MEDICAID LONG-TERM SERVICE AND SUPPORT

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>>SECRETARY OSBORNE: Good morning. How's everybody? My name is Teresa Osborne. I'm Secretary for the Pennsylvania Department of Aging. I'm here with colleagues of mine. Karen Murphy, the Secretary of the department of health and Ted Dallas is the Secretary of the Department of Human Services. Brandon Harris. I get tend demerits for that, trust me. Long ride back to Harrisburg. Brandon is the deputy Secretary of Department of Human Services. And Jen Burnett is the deputy Secretary for long term. It is my job per instructions I get from Kate who runs these shows for us, Kate to welcome all of you.

You have no idea as we sit here and look out to you and

you look at us how incredibly grateful we are for your presence. The fact on a Thursday morning you took time out of your lives and jobs to spend time here with us in this incredibly, I can't under score the word, incredibly important work we're engaging in in terms of our Commonwealth. When Governor Wolf selected and nominated the three of us successfully journeyed through a confirmation process. Governor Wolf said to us, first and fore most take care of the most vulnerable and the most vulnerable in our Commonwealth are many. But for our purposes, regardless of what your stakeholder title may be, as a consumer, advocate, provider or any title I missed, put them all in a group and that is what we do together. So this stakeholder engagement process is incredibly important to us. It's so vital that we hear from you. Your thoughts, concerns, ideas, challenges and struggles. We started this in Erie yesterday with a crowd similar to this. Which was impressive equally today. This conversation begins. It's important to know this is a beginning. Governor Wolf challenged us to be innovative and bold and creative. And that everything's on the table except the status quo. We cannot continue to do the same things and expect different results. So it is critically important that we work together. So let the conversation begin. It is a packed agenda. We look forward to hearing from you. And I will turn this over to Kate -- I

take that back. Secretary Dallas who is going to walk us through the PowerPoint presentation. Thank you.

>>SECRETARY DALLAS: Can everybody hear me? Great.

>>AUDIENCE MEMBER: I can

>>SECRETARY DALLAS: Let me echo a sincere thank you for being here today. This is a process that's been going on for many years. Today we're here to talk about a discussion document that the Department of Aging and human services put out that lays out a frame work for how we might move forward with managed long term supports or managed long term care. For us this has been a conversation going on for a while. There's been a lot of commissions and blue ribbon panels. We wanted to put a frame work out there and say here is how we can proceed. We're here to hear from you all. We're going to go through a short PowerPoint but we want to spend time listening to what you like, don't like, what makes you nervous and things you'd like to see us change. We want to get to this process. We were in Erie yesterday and next week to Altoona, Harrisburg, Philly and Scranton is our last. As you're hearing all the things, think about oh, I like this or don't like that. Or I'm nervous about this. Or if you change this one piece, I think it would be better. Those are the things we would like to hear. We have like 30 speakers today. So a lot of folks presenting their opinion. So I do ask you be mindful of the 5 minute guideline we have

so everyone has a chance to speak.

We'll start with the PowerPoint and we'll go through it as quickly as possible. The first slide. When we talked about this, Teresa and I talked about this. We want to share information and we want to hear from you. So that's the point of this. So there are some questions I talked to some folks before the meeting and said, is there more detail about how this would work and we said well some of it we left intentional vague because we want to hear from you and what you have to say before we make any decisions about how we might move forward we wanted to get as much input as we could.

When the Governor made the decision to move forward to manage long term support services we wanted to set up goals. So I'm not going to read every single one. These are the things we hope we can accomplish.

A couple things particularly important are the two in the middle there. Incorporating person-centered service design and consumer choice and having a choice. Consumers being able to direct their services is an incredibly important part of this. And also enhancing opportunities for community based services. That's extremely important to the Governor. He still lives in the home he was raised in. His parents are still living in the community. This is something that's a core value. He really wants folks to be

able to live in their community. So I think when I see a poll for this it's been 95 percent or higher of folks who say they want to live in the community and age in place. I haven't met any of the 5 percent who don't want to age in their home. But I'll take the poll at it's worth. Maybe they misunderstood the question. But for me in the Commonwealth we're at about 50/50. We're a little bit below 50 percent for folks being able to live in the community. Part of what this is about, there's a disconnect there. Folks want to live in the community and we have a system that doesn't help them get there. To me, people say -- one of the things we'll talk about later are what are the right outcome measures. To me one of the biggest ones is, are we going to be able to move that 50 percent number higher and closer to 95 percent. That should be one of the measures of our success. By the way we have copies of it -- you don't have to write the whole thing. It's also on our website. For me, that's got to be one of the measures. Are we giving folks the opportunity to have the best quality of life they can. And let them live in the community if that's what they would like to do.

So next slide. What is managed care and what does it mean for you. We were in Erie yesterday and had a couple questions. What does it mean. And for us, first look at the current system. You can see if we look at it generally

as three pieces. Physical, behavioral and long term. The only managed care is behavioral health. The other is fee for service. It's disjointed and unnecessarily hard to deal with. And may lead to providers of not of the highest quality because that's the easiest place for the system to take you. The idea is to combine them into a managed care system so folks can have access to high quality providers and coordination of care to help folks get the best care they can. We could combine this into one umbrella and managed care could be where folks get the best quality of care they can.

This is our draft schedule now. I was talking with many of you, Mildred, stand up say hello.

>>AUDIENCE MEMBER: Good morning.

>>SECRETARY DALLAS: And Mildred say that she thinks the time line is aggressive. I said I think it is but the reason I want it to be is for a couple things. First, there are folks every day not getting the best result they can because our system is not working the way it should. To me it's a balancing act. We will take the time to make sure we get it right. For me, I always think of the person who today is going to a nursing home when they don't have to and folks who really should be served in the community but we don't have a system that gives them what they want. I feel pressure on both sides and to me it's a balancing act. This

is our initial time frame for rolling out. The discussion document released on June 1st and in the process of doing our first round of public listening sessions. If you see here, the schedule is a little misleading. It says July 15th deadline for submission of comments and there's a blank space between now and October. There's a lot of communication and a lot of opportunity for further comment. Trying to get the presentation on one slide is between July and October we're taking those comments and giving more and more opportunity to comment. There will be multiple opportunity for folks to do that. For us we wanted to have that general frame work. Get input from folks across the state. And provide more detail and keep going through the process. By the time we get to October and release the RFP there will be multiple opportunity. It's a broad frame work. This is where we'll get great comments about here's the roll for the AAA here's the roll for other folks in the system. Those are the things we want to hear.

So you'll see a bunch of phases there. Our initial thought on this, this is also open for discussion -- was that we would phase it in across the state. First phase was targeting here in southwestern Pennsylvania we haven't picked all the counties exactly. Folks can guess what they'll be. I think it will be familiar counties for all of us. Do we do a ramp up period, and enrollment starting

January 1, 2017. And move to the southeastern part of the state and do the remainder in 2019. That's our initial approach. There are many different ways to approach this. And many different ways to implement. One of the things to think about as you guys are listening to what Jen has to say I'm going to introduce her in a minute. Is that the way folks want to do it. For us this is our initial reaction. Based on all the things we heard today. But we do want to hear more. I think that's the last slide I have. Jen is going to take over and go into more detail about who we think will be the population that we want to serve here and some of the details of how we want to move forward. So Jen take it away. We look at it more as a phasing, there are a lot of folks that have had multiple rounds of discussion. The goal is, here's one way to do it and we know we want to move in this direction but the question is how do we do it. It will be a pilot, every time you implement something you're going to learn along the way and we're going to learn from what other states did wrong and what other states did right. There are about 22 states that have already done this. Maybe 10 who are moving in that direction. So this is something that a lot of folks across the country did. Hopefully we'll take the best of what the states did right and avoid what the states did wrong.

>>JEN BURNETT: Good morning everyone. I'm really excited

to be here in Pittsburgh. And I've been here many times before in former roles but this role is one that I'm familiar with but it's a new role for me in that the Governor is very committed to figuring out how to improve our system in a way that really makes sense.

My name is Jennifer Burnett and I was the OLTL deputy Secretary from 2008 to 2011. In 2011 I went to work for CMS center for Medicaid and was asked to come back and asked to serve as OLTL. I've been on the job for five weeks. It's been a whirlwind so I'm happy to be back in Pennsylvania and I look forward to hearing from you. I'm not going to spend a lot of time on our slides but I want to go through quickly the target population and some of the program components. As Secretary Dallas said we're looking for your feedback. The discussion document is just that, a discussion document and people have been asking, there's not a lot of detail there. We don't know what you mean to do. That's because we haven't figured out that plan, so to speak. We really need to hear from all of you.

One of the things I would be interested in hearing about in terms of how we hear from you after July 15th is the best ways to do that. We can't come out and do round tables all over the state. And I don't think you all want to come into Harrisburg to help us with this. So we have to figure out what are ways of connecting with you and we could ask for

your input on that. What's the most convenient way. How do you want us to hear from you. That would be very helpful.

Our target population, this is our current thinking, include dual eligible adults excludeing adults with intellectual disabilities. Over age of 21 entitled to Medicare Part A, and or Part D and eligible for Medicaid benefits. The dual is they're eligible for Medicaid and Medicare. Targeting nursing home individuals over the age of 18 and eligible for Pennsylvania Medicare program. And the third population is nonMedicare recipients of the Act 150 program. Those are the three target populations. Do we have it right, should we not include people. So we're looking for feedback on that.

I want to talk a little bit about the program component, the areas we want to focus on because we think these are things that Pennsylvania has a long history of providing services to individuals in the community. We're not balanced. We're pretty unbalanced in fact. Less than 50 percent of Medicare funding going to home community based services. These are the tenants of how you build a solid community based system.

The first is person centered service planning. This is critical to us and we look to your feedback and what is working in that arena. We also have a commitment to self direction and to continuing making self direction available.

It's been around since the beginning of the Act 150 program which was 1985 and so we have a long history of it but we want to hear from you. That's consumer directed personal services. Services and supports coordination is key to a good managed care product. Having somebody who can help you navigate between physical health, behavioral health, and long term services and supports is an important activity today. When people go into the hospital, the hospital is not aware they're on a waiver program and therefore they may discharge them to an inappropriate location like a nursing facility or may not know what's available to the individual. So we really want to make sure those systems are connected.

Access to qualify providers. We believe that there is a whole network of qualified providers out there. But yesterday we heard about access to qualified providers in the version of accessible healthcare and that is a challenge in rural parts of the state. So we really want to push for and work on making sure people have access to qualified providers Secretary Dallas talked about community based services. Pennsylvania is one of the 22 states. We have the life program which is a program for care for the elderly. There are over 5 thousand people in that program statewide and that is capitated long term so we have some experience with the life program. We also have experience in the autism capitated program. We're doing it

successfully.

Performance based payment incentives. This is an important thing that we want to be able to do to help providers move to outcome focus and not just a volume focus. So we're looking at these as part of it and look to your feedback on how we might make that work.

Participant education and enrollment support is important to us. People have asked me, how do I know what product I should take and choices I have. We really want to have a solid availability of education and enrollment for individuals so people can navigate the system in a way that makes sense for them. And understand what the managed care options they have will best serve them. All managed care products will not be exactly the same. So that's another place we want to look at.

Preventive services. This is an area we are not doing very well in the current system and we really believe that by working on preventive services. Yesterday we heard testimony from a woman who had been very isolated in her home. She's younger and I think she's -- well younger for me is in her 40's. She talked about how isolated she was. And met somebody at the center for independent living and introduced to the opportunity to work out at an accessible gym and since then she has been more involved. Her disabilities have not gone away but she's able to cope with

them more. That's the kind of things as far as preventive. Not just exercise.

Participant protections are important to us. We want to make sure that we have a strong opportunity for people to get good customer service and be able to navigate when they disagree with some kind of decision and a managed care company or provider is made. So we want to have a strong appeal process and hope we are able to align our Medicare and Medicaid processes around hearings and appeals so it's not confusing.

The next one, outcomes of quality based focus is personally the goal that I am really most interested in, which is to improve outcomes for people and making sure people with getting quality services.

So with that, I don't think I -- we have a few questions up here but I think the 30 individuals -- we don't even need to ask these questions. We'll leave them up there. But I'll turn it over to Kate at this point because we really do want to hear from you.

>>SPEAKER: So as Secretary Dallas stated we have a lot of speakers and we're going to try to hold you to the 5 minute time cap please. So if you get close on your time you may see me waving you done a little. Please try to respect that. The first speaker we have is Fred Hess.

>>AUDIENCE MEMBER: My name is Fred Hess and I work for disability options network and I'm also a consumer of services. My largest concern is when we do go on to managed care everyone will receive the same amount of hours. For instance if you're blind you'll receive X amount of hours. All paraplegics receive the same amount of hours. It might take 5 minutes in the restroom. However another paraplegic may need 10 minutes. It can't be a one size fits all. I wouldn't tell you, you only have 5 minutes to eat breakfast and 10 minutes to get dressed. It can't work for you that way or us. The best person to know what I need is me. Not someone in an office 200 miles away. If you look on page 8 of the MLTSS discussion document, service plan development in the third PowerPoint it says, the use of a standardized and validated assessment tool. The reviews of individuals physical, psychological and functional needs and preferences. The words standardized jumps off the page to me in a negative way. I see it as being every diagnosis will be given a standardized amount of services and time. This we just can't have it. The phrase, nothing about me, without me, it has a lot of meaning. It means I have to have a say in the type of care I receive and being told how many minutes I'm allowed to be in a restroom is not going to work. There's one good thing I can see from this report and that's that you're trying to get more people into community

home based services. I myself I accomplished that by initiating the community first choice option. If you can get people back in their homes as fast as you can get them into a nursing home and institutional setting, save millions of dollars for the state. And make a lot of people very, very happy. Another issue I see is, catholic charities remain as the provider that disburses the services there will be bias in referral service for providers since they also function as provider of services so they will refer to themselves all the time. I recommend the state set the rules about what any managed care company is allowed to do. Don't let them set their own rules. They can come up with an all medical style of care. I believe if that happens the requirements for services may include having to use only nurses for home care. Or things like that. And when that happens, the only place someone with a disability will be able to go is in a nursing home setting.

The home and health care agencies will not be able to financially stay afloat and all home and community based services will be shut down. Accomplishing the opposite of what they're trying to do. I'm not saying it will happen but it's a possibility. My suggestion is simple. Include the consumers, the service coordinators. Care providers they're the ones with the experiences that will be critical to making the transition to managed care fair to all parties

involved. It's a simple thing, without us you're not going to know. Somebody that doesn't have a disability there's no way they can understand or be able to make a decision about somebody else that has a disability. It can't work. It would be like me trying to tell you how to raise your children. It's not just right. Thank you.

>>SECRETARY DALLAS: Good to see you again. Second, just want to clarify one thing you mentioned. The standardized tool. Probably a poor choice of words. We were trying to get at making sure there's a quality and validated tool doing the assessment. Where ever you are in the state you should get the same level of quality of care whether you're in Pittsburgh, Philly Altoona. I don't think anybody up here thinks that a one size fits all approach. Loss of translation. Making sure that assessment is done in a quality way so you have access to high quality services and where ever you are you get a high level of care.

>>AUDIENCE MEMBER: That makes me feel better, it really does.

>>SPEAKER: Kim Pirilla-Scalise

>>AUDIENCE MEMBER: How did I get lucky enough to be the second speaker. My name is Kim. I actually own two home care agencies. One is Medicare certified. Provides skills services, currently contracted in MCO network. And the other is a private duty agency. Does nonmedical care. Lots

of people are going to talk about what I want to talk about so I'll try to narrow my scope a little bit. I know that the discussion document was sufficiently vague enough to give us an idea while you build the specificity. I'll comment on two areas I think you need to be mindful of. The first is our current system of service coordination is going to need to dramatically change to meet the system you envision. Our service coordinators just like service providers, at least in region one have taken a cut so they're trying to do a lot with less. And there's really no way to approach a holistic level of service coordination. I presume across skilled and nonskilled services so you have the continuity without dramatically changing service coordination. And so that's a big task. I can't even imagine how you're going to do that because what is in place right now does not approach what will be needed. I don't know if you'll have multiple service coordination entities, like is in place now. Or if there will be one for each MCO. But that's probably going to take the most amount of time.

It also dictates everything else down the line for quality care. So it will be vitally important to pay attention to that. The other thing as a home community based provider I'm very encouraged at the focus we're giving on home and community services. I think often it's an after thought. Not as much attention is put on that as it should

be and we all know that's where most people want to be. Providers who do that work it's incredibly challenging but rewarding work. I liken it to parenting. There's nothing else more rewarding than being a parent. I wouldn't do any other job in the world. However we have to acknowledge one very important fact. This entire managed long term care system is going to rely on having the work force necessary to bring it to life and sustain it. And right now, we don't have it. We don't have it. We turn work away in the waivers every single week. And the biggest reason is because the rate doesn't support what we do. I can't -- 17.52 an hour. I can't pay a competitive wage and trained staff and the variety of care and provide supervision in the field. I just can't do it. So things get cut. And what gets cut is the quality part. Because that costs money and I don't have it to provide that. So we operate very lean. We try to pay our staff the most that we can, the top of our scale is 14 dollars an hour. That takes almost all of what we're reimbursed and we still can't attract caregivers. We're now transient work. People come here when they can't go to Wal-Mart or between a career. We want to make this a career for people. We want to attract the best caregivers and be able to keep them. And so in the planning of all this, I just ask that you consider that. Because we can build the greatest managed care system and never have enough

employees to meet it. To sustain it. Thank you.

>>SECRETARY DALLAS: Thank you (applause)

>>SPEAKER: Ray Prushnok.

>>AUDIENCE MEMBER: Good morning. Similarly drew an early slot. Thank you for the opportunity. My name is Ray I'm senior director for Medicare of special needs at UPMC I over see products with Medicare and Medicaid. Offers to 300 thousand recipients across the Commonwealth and our UPMC dual eligibility provides benefits to 19 thousand people who have Medicare along with Medicaid. And we proudly provide quality care to this vulnerable population at a lower cost than fee for service programs. I'd like to highlight a few items from the discussion document and give recommendations for how we move forward. First, this year, 25 states are expected to have some form of managed long term care program in place. States with MLTSS have a record of expanding community based alternatives. Greater rates than other places and these states have blazed a trail and give us in Pennsylvania the advantage of adopting their best practices. And we're encouraged by the direction the discussion document takes. When it comes to serving dual eligibles it's something near and dear to my heart. Working in state service prior to joining UPMC and working on waiver programs one of the first questions is how many waiver participants are we serving. Medicare and Medicaid don't speak to one

another. We're not doing right by our members and participants by not closing those gaps and managed long term services and supports is a key part of closing that gap. And I'll just give a brief example. We have a partnership with two areas, agencies of ageing where we can close this data gap and through that effort we have been able to do incredible things. Having higher than average rates on gap closure. More services in the home and that's just the beginning in these examples where we're seeing avoided hospitalizations reducing risk for nursing home.

Rely on the infrastructure that each side possesses. Secondly I do agree that we should begin with older adults and persons with physical disabilities. The infrastructure is similar and enhanced coordination. But the timing and implementation for people with intellectual disabilities shouldn't be forgotten between now and 2019.

It worked for a decade and we serve about 6 thousand waiver participants across the 28 counties in Western PA. Allow us to work for effectively to serve our customers. And also required by federal law. That contract can be used as a way to make sure the consumer protections and benefits are tied in. Additionally, I want to highlight it's important that we define counties early. The Medicare filing process for 2017 begins late in 2015. So it's important that we get ahead of the game. There need to be

strong consumer protections. The Commonwealth should establish an ombudsman as well as heavily invested education strategies to make sure the consumer choice is protected and standards should be established to make sure there's choice between managed care contractors and providers and the choice to self direct. We also think that assisted living should be a part of this frame work. Alternative care settings and also the state should be exploring shared living and other opportunities for serving this population differently than it is today.

I guess lastly, what I'll close with is there needs to be some flexibility for networks so we can help drive value based agreements and also be able to simultaneously cover all the mandated services and careful consideration needs to be there to minimize participant disruption and we can learn from other state's approaches to make sure that we minimized those risks and in summary, again I'd like to thank Governor Wolf Department of Aging and human services for proposing this MLTSS program. We look forward to working in the months to come. Thank you.

>>SPEAKER: Leslie Grenfell. Is Leslie here?

>>AUDIENCE MEMBER: Good morning, I can certainly see who registered first. Drew the short straw. Good morning, my name is Leslie I'm the executive director of southwestern Pennsylvania area of agency, non-profit. Serving and

advocating for seniors in Fayette, green and Washington counties. Our agency serves as the focal point for information and assistance about ageing services, protecting older adults most vulnerable. Assisting family members caring for older elders. Long term care services and supports and empowering older citizens to remain active, independent in their communities. I have more opportunity today to allow for the five minutes, I'm going to pretty much just get to the point if I may. Based upon the discussion document that was released, I would like to first and fore most talk about how we should ensure adequate planning process. The planning and implementation timetable. I believe is extremely ambitious and fast paced. There are only four months from the comment period to release of proposals to managed care plans in the southwest region. We urge the Commonwealth to allow more time for consumers and family members to be adequately informed of how changing from a fee for service system to a managed care environment will impact upon their lives.

A successful implementation will require on going outreach, education, choice counseling and other supports designs to specifically help the target population truly understand what is involved in a managed care environment. Substantial stakeholder engagement is also vital and is necessary to fully identify the needs and concerns of the

consumers to design a program that is really truly responsive. Therefore in addition to the strategies identified we recommend convening an over site committee. Comprised of all major constituent groups. To make sure we're gathering comprehensive for program and design and on going program operations.

My second comment is about the role of the area. The Pennsylvania ageing network has been integral part of a long term care system with the Commonwealth of Pennsylvania for over 40 years we have the direct knowledge, experience and expertise regarding the strengths and weaknesses of the current system of services and supports. Where's the Commonwealth as it considers it's program design to maximize the existing service delivery systems and utilize what the areas have successfully developed. Have community based long term care experience in all 67 counties. We have demonstrated the capacity in working with medically complex consumers and we believe the proficiency and performing face to face strength based assessment of individuals with physical disabilities.

As a network area agencies on ageing are truly committed and motivated to support and assist consumers with receiving the care in the setting of their choice for as long as possible. We value the opportunity to partner with the state in planning and implementing a delivery system and a

more comprehensive approach for managed care long term care services and support in order to expand the availability of options which is needed.

Our consumers have voiced their concern. Another critical element of a successful managed care long term services support plan is to ensure a choice of qualify providers. Consumers want assurances that provider networks in a managed care system will have the expertise and the capacity to provide the variety of services and supports they need. As network capacity is determined by the number of participating providers of the same time in a geographic region we truly encourage the administration to develop a set of clearly defined standards to guarantee a sufficient number and range of home community based services are available. Once again, consumers have voiced their concern and want to be assured there's a continuity of availability. Adequate supply of organizations that have been historically providing qualified services in the rural communities of southwestern Pennsylvania. I must comment on Kim's earlier testimony, we need to ensure that the right setting methodology is clearly defined but also provides for an adequate reimbursement so there are enough providers able to support the services. Additionally we recommend that careful consideration of the methodology be employed in transitioning the system from the current willing provider

to the proposed standard of any qualified provider that will not disrupt the current service and give consumers access to current providers during the transition period. And I'm finished. Thank you ladies and gentlemen for the opportunity to present today. Thank you.

>>SPEAKER: Mildred Morrison.

>>AUDIENCE MEMBER: If we were in congress I would have been more than happy to lent Leslie more of my minutes. Good morning. And all the other staff here. As the administrator of the Allegheny County area on ageing, Department of Human Services, I appreciate the opportunity to speak with you today about the discussion document and I come in the dual role as an advocate for older adults as well as provider of services. So first applaud the Wolf's administration to move ahead in a way that builds on the national momentum. With healthcare to supportive services to generate more beneficial results. Thank you for no more studies. It's worth noting that every state that created an MLTSS program including states smaller than Pennsylvania have ultimately requested an extension for their time line. Stakeholders and RFP vendors and selection in the negotiations one year from now is beyond daunting. That is over shadowed by a ramp up time of just six months. Before the first enrollment date is to be effective apparently in our region.

You know, Erie is a great place. Give them a shot. But, okay. These time frames are accelerated and one must sincerely hope one must learn. I appreciate that it takes a bit of time, sufficient external and internal resources and a lot of backbone. You're going to get flak and objecture. All that will be needed for the populations targeted in the document. Public confusion starts and stops, and other implementation snafus must be avoided by a rigorous yet realistic time line. Our concern is based on the real life experience of moving more than 4500 older adult consumers from a designated caregiver to another caregiver at a different subtracted agency. Four years ago the Allegheny AAA following RFP process resulted in moving lottery funded options care management from four existing vendors to three vendors with only one of them carrying over. With an excruciatingly well detailed process accompanied by an exquisite communication plan. To train new care managers on ageing and process and data base system and Chris cross all subagents and we did it with literally a handful. Less than 0.2 percent of any of those consumers encountering a problem. It took extraordinary staff and giving them any and every resource they needed. It took a little bit of backbone and I thank my county management for saying go for it. The quality of care matters most. We did that within an environment that allowed and assured that every one of

those consumers had the right to opt in, opt out, to change care managers and care agencies at the same time people are going in and out of hospital and moving from one location to another, in and out of the state. Changing from family, to care management. I repeat 0.2 percent encountered a problem. It's not that we're brilliant. It's that we were willing to give the time and resources it needed. Not that we're stupid.

A concern about the time line is some of the resources in this general document and the points on clarity. So one thing I think I hope I misunderstood is that the reference to the 318 thousand adults without long term services and supports who are not eligible for Medicaid if we're talking about people currently on Medicaid, okay. Then what happens to people who become eligible in terms of the process especially during time of transition? If we're talking about people who are not yet formally enrolled in Medicaid, then the process to get them through the county office appreciate you. So good to see you, you get it. The last thing I want to say, is to echo some of what Leslie was saying in terms of the AAA role is in areas of assessment and care coordination and that's because we have the experience of delivering those services along with transitioning people from nursing facilities to home and reduction of hospital readmission and hands on provider

services all within our breadth of knowledge. The Commonwealth has invested, get your return on investment by using it, thank you.

(Applause)

>>SPEAKER: Ransom Towsley.

>>AUDIENCE MEMBER: Good morning. Thank you for this opportunity. I'm director of executive services for Presbyterian senior care and home, dually licensed. Submitting comments by e-mail so today I want to focus on a singular issue. Individuals with dementia and I applaud the Commonwealth for taking this bold move. Combining medical and supportive services is an effective way to manage this high cost population. For the most challenged population this challenge is great. Require team based care management approach which may be different than what is envisioned in this discussion paper. In 2014 the Department of Human Services and ageing UPMC health plan and gate way were partners in a grant submitted by Presbyterian senior care to support living by a person with Alzheimer's or dementia in the community and prevent unnecessary hospital visits and nursing home placement. This team was designed to be a shared resource for Medicare and Medicaid product and the main goal was to determine those with remedial behavioral. Long term institutional stays, stays in hospitals, skilled nursing where emergency room can have debilitating effect on

individuals with dementia. It's a syndrome affecting individuals 65 and over. Such that by age 85 almost 50 percent will have some form of dementia or other cognitive disorder. Further more expected to double in the next 20 years. The prevalence, a strong influence on over all healthcare expenditures. Have higher health care costs. Hospitalization costs are 2.8 times higher in dementia patients than beneficiaries. Hospitalization often represents a pivot toll event for people with dementia. Permanent institution often being the unfortunate final outcome. Asthma, diabetes can be effectively managed, managing a total care of a person in the community with these comorbidities takes more expertise than these models typically contain. Overwhelms caregivers, navigating acute care and long term services and supports with dementia knowledge base and skill set. Reliance on long term care facility can be reduced by preventing emergency department visits and acute care saving Medicare and Medicaid dollars. This can be achieved by integrating support with in home management of dementia through community based. If the Department of Human Services and ageing, UPMC health plan and gate way thought this was a good enough model to submit last year, I suspect it remains a good idea with this MLTSS effort in 2015. As a lead agency in the CMA, Presbyterian would like to see supporting community health with dementia

become part of this MLTSS dual eligible. I offer myself and Presbyterian senior care to refresh memories and go over the model again and look forward to working with the department. Thank you.

>>SPEAKER: Debra Holden.

>>AUDIENCE MEMBER: Hi my name is Debra. I'm here to advocate for my husband who is a consumer delegated model, employer model and he should have, or all of those people, should have the right to be a part of getting their -- picking their caregiver or their attendant and being a process in the process of evaluating that attendant. We have gone through some trying times with that and it is very important that the consumer has the right to make the decisions in his or her care because they're the only ones that know how or what needs to be done. Also consumer first choice options have been mentioned here and in my travels going to Harrisburg I have used the example that if, say for instance, you're in the hospital. Care case manager comes to you and says, Deb, this is your options you can go here, here and here for rehab. I think everybody in this room should have community first choice option because I should have the right to go to my own home where I know how comfortable I feel. I'm not afraid of my surroundings. I have my family at hand. And also the consumer should be involved in picking their -- who they want to deliver their

services and who better than, in my case, Tri-County patriots for independent living because without them they offer a whole line of services such as volunteerism, computer cafe to teach people skills to earn a job, accessible dreams to help them find places to live. We have nursing home transition to help them go from nursing home to being in their own home. So I think that centers for independent living should be made the ombudsman's and you pay them the money to provide the services for this community who they know so much about. And besides that, people want to have their independence and we don't want to be dependent on a system that faults us every time. Thank you. (Applause)

>>SPEAKER: Richard Tommaso

>>AUDIENCE MEMBER: Good morning. Thank you for the opportunity to speak today I'm executive director of community life and I'm a member of the Pennsylvania health providers alliance. There are 19 programs in the Commonwealth caring for over 5 thousand Medicare eligible adults. 93 percent of these folks are also on Medicare, the dual eligible. I'm going to acknowledge my life colleagues today. Joe Ann from life Pittsburgh. Tony from Lutheran senior life and Mark from senior life. Together we offer life in 12 counties in southwestern Pennsylvania by our four sponsor organizations and we have almost half the statewide

enrollment.

And my joke about having to speak is that I arm wrestled Joe Ann for this opportunity but I lost. These are integrative Medicare and Medicaid plans that provide all physical health, behavioral health and long term care services and supports. The primary medical care coordination and majority of long term services and supports are provided by our own staff and we're responsible to manage our participants care in all settings, even when they go into a hospital or nursing facility. That close and immediate care coordination by the life team and the accountability that it's contract providers is not uniquely effective with a population with multiple chronic conditions but seemingly endless array of socioeconomic challenges. In Pennsylvania our success rate of keeping people living in their community is 93 percent and that's with limited housing where we can get services independently and having to use nursing facilities for permanent placing with out other options.

I'm here to ask you consider these goals when creating the MLTSS program for Pennsylvania. First to make clear the important distinctions between life program and health plan based managed care options and to maintain life as a separate enrollment option that people can choose during any month of the year. Secondary to that, due to the frailty of

the population, federal regulations require thorough assessment care planning process that in part determines the person's ability to live safely in the community. Sufficient time has to be built into the enrollment and options counseling process for eligible individuals so they can choose from their alternatives.

Second, to make sure that senior receive conflict free counseling in all long term care options. They should not have financial organizational relationships with providers of care and plans that would benefit from steerage.

Third eligibility is reliable and eliminate barriers this has been echoed by other people here today. Assessment instrument used by approved third parties could speed up the determination process.

Fourth establish rates, versus nursing home eligible. At the very least that align financial incentives and support consumer choice where people would be given the opportunity to reevaluate their options at the point where they become nursing home eligible.

Fifth we support the states approach anticipate problems. Implementing managed long term care and allow time to identify and address implementation issues.

And finally, to promote quality and accountability through measures that include goals and preferences of the consumers. Consumers, families and policy makers should be

able to manage. Very distinct needs that should be addressed, may not be aligned with everyone's care in how they want to live. Thank you for your time and attention. To assist the Commonwealth. In particular for our seniors and we look forward to working with you. Thank you.

>>SPEAKER: Kathleen Leiman

>>AUDIENCE MEMBER: Right now I'm the executive director of Tri-County patriots. But back in 1982 is when I really got started in this whole area with three rivers center for independent living. Back in 1982 community care was not on anybody's radar. In talking to people at EPW at that time it didn't go far. We went straight to legislator, we said when people want to live at home they don't want to go to the nursing home. Everybody woke up and say 10 million dollars in budget. The folks in Harrisburg said what the heck is this. And I'm serious that's what happened. When they said, okay since we don't know what it is, we're going to do demonstration grants. They put out demonstration -- we're talking about Act 150. Hardly anybody bid on those grants back then because nobody knew what the heck we were talking about. So we invented what we were talking about as we were talking about it.

And the Department of Aging got 4 million dollars, they let their money lapse. The department of public welfare,

started these demonstrations to try to figure out -- let anybody do what they want to do and see what works. That's how it got started. So whatever we invented in our little conference rooms that's what happened. And what we invented was a consumer employer model in which consumers gave the paycheck to workers themselves. That's where we started with consumer control. Nobody paid that worker, nobody handed that check over except the consumer himself. Now the system has changed, changed, changed. Has gotten bigger. We always knew when programs got big enough everybody would want to be involved. When there's lots of money flying around everybody wants to be involved. That's what's happened. We seen consumer control deteriorate. We saw big model, big contractors coming in. We're back at the point where people don't know what consumer control means. So we're still here. We still want to be part of this. We still want to work for it the way it is. With this most recent four years, all of a sudden consumer employer model got snatched away into this oblivion place where people are trying to make it work. Doesn't work very well. Back here at Tri-County, we gave them an opportunity to opt out in some way by reinvented consumer employer delegated model. Delegate the employment status to us and there are several centers for independent living who do it this way. And we'll run it like the consumer model. We'll let you

interview. Whoever you want we'll put them on our payroll. That model, it's focused in an agency type model because that was the only choice we had, we still give consumer choice. The agency model can be used as a consumer choice model and it needs to. It needs to work that way. People -- I mean when somebody is coming in and touching your body and this is a lifelong situation, and they're coming in every day and there has to be trust, it has to be done right. Over the years we have been using direct care workers and attendants but because of the way the system is set up. Paper cups, use them and throw them away. There's always another one. Because of the lack of support in the wages and benefits. There's always another one in the door, we'll go out and scramble and find somebody or you'll find your neighbor or a relative or something. That's not the way it should work. I think we all know that's not the way it should work. In our frustration, some of the centers for independent living got together and said the reason you guys are not getting represented is because you're not at the table. So some of us opened the door and said you guys, bring your union in or something to organization because we can't solve it for you because we represent consumers. And sometimes there's divergence in our interest. If I give more money to the program should I add more people to the program, or should I improve wages and benefits. I could

never say that improving wages and benefits was the answer. I couldn't say that as an advocate. Even though I knew the lack of wages and benefits made consumers insecure and made them more vulnerable. Everybody in these community waivers is nursing home eligible. That carries a lot of weight in terms of who they are. Nursing home eligible. That's the level of their need. So when you don't have a community service that works, as a support system which is institutional, if you don't make it work in the community, if you leave people without answers, without responses -- which is where we're at, it doesn't really work. And the only way anybody's getting by nowadays is because area agencies on ageing and centers for independent living will rush in and fill the gaps. We have to stay part of the system. We got to be supported. We would very much like to leave the ombudsman's, have that role. Because nobody's driven all this the way we've driven it. Nobody has done more for the nursing home transition program. Which again, this was invented in the 80's also with hospitals here in Allegheny County. Commissioner Tom forester. Once you went into the doors of an institution there was not much hope of coming back. And we started turning it around. We know what people need and we need to be at the table in the planning. There's a lot to say and a lot of people here that want to say it. We're in a hurry. I know some people

said let's slow this down. Don't slow it down. We're ready because the system is just about as unfriendly and hard to manage as it ever has been. And we need to move quickly. We're glad you came to southwestern Pennsylvania first we think that's fantastic because we're committed to making it better. And we'll do that with you. Thank you.

>>SPEAKER: Keith Klink

>>AUDIENCE MEMBER: I'm a consumer but I'm also a consumer employer. What I seen on that paper the other day, that webinar, I'm very concerned the consumer employer got forgot. A way to opt out the managed care bologna for lack of better words, I know what I want and I know what I need. I don't need people in Harrisburg telling me what I need or what time I need it. I just need, I like the consumer model and I'm going to try to make it work. I'd be willing to help you guys, but the consumer model got to stay. Thank you. (Applause)

>>SPEAKER: Brenda Dare.

>>AUDIENCE MEMBER: Thank you for the opportunity to speak today. My name is Brenda and I'm proud to say I've been an Act 150 consumer for the past 15 years. I'm still using the consumer model. So the first concern I want to raise comes from something I didn't see in the discussion paper is exactly how fiscal management agencies will be chosen when managed care comes into play. I'm concerned about

Pennsylvania dollars being put out to a company in Massachusetts doesn't meet our needs and screen employees or process paper work in a timely manner. A Pennsylvania agency deserves those dollars. And people committed to being consumer employers. I want to make sure and I know it was listed as a priority in the PowerPoint but the Act 150 program is not only carried along but strengthened. I hear every day from the work I do at Tri-County, from agency and individuals afraid to take jobs because they're afraid of crossing the income thresholds for waiver services. People are choosing between whether or not they have the right to get out of bed in the morning and the right for something productive to do with their day. I want to make sure that Sullivan baited choice goes away. People shouldn't have to choose between the ability to get their needs met and the ability to contribute to their communities. But the current system forces that choice. I know there's been reworking of the income eligibility for waiver participants to allow for more flexibility but that's poorly communicated to consumers and service coordination and not utilized in the way it was intended.

Everything about this process needs more input from the experts but you have to reframe who the experts are. The experts are the users of these services. I hear about protecting personal consumer choice. I'm able to coordinate

my own services. That may not be true for everyone. But to assign us any kind of a stringent service coordination entity is going to lead to wasted dollars for those of us who might only talk to service coordinators twice a year. I use many across systems as a Medicare recipient. I have doctors in the UPMC system and doctors in the Allegheny health system. I really worry about the ability of consumers to be able to find in any managed long term care support system a way to encompass all of the professionals they need access to. I want all qualified and willing providers to be mandated as accepted by any managed care organization who implemented long term support services. Because if they can cherry pick providers that creates a conflict of interest we live in a society where managed care entities often operate health systems that own nursing homes. I realize you're going to do the best you can to divert funds to community based but in the current system there is a financial incentive to keep us all under one roof and all in one system because those nursing homes are often owned by the same entities that are going to be providing our long term support services. That doesn't make sense. That puts our lives, our quality of life at risk. It's the right to choose. The right to have those choices respected. The right to make a phone call and say something happened and I can send you medical justification but I need more

services for the next six months and not have to wait eight months or fear that that increase is going to lead me toward a nursing home placement. Hospitals need to be educated so there is less of the opportunity for them to discharge people to nursing homes.

Consumers need to be educated but we need to be part of providing the education. Jennifer you said the state can't come into round tables across the state over and over again. And you didn't think we wouldn't come to Harrisburg to act as advisors. Create a stakeholder committee that has not only a place at the table but a voice in policy development and I'll be happy to serve in that room. Thank you for being here today but let this only be the start of the process. (Applause).

>>SPEAKER: Matt Taylor.

>>AUDIENCE MEMBER: Good morning. I'm Matt Taylor. I am independent living specialist with Tri-County for independent living. I have a unique perspective on all of this seeing as how I've been a part of the disabled community much shorter than a lot of people in this room. I had an injury four years ago and what I'd like to talk on has been spoken about already and that is choice. Because I've noticed from the beginning of my injury that people are going to think they know what's best for you. The day I

woke up after my accident in the hospital the doctor walked in and the first thing I heard was you should find a good facility for you son because he will not be able to live independently before he knew anything about me made that decision for me. I had a good support group and made sure that didn't have. But there's a lot of people that don't have that support that would have thought that is my life. I will be in a nursing home now and I don't have another option because they were not given the option from the beginning.

Also I think that managed care, to me it looks like will be doing kind of the same thing. It will be administrators making choices for people based on paper work. He stated that injuries will be grouped together based on hours. It's based on evaluation. But at the same time, what if someone costs the state too much money, will they be placed in a nursing home then. If it costs too much to keep them in their home, if their provider is not in their network will they be placed in a nursing home. That's what I fear. And I really don't want to see just because we're limited to the choice of providers we have, that it causes someone to be placed in a long term facility. We should have the ability to choose any provider in or out of network. Limits choices will limit our quality of life. And really everything else has been touched upon already. And I hope that we get to

make our own choices in the future on our quality of living. Everything's really been touched upon.

>>SECRETARY DALLAS: So when you said you woke up and heard that doctor say, have to find a facility. You mentioned your supports. Can you talk more about what you think made the difference between being guided toward a nursing facility and being able to live independently. What were the most important things?

>>AUDIENCE MEMBER: For me, was my family. They found triple. And they got me in touch with advocates that told me that is not your only option. It is about education. Like they said in the -- the hospitals really need to be educated. Their first option is put him in a facility. And that's not any of our first options, I know that. And that scared me when I woke up and heard that. My first thought was -- I'm 23 years old, I worked in a nursing home before I got hurt. Am I going to be in a room with out the choice of who will be providing me care. Right now I have someone I trust in my home every day that me and her get along, I get to work on time, and everything works for me. And in a nursing home employees are chosen by administrators not by the person in the room, not by the person receiving the care. And that's who ultimately should be making the choice of who cares for them. It's our bodies it's our choices. And really it's the advocates that helped me find where I

should be.

>>SECRETARY DALLAS: Thank you. (Applause)

>>SPEAKER: Kate Blaker.

>>AUDIENCE MEMBER: Good morning. From Washington Pennsylvania. I have received home based services for the past six years. It has allowed me to remain independent in my home and to work. This has had a great impact in my life because it allows me to advocate for programs that benefit people with disabilities. As a consumer and model employer I have several questions and concerns. My needs vary from day-to-day because of my disability and employment. My concerns are focused around consumer intervention and consumer control. How much choices and control will be maintained under the proposed plan. Who will be responsible for the financial management? What qualifications will be implemented for attendants. How will service plans be authorized and followed. Will I have the choice of provider, service coordinator and attendants. What about requested additional services? Is there a justification and physician script needed? And what if the requested services exceeds. It will impact consumers and providers. How can you assure sufficient services and providers. What about the appeal process? Will services be provided to those as a decision. I recommend centers independent living and offer legal support because they serve the population that will be

impacted by this proposed plan. Thank you.

>>SECRETARY DALLAS: Thank you.

>>SPEAKER: Deb Crouse

>>AUDIENCE MEMBER: I didn't know I was going to speak. That's okay.

>>AUDIENCE MEMBER: I'm sure you'll come up with something

>>AUDIENCE MEMBER: I guess. I'm Deb and pleased to be here today. It was quite a surprise but that's okay. I have been in the company of Jennifer Burnett for quite a long period of time. And I do nursing home transitioning. Have for quite a number of years. And my fear for the consumers, the residents and patients in the nursing homes, you know, you're talking about providers, you're talking about assessment, management, case management so on and so forth. We already have social workers and doctors that are already there saying, no, you can't go to the community. It's not -- you just can't do that. Because it's not your ability to do that.

So now we have you all coming in and saying, okay, what you're wanting to do. And my fear is the people already in a nursing home, how are they even going to step above that to move to the community? You understand what I'm saying? Because we go to discharge planning meetings and everything else all the time. And we hit these barriers and we hit these barriers and then you have to talk to the doctors and

say, okay, well, listen to what we're saying. We have a support system. We have the supports in the community. Oh we didn't know that. Well, listen up what I'm trying to tell you. Because the support system is there. You all have been there with me. And you all know the system. We know how it works. So let the consumer be in control. Consumer control is what you need. It's what we have. And what we depend on every single day. I would like for some of you all to come to our house and tell the boss, my husband that he is not going to go out there beneath that shade tree with his attendant. Do you know where that would end up at? But I'm just saying -- let them live their life. You all do. Would you want somebody telling you how to live your life? Who -- your doctor is going to be. No you can't go down the block to see him because you have to go ten miles down there to see that doctor. I don't think I have too much more to say than that. But nursing home transitioning has been a great, wonderful, we all know it. Jennifer's been there. You need to listen up girl, I'm telling you. Doing the right thing, but whatever anybody needs to have -- what you already heard. I don't need to repeat. Because we all know we'll be the first ones on your doorstep. Okay? I thank you very much. (Applause)
>>SPEAKER: It's already been said? Everyone else did, okay. It's up to you, you're signed up. All right.

Rosey Cooper.

>>AUDIENCE MEMBER: I found out today that I have no notes, I have to speak from my gut. My name is Rosey Marie Cooper. I'm assistant professor at the University of Pittsburgh within the department of science and technology. Near and dear to my heart is I am a practicing physical therapist and our centers for assistive technology as director for the last ten years.

So I'm very glad to see that my clients that have been using technology into the courthouse. Were able to get here. Use AC devices. Our center that we run through the University of Pittsburgh is a community based service but we also use it for education, we teach the future, we have professionals. Somebody mentioned we need to treat this as a professional. In every aspect. From the educational side we try our best. We use our center and learn from our end users. And if I would not listen as a physical therapist as a so called educated clinical service provider, not listen to my end users, but as you can tell I have a German accent. They don't get back to me that easy. Because it does have to make sense. I have to respect the policymakers, I have to respect the medical field. I have to, within our team that consists of a physician, physical occupational therapist, a rehab engineer, a sup pliers and the end user. We are at the time of a visit, when we make a decision about

technology or the impact of a consumers life, we sit together as a team. We insist on our model because it has to be all stakeholders, have to have an input. At the end, with my clients, I give you the education a decision you have to make. It doesn't mean the client comes in and they say, I want a chair that brings me to the moon, that might be a goal. We need to work within the system. We have found out that working within the system providing detailed documentation to Medicare, Medicaid, we get form letters of very unpersonal denials, which I have to say is a slam into our face. I'm a physical therapist that is certified. I'm a specialist in my field. I work with research. I do know the technology, I do have a tremendous support within our excellent research affiliated with the center of excellence from technologies, I have access to engineers and testing results, I know the quality I know what I prescribe. I know I'm within the realms of justification and then I get a denial. And I get a denial because maybe of 500 bucks. I have some clients that sit in ultra light wheelchairs, will pay 1800 dollars for ultra light wheelchair. But a wheelchair recommended for adults is 1200. I'm fighting for 600 dollars, I have to pull the research and show that we do testing and show that a lightweight only has life expectancy for only one year. Doesn't apply to set up and making it efficient. My client sits in a 1200 dollar chair. Next

year my client will be here. He will have no quality of life, I will get him another 1200 dollar chair. By the time five years is over we spent 6000 bucks. If you would have let me do my work the right way, for 800 bucks I could have saved the system 4200. This is a little bit sad that now in our field we as a clinical practitioner have to do the money count down. In order to get quality equipment and I appreciate the opportunity to talk here we have been in contact and we have a whole bunch of research we would love to see our service approach bringing everybody together and have a smart user outcomes, evidence, evidence at how you can save money and how you can improve quality of life.

The other thing is for quality of life, these are extremely smart end users. Completely integrated into society. Full time employees. But guess who paid for these chairs? Not Medicare. Not Medicaid. I have to retreat to the office of vocational rehab. Because the office of vocational rehab will pay if Medicare and Medicaid denied my recommendation. They are the next source. If I do not have the office of vocational rehab for my full time employee people none of these ladies and gentlemen would be sitting here and I think that is a shame. Thank you very much for the opportunity.

>>SPEAKER: Denise Wise.

>>AUDIENCE MEMBER: I hope I do good, I'm not good at talking through micro phones. My name is Denise as you heard. I'm a person with multiple disabilities and I'm dual diagnosed with Medicare and -- thank you -- I need somebody to help. I am covered under UPMC advantage for you. The only -- over the years it's changed a lot. I have multiple disabilities and the one thing is with the behavior health I have major anxiety and major depression and they have cut back on how many times I see my therapist. And I don't have trouble getting my medication but there's some days I don't want to get out of bed because I just don't feel like doing anything. Other days, I can't go to sleep because I'm worrying about everything under the sun, you know. I suffer from macular -- I was born with low vision like lady gaga I say, I was born this way. But macular degeneration just started. I've always had a problem with my vision and quite often I fail and now that I'm going to be 60 I'm starting to suffer from those pains. I have osteoarthritis. I don't like to talk about myself. I have four children. I just worry with me turning 60 in a couple weeks how the future is going to hold because things that I have don't get better they get worse. I have to watch everything I do. I have congestive heart failure. Cardio myopathy. I'm worried I'm not going to have coverage and that if there's too many people taking care of the medical things I don't want to be

told I have to go to a nursing home because I don't want to live in a smelly little corner with no one there I know. I like being around my family. We argue sometimes but they're there for me. And it's hard and they keep raising the age for a high-rise. So then I don't have to use steps, I could use an elevator. And I worry -- I feel bad worrying about these things because there's people who can't make a decision and they have to be put away some where in a place with no independence it's like a long time ago you read about where even if you were blind you were put some where and people with mental illness they didn't come out they stayed in the house because they were ashamed -- the families were ashamed to let them be seen in public. And I hope it don't ever go back to that. But I want to go out when ever I want to. And when I'm able. I don't want to be told I can't do it. And I just think that -- I hope that the behavior health don't get too messed up with everything else because there's a lot of different medical problems that people have, mental problems that it's safer for them to be, for us to be able to talk to our doctor when we have an episode than it is to sit and wait for six weeks until your next appointment. And thank you. (Applause)

>>SECRETARY DALLAS: By the way, happy birthday a couple weeks in advance.

>>AUDIENCE MEMBER: It's the day the fire works come out.

>>SPEAKER: Linda Custo.

>>AUDIENCE MEMBER: I have some prepared things to say. Here's some of the things I heard that inspired me to say other things. I feel like I'm being pushed into a medical model. I feel like some provider is talking about being my parent. I don't need a parent. God already gave me a parent. I have the right to take risks, I have the right to run my life. Not the way the medical professionals. I road a bike, medical people don't know what I can do. I know what I can do. Now that I've passed that 60 mark, there are some things I can't do any more but I did them and my life is richer because of it. I don't need people to tell me how to live. And I don't need a union either to tell me how to live. I think that it would be illegal for the state of Pennsylvania to say only agencies that use unions are allowed to be providers. I think that's illegal because you're not allowed to use government money to encourage or discourage a union. So therefore there must be providers that are not allowed to be providers that are union oriented.

I believe that I don't need my provider to have a special certification. Like Medicare. Everybody have a Medicare certification. That's not going to give me the quality of life I want. And also I employ my own people. But I think that the state doesn't have the right to tell me

who's going to come in my door and touch my body. I believe that's my decision. And since I'm capable of handling it that I should have a right to.

I think that when you start to get better into this thing that you all should abide by the same rules that center for independent living do and 51 percent of the people in that room should be people with disabilities who receive the services. Not just people with disabilities but people with disabilities who receive the services. Because we are the people who know what you're doing wrong to us. Because I hire my own people, I strongly think you need to have a penalty for providers that don't do things on time. I have to wait several weeks sometimes with nobody in my house. That's not okay. To me that's abuse and it shouldn't be happening and you shouldn't be able to tell me this is the one company I have to take. I should have more choices. When you have only one choice, the quality drops because they have no reason to be better. They're going to get the same money, no matter whether they do it well or whether they do it poorly. I've had to go to the hospital because it's the only way I can get them to fire somebody. They won't give me the application until they say I can get an application. They took the raise paper off the available things. So now I have to have their permission to give a raise even though I'm well within the range I'm supposed to

be in. What right do they have to say when I can have a raise paper. It's not their decision. I'm the employer. I'm staying within the rules so they have no reason to be keeping that from me. And it's wrong. It's wrong that somebody -- that I can't even get to -- can block my life. They live, even Arizona, they're all over the country these people I have to talk to and they use a gait keeper. Managed care worries me because I feel like I've been put in managed care already with PPL. They decide whether I have nothing or something. They decide -- to get a background check takes three days. They tell me they don't have it for seven weeks. There's something wrong here. And I feel like what they're doing is they're bringing costs down at my expense so they keep the contract. That's what I feel like they're doing. Because if they're denying me care then you're going to like them and keep them. And that's not okay. You know, and managed care can be like that. And I'm dual eligible and I very much like to be dual eligible but now it sounds like you're trying to take that away because I can cross systems. Well people with severe disabilities, who you're going to play with in this game, can't always use this doctor because this doctor doesn't specialize in this problem that I have. It's that doctor that specializes, and this doctor tells -- like right now. I finally got to the right professional and they took me off the pills they had

me taking because they're counter productive. I need to have access to the doctors I need. We got a great medical community around here. I did give them a hard time sometimes because they try to tell me how to live. But we do have very good doctors. And why do you want to limit my choices. Why do you want to take away the doctor that knows my disability and say I have to use these doctors because this high all mighty managed care system says I have to. I have to have a certified something or other as my attendant. Why can't I have the person that I want. I train my own people. I know what my disability is. And the medical community doesn't know what my disability is. So even if they have a doctor over there saying how many hours I need that doctor doesn't know my life and they're never going to meet me and never know what I want. They should have to come live with me if they're going to decide how many hours I need, for real. So I wrote some stuff down here, but the medical model can't come back. It can't. It can't where a doctor and this nurse -- when we need a nurse a nurse can come in and do the wound care, but we need choice of real people, not professionals. When you start telling me I have to see professionals my quality of life goes down. I don't need a nurse's aid to come into my house. I need somebody that I can talk to that can follow my directions. That doesn't take a certification. It takes just -- and I can

get rid of you if you don't listen to what I have to say. And that's good. What's bad is you make me wait 7 weeks and I have to go to the hospital because it costs you more money then because this company has a right to deny my care. (Applause)

>>SPEAKER: Robert Ferguson.

>>AUDIENCE MEMBER: Hello. I'm Robert. I'm the director of government grants and policies at the Jewish home health care foundation. We would like to thank the administration for it's leadership and expanding access to home and community based services and also beginning the phase of a managed long term services and supports.

And in the interest of maximizing the success of this directional we would like to offer some ideas and these are recommendations are addressing two points. One being that the long term care system needs are local and two if phasing in a managed long term care needs to be done carefully and transparently with adequate planning.

First the idea is to establish an advisory group of consumers and stakeholders with correct access to the leadership of the Department of Human Services. The Department of Aging and the Governors office in order to help guide the development, implementation and operations of a managed long term care. And second to also form a local advisory board in each county to offer and give a feedback

on implementation, to monitor consumer protections and quality measures and ensure on going quality improvement.

And a third to enhance the likelihood of success by a meeting with other states to talk about the lessons learned and their experience and consumer experience.

And fourth, in the request for applications from the MCO's we suggest to incorporate the best practices from the other states to ensure the availability of the nonmedical community services such as meals on wheels and respite services and transportation. And also to create roles for area agencies on ageing by assuring they have a role in the assessment over sight and care coordination process and also a role in, by giving service to Pennsylvanians at risk of nursing home placement to avoid preventable enrollment to nursing homes.

And measures to improve behavioral health access, palliative care access and advanced care planning. And lastly to include a program for a palliative care and advanced care planning based on the beneficiaries goals, values, preferences, and a choice list.

So in summary, these opportunities to include advisory committees, advanced care planning of palliative care and creative roles for the area agencies on ageing here in the community as well and avoid self interest. I hope these comments will help the administration phase in managed long

term care and we stand ready to participate in partnerships in the best interest of the Commonwealth. Thank you very much. (Applause)

>>SPEAKER: Patrick Griffith

>>AUDIENCE MEMBER: Pretty much everything that has been discussed is basically what I was going to discuss. The term nothing about us without us. That means choices. When you become disabled, when you have a disability, not having choices is something that all of us fear. When things happen in our life that we have no control over it brings on fear. If, when you get hurt or something and professionals always think the worst. The first thing they mention, as it was mentioned is going into a nursing home. Would you like to be told that? None of us do. And this managed care, that is the scariest part about this. We're going to be told that we're not really going to have choices of what we're going to do and what we don't want to do. I am a consumer. Consumer delegated model and I love having the choices of when my worker works and how many hours and so forth and that. Without those choices, it makes it really hard on us.

I'm not too good at speaking.

We should have the right to opt out of the managed care. If we're happy with our services we're receiving now, why should we be forced to take something -- I mean to be put

into the managed care. We should be entitled to the fee for service arrangement. To preserve our choices.

I feel that consumers are going to be pushed away more and more from making our choices. We're going to be basically told what we need to do instead of us being able to speak up and say what we want. But the part of nothing about us without us is basically being taken away from us. Slowly but surely. Not quickly but slowly but surely it's being taken away. I guess that's it.

>>SPEAKER: Matthew Lynch?

Terry Zellue? Marsha Simon?

>>AUDIENCE MEMBER: Hello everyone and thank you for allowing me to speak today. After hearing everybody speak I decided to take some notes, I wasn't prepared as I should have been for today because I wanted to hear what the participants of the program really had to say.

So with that, I would like to start off with a thank you. I would like to say thank you, first of all, Marsha, I work for comfort care senior service, we are nonmedical as well as skilled. The majority of our clients are in Allegheny County as well as Westmoreland.

I would like to start with saying thank you to Allegheny County area on ageing who has done more with less and stayed

committed to our community and ageing population. Mildred has strived to get to know our patients knowing there's nothing standard in community care. Going above and beyond for consumers after standard business hours and at the expense of their personal lives and regardless of personal feelings I would say no centralized call center in Harrisburg anywhere in the state or other states can do the same as the consumer can do for themselves or as a care manager can do for them after having spent time in their homes, listening to their stories and that is so important.

Bias lack of education and lack of training at the hospital level and not enough empowerment at the consumer level is the major concern. Funding is necessary at the fore front of this program. Realizing that it's the care givers and consumers that need the support. Not more policies or procedures, there is no money for that at the service provider level and no money in that at the consumer model level as well.

With a personal story yesterday I was on the phone with a mother who was taking care of her 33-year-old son who had an accident when we was 18 the day he was supposed to graduate from high school. When I spoke to her she said that over the past years she has had to step back from her job because it became so demanding and there was constant turn over in the home, care givers coming and going. She

wanted someone who would put their cell phone down and pay attention to her son. When that accident happened that was the first hit to her. And every time a caregiver walked out that door that was the second, third, fourth and fifth hit because that was someone giving up on her child. The same way the doctors and nursing home said she couldn't bring her son home. It was her having to step back and use a care coordinating agency like us that she was able to finally get service ins place for her son. So the one thing I would like to say is that as someone who is the child of immigrants, someone who has used those services for her grand parents where their first language is not English and they, you can spend hours and hours on the phone with someone in Harrisburg or in Medicare and they simply just don't understand and they still want you to sit with them and explain every form. Those service coordinators here in Pittsburgh and meeting with them and explaining and working with us, the providers of these services are the most important and crucial part to their independence. It is team work. It isn't something that can be managed. I look at hospitals owning insurances, owning nursing homes, owning assisted livings and home care agencies, they can come up here and provide more regulations and more training. Forget about that. We need to keep it simple. We need to provide the care and let our consumers choose their care. Thank

you.

>>SPEAKER: Bill Christner.

>>AUDIENCE MEMBER: Hi I'm Bill I'm a former executive director of centers for independent living, former team leader for the protection rights for people with disabilities at the disabilities right network. I'm a consumer and individual with disability. I'm over 65 and I'm usually the illest person in the room but maybe not this time.

I just want to say a couple quick things. The devil's in the details. And there's no details in the discussion document. And I want to reinforce what Mildred and I think Leslie said about the time frame. We need to see those details. We need to know what's going on and we can comment, I don't think that's going to happen in four months. So I'm a little concerned. I'm a lot concerned about that. And I want to reinforce what Kathleen said about the money. Follow the money. When there's money involved a lot of people get involved. And I think that managed care system, unless the managed care companies are going to be required to pay for nursing homes out of the capitated rate this will not work. Nursing home costs will not go down because the managed care companies, when they get people who use services that are close to the capitated rates they're going to do everything they can to dump them.

If it's separated cost from the nursing home they're going to push those people out of managed care programs and dump them into the nursing homes and it's not going to save money. But if they're required to pay for nursing homes out of that capitated rate they will work hard to keep people in the community.

I think that's the point. Follow the money, if there's a way for the nursing home industry to continue to grow then managed care is not going to work. The easiest way to fix this, by the way, is to change title 19 and make home and community based services the entitlement program and make people get waivers to go to the nursing facilities. This is a done deal. (Applause)

>>SECRETARY DALLAS: One thing to add, nursing homes are considered to be part of the program so the recommendation you made is something we agree with.

>>SPEAKER: MILTON.

>>AUDIENCE MEMBER: How's everybody doing?

First of all my name is mill ton. I'm independent specialist for the center of independent living Wilkinsburg. I've been involved with the center administration. Since Corbett left, up until Corbett we were able to dial up and talk with the administration. I'm glad we can talk to you guys again. I got this ADA 25th anniversary. I wish there was a button that said here we go again. I say that because

as we talk about service coordinators and coordinators, when it was caseworkers, now it's DHS and caseworkers didn't know what services was. I had to call the caseworkers. They would ask about a different waiver and the caseworker would say I don't know about the waiver. We had to go to a consumer system to find out what the waiver system was. The state had an obligation to train their caseworkers and didn't do that. How are you going to train service coordinators with what didn't do before. Before Corbett came in and messed up the world for Pennsylvania the system wasn't really that bad. Again nobody listened again. Here we go again. In Pennsylvania for the last 100 years, 50 years about what we need, what serves us best and here we go again. Telling us about managed care again. Why do you have to go to 15, 20 other states to get recommendations to bring back to us. We have been telling you what we want and need. Can one of you answer that question, please?

>>SECRETARY DALLAS: I think the reason we're here today is we want to listen. I was the executive deputy during the Rendell administration and worked for Secretary Richmond. I agree the department has listened as well as it could. Today is our effort to start changing that we're going across the state. The department has got cut off from the world. We're trying to change that. We're here today to listen. We're not just listening to other states. We're

listening to folks here and best practices and folks from universities and everybody we can. But we do want to hear. We're here to hopefully, why this session today will be treated as a sign of good faith and we are here to listen and try to figure out what works for Pennsylvania we may ask other folks from around the country but the most critical folks we want to hear from is from you. Over the last couple years agree with you. The department has gotten cut off from the world I'm going the best we can to change it. I can't do it over night but we're starting to listen.

>>AUDIENCE MEMBER: Again as you guys move forward we move forward to try to be as independent as possible and consumer control is number one. We must have consumer control.

Also again as you talk about coordinators, I don't want to have to train a professional. You know, when I call I speak articulate sometimes. And sometimes the professional don't get it. I say wow, I got to train the trainer. And the trainer says, well we'll put you on hold or get you that. It's like, wow there's something wrong with the system. We come back to the here we go again thing. I'm going to ask you guys again, throughout Pennsylvania you got a lot of testimony and documentation and saying things over and over again, some different. Please listen to the people of the state of Pennsylvania. Other places, you know, that's cool for them. But we're asking you to pay attention

to what we're asking you to do in Pennsylvania. And secondly, on Tuesday, he mentioned something about you guys were possibly questioning attendant care hours, working between maybe 6 and midnight. Have you had conversation about that? Time when attendants can work.

>>SECRETARY DALLAS: Jen might be able to answer your second. The most important folks in this conversation are folks from Pennsylvania it's a solution that has to be right for Pennsylvania. There are things that might work in any other state but it has to meet the needs of Pennsylvanians. Doesn't mean we're not going to listen to other folks but the most important voices are here in Pennsylvania

>>JEN BURNETT: I'm going to have to look into it, I don't know anything about it.

>>AUDIENCE MEMBER: Okay. Thank you very much. Give consumers consideration first. (Applause)

>>SPEAKER: John.

>>AUDIENCE MEMBER: I was so excited to be the first one to get to say good after noon and I don't get to be. I am a member of the disability community. I've always been a member of the disability community. Just didn't know it. You're a member of the disability community. And so are you over there. You may not be today, cognizant of it, but disability is not a question of if, it's a question of when. If you live long enough someone in your family, some of your

friends, yourself you're going to be impacted by the choices that you make here today. You're going to be impacted by this program because it's going to be in place for some time.

I work in assistive technology. And I started with three counties. Went up to seven. Met ten so far. And in that role, I work with folks in nursing homes, I work with folks in their homes, and I can tell you with no reservation that those who live in their homes live a better life. And it's a lot of times through what they can access with assistive technology and with home modifications. But the home modification and assistive technology access is limited. It's a problem. The process does not work right now. And when you hamstring people in trying to stay in their own homes by not being able to get ramps, by not being able to get that equipment and not being able to get what they need to be safe and happy in their own homes, they end up back in the nursing home. We need to address these issues to make sure people have what they need to be safe and happy and secure in place. So that they don't end up back in the nursing homes. I can tell you right now we have a fabulous community in southwestern Pennsylvania. But for all that, when people are on waivers, when people have access theoretically to programs that are going to pay for this equipment and they're told they have to wait, 3, 4, 6

months, I can't wait 6 months to pee. I can't wait 6 months to go to the grocery store. It's not going to happen. We have wonderful people in our neighborhoods who are willing to donate time and materials and generously give of their expertise to help people solve solutions in their own homes. And it's fabulous that we have these people. And I'm so glad to be part of a community that will do that for their people. But they shouldn't have to. Because they already have access through their waiver programs. Through the opportunities that we have set up in the state. But it takes too long. And it's too hard. I need you to make sure that these are included when you work on this program moving forward. It has to be part of the solution. Because otherwise nursing home populations are going to go up. And home and community based services are going to go down. Because people are not safe in their homes. Thank you.
(Applause)
>>SECRETARY DALLAS: We agree with you about the home mod process taking way too long. Sometimes the process just adding a ramp to keep them out of a nursing home is not excusable that the system is the way it is. The Governors budget includes an initiative to speed that up. We're already at work on that for us our commitment again folks are talking about the fear of going into nursing homes. We want this process to move to people in the community. This

whole process here we're not waiting to get started on the home and community based mod. That's a simple thing we can fix and it's not acceptable the way it is now. We're going through the process of fixing it but 100 percent agree with you.

>>AUDIENCE MEMBER: Three and a half years.

>>SPEAKER: One of the things we did, we put out a document last week which is basically a concept of trying to get to a more streamlined approach so we don't have these wait times and have accountability built in there. Too often we're seeing a ramp is installed but it's not right. Which defeats the purpose. So what we did is put out a discussion document to develop a new model and new approach to do this to speed it up and make it more accountable.

>>AUDIENCE MEMBER: Where is that document?

>>SPEAKER: It's on our website and I can get it to you. We can have conversations about it. Because it's a discussion document. We want to get some ideas and input in it and we want to move forward with substantial changes.

>>AUDIENCE MEMBER: I would like to ask them, there recently was a pro posed change to the IED waivers they're going to pay for less assistive technology in the attempt to provide more services to more consumers so they can pay for more hours but less access to assistive technology and less access to independence, they're going to be relying more

dependent on people coming into their homes to serve more people.

>>SECRETARY DALLAS: The last thing I saw in that part of the DHS with regard to assistive technology was expanding the use of assistive technology maybe we can follow up after the meeting and give me more detail.

>>SPEAKER: John was our last speaker. If anyone that hasn't been able to present -- Daniel?

>>AUDIENCE MEMBER: Last but not least, I guess. I'm David I'm here to represent adapt southwest PA and I want to say that we had a lot of great speakers here today. Brought up a lot of important issues. But one of the things I wanted to make sure got mentioned that I didn't hear was make sure that you communicate these changes to the consumers. Make sure that they know these changes that are happening because these are big changes. And there's nobody who takes better, or more active control in their lives than these changes would. And the last administration made a big change without giving a lot of heads up. They had about three months to notify that things were changing and they weren't really included into it. And not even the providers were very involved or included. So we want to make sure that this information transfer is not happening in a vacuum. Not all the consumers of southwest PA are here today but all consumers will be affected by these changes. Make sure as

you make these changes known, include them, please. It's too important. And I have to say this one more time -- nothing about us without us. Don't make these changes without letting us know what's happening. You'll get a lot more flak if you're finding out that changes are happening and I didn't know it was happening. We have a lot of heads up here, I feel like we have a little bit of heads up. Make sure that you get that information out there to the consumers. We'll do our best but you have a big audience and we don't have the reach that you guys do.

Secondly, you heard it a couple times that doctors and insurance companies don't always have the consumers best interest. Sometimes they want the safest environment, sometimes it's the most cost effective environment. Make sure there's checks and balances to make sure that someone's services aren't going to be -- oh well that doesn't really fit in our financial structure or if I don't know if it's safe enough for you. Make sure the consumer has a big input as much as doctors and insurance companies because when safety is all that you're thinking about, well a padded room is really safe but it's not a good place to live very long. It's not in everyone's best interest to be safe all the time. Sometimes you need to take those challenges and risks and get out in the community and live that better lifestyle. It's too important to too many people.

And last but not least make sure that the people who are at the highest risk or high need community members aren't shoved away because of their cost to the insurance company or HMO's. Those people are given the same rights and same opportunities to live in the community as everyone else. Just because they have a high cost to their needs doesn't mean that they won't be getting the same care. Thank you.

>>SECRETARY OSBORNE: Is there anyone else that wants to offer comment?

>>AUDIENCE MEMBER: We used to be able to talk to DPW that doesn't mean we always got our way. You know, I could tell you why this isn't going to work. And sometimes they change the decision, sometimes they didn't. But we can tell you before you make the mistakes. Because we know what's going to work and what's not. So keep us in the loop.

>>SECRETARY OSBORNE: Absolutely. I appreciate those words. We started a little over two and a half hours ago. For those that stayed we're grateful for your presence and those who had to leave, Secretary Murphy had to head back to Harrisburg earlier than the rest of us. In closing, those of you who spoke today and shared your personal stories and shared how difficult it was for you to get up and speak. We applaud your courage, your passion, your diligence, persistence and willingness to share your stories as personal as they are and those that advocate on behalf of.

This conversation we started earlier today it continues. I understand from someone who's been in the ageing network for 25 years now as an advocate for elder rights and persons with disabilities. I understand this is the same old stuff, here we go again. I appreciate that very much but if I didn't believe this was our time with this administration that we could make this happen in Pennsylvania I wouldn't have said yes to a nomination. None of us would. This is our time to make this happen. And we can't do it without you. So let the conversation continue today so that individuals who need to access home community based services can continue to have their voices heard and have choice and have direct care work force that's qualified and just as passionate as all of you are. I said yesterday as we closed in Erie and I envision saying it in the rest of the sessions, if passion in the room could solve all our problems we would have no problems to solve. A wise mentor told me that. But the conversation continues. The dialogue continues as you leave this room today if you have additional cares and concerns you didn't speak about today, it's been mentioned that there is a wall, that's not our baggage to carry forward. If we do that I hope somebody shows me the door. Let the conversation continue. Enjoy this beautiful weather. We enjoyed being in Pittsburgh and look forward to walking this walk with you.

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