

MEDICAID LONG-TERM SERVICE AND SUPPORT

PUBLIC FORUM

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>>SPEAKER: There are a couple seats in the front if you're interested. If you want to stand that's okay too. I know some people don't like sitting in the front seat, but if you want there's a couple seats up front. We have three seats right here.

>>SECRETARY OSBORNE: Good morning. Maybe I don't need a microphone. If I project can you folks hear me? Awesome. Good morning. Feedback is helpful. I know you are here, I said to Secretary Dallas. I'm Teresa Osborne. Secretary of Department of Aging. It's thrilling to see so many people filling the room with us this morning for such an important

initiative for our Commonwealth. Secretary Dallas and I as well as our colleagues in Governor Wolf's cabinet started our journey together. A journey engaged in human services to ensure that we have the capacity and the competence. We know we have the passion because if we didn't this room would not be filled with all of you folks here in Erie today. But our desire is to ensure that we provide the best experience possible for folks who engage in services, and supports in homes and communities. That is our challenge. This is our opportunity working in Governor Wolf's cabinet making sure we balance and reform to do whatever we need to do to ensure our system of services and supports in the Commonwealth of Pennsylvania is the best it can be. For me personally I have cut my teeth in ageing services working in the northeast part of our county. Secretary Dallas hails from Philadelphia. He'll take us through this PowerPoint before we get to the commentary today.

We cannot do it without your input. Each of you, if we had the time this morning to go around this morning could talk about your own life experience and your own journey, the good experiences, the bad. With regard to engaging here in the Commonwealth of Pennsylvania regardless of your age. Over 60 or under 60. Age is just a number. I didn't coin that someone else did. But regardless you have experiences and opportunities some good some bad. We need to hear from

you so we can again, make this system in our Commonwealth the best it can possibly be. To learn from mistakes when they happen. Not just here in our own Commonwealth of individuals who have engaged in the system but folks in other states who have done the same. That's why we have this team here today. From the Department of Human Services, myself and a colleague from the Department of Aging going across the Commonwealth and without this engagement our experience and opportunities would be fruitless. So we need to hear from you. Regardless of the comment, question or criticism. This is an incredibly important task that's before us. So the fact that the room is filled, seats are filled -- there's a couple available if anyone is standing in the back. Again, I am thrilled to be here with you, happy you're willing to engage with us and this is the first opportunity of many. The conversation continues. Conversation takes dialogue and give and take. This is the first of six public hearings. We need to hear from you ongoing. As our Commonwealth moves forward in the days and years ahead. With that being said I will turn a real microphone over to Secretary Dallas who will say a few words and walk us through the PowerPoint presentation.

>>SECRETARY DALLAS: Thank you Teresa. She said perfectly why we're here today. We have a short PowerPoint. There are copies of a longer PowerPoint. They are in the back.

We're going to walk through the shorter version today. I want to introduce a few folks. The woman to the left of Teresa is Jen Burnett department of long-term living and Brandon Harris. Which is the job I had when I worked for the department of welfare under Secretary Richmond. I worked for Governor O'Malley. It's beautiful out here at the convention center. And Mike took us to Altopachino and I'm getting a grand tour here for the first time. So it's beautiful here, thank you for coming here today.

Secretary Osborne said very well why we're here today. So go to the first slide --

>>SPEAKER: We're switching presentations --

>>SECRETARY DALLAS: Okay. What we did to kick off -- the Governor has a mission, transition to managed long-term services and supports. The reason the Governor is launching this is he wants to provide folks with an opportunity to have more choice, live in the community and age in place where ever they can and have care tailored to individual folks and needs and hopefully produces a better quality of life for folks and folks get the most they can out of life. For us the way we started this we launched a discussion document and it's what it sounds like. We put out a frame work for how we might do this. As Secretary Osborne said -- I might call you Teresa by accident -- but we want to hear from you. We want -- the first part of the discussion of

the PowerPoint we'll give you an over view and some basic information. You can ask questions about how this would work and all that stuff. But we also want to hear from you about the parts you like, the parts you don't like -- and the parts where you think if you did this instead it might be better. We're going to have meetings like this here, Pittsburgh tomorrow, Harrisburg, Altoona, Philly and Scranton. It's a road show. This is the first stop on the tour and we want to hear about what you have to say. Have we got to the right PowerPoint presentation yet?

So what I was rambling before is these two bullet points here. Hopefully today we can give you a better idea of what managed long-term care is. Please feel free to ask any questions about how it might work. But we also want to give you an opportunity to say, hey we like this idea, we don't like this idea. Maybe if you changed this piece it might work better.

A little bit of a curve ball -- can you go forward a couple slides? Okay. So can folks see this?

>>AUDIENCE MEMBER: It's very hard

>>SECRETARY DALLAS: Maybe take the lights down in the front a little bit. Look at that.

So when the Governor launched this initiative it was with a couple goals in mind and this is what we're looking for. I won't read this 100 percent to you. We want to

strengthen the care we have and promote health and safety and program innovation and the two most important to me which is enhancing opportunities for community based services and incorporating person-centered service plan design. We want to give people the choice they want. Every poll says 95 percent or above Pennsylvanians want to age in place. They don't want to go to institutions. Right now in the state we're a little bit below 50/50 in terms of being able to serve people in the community. That's largely a result of how the system is set up. It's disjointed and fractured. Our bet is if we do it the right care and manage care better more folks can make the choice -- which 95 percent -- there's not a lot of polls that definitive. 95 percent would rather age in place. Our hope is we can get the 50/50 split we have up to much closer to 95 percent. We're just not there yet. The other part is getting choices for people. Getting quality service for people and giving people the choices they want to make those decisions on their own behalf.

Sorry, but can you back up?

So I'm certainly not going to read all this to you. If you want to look at the PowerPoint at your leisure. But right now we have a fee for service model. There's a little bit of dismanaged care. And that leads to any provider willing to accept a payment can participate. We don't have

necessarily only contracting with approved providers, ones who provide higher quality of services. We have no care coordination. So we know folks don't get the best care if their care is not coordinated. We call dually eligible for Medicare and Medicaid. When their care isn't managed their health isn't as good. Our hope is by working with managed care companies we can get people better services and give more people the opportunity to live in their community.

So if you can see, this I think breaks it down more easily than the details and any detail questions. If you look at the three components, physical, behavioral, long-term services supports. Physical help, they're fee services. They're disjointed and don't lead to the best care. One part under managed care, behavioral health, but because the rest of the system is fee for service and a little fractured they have limited coordination. Our hope is taking these three pieces and combining into one organized system. Combining into one system so we can get you the services you want and let you make the choices you want and let you have access to the best quality of service we can. Keep going --

I'm going to turn it over soon to Secretary Burnett. I want to close, the discussion document we have is a frame work. We want to hear the concerns you have, the things you like and don't like so we can fill in that frame work and

move forward. Right now there are folks in Pennsylvania every day who would rather live in their own home, be in the community, who get pushed or nudged into nursing homes when they don't want to. And to me, I want to try to change that. The Governor wants to try to change that and Secretary Osborne wants to try to change that. Please let us know what you want and don't be shy. Hopefully with all the people in the room I have a feeling they're not going to be shy. I'm going to turn it over to deputy Secretary Burnett.

>>JEN BURNETT: Thank you. Can people hear me? Is this working?

>>AUDIENCE MEMBER: Yes.

>>JEN BURNETT: Okay great. Good morning Erie. It is really great to be here. We had a five hour trip from Harrisburg yesterday in nice weather. Arriving here in Erie we got to watch the sunset. So we're really happy to be here and I'm extremely pleased to see the turn out. Believe it or not we came here expecting 16 people. That is how many people registered. We knew we were going to have people walking in but we never expected such a great turn out. So congratulations to all of you for your interest and willingness to participate in this process. Because it will be a process.

I have a slide up here about the populations that we're

going to be serving in managed long-term services and supports but I just wanted to tie into a few things before I move into that talking about the populations. I wanted to tie into a couple things that both Secretary Dallas and Secretary Osborne spoke about which is our goal really is to improve the quality of care, to improve health outcomes. Health and well being outcomes. And make the system less confusing for people and we also recognize an opportunity in Pennsylvania and I'll talk about that in a second here -- that there are a lot of people who are dually eligible for Medicare and Medicaid and they receive services under those two systems under a disjointed way. There's not a connection between those two programs and those two programs are essential to people's health and well being. Part of why we're doing this is our opportunity in Pennsylvania. And I think one of the fact sheets that has been provided lays out the numbers of people that are in that dual eligible population.

Dual eligible adults excluding those with developmental disabilities over age 21 eligible for Medicare Part A and or Part D also eligible for Medicare benefits. Those are the groups we envision including in this. The second group is all individuals over the age of 18 and who are eligible for the Medicaid, Pennsylvania Medicaid program. And the third one is non-Medicaid recipients of the Act 150 program.

Those things I just mentioned are what our collective best thinking should be -- we do welcome your suggestions and ideas about whether those are the right targets. We started out by saying this is a discussion document. We purposely made it a discussion document. We're not dictating what this is going to look like. We want to stimulate conversation and your ideas. I have been meeting with people in Harrisburg about this the last week and a half and one of the things I consistently hear is that many people don't understand what managed care means for them and what it means in their lives. While I agree that it is a problem and we'll be out on the road over the next few years educating people, what is important from our perspective is your experience and what works for you. We want to hear about what's not working and we really hope that you can give us that kind of feedback so we can build this program in a way that's going to work for everyone that needs it.

Person-centered planning -- I like to say the areas we want to focus on. As we looked at this, some of you may have heard that we had engaged the University of Pittsburgh to help us with framing this out. They provided us with a lot of research. A lot of information that's available, mostly on the internet but they really did an environmental scan of all the research that's out there on states that have implemented managed long-term services and supports.

Before I started this job, five weeks ago, I had been working at the centers for Medicare and Medicaid services in Baltimore for four years, my experience there tells me a lot of states are turning their states into long-term managed long-term services and supports. At this time there are 22 that have that. Pennsylvania is one of them. For two discreet populations. We have autism program which is a managed care program and we have our life program, we have about 5 thousand people in life and that's the program of all inclusive care for the elderly here in Pennsylvania called, nationally it's called pace, but here in Pennsylvania because we have pace pharmaceutical program, here we call it life. In addition to the 22 states that already implemented long-term management long-term services, there are many states similar to Pennsylvania and put their hand up and said, we are interested, tell us how to do it and help us get there.

Taking the document we got from the University of Pittsburgh we looked to the CMS Medicaid.gov website, if you Google, there's a search engine on that website you'll find a whole section full of guidance on what is an appropriate way for a state to implement a good long-term management services and supports and this is outlined in that document. It provides a road map for how to do this right. That was guidance published by CMS in 2013. Fast forward to 2015 and

last week CMS published a notice of proposed rule making in which they're codifying this guidance I'm about to go over with you. This is the highlights of what CMS expects.

The first is person centered service planning. CMS is serious about states focusing on and using methods for doing person centered planning. It's about starting with the person and figuring out what they need and helping them figure out and articulate what they need. Everything we do around managed long-term service and supports, we're going to have expectations that it is person-centered. Whether it's service planning, service coordination or service integration. All of that we expect to be person-centered. We also will be -- Pennsylvania has a long history of a consumer directed program. When Act 150 came into existence. So we plan to continue that option of consumer directed personal assistance and that will preserve consumer choice. I mentioned 22 states, some have gotten it right and some have not gotten it right and we are out there learning from the ones that got it right and also from the ones who didn't whatnot to do. There's a lot of experience we'll be able to take advantage of as we move into this.

We also will be expecting -- this is really a core of any long-term managed. This goes by different names. Service coordination, care coordination -- all of the above. But we expect that all of the services in the service

package will be very broad. I mentioned the Medicare, Medicaid connection. So we are including in the service package the Medicaid state planned services, Medicare home community based. Medicare Part A, Part B and Part D. And as we learn more about the target population. We will be growing and adjusting as we go. We plan to use service coordination to ensure consumers have integrated. It goes beyond that. It really goes to supporting people to have integrated care between their healthcare, behavioral health and their long-term services and supports.

Access to qualified providers is really a key component of how states achieve good managed long-term services. Provider qualifications is very important as we roll this out. Secretary Dallas mentioned emphasis on home community based services. Some of the research that the University of Pittsburgh was able to provide us with really demonstrates that states that roll out managed long-term supports program we unanimously have gotten a better balance. And that is one of our goals we highlighted here because we wanted to be front and center of where we're going with this. We recognize that people want to live in the community and we also recognize a role for facilities, I'm sure all of you do as well. We have to figure out what that role is as we move forward.

This next one, performance based payment incentives.

One of the nice things about going to managed long-term services and supports system -- today as opposed to six or seven years ago before the passage of the Affordable Care Act states have a lot of tools to do some of these incentives and we're going to be taking full advantage as we look at rebalancing the system to incentivize for better outcomes and pay for performance. We're looking at doing some financial incentives to support better health outcomes.

Participant education enrollment support. This is a huge thing. As I mentioned at the beginning, we're out talking to people and providing education and talking to you and trying to help you understand what it is that's changing and how it's changing. This will be an on going thing as we move forward. We expect to have very strong enrollment support and participant education. And when this state rolled out health choices many years ago this is one area where we really learned about. We learned we had to do a good job with this or it might not work so much. We're committed to this idea of participant education. Some of the things I hope to hear from you today and people we listen to as we move across the state with this, is really how do we do that well? What works, what doesn't work. So we're looking forward to some input on that.

Preventive services. These are some preventive services but I will tell you, preventive services are not something

that are currently available wholesale and whole cloth in the current system. They're like, oh by the way kind of things.

So we really do want to focus on preventive services. The Affordable Care Act again has a tremendous focus on preventive services. There's a lot of new opportunities in the Medicare program for preventive services and we really want to learn from that and continue to make sure that we offer preventive services. Because we believe that the better you help people prevent bad things from happening, like a hip fracture or something like that, the healthier they're going to be.

Participant protections. We haven't really begun our journey for the centers of Medicare or Medicaid services other than talking with them. But we're going to be working with them to try to achieve. We really are hoping to achieve some alignment between how Medicare does participant protections. Today they're very different and confusing to seniors and people with disabilities.

And this is my favorite slide. Outcomes in quality based focus. Better health outcomes and better well being. And consumer satisfaction outcomes are really the kinds of things that we are hoping to achieve with this program. We have a commitment to putting in measures and learning about and learning from this listening tour, what kind of measures

really do demonstrate good health outcomes and good experience of care outcomes. And many of you are in service delivery. Others are recipients of services and this whole business of improving your outcomes is really a very personal thing. But it's an important one and one we want to get right.

This is our time line. And I have heard feedback that it's very condensed time line. I own that. It's true. It is. It's a very aggressive time line. But it is what we really are hoping to achieve. We issued the discussion document on June 1st. We're in the middle of this public comment period. These listening sessions are not the only opportunity people have for public comment and this document here gives you the discussion document response process. There's a whole lot of ways you can get in touch with us. If you don't feel like speaking today but have comments please go online. You can e-mail. You can call us with your comments. We have a number set up. You can also mail your comments and we have an address available. We really do want to hear from people. And we want to get your input on how this works. And if you're not comfortable getting up and speaking please after the session go back and think about what you heard and provide us with your feedback.

The deadline for submission of these comments is July 15th. It's about a six week comment period. And I also

will say that our notification about this process and the discussion document was published in the Pennsylvania register last Friday. So we're trying -- and we did a press release on the 1st when we released the document. So really trying to get the word out. I think this turn out today, the amount of people here today is evidence that the fact that at 9 a.m. on a Wednesday morning in Erie we were able to fill this room really tells us that you care about what we do here. And you want to provide us with feedback.

There is -- we anticipate that by the end of October we will be releasing an RFP which is the process that we go through as we contract with managed care organizations. The Commonwealth has a lot of experience in doing this and we are going to be learning from our colleagues and the bureau of managed care and medical assistance programs. They have a lot of good feedback on how to do this well.

We have three phases for our roll out. Our first phase will be -- we have a ramp up period where we do readiness reviews which will happen next July through the end of the year 2016. Our enrollment, we anticipate our first enrollment to be in the southwestern Pennsylvania. We haven't figured out the region. We do know what the health choices regions are but we welcome input if that doesn't make sense given the way the systems are set up, we welcome feedback on that. So we anticipate enrolling people on

January 1st of 2017. The second phase will be in the Philadelphia area in the 5 county region of Philadelphia. Although we welcome feedback on that as well. And that enrollment will begin January 2018 and we anticipate going to the rest of the state which would include this area in January 2019.

So here are some questions that we have. We are really wanting to know how we -- a long the way I have been asking questions -- the discussion document if you haven't read the whole thing is detailed but leaves a lot of room for providing us feedback. We were putting out our ideas and let us know what you think about them. These are some questions. I think I asked some of them along the way. What does quality of life mean to you and a third one is what does the experience of your care and services mean to you. The actual experience of receiving those services. Beyond quality of life I think it's important to get feedback on what that experience is. Are there additional groups you think should be included. We described the target populations at the beginning but we really do look for feedback on that.

And we also want to hear from you because come July 15th when we stop doing -- when we end our feedback process -- we don't want to stop hearing from you. And we anticipate that we will be continually working with you and this last

question about how do you want to continue providing input and receiving updates I think is an important one. So we look to hearing more from you on that.

Kate? I'd like to introduce Kate Gillis our press Secretary.

>>KATE GILLIS: We have 13 people registered. Each individual gets 5 minutes to provide comment. If you want to ask questions, you can do that. If we have extra time at the end we'll open it up to anyone. I can bring the microphone to you if you don't want to come stand up front as well. Is this working? Okay. Great. Carl Berry is the first individual.

>>SPEAKER: I'll get there.

>>AUDIENCE MEMBER: I'm almost there. Good morning and welcome to Erie, we're glad you're here. Thank you for this and future opportunities for stakeholders to give input into what surely will be the most significant change in recent memory of how Pennsylvania serves it's people in need. Managed care for long-term supports will be a different animal and we appreciate the opportunity for providers and family for making it work for Pennsylvania. That is what we want to help to make it work.

We applaud the departments for including many of the pillars illustrated in the 2013 guidance to state's managed care. Those pillars are to ensure that participants have

input, they have choice, consumers have opportunity to live in least restricted environment and viability is maintained. As you know those points are being codified by CMS in recent rule making. The goal is to lower costs through the use of community based services we applaud this and are excited to be part of that solution.

Now, some people say that the devil is in the details. I say that the proof is in the pudding. Regardless of the positive outlook on it what matters is how those pillars are implemented as a stakeholder, advocate and father of two children with disabilities and some day I might be a participant too, I want to help. I offer a few comments and questions as we work towards this answer.

Participant choice. Rhetorically, will consumers have a choice in managed care organizations? I believe choice improves services to consumers. Having a choice will encourage each MCO to do their best. They may take their business down the street. This benefits the participant and also the state as you are not locked into one MCO in an area and faster service means participants get the home based services they need soon. That's currently a roadblock in Pennsylvania. Will participants have the choice of service providers? This again is for the benefit of the participant. Managed care contracts should require broad networks so the participant can choose which agency works

for them.

Will participants be given protections to continue with their choice of provider? In a significant change as to changing to a managed care environment there's more than enough changes for consumers. Many are concerned their choices will be disrupted by a large scale switching to new providers. They want to continue with the providers they have already chosen. The managed care contract should require these participant provider relationships continue.

Pennsylvania has seen several aspects of home and community based long-term services be sent out of state when Pennsylvania should support Pennsylvanians. Pennsylvanians jobs and companies. I recommend that the department require the contracting of local providers and give preference to local managed care rather than shipping jobs off to other states, Arizona, Massachusetts, where ever, we can take care of our own.

We applaud the departments wisdom in including nursing homes in the managed care environment. If included there's incentive for them to care for people in the community. However in nursing homes are carved out there's direct incentive to send anyone who becomes the least bit expensive to a nursing home. This would drive up over all long-term care costs when we're trying to lower costs. Such a plan designed is contrary to the homestead decision and contrary

to what the departments intend. Common sense supports participants. Current home care licensing limits what providers can provide. I encourage the departments to work with the department of health to adjust the regulations so home care can do more common sense things to help people live independently. Some department of health auditors do not allow bowel and bladder routines. Yet unskilled family members do these basics and we cannot. I'm not saying scrap the licensing and protections but change those rules and allow to provide support to people in their homes.

Rural Pennsylvania is different to serve than urban areas. Lessons learned in the first two phases may or may not apply to the rural areas. My organization and other organizations in the rural areas have been serving older Pennsylvanians and people with disabilities in the rural community for over 25 years. We wish to partner with the state and explore how to make this transition work in rural parts of Pennsylvania. Getting there. We all acknowledge that the current system is in crisis. Northwest Pennsylvania in the rural areas do not phase in until January 1st 2019. That's three and a half years from now. Just a short comment, I know we discussed this recently but the providers need adequate rates to get us to January 1, 2019. We ask the state continue to examine and revise upwards the rates so we have a stable system when January 1,

2019 finally arrives. In closing, thank you for this opportunity to give input and advocate on behalf of older Pennsylvanians and people with disabilities and thank you for the opportunity to be part of the decisions. As a team to make managed care work in Pennsylvania. Thank you.

(Applause)

>>SECRETARY DALLAS: All right so that was fun. Just a couple of things, I thought you hit on a lot of very important points there. I wanted to touch on them briefly. The first one is ensuring competition and choice. That's got to be a hallmark for what we do. A key what we want to do is give people the choice to live where they want to live and use the providers they want to use so for us choice is a big part of this. So we absolutely hear you on this. The other thing I heard from you, there are two really big parts of this. One is what the world looks like when we're done. But it's also important how we get from here to there. Some of your other comments were there. I know when Jen was going through the schedule when she said January 1, 2019 I think I heard some grumbles in the crowd. I guess my question is that's one of the things we talk about is how we get from here to there. The source of the frustration is it takes too long. January 2019 is a long way away. Unless I was hearing things but folks were nervous about that. When you look at the time line what's your reaction? It takes

too long or too rushed, what are some of the concerns we can understand better?

>>AUDIENCE MEMBER: To answer your second question first, too long -- I hope that the -- obviously you're wise enough to know that if you hit a roadblock those dates may need to be pushed back. You're all very bright and intelligent folks and been down this path. January 2019 is a long time from now. We think that rural Pennsylvania can be prepared and can be educated in that time frame. My point is we got to get there. I'm not asking to speed it up any. Because you already have an aggressive schedule. Handing the Pittsburgh and Philadelphia roll out your hands will be full. But rural Pennsylvania and northwest Pennsylvania and the rest of Pennsylvania. Pennsylvania is more than just Pittsburgh and Philadelphia.

>>SECRETARY DALLAS: It should be the southwest and southeast. Not just those two places but I hear what you're saying.

>>AUDIENCE MEMBER: I'm sure you'll be learning lessons from those areas. Rural PA is a very different environment. But getting back to your original point. Is it too aggressive or not enough, I would say January 1, 2019 after southwest and southeast, it's still an aggressive target.

>>SPEAKER: Dan Shuffstall.

>>AUDIENCE MEMBER: Good morning, and thank you for giving

us the opportunity to be here. Kind of short notice. I found out we were coming up. Quite a few things I had to do is rearrange personal care attendants to come in. My morning started at 4 o'clock this morning. My morning routine, stretches, things I have to do on a daily basis. I have been doing it for 40 years and attendant care is probably the biggest thing that allowed me to be independent for the last 40 years and live in the community. Some questions that I have is, will a consumer still have access to local resources you guys say yes. I say are the big insurance companies going to come in and run the managed care and hire these services. That being the case are the big insurance companies going to be saying, we're going to be your resource provider, so we're going to tell you how to run your life. Consumer control going to be taken out? Are they going to be coming in and saying, well, Dan you used to have so much but we juggled the numbers and now we have to cut so much out of your care. Which is actually going to force some people back into a nursing home instead of back out. As you grow older, and your skin gets older and the ageing process takes it's process, we need more sometimes instead of less. And I think that probably a lot of people in this room feel the same way or need the same way I do. I think we have been successful with the attendant care program. I've been very happy with it. But I want to have

the ability to run my own life. Consumer control. When an individual comes in and does an assessment on me, I've had enough years, whether it be a doctor, an insurance company, or an individual come in -- I know my body. I've had to deal with it and I've had to stay alive. They say I've stayed alive for 40 some years because of the way my care has been provided. Most quadriplegics don't live that long. I'm the consumer, I do have the control. I can train my attendants. Yes an attendant should be trained but the individual attendant needs trained for my needs. My needs are not is same as everyone else's needs in here. I need to have range of motion and bladder routine, that doesn't mean I have to have a nurse come in to change that catheter. Any one of you sitting up there can be trained to change a catheter. It's a procedure it's not rocket science. It's a matter of having the person in there. Having the ability to have the stability to have attendants who I choose to have. I have been lucky. I have a fellow with me part time, been with me for seven years because he's also on social security disability. But he's been there for seven years and I went to John last week after I found out and I said we need to switch times here, we need to get up a little earlier. Well, it was fine with him. What comes next? Now I got to schedule transportation. I was lucky enough to get community resources to come down, pick me up in Meadville.

I don't think you have many people here from Meadville. Based on their inability to get here. Same as warren county and outer counties. Those are places you also need to hear from and get the word out there. Because managed care really, when you say managed care, it scares you. It says to me, are you going to be taking my ability away from me to make choices on my own.

We need to have the ability to choose our own providers and I think I did touch base on that. Choosing our providers and you may not get a long with a certain individual in an agency and you may want to change. And it may just be a matter of personal preference on who you do use.

Did you guys do the -- putting this together -- how many consumers are going to be involved in putting this together? How many local service providers? And how are you going to choose those? Consumers and service providers. Those are the ones who come in and do the job for me. As I said, important issues I think are consumer control and maintaining that high level of consumer control. Local service providers, being able to have the ability to get on the phone and contact that individual and not contacting somebody in Arizona or Boston -- and those individuals saying, oh yeah we'll get back to you and six months or six weeks -- a month later you might get an answer you might

not. But you don't have the ability to say, I'm going to take a 15 minute ride and see my provider. It's different. So when you're developing this plan, please take in consideration of all consumers that will be involved in this process because it's a big change in Pennsylvania when we started Act 150 I was involved in that. It took a lot of people out of nursing homes also. Please take that into consideration, I thank you for your time. (Applause).

>>SPEAKER: Doug Fugate.

>>AUDIENCE MEMBER: Thank you for this opportunity. One thing your plan doesn't specifically address which is probably the biggest issue for everyone in this room is either the lack of caregivers or the quality of caregivers. I didn't really come here to lobby for a higher reimbursement. But. If we can't pay these people more money, we're not going to get the people we need. And if you look at the rate of growth in the older population and you look at what we're faced every day trying to hire people to service these clients, it's going in opposite directions.

So I think some where along the way there's going to be an additional cost if you want this program to really work. There should be a significant savings not putting them in a nursing home. But we got to funnel that into paying for a better quality of caregiver and we need the numbers.

>>SECRETARY DALLAS: First I agree. Everything the

gentleman before had to say about quality. For us it has to be one size doesn't fit all. Everyone is an individual. If we don't find a way to do this where folks can participate in that. Make sure we have person-centered care we'll miss something and have failed. You got to an issue to how much it costs to provide these services. We're doing this because we want to improve the quality of care. I said before it's 50/50. It's 50/50 in terms of participation but about 68 percent nursing home and 32 home and community based -- dollar wise. You can see you talk about the need to make investments in the system and I agree with you. The other piece of it is there's an opportunity there. If you're looking at 50/50 and see it's 68 and 32 in terms of cost. What we do is give people the opportunity to live in their homes, there's opportunity to make investments in is system -- in terms of money we spend we're not so far out of whack. There's the opportunity as we do the right things for folks and let them live in the community, there's opportunity to invest some of those dollars into the system and making sure we have quality and protections and the choice and that's part of the way the finances work. To me, first and fore most we wouldn't do this if it didn't give people the choices of their own care and live in the community. There's an opportunity to take the savings and invest back into the community.

>>AUDIENCE MEMBER: I own a franchise and talked to a dozen other franchises in Pennsylvania more than half of them are not taking new clients on because you can't service them.

>>SECRETARY DALLAS: When you -- everything you said is true. The growth of folks that are going to need these services. Look at the demographics of it, it's another reason why we have to do something. I have concerned about it's ability to continue to provide the level of care provided now going forward. This is I think our best opportunity to make sure we improve the quality of services and give people those choices and ensure the future viability.

>>AUDIENCE MEMBER: The other question I have is, and I don't expect you to do it now, but it would be nice in some point of time -- a flowchart form maybe to see where we plug into this managed care. You got the managed care provider at the top, where do we slot into this. Is there something that's going to change substantially in our business and prepare for. Are we still going to work with a case manager and that's it. If that's the case that's fine but it would be nice to know that.

>>SECRETARY DALLAS: I would love to be able to do that for you today. But one of the reason we haven't is we're soliciting information from folks. We can put more detail there. You asked the most important question is what does

it mean for me. How is my life going to be different. As we learn these things and we can fill in those details we can answer that question whether it's a flowchart or whatever and say to folks this is the way you interact with that system and this is the way your life would be different -- or interaction with the system would be different. First we want to hear from folks as we're crafting those details we get it as right as we can.

>>AUDIENCE MEMBER: Two other things real quick not specifically related to this. Obviously there are e-mails going out from your department. A lot of these e-mails are intertwined, Medicare and Medicaid. A lot of providers do either Medicare or Medicaid. I found many times when looking at 120 page e-mail and I got to go through and try to pick out what is Medicaid, not Medicare. Can you separate them and send them separately. It would make life easier for the people trying to do it. There are important things we need, but there's also only so many hours in a day and you can't sit there and read 160 pages that doesn't apply to you. And lastly. Long-term living, my suggestion when you call the office they should have, for lack of a better term, a concierge. Okay, this is the person you need to talk to. I had an issue, from the audit team, we had an issue trying to find an answer, it took six weeks. It was phone calls, e-mails, I don't know what the answer is -- I

don't know who knows what the answer is -- you know. Simple system. If people were trained and had a list and said, okay this person does policy and this person does reimbursements it would make it easier on everyone and you guys too.

>>SECRETARY DALLAS: With regard to the communication, I apologize. I'm sure we don't get it right or anything close to perfect but I know from my -- when I was here a few years ago versus when I came back it seemed to me the department wasn't communicating as well as it had in the past. So we're trying to communicate more with folks. We may over communicate. But please know it's from the goal of trying to be as transparent as possible. We'll try to refine that process and get better at it. I'd rather air on the side of giving too much information.

>>AUDIENCE MEMBER: I'm trying to make it constructive criticism. Thank you.

>>SPEAKER: Farley Wright. Do you want to come up here?

>>AUDIENCE MEMBER: No I can probably project if -- can you hear me? I have been glancing at Matt's comments and Matt will be much more thorough and detailed than I could possibly be so I'm going to summarize a few things. I want to welcome everybody to the Erie area. It's great to have you all up in northwest Pennsylvania. My name is far LI Wright I'm HAR as the executive director of experience

incorporated, the warren forest agency or ageing and I'm here as a senior citizen and as a caregiver. I've worked with me wife for over four years in trying to provide the best quality care we could for her mother. We kept her at home for three and a half years and we went through the struggles of what should be a relatively seamless progression through a long-term care system that had more bumps and barriers in the road way. My wife's an MSW and as I said I'm executive director of the area ageing. I can't imagine what people outside of the system face as they try to wrestle some of these things. We're dealing with gram in her latter days, she's gone through broken hip, gone through two strokes, she's in a very advanced stage of dementia. We visit. Occasionally you'll see a little glimmer in her eye and you know she's still in there. But for the most part you can't communicate too much with her. But any way.

I'm very, very, interested in the process. I think we need to realize that we are asset rich with services and service providers and that's the good thing. I was a little disappointed in the Pittsburgh study not identifying that. We may have fragmentation and difficulties in communication between them. But we have a phenomenal amount of services available we just need to do a better job of getting the consumer connected to the services and letting them flow through.

I admire the fact that the Governor is engaging the stakeholders and welcomes input. I was particularly pleased to hear Secretary Osborne and Secretary Dallas acknowledge this is an on going and continuing conversation. I fear sometimes we get locked in the development of a process and if we're not careful the focus becomes the process and not the consumer. It's a dangerous trap to get into. I think these meetings should be the first of many. I think part of the problem I've seen in the system over the years is most policies are driven from the top down. I respect the University of Pittsburgh but sometimes in the mightiest halls of academia where the -- we need to continue to where the services are being delivered. There's a basic cost of doing business. This is déjà vu. There's a basic cost of doing business but there's a far, far greater cost in not taking care of business. We have to be very careful with the changes that we contemplate. Any mistakes we have going forward will have a devastating impact. We must be mindful of the demographics that create a legitimate urgency we must be as mindful with the precious commodity with which we work.

I think that as I said, I'm going to defer to Matt. I applaud the focus in looking at preventive services. I think we get too wrapped up in trying to deal with the issue at hand and we lose sight of something we should be doing to

kind of hold off the wave. The boomer is coming in the system. It's not a surprise. We have known this is going to happen. So we have to understand there are some inherent costs in that process but we need to tweak the system to make ourselves better able to accommodate the influx of the boomer. I think the move is in the right direction and as long as the communication linkages stay open and as long as local people at the local level have the ability to impact the services and impact the process, I think it will be a great change for Pennsylvania. Thank you. (Applause)

>>SPEAKER: LuAnne Maclasaac

>>AUDIENCE MEMBER: Good morning and welcome to Erie. My name is Lou Ann and I'm executive director of great lakes home health care and hospice in Erie. And president of the home healthcare association. I'm here today -- I applaud the consumers here and other providers as well. But want to talk about the agencies and the impact this will have on them. Pennsylvania home care represents 70 percent across the state. My agency as well as other agencies provide medical care, nursing physical therapy etc. But the home care agencies also have home care aids and attendants and they provide assistance in the home, activities of daily living, bathing, functional type things and of course end of life care which we all know is very important is provided by our hospice professionals. I appreciate the opportunity to

speaking here today in the Commonwealth's plans to implement managed long-term care services for many here in the area, many agencies have worked with organized care. We have been an ageing provider and as we do -- we do have experience providing those types of services. With respect to our time limit I will only really talk about a few items from the Pennsylvania long-term care commission that our president PHA president Vicki home was represented on. We need to fix the eligibility process. If we polled over here everyone would say they would like to stay in their own home. I know nursing homes are very important but most people say I want to stay at home. Yet under our current system, Medicaid funded takes 4 to 6 months to become eligible. When people need in home care they need it now not several months later and without a stream line process nursing homes become the only alternative because it can happen easier and we know it's a higher cost. If the goal of the managed care system is to coordinate care and contain costs, this part of the puzzle really needs to be addressed sooner than later.

I was pleased in the discussion document there will be increased emphasis on at home and community based services going back to people wanting to remain in their own home. With new financial incentives, plans to use community providers. In a managed care system the home and community based settings will become more of a fact for entitlement to

the enrollees. The recommendations of the long-term and stream line and standardize the eligibility across all settings. Currently, it takes 3 or more months to access care in the community while care in a nursing home can be almost immediately available. There's too much red tape. I think we all agree more paper work is not always better.

Providing back up and documentation, developing an individual care program. We're hopeful the managed care organization will take on that responsibility in doing the assessment and speeding up the process. Second we need to address reimbursement time lines. Agencies like mine are accustomed to receiving payment timely. We have slim margins. Improving opportunities for community based services. But I think we also need to look at how quickly these claims are paid. And recommending that the claims paid in a 15 daytime frame. Some small private agencies do not have the ability to secure lines of credit or secure other financing mechanisms. As PHA president of the board I talked to those agencies and clearly people -- the smaller agencies do not have the flow of money. So changing how we implement reimbursement timely would be good. A short payment time line on routine claims should not provide a problem. They are not authorizing home health, skilled services etc. But we should address that.

Third we need to educate our MCO's about home care and

what home care can do. PHA's in regular contact with home care across the state. That's something they're not familiar with what home care agencies can do. For instance a few visits a week from a home care attendant and I think you mentioned that what a difference an attendant made for you for 40 years of letting you remain in your own home. So attendants coming in to help monitor the health status in plan for preventive care. Weekly home visits to assist a patient. That makes all the difference for our patients in their home. And then regular visits from hospice workers. What if hospice was used more routinely in a home and nursing home setting. The research shows that hospitalization for hospice patients is much less when hospice is involved.

During the transition of long-term service program should host meetings with providers. So we can all talk to each other. It's important that stakeholders are involved in the development. I imagine most agencies. Who better to have at the table.

Fourth is rate setting. A negotiation of contracts. Home care providers under service waivers currently only interact with Department of Human Services to coordinate payment. Long-term would require providers to contract with organization. That comes along with different processes. Provider advocates call for that equal to Medicare. So

providers will not see a loss in revenue. Here in Pennsylvania MA rates as we well know and Karl mentioned that our personal assistant services needs attention now. Because we cannot cover our costs and if we are not really implementing this until 2019 we need to focus on that. For MCO provider contracts the current rates are not an acceptable starting rates. 10 percent so we can offer competitive wages and cover the cost of care. Open communication is very important and I think many have said we need to have that and really I do thank you for your time I will send this testimony into you so you have it. Any questions for me?

>>SECRETARY DALLAS: One thing I react to you were talking about the way the system is right now and other folks talked about not implementing until 2019 as we're going to do the best we can to implement please understand we're still looking at ways to improve the system. I agree it takes too long for home and community based services. The process needs stream lined. For us we will be trying to make those things better as we go along. We're not going to wait around until 2019 to try to make that process better.

>>AUDIENCE MEMBER: I'm sure everyone is happy about that. Thank you Secretary. (Applause)

>>SPEAKER: Mark Gusek

>>AUDIENCE MEMBER: Good morning. I do want to remind you

all that I 79 is open north of I 80 between November and February. Don't forget about it. It's great to see so many people from the upper offices up here in Erie. It's not often that happens.

I want to say one more thing and that is I had the opportunity a few months ago to meet with Secretary Dallas and still a bit shell shocked walking into the office. The first things I heard about were quality and home and community based. It's refreshing. I'll get on with prepare statements I have. I'm going to deviate because you hit a lot of them. But I do want to go back and talk about education. There's been a lot of these committees and there seems to be a common theme and that is education. To make sure when we get to a point where we're having these managed care organizations that there's true conflict free education given. We can't have a shell corporation of UPMC doing an assessment and saying, oh by the way here's a good plan for you. We can't have that happen.

The other thing I want to focus on and you touched on it better at the end of the last comments, I do want to remind the complexity. Whether it's the financial eligibility or the clinical eligibility. It is so easy to get into a nursing home and because I'm both ends of the stick there I can see how easy it is. It should be just as easy, whether it's into a life program -- I forgot to say I'm from a life

program. And it's nice to hear we're being mentioned in the state. I'm from a life program and how hard it is to get people in the life program. In that period they end up in the hospital or the nursing home and then we have to wait for them to recover to get them back. There's no reason why a sister of mercy takes a full 30 days to get financially approved for services. On the flip side while people do get better and need to be reassessed that service shouldn't be taken away because they're making it. For them to further decline and go back to a nursing home and go back on those services. We got to watch that.

One of the things, preventive. There's not enough talk of preventive. One of the things missed in the Affordable Care Act, the basis is preventive care. I used to sit there, life programs are doing that. Life programs are doing preventive. For two reasons. Yes we get a fixed amount. When they go into the hospital or nursing home that's key. We can't shirk that responsibility. So it's key for us to try to keep them home so they don't end up in a nursing home. And that preventive works to put 150 dollar hand hold in somebody's house to prevent the fall and the hospital the hip fracture and pneumonia. Unbelievable for 150 bucks. Take the chance. And we're given the freedom to do that. There's another thing I don't think I've seen yet and that is dental. Dental is a huge, huge area. In my

talks with bringing the program into Crawford I was talking with Meadville medical center. They gave me a stat that one of the top ten reasons people visit the emergency room was for a tooth ache. It was astounding. Meadville medical hospital went out and hired a dentist and oral surgeon to try to satisfy that need. That's also what's important. Community based means that. It's not going to be a huge corporation for profit that is managing care. It's where is the money going, and that is to the caregivers, the people receiving the care, and to have adequate facilities to do this.

So dental. I think there needs to be a little bit more focus on that. And I think that's it. And I do want to say that the life programs -- our life programs specifically I can speak for are looking forward to making this happen. We have been doing life programs and pace programs -- no one throughout the country -- have been doing it since 1979 so we're a good model. Thank you. (Applause)

>>SECRETARY DALLAS: Do I look less shell shocked?

>>AUDIENCE MEMBER: Less shell shocked but maybe because you're by the lake. I don't know.

>>SPEAKER: Matthew Trott.

>>AUDIENCE MEMBER: Hi I'm Matthew Trott the ADM of the GKEK AAA. Assistant manager of area of ageing. Community action agency has been around 50 years, I've only been at the

agency for 17 years we have a lot of experience and I want to try to impart that experience and lessons learned. One of the key things you have driven a long way up from Harrisburg you realize how far we are here in Erie.

>>SECRETARY DALLAS: It's a beautiful drive

>>AUDIENCE MEMBER: Exactly and a lot of times we have to do that. In Erie I see the same faces at the same meetings, we are all part of many different groups whether they're associations or links or collaborations or councils or whatever. We're all here trying to do the best for our consumers. A lot of time we developed locally systems because we meet so often. Because when GLADYS needs something we know we can call and get here assistance and they know they can call AAA to get meals delivered. There's already a large locally established network. And I think the biggest concern that's been voiced by a lot of people already is don't just let somebody come in and wipe out that local establishment. It will help you getting to 2019 because networks already exist so if we can support that and encourage that as part of the new managed care.

Another thing is as you drive up this way you see that there's a huge diversity in this Commonwealth. Not only geographically but demographically. It's an impoverished area. Now the area agency on ageing. I can't stress enough -- having a care manager or service coordinator or in

home provider, but somebody that the consumer can call -- somebody that's trained and knows the system that can easily get issues and barriers addressed for that consumer. One of the -- a lot of the calls I take are from people that are taking somebody out of a nursing home or whatever and they're frustrated with the system. The enrollment and eligibility system takes way too long. But the problem is they need knowledge. So that they can make the good choices that will be part of this plan. How we educate the general populus is one of the biggest cases. Whether it's options counseling through the link program. All those things, please do take the consumer input on what they want. Keep it simple. And do it as easy as you can for the consumer. That frustration compounded on to care giving frustrations is something we don't want to add to.

A third key point that care manager, that service coordinator, that conflict free person that Mark was talking about, make sure that they know the clear path. There has to be someone that goes into the consumers home and sees the environment they're in. It can't just work if an entity is saying, well you go to your doctor once every six months they'll know everything with your health meds. The barriers that exist are day-to-day barriers. Transportation. Medication management. I love the analogy of the lady who just has her meds in a fishbowl and grabs a handful and

takes it. The noncompliance is amazing. We see it when it all falls apart. And we're seeing it more and more unfortunately. And the other thing is, a lot of the faces and names in this room. It's harder and harder to come up with solutions in the current environment. So make sure that part of the process includes someone going into the home. And can't just be a service provider doing ADL's they may know certain components but someone who has -- I call case work 101. Look in the fridge, see what kind of food they're getting. They might be living on home delivered foods and that's it. There's social supports that need to be brought in the most difficult cases. I encourage that to be part of this process going forward. The other thing is, from Erie to Philadelphia, it's such a long distance. Not only diversity but also geographically. You can get to 7 states and a foreign country in less time than it takes to drive to Philadelphia from Erie.

>>SECRETARY DALLAS: I'm going to steal that one.

>>AUDIENCE MEMBER: I was a geography major, I had to map that one out. Remember, making sure there's an eyeball. A conflict free person that sees the environment and can help people over come those local barriers with local solutions. Quite frankly. So. One last comment while I'm here. The cognition for the older adult is sometimes a bigger issue than younger aged consumers that need assistance. So

there's a developed expertise that has to happen and come in play in that and the other thing is the fraud. I want to mention the fraud because there is really no local policeman out there -- except for service providers and people like -- it's the service providers seeing the fraud out there and we have to be that front face to report it. Puts us in a difficult position with consumers. As a gate keeping role. I have an appointment with a local magistrate. Someone turned in a falsified time sheet. It's a tough position that could be developed in a better way. That's it, thank you. (Applause)

>>SPEAKER: Shona Eakin.

>>AUDIENCE MEMBER: Good morning. My name is Shona. I want to welcome you to Erie and I want to say thank you. Thank you for seeking our input. After four years of living in a communication black hole it's wonderful to have the opportunity to tell you all once again and be able to help you make Pennsylvania the best long-term service and support community like it once was. As I sit here, I wear five hats. I am a consumer of Act 150. I am a wife of a consumer of waiver services. I am a mom, I am an advocate and last but certainly not least, I am the executive director of voices for independence.

As an consumer I use attendant care every day. As I have aged, I now receive 48 hours a week. When I started

this program 23 years ago, I had 26. My attendant comes in every morning at 5 to get me up and get me dressed for work. And let me tell you over the last 4 years, I have told more people than I can count because I was afraid of what was going to happen to our services -- because there was such a communication black hole -- that even if I had to come to work in my nightgown I would do that. But let me tell you, how proud I am that I'm not in my nightgown.

I think I lost a page -- sorry.

I am married to Michael who is here today with me. I'm very passionate. Mike is a 20 hour a day ventilator user. We have six attendants in our home. Up to 24 hours a day between both of us. I am ultimately the coordinator and back up for Mike's care. We are the perfect example of the spectrum or array of services that people of Pennsylvania really need. And true example of how when you blend low to moderate users and more high end users it evens out the system and it saves Pennsylvania money and enhances our quality of life. I am a mom. Why do I tell you that? Other than the fact that I'm proud of my son and daughter who are 10 and 11 it is an example that people with disabilities are real people too. And without my attendants they don't function as my children's parents. They don't function as my parent's caregivers but they enable to me, they enable me to use my time and my energy to take care of

my children and my husband as well. It enables us to give them all that we have. I am an advocate. I have worked in Pennsylvania to develop a strong long-term care system now for over 25 years. And you know, I started out as an advocate for myself. I worked at a center for independent living and one night I worked late. I was there until 8:30 at night and I looked at my boss and I said, I got to get out of here and she said why. And I said because I got to get up at 3 o'clock to get dressed to be back here by 8:00. And she said tomorrow, I want you to go in and sign up for attendant care. Not knowing anything about what that meant. Two and a half years later I got attendant care. Of course it involved sleeping on Governor Ridge's floor to make it happen. So I guess I figure that if I started out advocating for myself I could use those skills and abilities to advocate for others and that's why I sit here today.

I realized very quickly that it's a privilege to have a job. It's a privilege to be able to advocate for those who couldn't be here today. Unfortunately because 25 years later we still have a very fragmented system of support services. You know, if you live as close as GERARD which is only 20 minutes away you can't get here unless it's Thursday but there are a lot of people that would be able to provide testimony in person. But for not the fragmented transportation system.

And last, but most definitely not least, I am the executive director of voices for independence. I have the privilege of being here for 15 years. We provide personal assistance services. We provide NHT services and CI services, we provide home modification services all of which right now are under redesign and potentially going to be going under the managed long-term care system. As Pennsylvania makes the transition to long-term, managed long-term care system, I am fortunate again. I'm fortunate to be offering input today on what this new structure will look like. I find it difficult, sometimes, because our current system is wonderful and yet broken in many ways. Like one thing I'll never understand is how you can be eligible for a nursing home but when it comes to home and community based services, that same person who is sitting in the nursing home is not eligible. It does not make sense. And it's happened to us six times in recent months here in Erie. It does not make sense. And several of them are taken to the office of long-term living for individual investigation we heard nothing.

The other thing that is an under utilized program in Pennsylvania is our home mod program. We have seen so many people go into nursing homes because of that one fall. And you know, when you have somebody who thinks they know about the ADA and about construction specks but they don't know

how that person uses that equipment they're not doing that person justice in their home. And when people hear about managed care, they get scared. Because you -- when I first heard about it to be honest and I'm the executive director of voices and I'm experienced and I know how to advocate for myself and others -- it frightened me because the first thing you think of is capitated costs you think of somebody with CP like me putting through a cookie cutter assessment. Okay you have CP so the maximum you can get is X number of hours a week. Or okay, you're a quad so the maximum number of hours you can get per week is X. Don't do that to us. Remember these services were originally designed for functional need. My life is very different than somebody else's life with CP. No two people with CP are created equally. And so please remember that the individual must be considered.

You know, centers for Medicare and Medicaid use person-centered planning and for years we used consumer control. I hope they mean the same thing. I hope that consumers through the managed care implementation will still have control, will still have dignity and will still have the ability to manage our every day lives. You know one thing that has happened to us in the last four years is that options have been limited. We have one enrollment entity. One consumer directed provider of services, what that has

done is it's created a vacuum in which it slows everything down. People don't have options. They don't have a local face they can look at. When there's a problem, they're calling on a telephone and they never get a phone call back. So I'm not saying you need 22 or 35 or whatever. But you need a few more of each. You need more regional brokers for enrollment. You need more regional entities for personal care, for consumer directed personal care. I know my time is running short and I apologize but I need to get a few more things out. Choice is great. Control is even better. Please don't take away our dignity. There's no guarantee if I don't mention -- it scares me to think of a gate way health or UPMC entity making these decisions about our lives. It scares me that if I don't mention that we need more enrollment brokers and more options for consumer directed services we won't get them because they don't even see the value in it. Right now our independent enrollment broker doesn't go to people's houses and really get to know what that person needs. They don't have the time. We're lucky if we get a phone call back in a reasonable amount of time. I'm going to skip through some of my notes.

Please don't forget that centers for independent living have been an invaluable partner to you all over the last 30 years. Please remember that we are the experts in a lot of this stuff. I'm proud to say that voices for independence

is currently serving about 350 people on the home community based service program. I'm proud to say that as of to date, there's three more weeks left in the fiscal year. We have transitioned (individuals. I'm proud of that. When you're convening your meetings and I know you will, because the nursing home industries going to want their seat at the table, the home health agencies are going to want their seat, don't ignore centers for independent living and people with disabilities. It is so frustrating to be on the other end and to be ignored and to be dismissed. Governor Corbett and Alexander destroyed our system. I don't want that to happen any more. You need to understand that we will do whatever it takes to make Pennsylvania strong. And when we are ignored, it doesn't help you at all. It doesn't meet the needs of the people that you'll never meet. We meet those people. We get the tough questions asked of us. We get people saying to us, how come I can live in a nursing home and I can help paint walls in the nursing home, but I can't get a little bit of attendant care in the community because of a sudden I'm no longer eligible but yet I can live in a nursing home. It doesn't make any sense. It doesn't make any sense at all and it's frustrating when you make the phone calls and you try to talk to people and you send the e-mails and you get nothing in return and so I'm asking you as I sit here in front of you all and part of the

reason I'm so emotional is because this means so much to me. This is not a job. This is my life. I know that one fall, one broken hip can put me in a nursing home and do you know that I found out two months ago, because there's a policy change some where in Pennsylvania -- I don't know where because nobody will tell me -- but I found out while I was in Harrisburg in April the day before I met with you Secretary Dallas that if I end up in a nursing home, nobody can help me get out until I'm there six months and one day. That doesn't make any sense. And it's scary. I have a family to raise. I do not want to live even one day -- where does this information come from? I'm making myself very vulnerable to you, a lot of people won't do that. But if I hear that and it frightens me, think about the person that doesn't have your ear. Think about the person that can't pick up the phone and bug you, Mr. Secretary until you call me back. Because you know I will do that and if you don't know you'll find out soon enough. (Applause) but where does this information come from? How can we scare Pennsylvania residents into living in fear. We do that all the time. By misinformation. Now I've been told and was told six weeks ago that that policy was under review. I've not heard a word. I've not heard a word. Another policy they supposedly changed six weeks ago is that we can't do a home mod, an extensive home mod on somebody coming out of a

nursing home until they're out. That doesn't make sense because a temporary ramp might not be the solution and a birdbath might have been what got somebody in the nursing home in the first place. So when I hear a state employee saying that birdbaths are okay, it's not okay. And a lot of people with disabilities can't live in a construction zone while their homes are being modified. You might not understand that but I do. Remember I live with a 20 hour a day ventilator user who when he had our bathroom modified we had to live in a hotel for ten days because he couldn't be in the same environment with construction materials. And there's a lot of people who are not on vents who have that same issue. So thinking about that, making those kind of statements, off the cuff without looking at individual needs really has to change. And lastly, and I know I've gone way over my five minutes, I'm sorry about that.

I'm excited to work on any committee you want to put me on. You may however get more input from committee participants, especially those of us who live in the stepchild of Erie. If you have conference calls, video conferencing meetings -- because a six hour drive from here to Harrisburg is taxing. And difficult. I use attendant care, I can't always get an attendant to travel with me. So I'm fortunate when I'm able to. But that doesn't always happen. And that's me. So imagine what a consumer of

service who doesn't work in this every day has to go through to have their voice heard. So please make it possible for many of us to participate in electronic media ways. Any questions for me?

>>SECRETARY DALLAS: First, thank -- it's good to see you again first. Second I would say it takes a lot of courage to tell your story in front of a room full of people so thank you for that. I think I can speak for Secretary Osborne, the reason why we're here and doing all this -- you talked about a lot of things that's wrong with the current system and it starts with us saying it's not good enough where we are and the reason why we're here is because we want to hear from folks, you, everybody, what's wrong with the system and how we can fix it. And we can't fix it unless we listen to folks like you. Thank you for sharing that story, it reminds me why I took the job. And I'm glad we're doing these visits. (Applause)

>>SPEAKER: Ruth Ann Giaimo

>>AUDIENCE MEMBER: I have to modify my speech because I don't want to be stoned. I am humbled by seeing all the caregivers. I'm a caregiver, nurses aid, personal care tech and also I take care of my dad. My name is Ruth Ann -- can you hear me?

>>AUDIENCE MEMBER: No.

>>AUDIENCE MEMBER: My name is Ruth Ann, I appreciate all

the aids here. My dad uses aids. I'm an aid. I had my in home healthcare agency and elder care in my home and I lovingly cared for those people and cooked them home cooked meals and treated them as if they were my own. As aids you have a god given responsibility and gift and we appreciate that. The reason I'm here is I respectfully request an amendment be made allowing the person who was power of attorney to get paid through the waiver system to lovingly care for their family member. It's not that we're money hungry but we can't quit our jobs and live on love. It's a conflict of interest. In the past some family members said they were watching the client while not physically with them. Okay, maybe there were a few instances where this happened. But no one loves you and cares for you like your family. If you want to talk abuse and neglect it happens to my dad on a regular basis by the in home health agencies. They have a difficult time acquiring and keeping qualified employees. There's little if any training in cooking, cleanings and medicine. Common sense is rare. They don't have a car. If they can't take dad to doctors appointments and exercise and to the store they are of no use. Many aids can't cook basic aids like devilled eggs. Opened beans from the can and added them to a bowl. She thought you opened them and ate them. The most important thing, I have to be graphic, is the doctor has an excuse that he can't have

wheat. It constipates him. One aid told me that dad was having regular bowel movements. He had not gone in 3 months. Dad was doubled over. We didn't believe him because the aids swore up and down that she saw the BM in the toilet. He was in the hospital for almost five days and almost died. They had to dig it out of him and lost 3 inches off his belly. Another aid stole from him. Another took him to the doctor and said he wasn't eating and sleeping, had the medicine doubled -- went to the pharmacy, left it on the counter, she never locked it in the bag and had no authority to do that. I could go on for hours. This week I found his hearing aid in the shower. When I complained to the agency they told me to go to another agency. One agency stole dad's mail. The police were called but no one was prosecuted. When I became involved he had 0 in his checking account. A plaster chair, moldy sheets and process foods he was drugged up like a zombie. Less work. Tools in the silverware drawer. Nothing organized. Dad had no mental or physical stimulation other than shopping other than what the aids wanted to buy. People in the senior apartment building borrowed the money and never returned it. Only god knows where the rest went. I went every night after work, I switched agencies and the physical therapy he received doing out doorman things he was off his leg brace in a month. Off all but two small doses

of medicine. Extremely alert and great sense of humor. Lost weight, attends church. He's 88, cuts grass, paints hangs clothes on the clothesline. He doctor was speechless. Another doctor said he's never seen such leg muscles. He has a new bedroom suit. He's bought 3 recliners new sheets and towels plus he has a little savings for vacation. I love my father and I want to take care of him like he did for me. He's a live because of my intervention and I beg you to amend the PA waiver to allow other power of attorneys to save others lives. It's ludicrous for a stranger. If you worry about power of attorneys I'm willing to have unannounced visits, show pictures and videos. Even put a camera in the house if it will put your mind at ease. Thank you for your time.

>>SPEAKER: Malin. No? Jason Shuffstall.

>>AUDIENCE MEMBER: Hi I'm Jason and I am related to that guy over there. I'm here to talk a little bit about something different than what we have been talking about so far but it is in the plan. I was reading it yesterday and it's community integration, CI service ands the importance of those. It's vital to the development and growth of a person with a disability. It's used to eliminate the institutional. Have you heard of Shawshank Redemption? The theme was institutionalization. When they left or were

paroled -- I'm using this analogy because nursing homes are like prison -- so. But when people leave they don't know how to live in the community. If you remember the character red he actually committed suicide in movie. That doesn't happen to people with disabilities on a regular basis but I'm sure it does happen.

Community integration helps create confidence for people with disabilities on how to live outside of nursing homes. Their parent's home and be fully integrated into the community they live in. The current plan needs some changes in order to fully assist consumers so they can do that to prevent what we're talking about today which is going back to a nursing facility.

Currently the 120 day limit is insane. 120 days to learn how to read and do basic math. 120 days, really? It took us 12 or 13 years plus secondary education. To be able to fully do those things. I went to college my third year of college I was taking a math class.

Community integration services are those services, those services that provide people skills so that they can remain in the community. Instead of 120 days, I'm saying -- at least consider case by case basis. If there is a situation where a consumer needs a service and we know it's going to take them longer than 120 days to learn that skill, consider that. Example. How long did it take for you to learn how

to do basic math. Community integration should be able to be used in a classroom setting. Right now the ratio is a one to one setting. Aren't we in a classroom setting right now? Aren't we learning right now?

While we understand CI services are not solely responsible for consumers growth and development. Often times the public education system actually has failed people with disabilities. A gentleman I asked to come today, sitting here. He sued the city of Erie school district because they did not take the time to understand his disability. He won. They provided him a tutor, his name is Melvin. They provided him a tutor and they failed him because the person who didn't provide the service didn't have a disability. And didn't understand Melvin and what his needs are. And all it is, all I did when I sat in his living room, was I took a few weeks to figure this out. We made the font just a little bit bigger on his computer. That's all it took. That's from community integration services.

The consumer sitting next to me, Melvin I told you he sued the city of Erie and won. We fought and didn't hear back. We e-mailed several people with the assistance of another service coordination entity. Finally heard back and heard Melvin's story and approve the goal originally rejected. My question is, is that going to happen again.

Are we going to have to wait and wait and wait until after the quarter has ended to find out whether it's approved or not? Is that going to continue?

Peer support is vital as part of the process as community integration services and what I mean by that is peer support is empathy. We've all been designed and created to be able to understand other human beings to have relationships. Right? So that whole classroom setting concept I had, that I was talking about -- is simply much more comfortable for me to sit in a room of people that are just like me that are just like you that have a disability and learn. Sometimes it's even easier to do that because of the empathy that's involved. Because other people can share their stories and they can help me feel like I'm not alone.

So that one to one ratio, that's broken. Offering community integration services only during a life changing event is unfair because community integration might be exactly what changes their lives. It might take that community integration service for that life changing event. So they're not eligible if they don't have a life changing event. That doesn't make sense Pennsylvania.

I worked with a consumer for several months in reading class. There were some services that were taken away as a result of Tom Corbett so we saw a void and the void -- I've had conversations with several people including Tiffany here

about the need for math and reading. So I went to the executive director and implemented the reading class for people with disabilities, basic education. That system has failed people with disabilities. But basic education is what was needed. And during that process there was a lady -- I'm not going to mention her name -- but there was a lady who had never read before. Almost 50 years old. Came to the class, a few months later was learning basic phonetics through community integration services. Eventually learned how to read a book, read four books in a series in a summer. And I asked the question, have you ever been able to do that before? She said nope. I'm almost 50 years old and she did it. I won't take as long as Shona but I am almost done. Community integration can help people thrive completing goals as simple as socializing with other people. We exist for relationships. Manage their personal finances, which I admit when I was 19 years old I struggled with that. I needed community integration services back then. Using the E lift. Feeling confident to be able to go from the Mill Creek Mall to the peninsula and back to their home. Empowering consumers through self confidence. Because self confidence is the number one reason through my personal experience why people give up. I work with a consumer that tells me every day that I see him and we talk about this topic, I'll never get a job. I can't do it. I

can't do it. And I continually tell that person, yes you can. And we're here to help. And community integration services currently not in that man's budget because it did not get approved and the service coordination entity is passionate with us. And they want to do the right thing. But they know that the answer is going to be no. So sometimes they won't even submit it because it doesn't fall into those community integration -- that structure -- those policies and procedures, that in my opinion, just don't make sense. Your 20 page document I read it in my car yesterday thoroughly. I talked about person centered services and community integration services. Those services are a part of your plan and are detrimental to be able to fill personal assistant services and keep people out of nursing homes. If it's person-centered, are you willing to listen to us people? To those receiving those services and to those sharing the services, and those sharing our personal experience like Shona has. I just got to say I'm working for a great person here and I'm not trying to brown nose Shona -- well maybe a little bit -- but her passion is contagious. And where does that come from? Empathy, which is peer support. Which is a part of community integration services. Thank you. (Applause).

>>SPEAKER: Is Priscilla Lecher here?

>>AUDIENCE MEMBER: Hi, I'm a consumer for voices of independence. And to be quite honest I don't know what I would do without them. They're like a second home to me. If it wasn't for them I'd probably be stuck in my home and just be a big old couch potato. But I have a disability that I have to have IV's every four weeks to regenerate my coverings of my nerves and I have a nurse coming in from an agency and all she does is start the IV and put the needle in, access it. And I take care of the rest. And then I have to have somebody come and take it out because naturally I can't see my port because of where it's at. But also I'm home, a healthcare aid that comes in every day and helps me clean my house because I'm not able to do that. I go to voices of independence to strengthen my body. I have to keep motivated because if I don't, I'll be stiff and won't be able to move. I also have arthritis. And to do that, they have a gym there, a fantastic gym with a fantastic instructor Tiffany. That does one on one with me. She also does aerobics and she takes us out in the community and I bowl with a ramp but I do bowl and I get out and socialize and also Jay has a coffee, a cafe we go to socialize with other people that have disabilities and it's a wonderful place to be. I just don't know what I would do without them.

I also get peer counseling from them. Because I'm also

a PA of my son who is borderline mentally retarded and a long list too. He's a handful. And I have trouble with him and it's very, very depressing to know that sometimes, like this other lady up here was saying, she's a payee, I never took a nickel from my son. In fact I gave him money for making mistakes. And it's just a shame that there isn't more people here that -- I was surprised at the amount of people that were here -- but it's hard to explain to people what kind of situation we go through every day of our lives. And I would just like to say thank you very much to the voices of independence and thank you for letting me speak.
(Applause)

>>SPEAKER: Is Kathy Hertzog here?

>>AUDIENCE MEMBER: Hi thank you for offering us this opportunity for input.

I'm going to talk from a different perspective. I'm really concerned that I think that managed care is going to be a nightmare. I think it's going to turn independent living into a medical model. That we strived so hard to avoid. I'm a very independent person. I had an HMO Part D prescription plan at one time that also included regular health and they would call constantly and basically harass because it was managed care.

I'm very independent. I don't like to be annoyed with such calls. I know that I need to do certain things to

manage my care. And I know what needs to be done, but the primary problem that I have is that the medical healthcare system itself is not accessible. It's not that I'm not trying to manage my care. You know, my prescriptions my medications, my office visits, my preventive care. It's not just accessible. I have to travel two hours to go to Pittsburgh for women check ups because there are no accessible exam tables. There are no accessible rooms. There are no accessible facilities in Erie to meet those needs. Not even my doctor in Edinboro which is now nationally recognized accessible college campus in the nation, they just got a power door. But even their facility that sees the largest number of people with disabilities is not accessible. Other than just getting in the front door. They don't have the accessible exam table. They don't have an accessible scale. They don't have anything that you would expect to serve a person with a disability.

I'm going to talk about managed care from a different perspective. A friend of mine lives in Kansas and I talked to her last night. She just called to say hi. At midnight. And I told her managed care is supposed to be coming to Pennsylvania and she started screaming, she's like stop it, stop it, stop it. I'm like what's wrong? She says managed care in Kansas is horrible. Managed care has caused her to lose services. Lose medication. Lose transportation. She

cannot reach her care coordinator. She's lost her behavioral health services, coordination and supports because she has a cognitive disability. She's lost hours. She said Kathy, people with physical disabilities get everything. They'll even get more than what they need because when the managed care association comes in and reviews them they look at your disability and say, oh you're a quad so you should have X number of hours. Where they look at me and say I have a brain injury. Because I had a tumor and I had a brain tumor removed. They look at me and say you can do this, this, this and this and they took her hours away and her migraine medicine away because she only has two migraines a month and she's in the donut hole for the Medicare Medicaid and her Medicaid won't pay for it. So I took her information. I went and researched on the internet and I discovered that managed care, that's supposed to save money they're finding now that it saves very little money. And in fact, people are harmed by managed care systems. People with disabilities. An example is my friend Heather. And she says when she tries to reach a coordinator she gets an toll free number and they never call her back she never reaches anyone or sees anyone and her care is horrible. She has no way to really complain about it and no way to get anything done. She was trained by me. She knows independent living. She's got a bad name in her state

because she's one of those people that will call and harass you until the end of the world. Just like Shona and me. It's not that she has a bad name but she's blackballed because she fights for what she wants. She went without attendant care services for an entire month and ended up in a crisis residential unit because of them cutting her hours back. Because she lost her job, because she lost her job she had to slide from one program into another program and she lost her ability to have transportation and she lost her attendant care. I'm afraid that these kind of things could happen in Pennsylvania. Not just that we could be controlled and that we'll lose our input. They don't have a consumer advisory board I know of. And we need to have consumer control. We have to have independent living philosophy.

You know it just doesn't work. Yes there is a break in the system. There's lots of breaks. You know, I'm working with people that are trying to get equipment. Several appeals refiled and refiled. I'm in appeal right now because I'm trying to get an adaptive piece of equipment and although it was written into my appeal I'm still having trouble getting the equipment because the state doesn't understand that you can use one piece of equipment in this room to get on to the piece of equipment that I'm trying to get so that I can get into the bathroom. Well if you can't

get Part A into your bathroom why do you need piece B if you can't get into the bathroom. Because piece B can get into the bathroom but I need piece A to get me on to piece B. I don't know what's so hard to understand about this. But apparently somebody down there is not understanding. So the review teams and the people that input it needs to be here. You need to have people with disabilities at all tables and people with disabilities on all of these things. It can't be just some Aetna or UPMC or gate way or whatever the heck they are. Frankly I don't want to see managed care because I think it's going to be a nightmare and it's going to cost more like it does in Kansas. It's costing them more because they are having so many problems. And you have to have choice. What will that do to my attendants. Will I get it from my same providers? We have been traumatized in this state. We have lost consumer control. We cannot go backwards.

Let me see if I got everything. In my written reports I have the websites to the documents from the Kaiser foundation, the Kansas university study, on managed care and a lot of those documents that I read last night say that over 50 percent or possibly more of the people that were surveyed lost care and services. The university study states that there's real no measurable outcomes and in many cases the reporting that you guys claim you had to take

attendant care away from and ship it to Boston, the reporting and requirements, there's no real tracking and ability to track that. Because they're comparing apples and oranges. So the figures for cost containment and service quality is actually unmeasurable in many cases because they're not measuring the same things. So you have to keep a tight lid on that stuff and keep consumers involved and you got to listen to us if we say it's broken you got to fix it because we have been broken in Pennsylvania far too long and we need to get back to being the best attendant care state. Thank you. (Applause)

>>SPEAKER: We have one last speaker. Dave Tome.

>>AUDIENCE MEMBER: I agree with everything that's been said. There are people that can walk today this hour, that might not be able to walk next hour. In fact the rate of accidents happen every day. And we just got to be prepared as best we can for that sad eventuality that accidents happen every day. I'd like to think in terms of this conversation, they're presently able bodied and disabled people. And sadly, as we get older the able bodied people will become closer to the disabled people. Because there's no way anybody can avoid ageing. So I just want to say that, Pennsylvania has been one of the top states, I think in terms of attendant care and I certainly want to keep it that way. And with the people coming back from the war and

terrorism is never going to go away sadly, at least not in the foreseeable future, so we got to be ready for the people that sadly will be joining the many people that are disabled in this country and world and I want Pennsylvania to be on the forefront of that fight. And as Americans, we have rights too and I don't want to be taught, treated as a second class citizen. And for the most part I would say Pennsylvania's done a pretty good job in that fight. But it could always be better. That's all I have to say.

(Applause).

>>AUDIENCE MEMBER: Good morning and thank you for allowing me to have this moment. A number of years ago, I'd say within the past five years, I moved to Pennsylvania to come to school to finish a degree I started. And upon completion of my education my disability became a lot worse. I was diagnosed about two years prior to coming to Pennsylvania with my disability. However when I ended up in Pennsylvania and it became more severe I was without healthcare for six months. I couldn't open a jug of milk, couldn't write my name. I couldn't rake the yard. The difficulty standing. I'm standing today and I'm proud to be standing today because of the medication I've gotten and the doctors and care I've gotten in Pennsylvania. They manipulated and moved my medication and my medical allowances around and

I've been fortunate and very, very few that I know of can say this, that they're able to stay with their doctors and those that know them, and understand them. I too started a program, about the time of my disability being diagnosed, it's called when to change. It's here to help those get out in the community and enjoy and be a part of their surroundings. Not keep them trapped at home. Or care facilities. I want them to be able to access their community I know I have my challenges and I know they have theirs. We're all human. We all care about each other. Just please help us. Thank you. (Applause).

>>SECRETARY OSBORNE: On behalf of Secretary Dallas and myself and Department of Human Services we want to say thank you to those who spoke on behalf of your selves or agencies, your courage, your testament, your ability to articulate what your cares and concerns and fears are that's important information for us to hear not just today but every day moving forward. It's privilege that folks have physicians, jobs and engaged in life in the community. Secretary Dallas spoke those words and I reiterate them. We are public servants and we're here to serve you. This is not about Secretary Dallas and I walking in to say how are we going to make life better for Pennsylvania. This is how we together are going to make life better for those who we are called to serve. Let the conversation that began today continue in

the days and weeks ahead. If you leave here today and have additional thoughts, comments, concerns or fears, or job is to respond and address those and assure this is not a fearful moment but a moment of opportunity to make things better. While it's regretful to hear the fear in voices and fear of things that happen in the past, none of us in this room can change the hands of time. It's our job and duty and opportunity to pick up our baggage and move forward with it and make it better. If you have additional concerns please call our offices there are other opportunities to speak to us in person, to have written commentary to pick up the phone and call and e-mail and say, hey I met you but I didn't get to say this or that. We have to hear from you. As I started these words a few hours ago in this session here today, we will not be successful unless this engagement stakeholder opportunity continues and that's all stakeholders in the room and those not able to be here today. We rely on you to help us move forward. We're privileged to be here with you today and we're grateful for your time and supporting one another. A wise mentor of me told me if passion in the room could solve all our problems we would have no problems. The passion here is palpable. With every challenge becomes an opportunity. I heard the word hope mentioned here. I'm a pretty hopeful person I know all of you are. My dad taught me well, hope is not a

plan. We can only do that if we plan together. So that fears are diminished so realities are enhanced and folks can live as Governor Wolf and Secretary Dallas and all that work with and for us that the most vulnerable among us are treated with dignity and respect and live in the communities in the way they deserves. That is our charge. We look forward to working with you in the days and weeks and months ahead. Safe travels. Thanks.

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