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# Opportunities for Long-Term Services and Supports in Health Reform
# Kaiser Family Foundation
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**DIANE ROWLAND:** Good morning and welcome to this morning's briefing on opportunities for long-term services and supports in the health reform law and under the existing program that we have called Medicaid, which provides a great deal of the long-term care services and supports in this country today. I'm Diane Rowland, the Executive Vice President of the Kaiser Family Foundation as well as the Executive Director of the Kaiser Commission on Medicaid and the Uninsured.

I know you're looking at our large panel here this morning and thinking that really doesn't look like Secretary Sebelius [Laughter]. She has many, many facets to her but she's not really five other people but she will be, due to a scheduling change, showing up a little later in our program instead of as our opening speaker.

So we expect to see her after the discussion our panel will have first. So it's just a little reverse order but you will still get to have Secretary Sebelius with you. This time she'll give closing instead of opening remarks.

I'm very pleased that we can start with this robust discussion of the way in which long-term care services and supports are being provided today covering a range of services that are those needed by people who need to live independently

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in the community with services such as home health and personal care as well as services provided in the institutional setting.

As you know, the Medicaid program is a substantial way in which we, today, finance long-term care spending in accounts for over 40-percent of overall long-term care spending and over three million people rely on Medicaid for a range of physical and mental health needs that require long-term care services and supports.

It is a program in which the demand for community care has been growing and the efforts under Olmstead and other provisions to try and rebalance the way in which Medicaid services are provided from the institutional settings to the community-based settings has been ongoing over the last two decades but really is becoming more and more a part of the way in which we deliver services through Medicaid.

The Affordable Care Act contains several new provisions that expand the way in which Medicaid services can be utilized in the community the Money Follows the Person program is extended through 2016.

There are community choice options to provide statewide home and community-based attendant supports and services to individuals with incomes up to around 300-percent of the supplement or security income level are a little over 250-percent of poverty.

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It creates the state balancing incentive program that provides enhanced federal assistance to states to increase the proportion of Medicaid long-term care dollars going to home and community-based services. It makes improvements to the state plan options.

All of these issues will help to provide a better way for Medicaid to meet the needs of those requiring home and community-based services. It's coupled with a new program, the Class Act, the Community Living Assistance Services and Supports Act that is designed to expand options for working adults who become functionally disabled and require long-term care.

These adults who meet the eligibility criteria will receive a cash benefit that can be used to purchase non-medical services and supports and who will help, we hope, to alleviate the need for many to spend down to the income levels that would provide them with assistance under the Medicaid program.

So there's a lot going on in home and community-based services. There's a lot of future endeavors that are yet to be undertaken to primarily put long-term care services supports available and within reach of more and more of the public that needs them.

However today, the state budget constraints are overshadowing some of the progress that has been made in this movement. What we wanted to highlight today is really the

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progress that is going on, what the state is of the states in terms of their implementation, of home and community-based services under Medicaid, and to then be able to look forward to what some of the provisions in the Affordable Care Act may mean for further enhancing the way in which these services can be provided.

We're going to start our discussion today with a presentation by two of our reports that have just come out. The first is on Medicaid home and community-based services programs. We're going to have an update on that report. Charlene Harrington and her team at the University of California, San Francisco have put together annually for us a survey of what states are doing with their home and community-based services and Jhamirah Howard, a policy analyst for the Kaiser Commission on Medicaid and the Uninsured is going to share those findings with us today.

We're then going to follow with a discussion about the Money Follows the Person rebalancing demonstration with a snapshot and some discussion of the Ohio program that has been reviewed and Molly O'Malley Watts, formerly with the Kaiser Commission and now a consultant, is going to present that study.

Following our two presentations, as we always like to do, we want to give you multiple perspectives on what's going on, on the ground on what some of the challenges are and on how

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it's being put together. We're delighted today to have Barbara Edwards, the Director of Disabled and Elderly Health Programs Group at the Center for Medicaid, CHIP, and Survey and Certification and the Centers for Medicaid and Medicare Services, I like to change it around, to be with us today to share some of what the federal government is engaging in and putting these activities together.

John McCarthy, the Medicaid Director for Ohio Health Plans and the Ohio Department of Job and Family Services, is also with us having just come from the District of Columbia, so he shares a new adventure in Ohio and an old adventure in the District of Columbia on Medicaid reform.

Then Mercedes Witowski, the Associate Director of Community Access Unlimited, will provide some of the more beneficiary and provider and community-oriented perspectives. So without further adieu, I'm going to start with Jhamirah to update us on home and community-based service programs through Medicaid and then we'll move through the panel and the discussion and then be joined by the Secretary. So Jhamirah?

**JHAMIRAH HOWARD:** Thank you Diane. Today, I'll be presenting the findings from our recent study on Medicaid home and community-based service programs. We've looked at trends in Medicaid home and community-based service programs over the past nine years. To start, I'd like to provide just an

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overview of the current policy landscape surrounding Medicaid home and community-based services.

Nearly every state is facing record budget deficits right now and these are expected to persist well into fiscal year 2012. Additionally, to receive services under Medicaid home and community-based service waivers, people must often meet institutional levels of need but there are mounting pressures to address this institutional bias.

There's consumer preference especially among the disabled population. Consumers are really pressing for increased availability of home and community-based service options. In short, people do not want to be in institutions if they don't have to be and if they can be served in the community.

There are also legal pressures. The Olmstead decision and the Americans with Disabilities Act both send strong signals that there need to be increased options for home and community-based services for those who do not wish to be in institutions and can be served in the community. There have been several federal policies over the past several years as well to promote home and community-based services.

The Money Follows the Person program and the new freedom initiative are both examples of these. The Patient Protection and Affordable Care Act builds on many of these

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efforts in many ways and provides numerous incentives to promote more home and community-based services.

For our study, we looked at the three main Medicaid home and community-based service programs, HCBS waivers, the personal care optional benefit, and the home health benefit.

Our aims were to look at trends in participation and expenditures for these programs, to look at state policies within their Medicaid home and community-based service programs, and to track state efforts at controlling costs. To do that, we looked at CMS Form 372 reports for HCBS waivers. We surveyed the personal care optional benefit and we also did a survey of the home health benefit.

Just to provide you with a little background on what these three programs are, HCBS waivers are optional and enable states to provide a range of home and community-based services. To be eligible, individuals must be nursing home-eligible. States have the ability to limit the number of slots in the geography and expenditures within their HCBS waivers and can establish waiting lists. The financial and medical eligibility for waivers does vary across the states.

The personal care optional benefit is actively available in 32 states right now. There's a requirement that when states offer that benefit, it must be statewide and available to Medicaid categorically eligible groups. The home health benefit is a somewhat more limited benefit but it is

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mandatory in all states for all those eligible for Medicaid institutional care.

Now to the findings. In 2007, there were 2.8 million participants in Medicaid home and community-based service programs with the largest share being in HCBS waivers, 42-percent. The remainder were split evenly between the home health and personal care benefits.

On the expenditure side, nearly $42 billion in expenditures went to Medicaid home and community-based services in 2007 with the vast majority of those, two-thirds, going to HCBS waivers followed by personal care and a much smaller share towards the home health benefit.

Since 1999, there has been growth in the number of participants in Medicaid home and community-based service programs though between 2005 and 2007, participant growth was relatively flat.

There's wide variation across the states in number of participants in Medicaid home and community-based service programs though as you might expect, in states with the largest populations, there tends to be the largest amount of need. So states such as Texas and California and Florida among others have over 100,000 participants in their Medicaid home and community-based service programs.

Looking at expenditures, there's been steady growth in expenditures for Medicaid home and community-based service

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programs since 1999. Between 2005 and 2007, though participant growth was relatively flat, expenditures continued to grow at a relatively steady pace of nine to 10-percent per year.

The largest share of expenditures was always in the HCBS waivers. There's also wide variation across the states in the average expenditures per person served. but the majority of states were spending between $10,000 and $23,000 per person in 2007.

Now looking more closely at waivers because waivers are the largest share of Medicaid home and community-based service expenditures, we found that though 50-percent of participants in waivers were in the elderly or disabled categories, they represented only 21-percent of waiver expenditures whereas 40-percent of waiver participants were in the developmentally disabled category but represented nearly three-quarters of expenditures.

In addition to looking at trends in participation and expenditures, we also tracked state policies in their Medicaid home and community-based service programs including cost controls. Nearly every state was using some form of cost control in their HCBS programs.

We found that within HCBS waivers in 2009, the most prevalent form of cost control was waiting lists. Forty-nine-percent of HCBS waivers had waiting lists in 2009 with nearly a third of waivers establishing cost limits.

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When we looked at the state plan personal care optional benefit, 50-percent of the states offering the personal care optional benefit established hourly or service limits. We also looked at trends in consumer direction.

Consumer direction refers to policies that give consumers more control over their services. this may include giving consumers increased control over the hiring and firing of direct care workers or enabling consumers to hire family members as personal care workers.

Among HCBS waivers, over a third, 37-percent included some form of consumer direction. This was similar among the state plan personal care benefit that of states offering that, 38-percent included some form of consumer direction. Looking now at waiting lists, in 2009, there were approximately 1.3 million total waiver slots mostly for elderly and disabled and those in developmentally disabled categories.

When we look at the waiting list, we see that there were over 360,000 people on waiting lists with the lion's share being in the developmentally disabled and mental retardation categories with about 30-percent in elderly or disabled.

The number of people on waiting lists is not evenly distributed across states. There's several states with notable waiting lists. In Texas, there are nearly 130,000 people on eight waiting lists with an average wait time of 19 months. When we look at Oklahoma, which has a much smaller waiting list

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comparatively, nearly 15,000 people on three wait lists but there's an average wait tvtime of 62 months.

In conclusion, in 2007, there were 49 states offering 270 waivers. Thirty-four states had the personal care benefit but two were not actively enrolling participants, so effectively 32 states were offering the personal care benefit. Though Medicaid home and community-based services participant growth has been relatively flat over the past few years, the expenditures continue to grow steadily.

There's wide interstate variation in pending on home and community-based services. Lastly, long waiting lists for HCBS waiver programs persist in many states. So ultimately what this all tells us is that though we've made many strides in increasing the availability of Medicaid home and community-based services over the past decade, there's still much work to be done. Thank you.

**DIANE ROWLAND:** Thank you Jhamirah [Applause]. The full report with all the state by state tables and more data than we would let Jhamirah present in the time we gave her is contained n your packet. Now we're going to turn to Molly O'Malley Watts.

**MOLLY O'MALLEY WATTS:** Good morning everyone. It's a pleasure to be here today. As Diane said, my role on the panel is to present findings from the new Kaiser Money Follows the Person Survey. First I wanted to take a moment though to thank

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all the state MFP project directors for responding to our survey and also a special thanks to Barbara Lyons and Jhamirah Howard from the Kaiser staff for their help with the report.

So as most of you in this room know the Money Follows the Person rebalancing demonstration was first authorized by Congress as part of the Deficit Reduction Act of 2005 and then it was extended in health reform through 2016.

The Affordable Care Act made several changes to the program including broadening eligibility by reducing the institutional residency requirement to 90 days. It had previously been about six months and these do not count, I should note, days that are solely meant for Medicare rehabilitation. The ACA also expanded funding by about $2 billion.

The initial goals of the program were two-fold. One to reduce reliance on institutional services and two, to expand Medicaid home and community-based service options. The demonstration provides enhanced federal funding for up to one year to states in order to transition individuals living in institutions back to the community either to their homes, to an apartment or to a small group home. Thirty states are currently receiving funding and we've been told that another 14 states have expressed interest in using MFP funds in the year ahead.

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So real quickly about this survey, we conducted a survey with state MFP project directors this past summer. I should note that this is the second survey that Kaiser has done on Money Follows the Person. The first was a 2008 look at the program. So two years later, we went back to the states, asked them to provide a snapshot of transitions to date, key program services that are critical to helping transition. This year we've also asked about some per capita costs data.

We also asked states to identify some program challenges that related to housing, to community workforce supply, and also to the economic downturn. We received responses from 26 out of 30 states. So let's turn to the findings. Figure three, as you see here, shows that nearly 9,000 individuals have transitioned back to the community and another 4,000 transitions were currently in progress.

Among those MFP participants, as you can see, people were about equally divided across two different populations, those with physical disabilities and seniors. People with mental health issues are less likely to be candidates for transition because of their extensive health and long-term services and supports needs.

Compared to two years ago when Kaiser first conducted the survey, states have really made significant progress in transitioning people back to the community. Just two years ago

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when we conducted this survey, only 350 individuals had transitioned back to the community.

So states, at that point, were just getting their programs started, just getting them up and running and, as I said before, today 30 states including D.C. have operational programs but I should caution although states have made significant progress, they're still well off their initial transition goals, which were to transition 35,000 people back to the community.

We asked states about whether they had experienced delays in meeting their original transition goals and 20 states reported that they had and the biggest reasons why were due to a lack of affordable, accessible housing and a lack of community-based providers.

We also asked states to report on the number of reinstitutionalizations meaning any admission to a hospital to a nursing home or to an ICFMR regardless of how long the individual stays. States told us that only 300 people have been reinstitutionalized. That's a relatively small number. It represents about four-percent of all transitions to date. Of those MFP participants who have been reinstitutionalized, about half have been seniors.

In terms of services and costs, states told us that they offer a wide range of comprehensive services to help facilitate transition. These include services such as expanded

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case management and also help with one-time housing expenses such as security deposits.

States also wanted to mention several key partnerships that they have underway with different state organizations that help to often enroll, identify potential MDP participants and obviously the housing authorities help to locate safe affordable housing.

In terms of cost, MFP participants, we're told, states are spending less on MFP participants than they would have spent for a Medicaid institutionalized beneficiary. When we asked them to compare the costs of serving an MFP participant with serving other Medicaid home and community-based beneficiaries, responses were somewhat mixed. Fifteen states said that they were either spending less or a comparable amount comparing the two home and community-based populations. Six states said they're actually spending more per MFP participant.

On average, I should note that states said that they were spending about $5,000 per MFP participant but I caution you with the knowledge that that would vary based upon population.

For example, states that have targeted a greater number of people with disabilities, you would expect them to have higher per capita costs simply because these people use more costly intensive services than say younger people with physical disabilities or seniors.

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In terms of challenges facing the program in the year ahead, housing will remain an obstacle to transition for many states but states had a plan and 19 of them said that they were partnering with local public housing authorities to increase housing vouchers. Six states said they specifically employ housing coordinators within their MFP staff to help with housing. Other states mentioned that they were increasing funding for things like home modifications to help facilitate transitions back to the community.

States also have concern about workforce supply meeting up with the demands, half the states told us that there was an inadequate supply of direct service workers in their state and some strategies that they were employing to tackle this problem include coming up with the direct care service registry website, increasing the use of consumer direction and individuals' abilities to hire family caregivers and also instituting some online training programs for direct service workers.

We also asked states about some of the challenges that they were facing regarding the economic situation and while most states said their MFP programs were not directly affected by Medicaid cutbacks, we do know that cuts to benefits or provider rates does have an impact on programs like MFP. Those types of cuts make it harder to offer a comprehensive array of

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services. They also make it harder to locate community-based providers.

As Diane mentioned, also in your packets today, we have a case study report of the Ohio MFP program known as Home Choice. This, I should note, is the first in a series of case studies that Kaiser plans to conduct on state MFP programs.

We looked a little more in depth into the structure of these programs and I won't go into too much detail about Ohio because I know John is here today to talk about Ohio but as you can see from this slide, Ohio has transitioned a significant number of individuals back to the community. It offers a wide range of services, includes partnerships with key community stakeholders and I even included some cost data, which again as you can see varies depending upon a target population.

Before I sum up, just to remind everyone how policy decisions impact real people, we wanted to share the story today of Gail. He is a 78-year old man who lives in Ohio who ended up in a nursing home following a stroke over three years ago. His stroke left him confined to a wheelchair.

He has limited right side mobility and also some slurred speech. Gail was satisfied, he told me, with his care in the nursing home but his wish was really to move back to the community surrounded by friends and family. He was fortunate enough to find out about the Money Follows the Person Program through his ex-wife Sue and a social worker at the nursing

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home. Within five months, he was able to transition back home where he now lives with his ex-wife Sue. She serves [Laughter], no comment, Sue does serve as his primary caretaker.

As you can see here, Medicaid provided a range of services that helped facilitate his transition and helped keep him home today. When I spoke to him about living at home, he teared up. He said the best part was his ability to travel. He looks forward to trips every summer to local campgrounds around the state of Ohio.

He goes camping with his ex-wife and [Laughter] and friends and family and as he said, in his own words, I feel better every day that I'm home. It's things through a program like Money Follows the Person that a person like Gail is able to be home getting the care he needs and surrounded by friends and family.

So looking ahead, I think that the new 90-day residency requirement will likely increase the number of transitions both because it expands the pool of people eligible for the program but also because it may make it easier to transition people because they may not have lost ties with their community residents during that period of time.

I also think the new opportunities available in health reform to expand home and community-based services could increase the number of transitions. We've seen more interest

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in states just taking up the Money Follows the Person demonstration over the past year.

That said, I still think that the lack of affordable and accessible housing will remain the toughest challenge for states and despite state fiscal problems, we know that the demand for home and community-based services will remain high and states will be continued to be pressed to expand these options for people with disabilities and seniors who wish to be served in the community. Thank you [Applause].

**DIANE ROWLAND:** Thank you Molly and thanks for some insights into marriage Medicaid [Laughter]. Now we're going to turn to our panel and Barbara Edwards is going to begin our discussion.

**BARBARA EDWARDS:** Thanks Diane. I really want to start with thanks to the Kaiser Commission on Medicaid and the Uninsured and the Kaiser Family Foundation for their ongoing commitment to providing timely and relevant information to all of us about the Medicaid program. It really is extremely beneficial.

On this topic especially, CMCS strongly believes that one of the areas of greatest opportunity for states to reshape health care delivery and financing to improve outcomes and to gain better value, reduced costs on a per-person basis is through reducing the reliance on high-cost institutional

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services for populations that can and prefer to be served in community settings.

Many states have already made significant progress on this and Money Follows the Person and the example in Ohio is a good example of that but it's also true that for many people and in many populations, we still see a very heavy reliance on institutional services for the provisional long-term services and supports for people who are elderly and people who are living with physical disabilities.

Sixty-six-percent of spending on long-term care is still for institutional services. That represents a tremendous opportunity for states in this time of great fiscal stress to find some improvement in services.

As Diane mentioned in her introduction, the Affordable Care Act provides states with additional opportunities and additional tools for continuing to make progress in terms of reforming long-term services and support systems to promote at the availability of community services. She mentioned some of the most important ones and I'm going to repeat that a little bit here because I think it's important.

Money Follows the Person, which has been featured here has been extended and expanded by the Affordable Care Act. As a result, states are going to have more years during which to take advantage of the enhanced FMAP that's available to help support individuals once they transitioned to community

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settings. There's also the opportunity to do an expansion of the number of states that have Money Follows the Person grants.

We are close to announcing a second round of grant recipients as a result of the Affordable Care Act expansion. We're very excited because we're going to have 43 or 44 states across this country who all have MFP grants. We think it provides a tremendous opportunity for MFP to be a real foundation for states as they think about their system transformation efforts.

I think MFP could be particularly helpful as we begin to think about how it works in conjunction with some of the other opportunities that are available under affordable care and available already under Medicaid.

Balancing Incentives program, which was mentioned earlier, is a new opportunity also with enhanced funding from the federal government for states that are able to make a commitment to making some significant infrastructure changes with regard to the use of functional assessments, no wrong door for folks who are looking for services, conflict-free case management, and some other framework that's been set out by Congress in the law.

We think, in conjunction with Money Follows the Person, there may be a real opportunity for states to make tremendous progress as they work to transition the shape of their system.

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There are improvements that were made in the Affordable Care Act to section 1915I.

I always think we ought to find a much better name for that section not terribly descriptive but this was an opportunity that was already in the law from the Deficit Reduction Act that gave states the option through using a state plan option to offer home and community-based services to individuals including to individuals who don't have to meet a level of care, an institutional level of care.

As a result of changes in the Affordable Care Act, there is now the ability of states to target those benefits through waiver of comparability. There's also a broadening of the benefits, the services that can be offered through a 1915I.

We think this is going to become a very important tool for states who are looking for new ways to approach the delivery of home-based services and community-based services for vulnerable populations. We have another new service available through the Affordable Care Act, the Community First Choice option, which again comes with enhanced federal funds. This is a permanent six-percent enhancement to the FMAP.

This is an opportunity for states to offer community attendant services and other home and community-based services again to individuals who don't have to meet an institutional level of care. It goes a long way towards equalizing the

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access to services between institutional and non-institutional services.

I don't want to fail to mention the health homes provision that's a part of the Affordable Care Act. It's not, per say, a long-term care service option but it's a critical new opportunity for states to offer better integration of care for individuals with multiple chronic conditions or who have a serious mental illness.

It stresses, through enhanced, again enhanced FMAP for states for the first eight quarters in the provision of health home services integration, coordination services, transition services, family support services, linkages to social as well as medical services with an emphasis on integrating physical, behavioral health, and long-term care services for individuals. We think it's a tremendously important opportunity to help reshape systems.

CMCS is committed to working with states to help them tailor these new opportunities and the existing opportunities in Medicaid to meet specific needs that states have. We are especially interested in helping states figure out how to leverage across these different opportunities to bring together comprehensive approaches to system transformation and to take full advantage where they can of enhanced FMAP while it's available and in some cases, it's available on an ongoing basis. That's the good news.

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We know that there is great concern among advocates and consumers and frankly among some states that the current fiscal crisis for states could result in disappointing or even devastating setbacks in the progress that states have made in terms of moving toward community-based services for individuals.

We have certainly already seen states that are filing to amend their programs, to hold back on services, to rethink the way those programs are being designed. Certainly for people who have been in the field of delivering community-based services, we are going to see an increased emphasis in the cost effectiveness of those services.

There's going to be more attention being paid to the rate of growth and to the value of the services that are being obtained for the dollars that are being spent but I think that this could also be a time of great opportunity.

There is still a very significant bias toward institutional services in many of the programs that states offer, frankly inherent in the Medicaid design itself. Congress has gone a long way through the Affordable Care Act to try to create better balance and to create new opportunities.

We think that with the added fiscal stress on states, this may be exactly when states will take a harder look at the current design of their systems and the fundamental unsustainability of a reliance on institutional services as the

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primary way in which long-term services and supports are delivered and that we may see an opportunity here for states to really fundamentally rethink and redesign their systems so that community care becomes the first choice. We stand ready to work with states in that effort and believe that we can help them find opportunities even in these difficult times. Thank you [Applause].

**DIANE ROWLAND:** Thank you. Now John we'll turn to you for the state perspective.

**JOHN MCCARTHY:** Thank you Diane. Thank you for having us, having me here and also the fact that I'm representing all the states or as much as I possibly can being two weeks into the job in Ohio [Laughter].

However I did come from D.C. I was the Medicaid director there for two years. So I bring a very different perspective because I bring a perspective from a small state and now a large state. I can tell you this, the perspective that Barbara just talked about the fiscal crisis that's all encompassing right now. Just to give you all kind of an idea where Medicaid directors like me are, many, many Medicaid directors right now are new just taking on the job having had many gubernatorial changeovers.

Right now, the state of Ohio is facing an $8 billion shortfall. The Medicaid program itself just in JFS, Department of Job and Family Services, has about a $12 billion budget

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total. If you add up all Medicaid in the state, it's about $18 billion. Just the portion in the Department of Job and Family Services, if you're looking at the local funds, looking at July 1st, we're facing a $3.2 billion increase in local funds for our program. That's a 49-percent increase in our local funds. So that's the type of difficulty that we're looking at.

On top of that because of the gubernatorial change in Ohio, between when the Governor took office and March 15th, we have to propose a brand new budget. So we have, in all of about four weeks, to do that to get something over to the legislature.

So while there's many, many opportunities out there, which we really, really are grateful for, to be able to think through all those different things and put them out there and get them into a budget process is very, very difficult especially when you have budget officers coming to you and saying John, we need to know the exact amount that you're going to save on this program, where it is, how much is it?

On top of all that, while I love CMS and the great changes that they've made and some of this is not their fault at all, I will not blame CMS for this, the process to get a change made takes time.

Just so you get an understanding, when you submit a state plan amendment, CMS has 90 days to review. Yes, you can

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go retroactive but believe me, there's many times it's difficult to go retroactive.

So they have three months to just review it. Most states, even if we want to submit that state plan amendment, we have to wait until our budget's approved so we even know what to submit to CMS. You can't just submit something like well here you go, here's the draft of what we're going to do and please approve that. So those are the kind of the difficulties you're looking at.

So for the next fiscal year, many of the opportunities that we're looking at the state can't really implement those until January. So you're only going to see some maybe six months of savings on some of those initiatives. So those are the budget crises we're facing right now and how do we deal with it? On the flipside, as Barbara said, these are opportunities.

It has, with my staff, given us the chance to really think outside of the box, really come up with new ideas and looking at different ways to deliver services, which we are doing. We've submitted a proposal to the Center for Medicare and Medicaid Innovation of looking at how services to duals are going to be possibly changed, services delivered to them will be possibly changed.

One of the things that comes up especially around home and community-based services and the importance of MFP, I know

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you won't be able to see this in the back but in Ohio, this is our chart of our waivers. Eight different home and community-based waivers we have.

I showed this to the Governor the other day and he was like what? I said exactly [Laughter]. They're all great waivers. Some of them I actually helped create back when I was a consultant. However, that's also led to the problem of people moving into the institution instead of a home and community-based service because at times, it becomes so complicated just on the elderly and persons with physical disabilities side, we have five separate waivers. On the DD side, we have three separate waivers.

Myself, in trying to get services for my father-in-law just over the last few months, I was the Medicaid director in D.C. okay and I couldn't figure it out [Laughter]. Now this was not in D.C. so it wasn't my own program but it's difficult. It's difficult to do and it's hard to find that right person that understands it.

So even in Ohio when we're looking at this, five different waivers, how do you choose which one? How do you know which is the right service? Why is it that we have five different waivers? Some of the reasons we have five different waivers were really important years ago when they were created. Now I'm not sure.

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In the District, we actually only had two waivers. We had one waiver to serve the GD population and one waiver to serve the elderly and persons with physical disabilities population. So that's one of the things that we're looking at. How do we do this? How much administrative burden do we have in the program or what are we paying for three or four times over?

Discharge planning, that's the other big area that we're taking on. People coming out of hospitals, why are they not being discharged back home? Why are they going to nursing homes? One of the things that's come up with Money Follows the Person, which we're really concerned with is the fact that for the dual population, those first 09 to 100 days for the dual population of a person going from a hospital into a nursing home, those days don't count towards MFP. You then have another 90 days that you stay in the nursing home before Money Follows the Person can step in.

Every day in the nursing home is just that much harder to get the person out of the nursing home and there's all different situations, all different family situations. The case that we had here was a perfect example right? You're looking at that individual moving back in with his ex-wife and lucky enough to have that opportunity to do that.

Where I want to finish is talking about our MFP program, which in Ohio, which I'm very, very proud of, I met

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with the staff this week and they are an amazing, amazing group of people and I think one of the things, the difference between what I saw in the District and Ohio is in the District, we probably didn't start out in the right area. We gave the program to somebody who is already doing five other things.

In Ohio, they took one of the rising stars in the program and said you know what, you work on this. You develop this. It's Erica Robbins. She did a great job and she got approval for 13 FT, full time equivalents, 13 positions. She hired 11 and they're doing a great job.

They're out there. They've gotten awards working with housing authorities around the Cleveland area and getting people out and integrating the sister agencies into doing this. So there's really a focus on this.

They've also done a great job with, as the enhanced FMAP comes in, turning that around and reinvesting it back into the program and have some really great programs that are bringing up. One of them is workforce development that they're working on that Ohio, just like many other states, there's a lack of individuals that provide these services. So how do you get that moving?

Talking to Erica, just like other states, we had the slow start just like a lot of people for various reasons, often administrative and my other favorite because I'm implementing a new claims payment system right now, IT system changes. Until

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you get into Medicaid, you would never realize how big of a pain your IT system is and in getting changes to those things but once those got in and running, they've really taken off and are really moving forward.

So I think in Ohio what we're looking at is continuing moving towards more home and community-based services. I'm concerned though from a Medicaid director's perspective of as we've moved through the system, you first obviously start moving people who are, let's just say, the easier individuals to move because should they even be in a nursing home? Probably not. You start moving them out.

Now we're getting to, what I'm hearing, is a little bit more difficult cases and you really start running into this issue with your home and community-based waivers and budget neutrality around the cost associated with the services for those individuals especially individuals who are going to need one-to-one services.

You start running, if they live alone and they need one-to-one services, that is often more expensive than an institutional setting. So how do we balance some of those things and work on other community supports? So I'll stop right there but just have to say once again, give a plug to my staff [inaudible] really done a great job [Applause].

**DIANE ROWLAND:** Thank you John and I'm glad you're in Ohio to keep that program going. Mercedes?

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**MERCEDES WITOWSKI:** Okay, thank you. Thank you to the Kaiser Commission for this unique opportunity for a provider from New Jersey to be here before you today. A little tidbit about community access, we are a social service non-profit agency in Elizabeth, New Jersey and we provide supports to about 3,500 people with intellectual, physical, and developmental disabilities in our great state.

Our agency was founded by an Executive Director in 1979, our Executive Director, Sydney Blanchard, and he had the goal and made the decision that it was right to move people from developmental centers into the community. Today we continue to do that utilizing a self-directed approach to support people.

I also have to share with you that I'm the proud parent of two children. I have a 12-year old son Anthony, plug for Anthony, and I also have a daughter, Tina, she's 21 now but at 16-and-a-half, she suffered a massive stroke. No one knew that it was coming and it certainly has changed our lives.

It's been her determination to succeed in her recovery that really gives me the motivation to continue the work that I started 28 years ago at Community Access. It also tells us how truly fragile our lives are and how at a drop of a dime, they can change. So thank you Tina.

Tina gets supports that made it possible for me to come here today. She gets supports at home utilizing the self-

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directed service model. She gets supports at school with an aide and an assistant and without those supports, I would not be able to work full time and probably not be able to support my family.

I'm grateful that the American Care Acts Class program will be available for Americans including Tina and other families of children with disabilities who can work. It's obviously a long overdue national mechanism for us to plan for the future in the likely event that we all too may some day need those long-term care services.

The ACA's provision for expanding and extending children on our insurance through 26 and eliminating pre-existing conditions, I know, has helped tremendously a number of families and benefited those in New Jersey. When I started my career at Community Access, I realized very soon on that people with disabilities have the same dreams and strive for the same goals as all of us. With Money Follows the Person and its extension through 2016, Community Access and many providers in New Jersey and across the country have helped many people realize that dream.

Last summer on June 19th, a 52-year-old woman by the name of Merda made the decision to leave Woodbridge Developmental Center. She didn't have an ex-husband to go back to [Laughter] but she did choose another individual, her name was Elda who lived in a different institution in New Jersey and

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with the help of a support coordinator, she was able to choose a home, choose her roommates, choose her staff in an interviewing process that she conducts, and when we first met Merda in the institution, she was in a wheelchair and a walker.

Today I can tell you that Merda steps lively into her day. She bounces down the hall. She has a job as an advocate, a consumer advocate, helping other people problem solve and come to decisions around their critical needs in the community.

Unfortunately not too many Merdas have been able to leave our developmental centers in New Jersey. There are about 10,000 people additionally on the waiting list in New Jersey. We didn't make the charts here but families are waiting a very long time. With no end in sight, most families are just hoping that before they die, they will have the opportunity to see their sons and daughters placed.

With a national focus on home and community-based services, we must have the provider capacity in order to assist in meeting the needs of people in the community. In New Jersey, many providers are struggling, some providers, even closing their doors. The access to decent, affordable housing is certainly the number one barrier that we see.

When it costs 133-percent of an SSI check for a one-bedroom apartment, figure out the math on that one. It just doesn't happen. So the HUD and HHS' joint announcements of

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5,000 rental assistant vouchers last year and 1,000 additional vouchers last month is certainly a welcomed opportunity.

Community access, in our work, we work with the public housing authorities. We work with the New Jersey housing coordinator and we have also utilized the low-income housing tax credit and developed over 200 units of housing in Union County, our county in Elizabeth, New Jersey.

We work in partner with numerous state and local level sources in order to build decent and affordable housing for people with disabilities with an emphasis on people with physical disabilities because none of us know at what point in our lives accessible housing isn't a necessary means.

Both the class program and the new Medicaid Community First State Option provide a new focus nationally with opportunities and even fiscal financial supports to assess and hopefully address long-term workforce issues. My own national organization, Anchor, has been engaged for years in a national campaign to address the critical shortage now and in the future direct support workforce. CMS has worked with Anchor. However, we need greater national and state focus on this challenge to provide a workforce to care for people with disabilities well into the future.

New Jersey providers are also struggling with worker wages. Community providers, on average, pay 30-percent less than what the state pays for a direct support workforce. The

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new Affordable Care Act provisions discussed by Barb Edwards to help states reconfigure their delivery of long-term supports are now the focus of advocates in New Jersey.

We're beginning to discuss new Medicaid state options to provide providers the demand to meet the growing needs of people who want to live and work in the community. Our job will be working with our states even in these tough economic times to see that reinvesting federal and state expenditures on community services will help now and hopefully the future of our Medicaid budgets.

While a challenge, providers believe that the new opportunities we must take and we must look at now, the Community First Choice State Option with a permanent six-percent enhanced Medicaid match to personal assistants to help individuals with disabilities will help community access and other New Jersey providers meet the challenge especially with the additional housing vouchers available.

I also hope that New Jersey will take advantage of the Balancing Incentives program not only to help us refocus on expanding home and community-based services but also in redesigning our system regardless of the various funding sources.

I've got to say that it's an exciting point in my career and for all of us to know that we're focused on health care. We're focused on the needs of people with disabilities

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living in the community and helping the most disadvantaged of our population. Thank you for the opportunity to be here [Applause].

**DIANE ROWLAND:** Since we're waiting the arrival of the Secretary, I thought we would take this opportunity to give you a chance to ask a few questions of our panel if you have any. Would you please raise your hand so we can get a mic to you and identify yourself and we'll, of course, cut you off as soon as the Secretary arrives [Laughter]. Thanks, in the front.

**TOMMY HOUSNER:** Hi, Tommy Housner, formerly with CMS. I'm now under contract with Senate for Budget and Policy Priorities. We're looking at the implications of various Medicaid provisions in the Affordable Care Act for beneficiaries. I'm interested in panel thoughts particularly on dual eligibles, what kinds of things can CMS do to try to integrate programs, Medicare and Medicaid programs for the dual eligibles, interested in audience thoughts subsequently.

**DIANE ROWLAND:** Okay you want to start Barb?

**BARBARA EDWARDS:** I'll start. I will try to channel my colleague Melanie Bella who was the head of the new Federal Office of Coordinated Health Care. We have a tremendous resource in this new office that is focused every day and frankly knowing Melanie, 24/7, on the issue of finding opportunities to better integrate the care and rationalize, so we're never supposed to use that word right, to make sense of

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the services for individuals who have both Medicare and Medicaid coverage who, I will just say for anyone here who doesn't know, represent about 40-percent of the cost of the Medicaid program at the state level on average and are in fact a very expensive population within Medicare as well.

We are working very hard to identify opportunities within federal policy to make the systems work together more effectively. Melanie has a very large hit list of issues that we've identified and that she's heard from states where we know there are challenges between the two programs operationally and we're going to begin systematically working through that.

But there are also opportunities, in fact states have been given an opportunity to seek grant funds, contracts with Innovation Center funding through the new Federal Office of Coordinated Health Care to do some planning, to create and bring up dual eligible strategies where states would become engaged in trying to integrate services across Medicare and Medicaid. We know that there are a couple of big barriers that have made it difficult for states to play that role before.

One is a lack of access to real-time information particularly on the Medicare side so that they can have the kind of information that is needed to support integration of care and care management across both funding streams and Melanie and her team are working very hard to overcome that problem and think that we will be able to, early this year,

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provide states with the kind of data that they've been asking for. There's a lot of effort going into that and we're keeping our fingers crossed on that one.

The second is that states have said one of the real challenges is, is that when we look at this just sort of from an actuarial perspective, the things that we can do through Medicaid to provide better access and better care coordination for individuals that would create a better utilization of services and better outcomes typically will cost Medicaid money to do the care management and the upfront interventions and saves Medicare money in reduced hospital utilization and reduced emergency room utilization and so forth.

And that savings for states take a little bit longer to accumulate because it has to do more with changing the direction of long-term care or even reducing the need for long-term care over time. That has been a barrier for states becoming aggressive. Stepping up on this aggressively is that it takes an investment and they don't see a return quickly on their investment.

So part of what the Office of Coordinated Health Care is working on is finding ways that we might be able to offer some shared savings to states in terms of realizing some of the benefit of Medicare savings. There are challenges around that but there are people working very hard toward that. I think that would be the intention of the contracts that will be

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issued soon to states to help them develop ideas that would lead to a foundation for shared savings. So we're hoping that will help move it forward.

**DIANE ROWLAND:** Thank you. Another question? Josh over here in the red tie, forward.

**JOSH WEINER:** Hi, Josh Weiner, RTI International. I was struck by the numbers on Money Follows the Person basically 9,000 over two years. Over the last two years have probably been a million-and-a-half people in nursing homes not counting people in ICF IDs. So what is it going to take, I mean is it going to be possible to get this up to real numbers that are meaningful or is this really going to be a program that's great for the individuals that are transitioned but it's going to be a very small part of the picture?

**BARBARA EDWARDS:** I'll start again. That's the question. It is a demonstration and it's about learning and what we have been learning from states is fairly intuitive and that is states need different infrastructure to support a different program model, a different delivery model. States don't have it. Some of that infrastructure's missing in states when they start down this path on attempting to balance their delivery systems.

One of the challenges of MFP is that the Money Follows the Person, which means states are not given significant

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upfront dollars to build infrastructure before they then began to move people.

The enhanced FMAP comes as you move people out and that means that it's been a bit slow going in the beginning for states because they haven't had significant funds to make those early reinvestments but as they begin to get people out and the enhanced FMAP flows, states are, in many cases, very deliberately reinvesting those additional dollars in speeding up the infrastructure changes.

I think that we are already seeing some, I think John was reporting that in Ohio, Molly reported that that was one of the experiences there. It took time to get some of the relationships in place, to identify the housing options, to learn how to identify the individuals who would be well-suited to movement but once those relationships, once those tools are in place, it becomes faster.

So I think we are hoping we are going to see this speed up as states are able to make more infrastructure changes. We also hope that Balancing Incentives program will be an additional boost to getting funds to states through the enhanced FMAP.

In that case, it's across all HCBS spending not just for those individuals who are transitioned. So again we're hoping that that may also get more dollars flowing to states that can be used to make some of that infrastructure

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investment. So I think it does take time before we can move more quickly. The whole idea behind MFP is to help create that reformed infrastructure so that the system can operate differently over time when the grant funds disappear.

**JOHN MCCARTHY:** I think one of the things that's hard to understand when you're on the outside looking in, because you look at government as just one government, is how siloed these programs are and then within the program how siloed they are to the point of if you're looking at where progress has been made, often on the programs that serve individuals with intellectual or developmental disabilities, they're out front and why are they out front in Money Follows the Person? Because they already deal with housing.

With all of their waivers, they often have a housing component that either the state's picking up, in the state of Ohio, it's the counties pick up the cost for that. That's already there and people are thinking of it but then to rethink that piece even, to not just have the county or the state pick up those costs and use the housing vouchers, that was a huge step. I mean that's a big step for people to start working with the other agencies to figure out how do you integrate those two?

If you then move over to programs for the elderly or the physically disabled, which are often run in the Office of Aging, Departments of Aging or the Medicaid agencies

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themselves, there you never talk about housing because of the ban on Medicaid paying for housing except in an institutional place.

So that's why many of the early home and community-based waivers really was just people going back to their home. If they didn't have a home, it was all over. So there is no connection there at all, so again building those connections. I think in Ohio that's what I saw, those connections have been built and those are the things that are starting to roll forward and having Money Follows the Person to allow a Medicaid agency to hire housing coordinators is so important and especially in times like this.

Even there's opportunities out that are 90/10 funding, I don't have the 10-percent. I mean it is not there. You might be cutting off your nose to spite your face but that's just the reality of it. So when you have the opportunities with Money Follows the Person if things are 100-percent federally funded, you have the ability to hire those people to get those things moving forward. It's still very difficult though to do across the various programs. I do think though that you'll see it moving forward.

**FEMALE SPEAKER:** [Inaudible] with SCIU. So several people on the panel mentioned that having community workforce or the lack of it is a huge problem with being able to get people back into the community. So I'd be very interested in

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hearing the panelists' thoughts on the best way to address that problem.

**MERCEDES WITOWSKI:** Well I think in this economy it's been a little bit easier to recruit and hire staff. We have a lot of individuals that come every month. We hire at least a dozen individuals at our organization and every week we run an open house so that people can know that there are jobs available typically outside of their field, many individuals who have been downsized from large corporations that are deciding that maybe a career in social services is not a bad idea.

So once we are able to retain people and bring quality people in, we are able to keep them in the door, offer them, while not the wages that they experienced before, certainly a living wage to do good work in the community. So we're seeing our employees come from a different workforce. I don't know how long that's going to last.

Many agencies struggle with huge vacancy rates in their staffing and it causes problems in delivering the vital services that you're delivering to people with disabilities. They need consistency in their lives in order to succeed and very often, that's not available.

**LARRY MINNIX:** Yes, my name is Larry Minnix with Leading Age and perhaps this would be best directed toward Barbara but what, if I'm understanding the ACA, there is

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flexibility in the ACA to create things like accountable care organizations but if I read it, there's also flexibility for those kind of organizations to work with networks of non-medical kind of services like housing with services or home, community-based services to create a broader kind of continuum to have potential better seamless kind of services for challenged people as well as impact on Medicare and Medicaid.

Am I reading correctly, there's flexibility in there for the acute care in the doctor world to work with long-term services and supports world in more formalized kinds of ways to address some of these issues and if so, would you encourage providers to be thinking about those kinds of partnerships more than they ever have?

**BARBARA EDWARDS:** Boy it's a great question and the answer is absolutely. I think the Affordable Care Act creates some new encouragement for that. I think actually without the Affordable Care Act, there were opportunities to do that but I think it's easier with tools like health homes, with the new possibility of thinking differently about reimbursement models through affordable care organizations.

There's an opportunity to begin to be much more holistic in looking at the individual's needs and providing, we hope, funding streams that will support that. So we do encourage states and providers to look at those opportunities

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and we're very interested in the models that folks are going to bring to us and ask us to approve.

**DIANE ROWLAND:** If you have a question, please raise your hand high so we can see you. There's one back here.

**CHRISTINE AMOROSI:** Hi, good morning. I'm Christine Amorosi. I'm a nurse and health policy consultant. My question sort of goes to the panel in more a broad sense. I think one of the panelists discussed the issue of value and more focus on cost effectiveness.

My question is, as we talk about Money Following the Person, my concern is the value of the program we're getting, the quality of the program, oversight, and unfortunately potential abuses in the program of non-credentialed or bad actors sort of gaming it. So what kind of checks and balances do we have for these vulnerable, disabled persons? Thank you.

**BARBARA EDWARDS:** It's an important issue. Again I think it's one of those issues about a demonstration and as we look at it is how do we build in quality checks as the programs are implemented. That's a challenge and I think that it's something that states are paying attention and we're paying attention to.

There are the normal checks and balances in the programs around accountability and audits and requirements for quality. There are some new provisions in the Affordable Care Act that are going to give states the ability to do more

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background checks and other things, the kinds of services and checks around direct care workers. We're very excited about that opportunity for states.

I think that one of the things we've seen in the Affordable Care Act as well is that in many of the provisions that are new, the health home, Community First Choice, and some of the other provisions, there's actually more quality reporting built into these new models, a higher level of attention being paid to that issue than perhaps we've seen before.

Our job, I think, our charge at CMS is to figure out how to be as consistent and reasonable as possible as we put those into application so that states could actually implement these programs and be effective as partners in monitoring quality but it's an area in which we have more to do and we've learned a lot in home and community-based waiver programs.

We're actually committing to step back and take another look at those programs to make sure they're being as effective and as strategic as possible. We're looking into broaden that interest and that approach across all of the different various state plans as well as waiver services.

**DIANE ROWLAND:** Mercedes, could you comment on the ground?

**MERCEDES WITOWSKI:** Yes, on the ground, I'll comment firsthand. My daughter is in a self-directed program called

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the Personal Preference Program, which is an opportunity that we have to interview and hire directly the individuals that support her.

I'm not sure how much more direct you can get to knowing who you're hiring when you're spending the time with an individual, you're not just doing their background checks but actually identifying that individual as the right match for your need.

In a provider agency, while there are great services and certainly we can screen and train the individuals that we employ, an individual consumer who lives in the community who's choosing to self-direct services and takes the time to screen and meet with their potential employees as well as typically finding them from a network within their community.

So the natural ways through church, through civic groups, through meeting at the grocery store, you're actually able to identify with people that you believe that can provide the most personal care. So those are some of the, on the direct side of self-directed services, ways in which an individual can pretty much know best. I think my daughter knows best and I know best in terms of who would provide the right care for her.

**DIANE ROWLAND:** The Secretary's en route but we can still take some comments.

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**MAYA ALTMAN:** Hello. My name's Maya Altman. I'm from the Health Plan of San Mateo, which is a special needs plan in California. Special needs plans haven't come up yet today and it seems to be a vehicle, they're already serving Medicaid and Medicare dual eligibles. It seems to me the next step would be trying to fold in the long-term care supports and what are your thoughts about encouraging the further development of that model to do that?

**BARBARA EDWARDS:** Special needs plans are clearly one of the vehicles of integration that are available today and are being looked at as a part of the options that states might choose to work with through the efforts of the Federal Coordinated Health Care Office.

So I think that's absolutely one of the vehicles that there's a lot of interest in. We're hearing a lot of states looking at SNIPS as potential partners as they think about reform. I don't see any barriers to plans being able to participate in that way.

**DIANE ROWLAND:** Next question? John, did you have a comment?

**JOHN MCCARTHY:** Yes, just real quick. From Ohio's perspective, it is one of the places that we're looking at to do some innovations because while SNIPS do integrate some of the care, much of it's not integrated and there's still the chance to push costs into the Medicaid program.

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When you are looking at what's in the Affordable Care Act and you're looking at the integration of care, you're looking for that one entity that's responsible for all parts of the delivery of health care services. We're not there with SNIPS.

So as one model, maybe it's something that we change and how do you work with that? I'll tell you that the difficulty you start running into is on the regulatory standpoints of how do you pay for the services? You have the Medicare actuaries. You have your Medicaid actuaries. How do you get those two groups to work together to figure out what's the right amount to pay for the services there? We can break down some of those barriers. I think this would be a great way to move forward in that area.

**DIANE ROWLAND:** Great. Question in the back?

**MARK PODRAZIK:** Hi, Mark Podrazik, a consultant with Burns & Associates. This is probably for Barbara. You mentioned that under 1915I, the ability for states maybe to expand benefits. I was wondering will the states have the opportunity to possibly create an expansion population where they would be limited just to HCBS services and not acute care services?

**BARBARA EDWARDS:** If I'm understanding the question, I don't believe that's an option under I but we could follow up if you think I'm incorrect on that.

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**DIANE ROWLAND:** Okay back here?

**STEWART GORDON:** Stewart Gordon, Amerigroup. Barbara, this one's for you. The Balancing Incentives program requires the states to have conflict-free case management. Have you guys figured out what that is yet and how you do it in rural areas where the resources are fairly scarce?

**BARBARA EDWARDS:** Well we haven't figured out what that is yet. We will be doing regulation, actually with BIP, I think we are going to do a state Medicaid director letter soon that begins to discuss what we think the requirements are around that opportunity and clearly we have a lot to learn and figure out.

There are folks that have been looking at the idea of conflict-free case management in the community in advocacy groups as well as in CMS. There's a lot of attention being paid to that. There are some real challenges. So I think it's going to be one of those areas where we all have a lot to learn as we go forward.

It's an important issue and it's one we hear from advocates fairly regularly that they're very concerned about those kinds of issues but, as you point out, there are systems issues in terms of the availability of services and I don't think anybody would want to be in a situation where people can't be served because there's not two of every provider available.

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**DIANE ROWLAND:** We know that Barbara will work on figuring it out since the Secretary has arrived. I heard her say she was going to figure it out [Laughter]. So we're honored to have the Secretary join us today to share her insights about the future of long-term services and supports. She's obviously been involved in these issues as a Governor and insurance commissioner in her home state of Kansas.

So yes, she is a Jay Hawk fan as are others in my household. She's now the head of the U.S. Department of Health and Human Services where she will oversee most of the key agencies that are focused on long-term care supports and services for those in need as well as having the new challenge of implementing the relevant changes from last year's health reform.

She obviously will have major responsibility to bring the Patient Protection and Affordable Care Act to fruition. That includes the many provisions of Medicaid we have been discussing this morning as well as the new program for long-term services and supports assistance called the Class Act.

I wanted to note for the Secretary that there are many who are opposed to key provisions or to the overall health reform legislation but in some of our recent public opinion work, we asked them about the Class Act and found that it was quite a popular provision in the health reform law with three-quarters of those polled having a favorable view of that.

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Perhaps most remarkably when we broke it down by party, 87-percent of Democrats favored it, which is not too surprising but also majority, 69-percent of Republicans thought this was a key feature. I think it speaks to the need for everyone to have some assurance that if they have the unfortune to need long-term care services and supports, there'll be a way to obtain them. So we're delighted to have the Secretary and please join me in welcoming her to the podium [Applause].

**KATHLEEN SEBELIUS:** Well good morning everybody and thank you Diane for that nice introduction but more importantly thank you to Kaiser for convening this very timely and important conversation on long-term care services. I know as a Governor this is one topic that is front and center of a lot of agendas and one that I think is long overdue. In last month's *Health Affairs*, many of you probably read the story of Michael Og.

Michael was diagnosed almost 14 years ago when he was 42, with MS. He's deteriorated since then. He's lost movement in his legs and left arm. His neck muscles are so weakened that he needs his wheelchair to keep his head upright. He lost his ability recently to control his bladder and has to urinate now through a catheter into a bag that's strapped to his thigh.

Now despite those significant physical challenges, Michael continues to live alone in his own home nearby his two daughters. He goes to the grocery store. He cooks for himself

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and he's continuing to audit courses at the nearby university. He's an advocate for people with disabilities in his neighborhood.

Michael can live independently as he prefers to do because he has part-time personal care assistants who help with the daily tasks he can't do on his own. He pays for those assistants with long-term care insurance that he was able to get through his former employer but his policy is going to run out soon. Then he will be forced to rely on Medicaid for his care once his assets are depleted. If that program can't cover the services he needs, his worst fears will be realized and he'll be forced out of his home into a nursing home.

Now with every year that passes, many, many Americans face the same choices as Michael is facing today. We have about 10 million Americans who need long-term services and supports today ranging from having an aide visit for a few hours a week to living in a nursing home with round the clock care.

As America ages that number is steadily rising. By 2020, it's expected that 15 million Americans need some kind of long-term care services and yet people who want to plan for the possibility that they would be in a situation like Michael's currently have very few good options.

You can pay out-of-pocket for your own care but at $75,000 a year or more for nursing home care or about $18-

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20,000 a year for just 20 hours of home health care, money can clearly run out quickly and not a lot of people have that financial wherewithal.

You can purchase long-term care insurance but some insurers have stopped offering plans and the price of long-term care insurance puts it out of reach of a lot of American. If you qualify for Medicaid, depleting assets, you can get coverage that way but many people aren't eligible until virtually all their savings are gone. So we currently have a looming needs situation and Americans need better choices.

We know that one out of every six people who reach the age of 65 will spend more than $100,000 a year on long-term care. If nothing changes, we'll see more and more of them either forced into a dependent living situation against their wishes or forced to clear out their savings to afford the services and supports they need to live independently. That's where the community living assistance services and supports or Class Act comes in.

Now President Obama was one of the sponsors of this bill in the Senate when he was a Senator and I have been a longtime supporter of this program before it was included in the Affordable Care Act. We continue to believe that it has the potential to make a huge difference in the lives of working families.

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As Michael Og puts it, it's too late for me but Class could provide long-term care, significant benefits in the future for people in a situation just like mine.

That said, the President and I have also realized that the Class statute, included in the long-term care act, was certainly far from perfect. Many of the changes that were debated and proposed to the reform bill that would have improved the program's financial stability were not included in the final legislation.

So it wasn't surprising that recently the President's own fiscal commission identified these same unresolved issues in December and recommended that quote we reform or repeal Class but it's important to also realize that the law, while the structure in the statute wasn't perfect, provided ample flexibility to make sure that Class is successful.

Today, I just wanted to tell you who are interested in this area and talking about these topics that we, at HHS, are committed to using that authority to making sure that both the program meets people's needs while remaining fiscally sound. As we do that, I want to make one point perfectly clear.

The law says clearly that the program must be able to pay for benefits over the long-term with the premiums it takes in, that no taxpayer dollars will be used to pay for Class benefits. This is non-negotiable and it's been the starting

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point for every conversation about flexibility that we've had. So that becomes a fundamental principle.

Moving forward, we're also guided by two other key principles that are at the heart of the Class statute. First that consumer must be able to direct their own services. This program is all about giving people more control over their own care and we want to make sure that along the way that freedom isn't taken away.

Secondly that there can't be underwriting of the kind currently found in private insurance. The Class needs to be open to any American who meets the requirements regardless of their health history and that's very consistent with the current underlying goals of the Affordable Care Act.

So with those principles in mind, my staff and I have really spent the last 10 months studying the new program. We've discussed Class with some of the strongest supporters and some of the toughest critics.

We've reviewed every major study of Class and discussed those studies with leading actuaries and economists, conducting our own research and looked at how Class fits with other long-term insurance options. More importantly we've spoken to consumers across the country about what kind of program would give them the piece of mind against potentially devastating costs of long-term care services and supports.

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So those range of discussions have given us a clearer picture of where the Class program needs to be strengthened in order to give enrollees the security they need while making sure that we remain on a stable financial path. I know that some of our experts are in the room today and you all have been likely also heard from them and involved in that outreach effort.

Now in particular, we realize we needed to focus on several additional areas, which we also are currently exploring. Like all insurance programs, Class needs to be able to attract a broad base of enrollees. Private insurance solves that problem by underwriting, charging higher rates to those more likely to receive significant benefits and lower rates to others.

So they guard against an adversely selected pool by their underwriting strategies. That's not a legal option for Class. So one question we've heard over and over again is how will Class successfully spread financial risk to keep premiums down while maintaining benefits?

Now as a former insurance commissioner, I certainly understand how important it is to have a good answer to that question or you immediately have a program that solvency is questionable from the outset. The first step we have to take about the solvency issue is raising awareness about the fact that this program even exists and I would tell you that we know

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that conversation is among a relatively small group of people right now.

We know that there are lots of folks who don't even consider needing long-term care services or support in the future particularly people in their 40s and 50s who are thinking that they'll live forever and they're just going to be fine.

Others prefer not to think about the chance that they'll some day need to rely on others for basic tasks like getting dressed and washing themselves. So we have to work aggressively to make sure a whole wide range of people, not only know about the new option but know how much they may need to rely on it in the future.

Secondly, we want to make sure the program is appealing to employers and their employees. We're looking at ways to use information technology to make it as easy as possible to enroll and pay premiums. For example, we could calculate premiums for people interested in joining the Class program so employers don't have to. We're studying other ways to make the program more flexible for employers who want to partner with us to do that kind of outreach and enrollment.

Another option would be to change the employment and earnings requirement for the program. Now the Class program was designed to protect the workers of today against future needs. That's why it included a requirement that people earn a

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certain amount of money in order to participate but we know if the standard is set too low, we may have way too many enrollees who will quickly claim benefits thereby threatening the financial stability long-term of the plan. That isn't the intent of the program. So we need to look closely to make sure we've picked the right cutoff point for those earning requirements.

Finally, the program contains loopholes that could allow people to skip premium payments and then re-enroll in the program without paying any penalty. So we're also looking carefully at ways to close those loopholes to ensure that all enrollees actually pay on a continued basis their fair share.

If we can spread the risk across a broad basis of enrollees, we definitely make the Class program much stronger but we also need to keep a balance between the premiums and the benefits. As currently written, the statute keeps the premiums flat while calling for Class benefits to rise with inflation. That gives us two options.

We could set the initial premium extremely high making it difficult then to attract a broad base of enrollees violating one of the earlier principles or we could set lower initial premiums and watch them quickly be at lips [misspelled?] by rising benefits. Neither of those options is appealing.

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Fortunately, the new law also provides a lot of discretion in structuring the premiums to keep the Class program solvent. That's why we're currently looking at options for indexing premiums so they would rise along with the benefits.

We know that Americans have had their confidence shaken by large premium hikes over the last years especially in the long-term insurance market. The indexing system would have to be completely transparent from the outset. That way, people can actually plan ahead and not be surprised by sudden rate increases.

The last area in which we can strengthen the program is tailoring benefits more closely to individuals' needs and preferences. Right now long-term care comes in many shapes and sizes. One person may be able to live on their own with just a few hours a week of assistance with bathing and toileting and dressing on their own. Another might prefer an assisted living facility and a third might need that round the clock assistance you can only get in a nursing home. Given those differences, we're looking at ways to make the program appealing to Americans with a wide range of long-term care needs.

A Class program that doesn't have a one size fits all approach not only serves consumers better but also is more attractive to a large number of people. So those are our goals. They're tough goals, which will require us to make

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difficult choices today to put the program on firm footing for years to come but they're necessary if we want Americans to enjoy the benefits of a strong Class program that continues to exist into the future. I believe they're achievable if we use the flexibility and authority the law has given us most effectively.

As we begin to design the specific features of the program, we'll have even more ideas about how to make Class stronger. In the years to come, nearly every American family will have a grandmother or father or sister or son who needs daily help because of some kind of disability. They deserve to have the choice of a program that will allow them to prepare for the chance that they'll someday need long-term care services and supports in order to live the life they want.

It would be irresponsible to ignore the concerns about the Class' program long-term sustainability in its current form. We haven't done that but it would be unconscionable to ignore the likelihood that without the Class Act countless Americans will have to either clear out their savings and leave their homes or loved ones in order to get the services and support they need.

Now there's nothing Michael Og could have done about his getting multiple sclerosis but if the Class program had existed, Michael could have taken steps to ensure that if something did happen, he'd have the resources to keep living

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the life he wanted. As more Americans come to depend on long-term care services and supports that's a freedom we need to fight to protect. So we know there is a lot of work to be done. We appreciate those of you who've been involved in these early conversations about some of the framework of the program and we'd urge that you continue to be involved and engaged.

The President and I are determined to give Americans the choice of a financially solid Class program. That's what this administration and our department will work to do in the coming months and years. Again thank you for gathering today. I look forward to having your ideas. Thank you [Applause].

**DIANE ROWLAND:** Well please join me in also thanking our panel, which gave us much material to review and much food for thought as well as the Secretary's comments. Long-term care services and supports are a critical area that we need to keep in focus so that as we talk about health reform, we're not just talking about health insurance for acute care. Thank you [Applause].

[END RECORDING]

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