn't go through 1960 in Alaska.

So please, please, if we go to any committee, minorities in Alaska are totally ignored. It's not even safe to go to a meeting. So HUD said that we have the perfect score for HFC, and we call the public housing "House of Hatred." We cannot say anything because the retaliation is so harsh.

We have go to outside, minus 35 degree and die. We have no place to complain, and nobody to monitor and force the regulation and the quality control. It's everything done deep, dark secret and invitation-only.

And I called Seattle, but they said, well, back and forth, back and forth, and consumers of Alaska of color are no representation. So I hope somebody address for this racism and discrimination in mental health services. Thank you.

K. Rama We understood your comments perfectly, Ms. Kenaston.

K. Kenaston Thank you.

K. Rama And we appreciate you bringing up that topic, since you are the first one to do so.

Coordinator Once again, if you'd like to make a comment, please press *1.

K. Rama We have a number of other people registered, and we want to make sure we're allowing all of our callers to have the opportunity to provide some

input, so please don't be shy, and we encourage you to hit *1 – is that what it is, Theresa?

Coordinator Once again, if you'd like to make a comment, please press *1. Our next comment comes from Bonnie Ryan, and please state your organization.

B. Ryan Yes, good afternoon. My name is Bonnie Ryan and I'm the deaf attorney who requested the Webcast captioning of this listening session. And I'm encouraged that those of us with hearing loss are able to participate real-time. I want to commend Liz White at HHS and Brian Millen at FCC for working together to ensure this access. It's a fine example of what can be done to remove federal barriers with effective interagency partnering, and I hope this becomes a government-wide model for providing public input.

I'm viewing the captioned telecast here intensely. I serve as a member of the boards of the Citizens Advisory Commissions of Arlington County, Virginia and that's the Disability Advisory Commission and the Community Development Block Grant Commission. I'll be submitting written comments at a later time and attending the New Freedom hearings.

But I'd like to also share in the next few moments some brief personal comments on a typical day dealing with Medicare. I tried to make a call this morning to the TTY number for the Medicare help line. And the call was answered initially by an audio or a voice recording; and I think this is something that's easily fixed. People using a TTY number expect to immediately be responded to with a TTY answering.

Second of all, the question involved the difference between hearing – coverage of hearing aids under Medicare versus coverage of cochlear implant surgery and devices. There is a marked difference here as you may know. Hearing aids and hearing aid evaluations, even everything being equal between cochlear implant and hearing aids both being medically necessary, one receives coverage and the other doesn't.

Since being able to hear in an information-intensive society, for those of us who choose to use our residual hearing, it would be a very good thing to look at, whether we can make hearing aids, especially the more sophisticated digital ones which can cost up to five to \$6,000, more available through Medicare program and Medicaid program. And that's basically it for now. I appreciate the efforts that have gone into making this teleconference accessible to those with hearing loss.

K. Rama We appreciate that you're listening, Ms. Ryan, and I'm glad it's working well for you. Thank you for your comments.

B. Ryan Thank you.

Coordinator At this time I'm showing no further comments. Once again, if you'd like to make a comment, please press *1.

M We'll wait another moment –

Coordinator Excuse me. Eileen Robinson, you may make your comment, and please state your organization.

E. Robinson This is Eileen Robinson in Elking Bow, Texas. My sister is a resident at the Richmond State School in Richmond, Texas and she is profoundly retarded. I just want to tell you all that a lot of people have said wonderful things and pointed out an awful lot of problems that exist, helping people to go into the community. I want to tell you that there are some fantastic things going on in institutions for people that have profound mental retardation, at the Richmond State School.

There is therapeutic writing. There is an indoor pool. There is a gymnasium. There are special Jewish religions services, just designed for the clients that are of that faith, which we happen to be. There's education. There's a full-time – there's a group of doctors on staff. And I could go on and on, therapeutic horseback riding. And I just want to say that a lot of people can go out in the community, but there still an awful lot of people who need to be in the care of an institution like the Richmond State School. And I hope when you all look at Olmstead, you will look strongly at the fact that there needs to be a choice, and not let those people who are being served in the institutions presently fear that they're going to be kicked out and put in a place where they're very uncomfortable. Thank you so much.

K. Rama Thank you for providing your input, Ms. Robinson.

Coordinator Our next comment comes from Judy Roy, and please state your organization.

J. Roy I'm Judy Roy, and I'm with the Birmingham Independent Living Center in Birmingham, Alabama. In Alabama, family and friends have provided an informal kind of personal care assistance for a number of years. This

original home and community-based care system was meant to delay an elderly family member's entrance into a nursing home for as long as possible. Today, families are faced with some terrible choices. Either they give up their jobs and their family life and take a job, or put a family member into a nursing home.

Disability is a natural and normal part of the human experience and in no way diminishes a person's right to participate fully in the community and in all aspects of life; but people with disabilities in Alabama are facing having to make those very real choices. And realistically with Alabama being the poor state that it is, there's going to have to be more of a federal match for the State of Alabama to increase the expansion of services, long-term care services and waiver services for people in Alabama. I appreciate the opportunity to have input today. Thank you very much.

K. Rama Thanks for joining us, Ms. Roy, and for participating.

Coordinator Our next comment comes from Grace Burns, and please state your organization.

G. Burns

Hello. My name is Grace Burns and I'm a parent of a child with multiple disabilities who is blind. I just wanted to share my vision about the home-based waiver as I envision it for my son, and what I'm hoping to see it happening. That my son would live in his own home that has automated greenhouse and I would have switches and sensors, and he could grow his own herb that has a – and I think that that is a possibility for my son. He could grow his own potted herb in his own home, in his automated greenhouse, and that's what a home and community-based waiver could help with something like this, so that my son could be a contributing part of society. People would come from all over, see him and enjoy his plants with him and his animals with the farms and nature and with the wild geese and the wild animals.

And I see that a possibility for people to be part of their community. Why should they have to be in an institution? Why should the horseback riding be in an institution? Why couldn't a family, if they choose to raise their child at home with a little bit of support, maybe a little financial backing, so that they can get the switches and the sensors. And maybe some kind of engineering design backing through this Agribility, a lot of federal programs. There's a lot possibilities out there.

I know the government are working so hard with making the programs flexible and everything else. We have the know-how, we have the technology, we have the funding. I guess and vision, but I just wanted to reach that so that it does not get lost in the middle, along the way, because we've done it for so long, parents and families cannot get the help directly; they have to be at the mercy of a lot of agencies. And yet they're too busy trying to budget their own overhead and their own buildings, when the care and the actual need can be met if it's done directly to the people who needs it most. And the money could go a long way.

And yet if you go further in the dream, if the businesses are nurtured in that way, these children with multiple disabilities and adults with multiple disabilities can even earn money and so that they can be a taxpayer and have some kind of pride, and be the actual participating part of this society and not just a burden, not viewed as a burden. And that is my dream through this home-based waiver.

And we have a long way to go, but I still see that dream and that hope, and I have a lot of hope for this. And I just hate to see it fall on the wayside because everybody is trying to fight for the money and the funding and using it everywhere they want to. Yet somehow get bogged down with

liabilities and everything else, and the rules and regulations, so and the bottom line is, if it's directed directly to the people who needs it, it can go far more.

K. Rama Thank you, Ms. Burns. We really appreciate hearing about your personal experiences today and hearing about your son, so thanks again for participating.

Coordinator Our next comment comes from Darlene O'Connor, and please state your organization.

D. O'Connor Hello. I'm Dee O'Connor with the National Home and Community-Based Services Resource Network. The Resource Network is actually assisting in collecting some of the information from this listening session, so I wasn't planning to speak; but I'll speak in my private capacity as an associate research professor at Boston College.

I just wanted since we had some extra time, to highlight some issues that I hadn't heard come up, or to reinforce some things that have been said. Certainly the issue that people have raised about housing and transportation, transition assistance, employment have all been major

issues that we've heard a lot about. The woman who just spoke, Ms. Burns, has emphasized a couple of times the desire to have flexibility and funding for families. I just wanted to reinforce that the states that have tried that, who have given families individual budgets to work with, have had some good success with that and have proven to be good purchases. So I think that's a very important solution for us to be putting a lot of attention to in the future.

One that hasn't been specifically mentioned was the Medicare Homebound Status, the requirement that people be perceived as homebound, in order to access the home health benefit under Medicare. It seems to me that at this point in our development of services, that we know that there really isn't anyone who's homebound, and so it would be real helpful if the federal government could begin to look at that and to recognize that in its policy.

There are still some institutional biases in the Medicaid eligibility rules; I know some of those have been mentioned in the past, but not on this call. Where people can qualify in institutions but not be able to qualify in home and community-based services because of how some of the spend-down

rules work, and I think that's a serious issue that we would gain a lot by trying to address.

Some people have mentioned the differences across populations, and I just want to reinforce that we have so many – because of the variability, which is the positive thing in how we run the Medicaid program, we also create lots of situations where people in one state can get access to diverse services and cannot get the same access in other states. People have mentioned mental health in particular; we have certainly stronger biases toward not covering those services as effectively, home and community-based services under Medicaid.

I'd particularly mention some that I've noticed and learned about in Massachusetts where elders who have mental health needs, because the system is so much more dependent on state dollars than it is on Medicaid dollars, it tends then to encourage the states to put their priorities on younger people. And so that leads to an encouragement that elders who have mental health needs be encouraged to go to nursing facilities, because then the dollars shift over to Medicaid, and the state mental health agency doesn't need to deal with it as well. I suspect that's a problem in many states.

One last thought is regarding a question somebody had asked about the number of people who have been de-institutionalized, and it might be a helpful thing for the Center for Medicare and Medicaid to begin reporting on that. I think there is some data in the 372 Reports that does distinguish between people who are de-institutionalized and those who are diverted. I'm not sure how good the data is right now, but perhaps encouraging the states to really have that data be good data, so that we could get a good picture of how many people have actually come out of institutions in recent years. Thank you very much.

K. Rama Thank you, Ms. O'Connor. We know you're helping us today, so special thanks for stepping out of that role and stepping into the participant role as well.

Coordinator Our next comment comes from Mary Lopez, and please state your organization.

M. Lopez I'm a person with a disability and a member of Not Dead Yet. And since the issue today is accessibility to care, there is an ironic situation where people with disabilities who lack adequate care reach such levels of despair, and they look to assisted suicide as an answer to that despair.

Non-disabled people who express despair are directed toward counseling services, but it is too often that those who care for people with disabilities only see that despair is natural and inevitable if you do live with a disability. If the topic is barriers to accessibility, there is no more important need for accessibility than accessibility to adequate, life-sustaining care for people with disabilities. Thank you for the opportunity to express my comments.

K. Rama Thank you, Ms. Lopez.

Coordinator Our next comment comes from Carol Boyer, and please state your organization.

C. Boyer This is Carol Boyer with the Res Nok, and I also am a project associate with the Resno Technical Assistance Project. I think I want to reinforce what the parent said, Grace Burns, who mentioned that her son lives totally with the supports of assistive technology. And I think one of the major issues in the disability community is that we lack data on studies, and we need more national studies, on the cost benefit analysis of, not only increases in the economic development to the community with people with disabilities living in institutions versus people with disabilities living

in the community, but also the cost benefit data to the states of institutionalization versus community-based services.

I'm also a member of the Consortium for Citizens With Disabilities Task Force on Employment, and we are going to be submitting written comments that also address the needs of Medicaid, addressing the work-related issues with assistive technology. It really needs to be addressed. We've all been talking about it, and I'd love to see CMS at HHS fund a national study on these cost benefits. Thank you for the time.

K. Rama Thank you for your comments, Ms. Boyer.

Coordinator Carolyn King, you may make your comment, and please state your organization.

(Audio quality compromised:)

C. King I'm a family member and I am coordinating a group of other family members, a support group called FANT in Tennessee. I have a mother who is 85 with advanced Parkinson's Disease, and I have a niece who is 30 who is developmentally disabled, and I'm concerned about some cross-

over of services that might make sense for families who split the family unit. I'm told my niece is eligible for help, but not my mom, and – the same help, and there's no help for my mom and that sort of thing, so that's one concern. I think that if there were some way to look at what families really need versus program parameters, that more might be accomplished.

And another comment is that in this particular state at this time, there's a real problem with home and community-based services for the developmentally disabled people. I am considering trying to get services in another state, but I'm told that I would never be able to bring her back here once services become available if I change states. I have the same concerns that others have expressed about the lack of consistency among the states and also the programs' eligibility going with the person, as opposed to being dependent on some state waiting list.

I'm also wondering what approaches have been taken with – to ensure that all families who have people in need of help have been contacted. Like for example this call today, I only happened to hear about it from somebody who happened to see it on the Internet. And what approaches, I'm wondering, have been taken to reach families who really need help, but who might not be assertive enough to reach out and find what

opportunities there are available to get input and to seek opportunities.

I'm understanding that there are families who – in which the adults can't read and there are families without telephones. There are certainly families without computers and so forth.

I think a better system is communication going directly to families ... help. There are advocates and there are groups that involve certain family members, but I'm thinking the population at large is uninformed today. Thank you for your time.

K. Rama	Thank you for your comment. And could I ask, Ms. King, if you have suggestions on how we might reach those other people, if you could write them in to our written comments, that would be a great help.
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Coordinator	Our next comment comes from Kay Marcel, and please state your organization.
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K. Marcel	Hello. I'm a parent of a young adult with a developmental disability, and I'm also serving as the state coordinator for a
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(cutting out)

organization in our state that advocates for increased community support.

And my comment is related to home and community-based waiver services. My son is on our state's waiting list for our home and community-based waiver, MRDD waiver. He's been on the list three years, and given the pace at which our waiting list is moving, he's looking at being on that list at least another three, possibly four years before he has access to supports to help him live in the community as independently as possible.

I guess my primary comment is that there remains a huge inequity and even an institutional bias in Medicaid funding, in that community-based services remains under waiver programs. I would like to see that inequity and institutional bias removed, so that those services are mandatory or at the very least optional services like the ICFMR program.

Waivers for these services have been around for quite some time now. They are proven effective in cost and in improving the quality of life for people with developmental disabilities and helping them to be integrated and valued members of their community. I just think it's an outrage that our tax dollars and actually the money that my son generates through Medicaid, is held hostage into an institutional system, when that is not his

choice. And the majority of people now today want these home and community-based services, and they can't access them because of institutional bias. So thank you very much for the opportunity to comment.

K. Rama Thanks for taking the time to provide your comments today, Ms. Marcel.

K. Marcel Sure.

Coordinator Our next comment comes from Bill Coffelt, and please state your organization.

B. Coffelt Good afternoon. I'm co-chair of the National Coalition of Self Determination. I'm also a parent of a young man with significant disabilities who has resided in a state institution here in California and had the opportunity to grow up in foster care in a program we helped design, called Extended Family and now lives in his own home with 24-hour support.

My concern here in California is federal incentives through Medicaid to make the state do the right thing. California doesn't put a high priority on

Medicaid funding, in the sense that we rank last in the country in accessing availability or available Medicaid, FFP. We rank near the bottom in FFP for ICMFR programs, as well as the –

(Audio interference.)

B. Coffelt -- as well as the home and community-based programs.

(Audio interference.)

M Excuse me. Could you make sure that if you're not making the comment itself, if you could make sure your mike is on mute. Thanks.

B. Coffelt Am I still on?

M Yes, you are. I'm sorry for the interruption.

B. Coffelt Well, again, my concern is California doesn't put the priority on Medicaid funding that other states, such as New York or your New England states do, to develop programs.

What I would like to see is attitudes change, as well as give states an incentive, to develop their home and community-based programs and a disincentive to continue reliance on the ICFMR program. California maintains five of the ten largest institutions in the United States. We have the largest public institution in the United States, the Sonoma Developmental Center, which my son was in for two years. I was a plaintiff in a lawsuit in California, *Coffelt v. EDS*, where in just three and a half years we moved over 2,000 people out of our state developmental centers. I compare that to the *Olmstead*, as I think we, in the three and half years, we've moved more people out of state institutions than the *Olmstead* Decision has caused nationwide.

Again, my concern is that the state still continues to receive a 50% FFP for our state institutions. Our Developmental Services director has publicly stated his concerns of why he should move people out of institutions into the community, because the fixed cost of the state institutions remains the same, so there's really no savings. I'm sure if federal participation, either through more federal oversight over our programs, we have a state—again, Sonoma Developmental Center received certification – having certification pulled for almost a year, received it. Shortly after they received it, it was found that there were many allegations of abuse that had

been withheld from the surveyors until after the survey was completed and they received their certification.

We continue to have situations and stories like that in our state institutions and again, they remain alive and well and big because the federal government continues to subsidize this. So those are my comments again, more incentives for home and community-based, and disincentives for the institutions. Thank you.

K. Rama Thank you, Mr. Coffelt.

Coordinator Our next comment comes from James Secor, and please state your organization.

J. Secor Yes, this is Jim Secor again from The Whole Person in Kansas City. A part of the choice that I think has not been addressed yet is the fact that someone who is on benefits and receiving HCBS services, when they turn 65, they have absolutely no choice in the matter. They must move over to retirement benefits. And when they do this, they lose their HCBS services. And I think this needs to be addressed. Thank you.

K. Rama Thanks for your additional comments, Mr. Secor.

Coordinator Our next comment comes from Wally Dutcher. You may make your comment and please state your organization.

W. Dutcher Yes, National Alliance of the Disabled, a follow-up comment to Mr. Coffelt, this is one of the problems that occur in the community of advocates for persons with disabilities, as well as persons with disabilities themselves. We reflect a microcosm of the national population. There was another comment about the – I believe it was a place in Texas that provided adequate and comprehensive facilities for persons with severe or profound mental retardation.

They should, too, be allowed the choice, and for Mr. Coffelt, too, and for any federal program that considers a disincentive, I think this is doing a disservice to those individuals who wish to have that choice of an institution. I'm not suggesting that I'm in favor of it necessarily, but that's not my point, nor is it the position of NAOTD and that would be to provide pure choice. And that has to do with the rights of individuals to select where they want to live.

To follow up also on the comments regarding the cost of personal care assistants, as you know, there have been widely reported shortages in the healthcare industry for skilled nursing positions. And for an individual in the community to be able to compete for personal care assistance, the wages and benefits must be comparable to that, as well as the providing of funding for the payment of the employment taxes, which would be the employer's share, which would normally be incurred if an agency situation was used as the provider. Those are the two additional comments I wished to make. Thank you.

K. Rama Thank you, Mr. Dutcher.

Coordinator Our next comment comes from Meg King, and please state your organization.

M. King Yes. I'm Meg King, I'm the parent of a child with a significant disability and I would like to respond to individual funding. As I perceive it, my son when we needed help, we did not have real choice. I hear Mr. Dutcher talking about choice; there is no real choice. It was a decision, because there was no community services available; it was just an institutional setting. And at age nine, my son had to leave home. It was not a choice;

it was a decision.

And I would like to see CMS look at the situation where if funding were attached to the person, that perhaps more people would have those opportunities to live and stay and be with their family. That's something I feel very strongly about, and I think we need to look at that more significantly in trying to configure services for people. Thank you very much.

K. Rama Thanks for your additional comments, Ms. King.

Coordinator Our next comment comes from Grace Burns, and please state your organization.

G. Burns My name is Grace Burns and I'm a parent of a child with severe multiple disabilities. He has a lot of medical equipment in his stomach; he's got a tube feeding, he's got a pump. He needs a lot of skills to handle him, as far as positioning, a lot of technical know-how as far as making sure that no deformities in the bones continue to happen.

And so that I think that as a skilled parent, we should be paid, because there are a lot of shortage of skilled care out there. And so why should the people who do minimal – they can't even do tube feedings and they can't even do special handling, as far as lifting and repositioning – they were getting paid minimum \$7.00 an hour by the agency, and then the parents have to pay the agency \$13.00 an hour. And yet where are we supposed to come up with that kind of money and still be able to work so that we can afford that?

And why couldn't skilled parents like us be paid for all that sort of job? I went through training to do what I do with Jack. I went to school for physical therapist assistant and that's how I learned about decubitus ulcers and the special handling, and what can happen if those are not kept in mind; and how the tube feedings are supposed to be kept clean, and the nutrition. The very importance of nutrition as far as how the cells heal themselves, and as far as how the brain stay healthy through nutrition, and the special environments like with the soothing music and all of that.

It takes a lot of years of experience to become this skilled, and therefore, I am not about to hand that over to an institution. And just because they have many degrees behind them, they can be more qualified than I am?

And therefore they can get lots of money and I can't? I don't understand that.

K. Rama Thanks, Ms. Burns, for your comment.

Coordinator Our next comment comes from Mary Williams, and please state your organization.

M. Williams My organization is New Start Healthcare Corporation, and we're located in Los Angeles. I'm a provider of services for spinal-cord-injured patients who are aged between 16 and 40, 45. These patients want to live independently in the community and over the past 18 years, I have developed a program, through which they can be trained to live and function independently in the community at a lower cost.

I agree with some of the other previous speakers in that there is definitely a shortage of nursing and skilled nursing and just like many years ago, lower-level people can be trained to do the same jobs. And as we know now, there is a need to cost-contain. I believe that if we really look at a program such as mine over an 18-year period, that the results can speak

for themselves, and that we could really provide a model for many states, through which they can access the community.

Some of the major changes I would suggest are that there are many patients that are on private insurance and many insurance companies will pay for a program by flexing their benefits of skilled nursing. However, this is not a rule or a law. I would suggest that in order for more people to have the opportunity and an alternative to a community program is that we look at making funding available for MediCal's patients, as well as private-insurance patients that could be flexed, so that those funds can be used in the community.

And I would also comment that the home health agency, which I have provides a continuum of care for the independence training program. That quality of care for a type of program such as mine could be tied to a home health agency. Where they would be an oversight to any either group or individual that would like to set up a specialized training program, so that these people can access the community safely. It does not happen until these patients have been trained and the families are also trained, so that the milieu is actually as safe and steady, so that everyone wins.

Housing is a huge problem for accessibility. This is I know being addressed at the federal level now, but housing is keeping more patients in institutions than anything else at this point in time. I thank you for letting me comment on this.

K. Rama Thank you for sharing your experience, Ms. Williams.

Coordinator Our next comment comes from Nicholas Dupree. Please state your organization.

W I'm speaking for Nicholas Dupree. He is with the National Coalition on Self-Determination and with Nick's Crusade. We have a situation in Alabama where after 21 years of age, we are no longer eligible for EPSDT. Alabama doesn't have another program that provides home care for anyone that would need it. That's what Nick's Crusade is about: changing it.

Currently, home and community-based services are not a mandate. That's just an option that states can take or leave. They can take or leave, fund or cut at a whim or according to their fiscal situation. However, states have no problem stripping citizens of their freedoms and segregating them in

far-away institutions because this is a required service. This is absurd and must be changed. The civil right to live, work, play in the community among family and friends, regardless of color, religion or disability, should not be optional for states. In this free country, no citizen should be denied freedom just because states do not have the resources or political willpower to adequately fund or set up home and community-based services programs.

We are in a situation where if we cannot change the law, we will have to move to another state. Should families be forced out of their homes to get the care that they need? It's not right, and I hope that you at HHS can change the situation. Thank you.

K. Rama	Thank you, Mr. Dupree, for sharing your comments with us today.
Coordinator	Our next comment comes from Steven Eidelman, and please state your organization.
K. Rama	Your mike might be muted. We can't hear you.

S. Eidelman Okay. Sorry. This is Steve Eidelman from the ARC of the United States, and I'd like to weigh in on this choice issue once more. We don't believe there is a significant number of people in institutions who if given a real choice as opposed to someone making that for them, would choose to stay there. And second, I'd like to point out in most states, people choosing that option are taking up five or \$600 a day out of the system, when you've heard from many callers today that for want of a fraction of that, could be adequately supported in the community. So we don't believe that choice is the real issue here.

We also see a flaw in some of the discussions surrounding Olmstead. It's hard to imagine a contemporary-trained professional saying that a person is no longer capability of living in the community. We now have about ten states that have no institutions, and if you use the same standard that's used in medical malpractice cases, it's essentially state of the art, what is known. And it's now known that we don't need large facilities. So for a professional to continue to recommend one for a person with a developmental disability seems out of context with accepted professional practice. Thank you.

K. Rama Thank you, Mr. Eidelman, for your comments.

Coordinator We have another comment from Grace Burns and please state your organization.

G. Burns My name is Grace Burns and I'm a parent of a child with multiple disabilities. I would like to reinforce the comment previously made by Steve that if there will be no institution – and I'm not proposing that there should be an institution. I just hope that when the state decides to not have that, that they would have a good home and community-based waiver in place. That is such a vital source of the livelihood of the children with multiple disabilities, is that full support of the government through home and community-based waivers, so that the population with disabilities could live a life with the family and with nature and be part of the community and be a contributing part of society. It is such a vital piece of – source of – it's the livelihood. And it's medically necessary.

I'm just saying that the institutions are there for someone that does not have that in place, that does not have the support. But why choose that over having to support a family that could care for before the family breaks down. Have the support ready in the family, so that the family could stay together, the community could bond together through church, through whatever, employment and community contact. Reinforce that;

nurture that through home and community-based waiver. And that's the most important piece there, is that support in the community through home and community – I cannot repeat it enough, because that is so important.

I'm saying I'm so glad to see the sheltered workshop be gone, I will be so glad to see institutions be gone. But the other edge of that sword is if it's gone and there's no home-based waiver, then you have neglect and abuse and no shelter, nothing. So it's important that home and community-based waiver be the way – that's what it says. It's in the home and it's in the community and it's nurturing the livelihood, the participating part in the community, so that people with disabilities can gain self-respect by a little bit of money that they can earn for themselves, whether it's through assistive technology or anything, support by an individual.

I cannot reinforce it enough, how important that source, that home and community-based waiver, the more it becomes flexible, the more we can utilize it, the more it can affect in a profound way in a positive, hopeful way and dreams can come true.

Now, I am disappointed with a lot of organizations up there, as far as assistive technology. I do need a lot of assistive technology support for

my child and I have all these ideas; I have all of these design ideas. And yet, I cannot get hold of the physical part that I need, the physical support that I need. And that's the only thing that's stopping me and my son from our dream. I don't want that to happen. My son is not going to be young too long. He's not going to be a child for too long. The waiting list is forever. I need those materials now. I need it to work for my son now. I need it to work for everybody now.

K. Rama Thanks, Ms. Burns.

Coordinator Our next comment comes from Rhonda Grossman, and please state your organization.

R. Grossman I'm a member of the Government Relations Committee of the Northeast Ohio Chapter of the National Multiple Sclerosis Society, NMSS. And my comments today are totally passionate, personal and general. I'm just so grateful to be both disabled at a time when so many positive things are beginning to happen, I mean, if I had to be disabled at all, for Americans; and I'm grateful to this administration, to the President for his executive order; for Olmstead, which is my personal passion. And I would like to talk to – is Mr. Leggett on line? Hello?

I would like to offer a wonderful educational tool for everybody to understand the mission of Olmstead right now and implementation of it. And through our own chapter of the NMSS, we have available a wonderful, a passionate portrayal of three individuals who are living in the community and exercising their rights as Americans by the benefit of having personal assistance services at home. Our videotape is eight and a half minutes; it's called A Vote For Independence. It's to educate all Americans how important the implementation of this executive order is. And if we can bring it and show it to anybody or send it to you, we'd really like to.

I personally was a geriatric advocate professionally as a clinical social worker for 25 years; then I got into advocating for neurology patients. And then eleven years ago, I was I guess lucky enough to get multiple sclerosis. Now because I'm one of the non-developmentally disabled but mobility-impaired, sometimes I'm visibly impaired, I'm affected, too. And so this passionate fight right now is for me, as well as for everybody.

So if there's anything we can do to just bring the implementation of Olmstead and show the country that it's the right thing to do, the legal thing to do, and we could save money doing it, I'd like to help.

K. Rama Ms. Grossman, would you be willing to share your phone number, so people who would be interested in that tape might be able to obtain it?

R. Grossman Ah – sure.

T. Hamilton You don't need to do that over the phone here; in fact – this is Thomas Hamilton, I'm the Director of the Disabled and Elderly Help Programs Group. There's a number of individuals that we'd appreciate or invite to just call my secretary and leave their contact information, if they're willing. We have not wanted to engage in any kind of dialog in this conference call, because we wanted to make sure there was a maximum amount of time for people to make comments.

But there are some people who made comments that we'd like to understand the issues a little bit better. And strictly invitational and optional, but if Wally Dutcher, James Secor, Ginger Ratcliff, Nicholas Dupree and yourself, Rhonda Grossman, could call my secretary and just leave contact information, her number is 410-786-6763, and just leave contact information.

R. Grossman Thank you.

Coordinator Our next comment comes from Robin Simms, and please state your organization.

R. Simms I am a parent of two children with developmental disabilities. My comments are, my son Benny turned 15 yesterday. He has fragile-X syndrome; he is mentally retarded. And as a result, he can't attend to his personal hygiene, understand danger, cut with a knife, tie his shoes, or fully read and write. He can only be left alone for the briefest of time. When he reaches adulthood, he can benefit from life in the community, but in a strictly supervised environment. My husband and I will be a part of his life as long as we live and we will protect him.

My daughter just turned 18 this past May, and she was a beautiful blond-haired, blue-eyed baby, bright and verbal and precocious until after her second birthday when she regressed, and by age five was totally non-verbal. She is now diagnosed with Landau-Cluffner syndrome, which is a regressive form of autism. By the age of 12, she was violent and aggressive towards herself and others. Our home was a shattered mess, looked like a war zone.

Four years ago she was placed at an ICFMR in New Jersey. While at first

I saw this as a tremendous defeat, I soon realized that the placement was exactly what she needed to survive and live with dignity and peace. We see her on a weekly basis. We take her into the community where she expresses her wants and wishes through gestures and grunts. As long as the word “no” is not used by us, all goes well.

By the end of each day, though, she is more than willing to return to her cottage, where life there has a rhythm, order and a routine that fits her needs to a T. Let us not forget that our ICFMR’s serve a population that cannot benefit from any other environment. Let us not for a moment think that there are no longer children out there who need this placement, and even though they only represent a fraction of the entire population of the development disabled, they are our most vulnerable.

The staff at these facilities across the country should be used as trainers, and the facilities themselves should be used as centers of excellence. The Voice of the Retarded is a National organization of family members whose children live in ICFMR’s across the country, and they have very strong evidence that their placement is most appropriate for their children. These children and adults cannot be served in the community without sacrificing a great deal of resources that could go to help many more who

can derive greater benefit from it. And until we recognize that people are entitled to the full range of choices and we keep the quality of all the choices at a high level, we're not able to assist those individuals with mental retardation, developmental disabilities and severe physical limitations to reach their full potential and to live happy lives.

I want to say in closing that it's not what I wanted for my child – sorry, I wasn't going to do that – I wanted to be sending her off to college. I get notices every day from the United States Army, from credit cards. I wanted to dance at her wedding and I wanted to be a grandmother. Instead, I need to fight to give her what she needs, let her live her life in peace and dignity and make sure that all the options for both my children are available always. Thank you. I wasn't supposed to cry.

K. Rama	Ms. Simms, that's okay. We really appreciate you sharing your personal experiences with us; I know it can be very hard. Thank you.
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R. Simms	Thank you very much.
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Coordinator	We have another comment from Wally Dutcher, and please state your organization.
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W. Dutcher Yes, thank you, National Alliance for the Disabled, but the comment, I just wanted to make a request to repeat – I didn't get the individual's name and the telephone number to where we can – who wanted to get contact information.

K. Rama Okay, so you're saying the tape from the Multiple Sclerosis Society?

T. Hamilton You're looking for the number that I cited earlier. It is 410-786-6763. That's 410-786-6763.

K. Rama Any other commenters, Theresa?

Coordinator We have another comment from Grace Burns.

G. Burns I just wanted to reinforce that – about this choice, that the parent and family who choose to keep their child at home with severe multiple disabilities, who are supposed to be in an institution somewhere, if they choose to care for the child and they have 24-hour skilled care, that they should be able to live at home and be supported there financially. So that they do not have to make the choice of having to put them in an institution because that's the only way to be. That's the most important message I

wanted to convey about the home and community-based waiver, is that for families that have to have them in an institution, not to have all the money go to an institution, but for families to choose to keep them at home.

And the needs of my child is just as severe. He drools, he doesn't sit up, his trunk is very placid; he's very heavy to lift up. He needs total support. He needs a lot of positioning and everything medically goes wrong with him because that's the way it is. When the brain doesn't function, he doesn't have a BM on his own, we have to induce his BM constantly with the suppositories or enemas. I mean, the life of having a child with disabilities in the home can be very challenging. So we're just asking that this is skilled care we're providing, but we choose to. And just because we choose to love our child, it should not be that because it's emotional that we love our child that that means that they should not get the funding at home. I don't think that that's fair.

K. Rama Okay, Grace, thank you very much. We just want to be sure to give everybody equal opportunity, so thanks again.

T. Hamilton We have time for about two more questions, if anyone – or, not questions, but comments. We've got the questions.

Coordinator	We have a comment from Richard Spomer, and please state your organization.
R. Spomer	I am an advocate for the disabled population. Hello?
K. Rama	Yes. Mr. Spomer?
R. Spomer	Spomer.
K. Rama	Palmer?
R. Spomer	Spomer.
K. Rama	Spomer. Thank you.
R. Spomer	Yes. Think of Homer Simpson, but it's Spomer.
K. Rama	Okay. Spomer. I got it now.
R. Spomer	Thank you. Now, what my comments are for the disabled population, they have been the last rung on the ladder, way below race, ethnicity and

that needs to change. I have gone through Partners in Policymaking with in the Commonwealth of Virginia. And let me tell you, Virginia is several hundred years behind times to all those out there. And there are other issues in relation to housing for individuals with disabilities, even with the Section 8 voucher system, pretty inadequate. And that's federal, through the HUD programs and Home of Your Own Alliance. Home of Your Own Alliance, it would enable many individuals to own their own homes, and then they have a choice of who comes in to be their service provider.

And then we have the increase – well, President Bush would have to put a bill forth or make an executive order, so the service providers even family members would be paid for providing service to family members in the home of their own. Now, how do we bring this about? The greatest good for the greatest number, and the more people that can join on this sort of task force, it would benefit many in Virginia and elsewhere. So it becomes a community-based service provision rather than a systematic one, such as a group home setting or a residential facility as such. Because that's where a lot of money goes the way it is right now, even though families want that to change. Thank you very much for giving me the opportunity to share my two cents.

T. Hamilton Thank you very much, Mr. Spomer. We have time for one more comment, from someone who hasn't had the opportunity to speak yet.

Coordinator Marilyn King, you may make your comment, and please state your organization.

M. King I'm a family members of two individuals with developmental disabilities and Parkinson's Disease, physical disability. I just wanted to say that when we talk about community programs, the word "community" kind of conjures up this vision of a support system in place with people surrounding, meeting one another's needs and interacting and so forth and years we've looked at the problems in this state. We've seen that's not altogether there and it's really not nurtured very much. And it's really difficult to find the pay for people to really care.

And yet we look to those who would ordinarily care, like the churches and people in civic groups, and it seems that there is an attitude that the government must have an agency that does this, and they turn away. So it seems to reason that if the government could invest some money, even just reimbursing expenses or some kind of fund with family members who could then go out and educate the community around them and put in

place those supports, then there would be less demand on the government programs.

There are a lot of different needs that people with disabilities have, and some of those are a lot of little things that could be met by individuals, neighbors, friends, people in church and so forth, if they knew how or if they were motivated to do that. So it just stands to reason that it would be nice if someone would take a look at offering support to the families who want to educate and nurture community support.

T. Hamilton

Thank you very much. We are approaching the end of our allotted time to receive comments, but I want to remind you that we have other avenues to do that and Robinsue Frohboese mentioned those at the beginning of the hour. I would particularly call your attention to the invitation for written comments that we will be accepting through August 27th; and just make the observation that if there is a particular barrier or solution to that barrier that you are aware of, then that is very much invited.

But also as has been the case here today, if you simply wish to share an important life experience in which you have encountered barriers, or again, as has happened many times today, it's also very useful to know

your particular vision of how you think things ought to be and how they might be changed.

So in terms of – anyone can submit those written comments; they don't have to be citations of law or rules or regulations when you're pointing at barriers. But in many cases, those individual life experience descriptions are even more poignant and persuasive.

Secondly of course, we have that National Listening Conference on September 5th. We designed this particular teleconference, particularly for individuals who may not have the opportunity to travel to a listening session or be able to take time to send in written comments, so I want to conclude with simply a few words of thanks.

First, thanks to all of you who have been commenting, who have taken time out of your day to share important thoughts with us. We are taking all of those comments down. We are transcribing them for our use in preparing the final report to the President, and in trying to look at the barriers and fashion appropriate solutions. Thanks to all of the officials from the various federal agencies who have taken time out of their schedules to sit and refrain from speaking, as we've all tried to do, so that

we could do a good job of listening to the comments and take in that information.

Then also, thanks to Kathy Rama and Gina Clemens in particular, as well as the Home and Community-Based Waiver Resource Network that helped organize this opportunity for us to engage in some real thinking about the barriers and possible solutions that would support the Americans With Disabilities Act. Again, we encourage your written comments and also encourage your getting the word out about those additional opportunities. We appreciate that not everyone is a regular reader of the Federal Register to be aware of opportunities; so whatever you can do to convey the word to people, we would very much appreciate it.

Kathy Rama has a little more information to share with you before we conclude, and then I would ask, if Robinsue is still on the phone call or anyone else at OCR, if there are any parting remarks that you would like to make as well. First, Kathy?

K. Rama

Thank you. I just had one piece of new information that might be of interest to you, and that is that there is a Webcast, a video Webcast of certain parts of a conference that we held in Washington, DC in May. It

was titled “New Opportunities for Community Living, a Systems Change Conference.” And it was targeted toward states, consumers, providers and advocates to share information and ideas on home and community-based systems change initiatives.

The Webcast highlights two distinct tracks from the conference: Choice and Responsible is track No. 1, and Whole Person Support Systems is the second track; as well as the plenary sessions are also available on the Webcast. To view this video Webcast, the Website is www.hcfa.gov/Medicaid/systemschange – and then I’m not quite sure, so I’m going to say this, and you can try it with and without – slash, default, dot, htm. Some people tell me it doesn’t work when you put that on, but it is there.

Right now, there’s a small problem in that if you do not have Real Player, it won’t play. Real Player is some software that you can install for free and we’re going to have that set up, so that you can do that right from the Web site. But I just wanted to let you know it’s there, and hope that you can take a look at that.

R. Frohboese Thank you, Kathy and Thomas. This is Robinsue Frohboese from the Office for Civil Rights, still here in Washington, along with my colleagues from the Department of Justice, the Social Security Administration and the Office of Personnel Management. I would also like to add my thanks, along with Thomas, both to all of the federal agency staff who organized this, and to our federal partners in this effort.

I have now worked for the federal government for about 20 years, and I really think that this has been an unprecedented effort in terms of the kind of interagency collaboration and coordination. I think as many of you who called in and shared your thoughts recognize that, it's really important for the federal government to work together to accomplish this very important goal. So we are pleased that this has presented an opportunity to have that kind of coordination. We very much appreciate the really important thoughts and heartfelt stories that all of you have shared with us, and we have listened very intently to your comments.

We look forward to hearing additional comments from you and as Thomas also shared, that we want to hear your real-life experiences. We want to understand the barriers, and we want to come up with good solutions.

Thank you very much, and please look for the report that we will be presenting to the President on October 16th.

Anything else from CMS?

T. Hamilton That's it. Thank you very much, everyone.

R. Forbosi Bye bye.

T. Hamilton Bye now.

K. Rama Thank you.