COMMONWEALTH OF MASSACHUSETTS

EXECUTIVE OFFICE OF HEALTH AND HUMAN SERVICES

IN RE: Integrating Medicare and Medicaid for Dual Eligible Individuals

Public Hearing on Draft Demonstration Proposal

Friday, December 16, 2011
1:00 p.m. - 3:00 p.m.
Worcester Public Library, Saxe Room
3 Salem Square
Worcester, Massachusetts

Moderated by: Robin Callahan, Deputy Medicaid Director, MassHealth

Reporter: Cynthia C. Henderson, CSR/RPR

MS. CALLAHAN: Before we get started, just to make sure everybody has been offered a chance to sign up and to speak today by writing your name on a sign-in sheet, is there anyone who wishes to speak today who hasn't yet signed in on the sheet here? Okay. Well, thanks a lot for coming. I am Robin Callahan, and I am the Deputy Medicaid Director, and I appreciate you all coming in today for this public hearing about a proposal that we have recently posted that would be our proposed programs at CMS for integrating Medicaid and Medicare services into one combined program. So I trust you've all found the proposal, and we really are looking forward to hearing from you today.

Joining me when they get here, and we have been told that there is a little delay in transit, we are expecting to have the Medicaid Director, Doctor Julian Harris, join us, as well as Christine Griffin, Assistant Secretary of Health and Human Services for disability. So both of them are en route, so they will join us when they can, and I believe

they will probably each have maybe some closing remarks. Oh, I'm sorry. Was someone telling me something? Christine is here. Very good. Okay. Hi, Christine.

So this is the first of two public hearings on the public comment period on the draft proposal. The purpose of this meeting is to give members of the public an opportunity to present oral comments to the proposal and for us to listen to those comments. So I guess before I go any further, do you want me to keep going?

MS. GRIFFIN: (Christine Griffin) Yes. You know, I think just on what Robin said, we are really here to listen to people and we want to hear what you have to say and we want to make sure that the proposal reflects what you tell us today. And we are really, really interested in hearing from consumers, especially those who are dual eligible, that can tell us what works for you now and what doesn't. That would be really key, and I know we have to limit the time because but there is also opportunity to comment after this, comment on the proposal, by even just writing us and letting us know

what's working for you and what isn't. We truly want to make this a proposal and ultimately implementation of a system that works for you and provides you what you need. So we are here to listen.

MS. CALLAHAN: Just in terms of general format, those of you that have attended, we have had a series of open public meetings over the last several months. This one will be a little different. In the past we've done quite a bit of back and forth, but again, we really have reserved these two meetings to be literally hearings that we are here to hear you, so we don't have any presentations. We are not going to do a lot of talking ourselves, and we want to spend as much time at the hearing as possible.

So I'm going to be calling names in order of the sign-in sheet, and when your name is called please let us know where you are and someone will bring a microphone to you. When you are speaking we really would appreciate it if you would please restate your name. I might not do a very good job of reading your

name off the sign-in sheet, and if you are speaking on behalf of any group or organization, we would appreciate knowing that as well, but certainly you don't have to be speaking on behalf of any organization. We are thinking that, given the number of people who have signed in, in order to make sure everybody gets heard we are going to ask you to limit your comments to four minutes or so, and we are going to, you know, let you know when we are getting close to that to encourage you to wrap up. Perhaps we will have more time at the end once we've made sure we've heard from everyone. If you wish to submit written comments in addition to your oral comments or instead of oral comments, we will be taking written testimony today, but you also will see on our web site where you can send those comments throughout the whole comment period.

This hearing is being transcribed by a stenographer. Oral comments today are considered official public comments and will be considered in just the same way as written comments are to us. There is no difference in

value on that. All comments received by us over the public comment period will be thoroughly and carefully considered, as Christine just said. This is a true effort on our part to make sure that the proposal that we put before CMS reflects in the best way we can a program that folks feel will be valuable to them. We expect to revise the proposal that was posted based on the comments that we receive before we submit anything to CMS. The public comment period closes at 5:00 p.m. on January 10th, 2012. The handout you received at the sign-in desk includes an e-mail address for anything you want to send us and a mailing address for submitting written comments.

So with that, I would like to start the testimony. The first name I see is Christa Brown.

MS. BROWN: (Christa Brown) Hi. My name is Christa Brown. I work at Northeast Independent Living program, an independent living center in Lawrence, Massachusetts. I am the staff interpreter there. I work within the deaf and hard of hearing services program. I

wanted to bring up the point today that one of the things that we want to point out is that American sign language is often not recognized as a true language, and it is, just like Spanish, German, English, all of your first languages.

One of our goals is to see that American sign language gets the same recognition as these other languages, so when you go into your hospital or when you go into your doctor's office the expectation is that you should be able to communicate in your first language, whatever that language happens to be, and for the deaf and hard of hearing community that is American sign language. So we want to see it get the same recognition. And also, it's so important for our independent living centers to continue to be a strong advocate and presence in your community, and we want to see those continued as well.

MS. CALLAHAN: James Orlando.

MR. ORLANDO: (James Orlando) Hi. My name is James Orlando, and I am a consumer at Northeast Independent Living Program. I am also

dual eligible myself. One point I wanted to mention is that the Beverly Hospital already has interpreter services set up, so when you enter the hospital there is already an interpreter there, there is services provided for deaf and hard of hearing people. So it makes the process very smooth and very easy for us when we go into the hospital, and we would like to see those kind of services set up in other hospitals as well.

Interpreters are important to be a live, an actual live person, but if that's not available you can also get interpreter services through a laptop or through the Internet, and so that would be a good second option. As myself, I prefer to have a live interpreter. That's better, but that's another option as well. Thank you.

MS. CALLAHAN: Thank you very much. Laurie Johnstone.

MS. JOHNSTONE: (Laurie Johnstone) Hi, everybody. My name is Laurie Johnstone, and I work at Northeast Independent Living Program as a deaf specialist. I work with people to

stay in their homes, in their environment.

I just wanted to say that I live in New Hampshire and I work in Massachusetts. New Hampshire has a model already with American Family Living interpreters. There are three hospitals in New Hampshire that have that model, emergency medical interpreter services, as well as there are two or three hospitals that hire interpreters who work with the deaf interpreters as well as running services.

I have patients coming into the emergency room, and the interpreter will be right there in case you have an appointment, and if they have no luck finding an interpreter, that interpreter will be there.

Also, I just think that it's important that the interpreter is available for deaf and hard of hearing patients.

MS. CALLAHAN: Thank you very much. If you will indulge us going out of order for one moment. Speaking of translator services, we had to pull the folks from the library that have been gracious enough to offer us some Spanish translation assistance, so if we

have someone who could use that. Is that okay with everybody?

So we have Evan Arroyo?

TRANSLATOR: Her name is Evan Arroyo. I am Iris, and I work at the library. I just came here to help her translate. She wanted to know first of all what this is all about.

MS. CALLAHAN: Well, I guess you can say we are here on a public hearing about a proposal to have Medicare and Medicaid services joined together in a program for people who are eligible for both Medicaid and Medicare. There is a new program that we are looking to start, And the program is for a person with disabilities who is eligible for both Medicare and Medicaid, and we want people to tell us what would be helpful to them about a program like that.

MS. ARROYO: What would be the benefits of combining both? You might have said this, but I missed it.

MS. CALLAHAN: Yes. I'm sorry. We didn't really do a presentation, but there is

a proposal we have out, and the benefits are generally that people should be able to get both sets of services in one program, and we are trying to find a better way to do that than what we do today. And you can let her know that we will be more than happy to find a way to spend time with her to talk about that after this. Our purpose today is to hear people tell us what they think about what we've proposed. Okay? Thank you very much. Sharon Sachs.

MS. SACHS: My name is Sharon Sachs, and I'm a consumer at the Northeast Independent Living Program. I'm also deaf and partially blind. I myself am a dual eligible. So I had to go to physical therapy, and in that situation they had requested an interpreter for me, and they made the calls necessary, but there were several times that they didn't show up so I had to go without an interpreter. They only came twice, so I had to go to my therapy with no interpreter. So again it was a bad situation because I didn't have interpretation that I needed.

Also, I feel that deaf blind

consumers should be provided with interpreters on a weekly basis so they are not isolated because that's a human rights issue. That's a violation of their human rights because they are isolated, and we feel like to provide those interpreters would help remedy that problem.

MS. CALLAHAN: Thank you. Deborah Hallissey?

MS. HALLISSEY: Hi. My name is Deborah Hallissey, and I'm a dual eligible. So when you go to the hospital, whether it is for a procedure or maybe just for regular appointments, sometimes you can wait and wait and wait to get an interpreter. It's best to have a real person there to be with you during that time, and it's very important that we don't close down the IL centers. The independent living centers need to partner with the ICOs. Thank you.

MS. CALLAHAN: Thank you. Jill Bower.

MS. BOWER: I am testifying today as an advocate for those who are dual eligible for Medicare and Medicaid. My name is Jill

Bower, and I am the Director of the Northeast Recovery Learning community that serves people with mental health conditions in the northeast part of Massachusetts.

As a Medicaid recipient myself, I have a secondary concern that some of the provisions in this demonstration might one day apply to me were I to become Medicare eligible as well. One of the key things I want to say today is that the recovery learning communities and the independent living centers must be contracted partners in this demonstration because they are the bedrock of both peer support and peer services for people with disabilities, and there is no substitute for these services in Massachusetts.

(Applause)

MS. BOWER: The right to choose one's own services is a fundamental choice which must not be compromised by the proposed demonstration. It is the cornerstone of health choice for all individuals. This lack of choice can lead to disempowerment, misunderstanding, disenfranchisement, and bad health care. Only

certain care providers have both the requisite experience and expertise to meet the complex needs of people with disabilities. Many individuals have searched long and hard to find these providers and would be outraged, not to mention poorly served, were they to lose access to their specialized care.

Second, neither health insurance companies nor hospitals nor physician groups have any experience in judging the quality or efficacy of community programs. These entities are far removed from the day-to-day work of community providers, the challenges they face, and whether they do a good job at the local level. The world of insurance, medical and hospital care are far removed from the realm of community-based services.

Unfortunately, traditionally the insurance companies have generally biased their financial resources to the former and shortchanged the latter. Recent efforts to expand the community system are only beginning to make headway. To hold fledgling gains hostage to the medical community would be

terribly shortsighted.

As a person with multiple disabilities, I would far and away prefer a person from a recovery learning community or an independent living center to coordinate my care rather than a medical entity. This is because I am more than my disability, and the medical model looks only at the disability, the pathology, rather than the mind, body, spirit totality of the whole person that I am.

Finally, it is critical that the Statewide network of recovery learning communities and independent living centers be one of the cornerstones of the dual eligible demonstration because they provide vital services and support in the community at lower cost and a better quality of life, which is a necessary complement to the medical services to be provided in the ICOs. These agencies must have central involvement in the demonstration to ensure that the needs of the whole person are met and are not dictated by agencies which are based on the medical model alone. Thank you.

(Applause)

MS. CALLAHAN: Thank you very much. Mike Allen.

MR. ALLEN: Hi. My name is Mike Allen from the Northeast Independent Living program in Lawrence, Mass. It is important that all doctors are required to provide interpreters. Without qualified ASL interpreters, quality services cannot be provided.

An example of this is that quality medical interpretation increases insurance cost and it increases personal medical problems and pain. The IL philosophy is the rational choice to correct the above-mentioned problems. The Independent Living Centers in Massachusetts have had decades of experience with helping the disabled achieve their independence and should be the first choice of this new program. Thank you.

MS. CALLAHAN: Thank you. James Lyons.

MR. LYONS: Good afternoon. I am James Lyons. I am a community development and advocacy director at the Northeast Independent

Living program from Lawrence, and I thank you for the opportunity for us to come here today and provide some very positive and very strong recommendations for providing a program that works for us and that provides the things that we need.

My recommendation specifically is that the ICOs, which are the integrated care organizations, they need to provide actual contractual relationships with the Bills* (phonetic) programs, the deaf, hard of hearing Independent Living Services programs in the State, and that's to provide them with training on the cultural interests and needs of the folks who are deaf and hard of hearing and also training on the assisted technology and technological equipment that people may need, and they are the best folks to provide training and can provide really quality assurance, and I think that would help quite a bit. Thank you again.

MS. CALLAHAN: Thank you. Nanette -- help me?

MS. GOODWIN: Thank you very much.

I am Nanette Goodwin, Assistant Director of the Northeast Independent Living Program, and I'm here today to express my concern with the proposed plan that people who are deaf or hard of hearing or who have a disability will lose our ability to choose our health care providers, the facilities that provide what we need, and the types of services and equipment that we need.

Also, I am concerned about the peer support and services that RLCs and independent living centers provide will no longer be available to us. We need to preserve the independent living center model, and what we don't want is these services provided by ICOs that don't have the knowledge and the experience to provide these services. What we do want is contractual relationships between ICOs, ILCs and RLCs and an independent care coordinator on my care team. Thank you.

MS. CALLAHAN: Thank you. Paula Callinan.

MS. CALLINAN: Thank you for the opportunity to speak to you. I work at

Northeast Independent Living Program and have for quite some time, and looking at this demonstration it is stated in the written language that it's going to look like a SCO, and we have had individuals at the IL center enroll in a SCO, and unfortunately they were very unhappy. They did not have a person that they could call, they were no longer able to receive services through an independent living center, their personal care attendant program. So they disenrolled.

The ICOs should have representation on their care team, representation from an independent living center or an ROC. What will happen is the independent living centers will become nonexistent. They won't exist for individuals who are dual eligible. Individuals that are in a facility and are approached and asked if they want to enroll in this demonstration are not going to fully understand what that's all about, and it hasn't worked with the SCO in the past, and I don't think it will work with an ICO. Thank you.

MS. CALLAHAN: Thank you very much. Matt Pelligrino.

MR. PELLIGRINO: My name is Matt Pelligrino. I work at Northeast Independent Living. We think that medical coverage should be based on the unique situation of each person and their doctors. Brian was telling me that at one point he was forced to take a certain medicine that was difficult to take because of swallowing issues he had, but Medicare only paid for a capsule form. So despite his doctor's request that he get a different type of this medicine, he was not able to do so. So that is an example of where they don't take the consumer and the doctor's advice in considering whether to cover something. I know I don't want to repeat everything the other employees have said, but consumer choice is a big issue.

Brian was saying how with durable medical equipment he was trying to get a wheelchair a little while ago and he had to pick a certain vendor, and the vendor didn't really understand his wishes on the type of wheelchair he wanted. I don't know if they didn't care to

understand his wishes, but they gave him some bad information on what wheelchairs were available to him, and Brian was frustrated because there weren't a lot of vendors in his area that he could chose from.

I'm thinking with the ICOs -- I was reading a proposal that with the ICOs they are going to be separated by different areas, and I am just thinking that consumer choice is going to be limited even more, so that if they only have one or two vendors in their coverage that gives someone a wheelchair, that's not much choice.

Also, like Brian, I am a dual eligible. I am a PCA consumer myself. I would not want to ever have to receive PCA services from an organization that didn't have our philosophy as its driving force, and I know Brian agrees with that as well. Thank you.

MS. CALLAHAN: Thank you very much. Florette Willis.

MS. WILLIS: Thank you. Hi. I'm Florette Willis from the Disabilities Policy Consortium, and I am also the coordinator of

Empower. And that's Massachusetts People Empowered for Wellness and Rights. What I wanted to comment on was the reduction of long-term support services. I think that a reduction would create a lot of problems for me personally. My mother is dual eligible. My mother has been sick for many years, and my sister and I are her primary caretakers. If we didn't have PCA services my sister and I would not be able to work. Due to my mother being ill for so many years, my sister and I suffer from depression. We both are in recovery for mental illness, and we work on our recovery, so we need time to want to work to have a complete and fulfilling life and also time for us to go out and to access community services such as the RLCs so that we can stay connected and take care of her but be able to take care of ourselves as well. If the PCA services were reduced or we did not have services to cover us, my mother would end up in a nursing home, and that's a really big concern for me.

Over the years my mother has been institutionalised, and she's not always done so

well there. At home my mother is doing very well. She is thriving and she is happy, and to me it means a lot, especially since growing up as a child I was always prepared by members of my family, for my mother to die and to not be here. The fact that she is here todays means a whole lot to me, and her care has been properly coordinated, and my family is very happy with that. So we see a big need for these types of services and peer support services as well. Thank you.

MS. CALLAHAN: Thank you. Hasom Hifal.

MR. HIFAD: My name is Hasom Hifal. I was born in Palestine. I came to this country back in 1980. I have a nurse. I am a PCA beneficiary, the Center for Living and Working.

What I wanted to say is this program has saved my life. They did a tremendous amount of change in my life. About ten years ago I discovered this problem, and I was on the verge of getting divorced, getting kicked out of the house, almost died, and my

wife was coming down with depression. She became also dependent on other things. My children were too young to continue. Right now since the program has been introduced to me I have people that help me out. I am still alive. I am almost fifty years old. My children when they grow up, my oldest is on her way to law school, Northeastern, and the second one is a premed. I myself am a chemical engineer, but I never worked in that field. I never have had the opportunity to work. I came up with this disease when I was 23. I am a very proud citizen of the State. I just cannot tell you enough the amount of changes that helped me. It is the difference between me being dead, divorced with nothing, nothing over my head, to being a good citizen, having two children, being a very great citizen.

Again, this is the United States. For God sakes, we can't allow anything to happen to make it Russia or other countries. This is our choice, to be the best we can be, and I don't know which direction we are going. If this program is dissolved, I know I am dead. I

know I will be divorced. I know the whole thing is going to fall down, everything will fall apart. This is all we have. This is all I have. Thank you.

(Applause)

MS. CALLAHAN: Thank you. Dennis Sepe.

MR. SEPE: My name is Dennis Sepe, and I am speaking as a citizen of Massachusetts today and as a dual eligible, and I am going to share a story of what happened when I became part of an integrated care type entity. I had been using a urologist for a number of years and had a great relationship with this urologist, and then I was told that I could no longer go to that urologist because of the hospital that he was in, that he did not have rights, and the care plan that I belonged to didn't have rights in that hospital, so I had to go see the doctor within their plan. I went to this urologist, and what would normally have taken twenty to thirty minutes became an hour and a half and a two-hour ordeal. I had to go to preop for a simple urological exam, and I ended up bleeding

for two days.

I share this story because I am deeply concerned as a dual eligible that my current care provider will not be a part of the integrated care organization and that I will not get a contract and that I will be put into an integrated care organization where I am told -- and this is what frightens me the most -- is the paternalistic medical perception that a doctor knows what's best for people with disabilities and they can take care of us. I am deadly petrified that for myself that I'll go into a new ICO-type thing and then I will be required to go see their specialists and I will lose touch with the specialists I have and I will go through similar nightmares that I did with this urologist.

I am afraid of the medicalization of the services that we receive, and that as a PCA user I am also very much afraid of my personal care attendant services being subsumed into an ICO and that all the progress and everything that I've fought for myself personally over the last twenty-plus years will

disappear because of what with good intentions is being put forward, and I just am afraid. Thanks.

MS. CALLAHAN: Thank you. Joe Bielette.

MR. BIELETTE: I am Joe Bielette. First, I want to thank the Executive Office of Health and Human Services for working on this, especially the dual eligible initiative, especially in the day with all these proposed cuts, especially federal cuts, with hearing that it doesn't look like the class act will go through. I am glad we are talking about these long-term care services. We support the disability advocates advancing our healthcare rights, priorities, and principals, which include -- I just want to go into one of them, the voluntary opt-in enrollment. I know that's not the most favorable for insurance costs and things like that, but at the same time to me, which I've read many times about it being person-centered, and thinking that if this is really going to be a better program for folks, then people should be wanting to opt in

voluntarily, and I think this is going to force clearer instructions.

I don't know how many people have received different types of medical information, but a lot of times it is very complicated, and I think we need to have it in more simplified language, understanding clearly what benefits, what choices a person has. I think people need to understand that there are better services. Why should I do this? I have talked to different people who are dual eligible right now and they're saying "Well, I get the services right now. Why do I want anything different? What's the benefit going to be?" And I think it's also going to help push medical folks really understanding or really needing to better understand disabilities, and that includes disability etiquette.

I think sometimes we're not seeing that, the accessibility of locations. I think whether it's everything from accommodations, sign language interpreters, accessible scales to other accessibility issues, needs to be addressed, and I think that's going to be an

important piece that could help sell a person into opting into a policy.

The other thing I am hearing nowadays too is about the needs for -- people with disabilities are aging, and I think it's important that if there are specialists out there that can say "Look, we have this kind of knowledge on certain types of disabilities." I mean, that could be a great selling point.

I think it's going to be important to have these contractual relationships with community members such as living centers, the aging organizations, and other groups because I think it's going to be important to be able to talk to somebody else to get additional information, some peer support, as to what's going on. I think it's very important.

And as we're looking at this in total, there are two pieces I didn't see in the proposal, or at least see that often. First is employment. I think as we look at folks who are dual-eligible, we also should be thinking about the possibilities of that individual working. A lot of times I think people don't even think

about that, and I think it needs to be thought about, and actually, I think the person should be thought about working versus not working, whether it's volunteer, part time, whatever. I think that's an important piece of being independent in the community.

The other aspect is the recreation. A lot of times folks who are going into medical facilities or whatever, their goal is to be able to do what they were doing before, participating in different activities and things, and I think having the community organizations being involved will also help in the awareness of other recreational opportunities. To me it's all part of life, so I would just encourage those thoughts. Thank you.

MS. CALLAHAN: Thank you. Nick McNamara.

MR. McNAMARA: I thought I was later on the list, but I am actually here as a dual eligible individual, and I actually wanted to start off by saying that I have been receiving Medicare and Medicaid for the last ten

to twelve years, and I'm thinking maybe that -- and you don't hear this that often -- but I am very satisfied with the care that I've received, the freedom of choice. I am allowed to utilize PCA services through Mass. Health, and my life is going really well. I feel really good about it, and I'm worried that with the proposed changes that we have that these freedoms, freedom of choice mainly, will no longer be there.

I also work for an independent living center, and I know that we should be almost in a sense guaranteed a relationship, but I didn't see in -- the proposal was talking about contracted -- and there were some parts that worried me where it said that the ICOs will be encouraged to maintain these contracts, but I didn't see anything that said absolutely the independent living centers will be here and will remain, and that worried me. Thank you for your time.

MS. CALLAHAN: Thank you. Al Norman.

MR. NORMAN: I am going to be

submitting a twelve-page statement, so I am just going to summarize some thoughts. Number one, Mass. Home Care is a network of thirty nonprofits. They are controlled by local senior citizens, and they were created by the State. Our goal is to keep people living in the community in the least restrictive setting possible. This plan today is for people up to age 64, but it's clear it will eventually be the template for serving the elderly. The program is designed as part of an initiative to provide information as to how to enhance options for people who are dual eligible for all ages. That's why I am here today, because it will affect the folks that I work with.

This plan by design gives all the Medicare and Medicaid money to large insurance-based or profit-based entities, most of which have little or no experience with long-term care and some of whom put shareholders ahead of healthcare consumers. This ICO plan will attract large investor-owned insurance companies, and yet there is no medical loss ratio on the plan to protect consumers from

excessive profit taking.

The ICO plan lets managed care organizations do their own care coordination in the community. It contains no independent, conflict-free care manager to serve as the agent for the consumer, despite the fact that the federal government has suggested to states that you ought to have that as part of any kind of long-term support program in the state.

At a minimum, we at Mass. Home Care want every member who joins an ICO and turns sixty to have a geriatric services coordinator provided under Chapter 19A. This is current State law under the SCO program, and this is what our plan mandate is to do, and until you change that law, we want it to remain.

Coordination of benefits for the elderly means including State-funded home care, federally funded Older Americans Act, none of which are coordinated under your plan. The ICO plan guarantees members access to nursing facility care, but it doesn't give them access to equal community-based care under residential services 24/7. So it maintains the bias

against keeping people in the community that I thought we got rid of with the Equal Choice Law in 2006, but here it is again.

We believe that under Section 1932 of the Social Security Act that people on Medicare are exempted from being required to enroll in a managed care plan, and they should at all times have the right to get out of that plan and go into an original fee for service Medicare. If the Governor and the legislature decide to end fee for service, then this plan will look like a medical Hotel California where you can check out any time you want but you can never leave. This plan is predicated on performance-based contracting objectives, and yet there are no quality measures at all in place that address long-term care functional needs. It's all medical.

It also appears that people sixty to sixty-four in the current frail elderly waiver will be carved out in some way, but over time when these people die that waiver would die as well. The Commonwealth expects the distinction between SCO and the new

demonstration to diminish over time. It looks to me like SCO will also disappear.

We believe that any plan that will impact a quarter of a million poor people in our State and involve several billion dollars in taxpayers' money should have a legislative framework to protect consumers. So we will be pushing the General Court to write a law to protect people who will need these services long after everyone in this room is gone.

Mass. Home Care has worked for years to fully integrate health and long-term care, but we cannot support a plan until major design changes mentioned above are addressed. This is not the plan that stakeholders repeatedly asked you for and we believe that we have lost, and that we must and can do better. Thank you.

MS. CALLAHAN: Michael McGinnis.

MR. McGINNIS: I am Michael McGinnis. I am the Chief Relations Officer for the Central Mass. Recovery Learning Community, and we are located here in Worcester.

ICOs should be required to

contract with recovery learning communities, independent living centers, and other community organizations to provide PCA services, peer support and ADA compliance. There also needs to be a separate disability oversight organization to ensure that the rights of all those with disabilities are protected.

MS. CALLAHAN: Thank you. That's the last name that I have. Let's raise hands and do what we can. I'm sorry. Did I miss someone? I have two pages.

ATTENDEE: We know you burned that one!

MS. CALLAHAN: I swear, none of them are on my list. We will just raise hands. We've got plenty of time to get everybody.

MR. TRAPAZANO: Hi. I'm Peter Trapazano from the UMass. MediPlan, and I just wanted to echo a comment that I heard a little earlier about importance of employment for people with disabilities. I think it's crucial for people's wellbeing to get back to work, and I think it's also cost effective in that people that are working often find themselves in a

situation where they are no longer receiving benefits.

One of the things that we provide at the plan, at the BETI plan is an important service where we work with people so that they understand the benefit system as they are going back to work because of the complexity of the healthcare system, both healthcare and Social Security benefits. So we work with beneficiaries so they are able to understand these things and make important decisions so they are able to get back to work effectively.

I would like to see in the ultimate proposal that benefit counseling for people with disabilities be included as a service that's built into this program. It's a very inexpensive service, but it's a crucial service in helping people get back to work and live fulfilling lives. Thank you.

MS. CALLAHAN: Thank you.

MS. CAROL: I am Martina Carol from Stavros out in western Mass. We serve about five thousand people with disabilities in Franklin, Hampshire and Hampden Counties.

Much of what I am going to be mentioning has been mentioned before, but for rural concerns we simply don't have enough primary care doctors and specialists, especially to meet the complex care needs. I'm worried about the ICOs denying transportation to Boston to see a specialist when they say "Well, you can see someone in Springfield." It's just not safe. If cost is going to be a bottom line, I am worried about this, and I think a lot of that -- if ILCs and RLCs have contractual arrangements with the ICOs, that will go a long way towards solving that, but there has to be some teeth in it for the ILCs and the RLCs. I see no rural protections.

I would like to see an advisory board made up of consumers and advocacy groups, some kind of oversight over this. Call me cynical, but I just don't believe that the big insurance companies really care that much. Their bottom line is cost. I don't know. Maybe it's different in the Boston area, but we don't have a whole lot of accessible medical settings, whether it's a hospital clinic or doctor's

office, and I don't want even to start talking about communication access.

We really need that independent consumer-based review, especially denials of service and modifications of service. We need to have someone reviewing them other than the ICOs. The care plans, I'm kind of interested in how they are going to write 115,000 care plans right away. I really think it makes a whole lot of sense to roll this out slowly so that the ICOs can actually learn how to serve people with disabilities, which is complex care needs.

Long-term supports and services aren't really medical, and we don't need them to be medicalized. We don't think that -- the PCA program, we want that to be based on functional need, not medical need. Long term what's going to happen is eventually the ICOs -- we see them moving to an agency model PCA because they're going to think they can save money. They'll be switching services by trying to save money.

The other big concern is ICOs co-own nursing homes, so what's going to keep them from keeping them filled? They're going to

keep their bottom line, and it has been a little disorganized. I'm sorry. I will be submitting some comments as well.

MS. CALLAHAN: Thank you very much.

MR. SPOONER: Thank you very much. Good afternoon. My name is Paul Spooner. I am the Director of the Metro West Center for Independent Living. Let me say first I really want to commend you all for coming up with a very innovative idea or concept to try to solve some of the inherent problems that have existed due to different coverage issues, different levels of eligibility, and different cost factors that are related to dual eligibles. There are many cases where things that are under Medicare that aren't provided for that can only be gotten through Medicaid and vice versa.

Now, this afternoon you have obviously heard many stories of people's concerns that they have already experienced as being dual eligibles and the concerns that they've seen in reviewing the draft proposal as it's currently presented.

I would like to make a couple of comments, but most everybody today has outlined the specifics that I'm concerned about, such as having independent care coordinators or maybe independent long-term care coordinators would be a better term. I don't think we want to care or take care of people. We want to assist people to ensure that they get the best quality services that they are entitled to and want.

So there needs to be a component in there that's going to be assisting these ICOs to develop a truly person-centered, person-driven plan of care for both their acute care needs and long-term care needs. This is a pretty bold step to be taking to actually have the acute care world, better known as the medical homes, actually embrace and provide long-term care services.

To my knowledge, there is no evidence that this has ever happened before, and I think on a very positive level it's encouraging to think about the possibility of doing that, but at the same time it scares the living piss out of me as to what might happen as

a result of this bold experiment.

My other big concern is I'm not a dual eligible, but any time in the future due to my progressive disability I will become a dual eligible, and my concern is that I have spent the last 32 years on the PCA program, I have a relationship with my PCA agency, I have a relationship with the evaluation nurse who has seen me for the last I think six or seven reevaluations. It's a program that has enabled me to finish college, go to work and start thinking about what my world will be after I retire, if that ever happens. However, I don't see nor have I seen in those past 32 years any of my medical folks, whether they were doctors or specialists or nurses, truly understand what my PCA eval means or what those services really mean that enable me to even come to their office for a doctor's visit, and the fact that I need people to get me up out of bed in order to do that. So I'm very concerned that that blending of long-term care and acute care is a great design, but I'm scared of what it may actually end up looking like.

In addition, you have proposed some rather unique additional services that would be offered to individuals in this proposal, and I think those merit very strong support. They include adding queueing and supervision and monitoring for PCA services, which will open up PCA services to so many more people with disabilities who need and deserve those services. There is some additional added services that will be helpful for people in the community. However, again, it comes revolving back to the fact that your proposal requests or encourages the care coordinator's medical staff to be knowledgeable about all of these new services and how they impact people's lives in the community, and I think you are, quite frankly, asking too much without having some real strong incentives for community partners to be on that team, whether it's folks from the elder community, folks from the disability community. They are the folks who are aware and knowledgeable about community-based services, including some of the proposed new models of services that you've provided.

Two last things and I'll be quiet for the moment. The first thing is it's clear your proposal has kind of danced around the issue about carping out waiver-based services for being included in the capitation rate in this proposed project. While you know from reading this morning the CMS just approved Tennessee to have that exact thing happen in the State of Tennessee, and I think that's a smart move because there are real concerns from particularly the DD community and other folks on waivers shouldn't be included in this proposed capitation rate.

So I propose an additional group to be added to this proposal, very specifically, those folks are who are dual eligible and also folks on the current PCA program. They should be carved out, and their costs should not be included in the capitation rate. However, I will suggest that those same people be given an opt-in option so that if those individuals feel that they are going to get better PCA services than they currently have, that they have that opportunity to use those services provided by

the ICO, but it's imperative in my view that you understand that the heart of the disability community that we based our independence on for the past 30-plus years is the PCA program, and from my read that program is in severe danger based on some of the language that's been put in this proposal. Thank you.

MS. CALLAHAN: Thank you. We had a gentlemen over here. Do you want to speak, sir?

MR. LARANGE: Hi. My name is Peter Larange. I am an independent living specialist with the Center for Living and Working. I am also a benefit specialist. I assist my consumers with accessing different programs of Mass. Health as well as through an application for Social Security, allowing them to access the Medicare program. I myself am also a consumer for the Center of Living and Working, a PCM consumer, and a dual eligible individual myself.

Recently I experienced neurological deficits in my hands from some things that are going on in my cervical spine.

I sought out neurosurgeons to examine what the possibility would be to surgically repair or consolidate the situation in my cervical spine. The local doctors said that there was really not anything they could do surgically, so I sought out my own surgeons at New England Baptist Hospital where they had a spine clinic, and they specialized in these neurological surgeries. The only problem was they don't accept Mass. Health, but being dual eligible I was able to access them with my Medicare coverage.

If lumped into a managed care type situation where I would only be able to access services accepting of both coverages, I think that would limit a lot of our options with specialties. I am just looking out for our consumers and I am trying to process all that you have proposed so that I can interpret it and share it with my consumers when they come to me with questions, and I'm also agreeing with Mr. Spooner in that the dual eligibles who are currently on the PCM program should be given the option of opting into this proposed program versus having to opt out of it. Thank you.

MS. CALLAHAN: Is there anyone who hasn't spoken who wants to speak?

MS. KOFFMAN: Hello. Can you hear me? My name is Evelyn Koffman. I am 63 years old living -- I am a psych survivor and living with bipolar disorder, and I am also a dual eligible, and the thing that concerns me is if we have our things in one place we may not be able to keep our providers. For the past 38 years I have had all my medical treatment almost at Brigham and Women's Hospital, but for the last seven years I have been seeing psychiatric providers in a different location, and I'm afraid that under the program that I might be forced to leave for some other program. I feel that's going to be catastrophic for me.

It's important that we keep providers that we have rapport with and that we trust and who are supportive of us. I might not get that if I am forced into certain places and certain areas, and I think a lot of other people with psych disabilities feel the same way. I feel that if we are torn off from providers that we have a rapport with, a lot of us might not be

able to trust our new providers and will drop out, will fall through the cracks, will decompensate. They will turn to drugs and alcohol to ease the pain, and some of them will commit suicide or even worse, suicide by police homicide, as Carol Kingsley did two summers ago.

I really feel it's important also not to just embrace medical model services. I feel it's important that we continue peer RLCs, peer recovery programs, especially have providers that deal with recovery models and trauma-informed care models. I really feel fortunate that in almost forty years I have only had three hospitalizations, and that's because I have had good providers, and I don't want to be forced into a disempowering program. I feel it's so important that peer-run programs, peer-run that are not medical models with them over us but are egalitarian such as respites, that they be open to all dual eligibles. I feel these are important. Our physical is one thing, but we need to keep our mention options. Don't force us out of our programs. Thank you.

MS. CALLAHAN: Anyone else who

hasn't spoken that wants to speak?

MR. CRATANIER: Thank you. My name is Jim Cratanier, and I am from Stavros. I didn't want the afternoon to go by without somebody talking about Newt Gingrich. He did recently warn about the dangers of right-wing social engineering and included it as a danger, along with left-wing social engineering. Certainly the proposal that the Commonwealth is putting forward is a huge example of social engineering, and there are risks to that, particularly with unintended consequences.

I am especially concerned about the integrity of the PCA program going forward. While I very much appreciate the intentions with regard to the program -- Paul has mentioned the addition of queueing and supervision, which is going to be a huge benefit to many people. I am also concerned about what has been sort of the crown jewel of services for persons with disabilities of Massachusetts could end up down at the corner pawnshop, and I will say that because you have got two pillars to that program as far as I am concerned.

One is an assessment which is made based on what an individual needs to live independently that's independent of any other considerations, medical costs, whatever. And so people get what they needed for the most part. And the other pillar has to do with consumer control and the ability of the consumers to hire the people that they want to hire and train them the way that they want to be trained. My concern is down the road what happens is when you have a blended rate of long-term support services, services and support, as well as medical care and the costs on the medical side go way, way, way up, as they have for many years. There is no reason to expect that to change.

What kind of pressures are going to be exerted to cut back the cost of long-term services and support, especially to PCA programs? Are people going to see reduced hours? Are they going to get lesser services because they are less expensive?

On the other hand, if you have got ICOs contracting with large providers who were

providing the skills, training and the introduction to the PCA program, what's going to happen to the whole idea of consumer control and what are we looking at down the road there as their incentive in fact to move towards what was mentioned early, an agency model where basically it may well be cheaper to bring in PCAs and just provide them to consumers, and so we lose that pillar as well.

As I said, I am very concerned about the integrity of the PCA program under this initiative down the road. I'm also concerned about homestead. And while the proposal primarily focuses on cost issues, and I don't know what happens with the State's commitment and the Commonwealth's commitment to community first and to homestead enforcement in that kind of situation, it may well be cheaper to keep somebody in a nursing home.

MS. CALLAHAN: Is there anyone else who hasn't spoken?

MR. ALLEN: Thank you. My name is Bill Allen with the Disability Policy Consortium. I just want to say first thank you,

Robin, for being sensitive to the time of the January 4th meeting and changing that, which was announced today, to ten o'clock instead of nine.

I want to follow up on something my friend Martina said. I believe she said something to the effect of "Don't get me started on accessibility of facilities in western Massachusetts." I want to ask you how can that even be an issue today? The ADA has been in effect for 21.5 years. The Commonwealth knows it has responsibilities under Section 504 for enforcing the American with Disabilities Act, yet if Mass. Health contracts or anything with like DPH, it's a check box, "Do you comply with the ADA?" "Yes, of course, because otherwise we wouldn't get the money." That has got to change.

Your application was woefully short on specifics. There was a line in there about "We expect applicants for the ICO to comply with the Americans with Disabilities Act." That is not enough. We have to establish in the RFP or into the proposal that we are going to set some standards and we are going to

make sure that those organizations that apply for this money meet those standards. Thank you.

MS. CALLAHAN: Thank you.

MS. WEAVER: My name is Anna Weaver, and I am a member of DAR. I am also here to represent of the National Empowerment Center, which is a national consumer-operated advocacy policy organization on behalf of people who have mental crises in their lives.

I would like to note that 34.9 percent, according to the recent proposal, of the dual eligibles have had diagnoses of serious mental illness, and I would like to speak on behalf of those people.

We are concerned that ICOs may not actually buy into the concept that recovery is possible for people with serious mental health diagnoses, and recent conversations that I've had as a member of the DAR committee with providers who may in fact be bidding on this demonstration have only reinforced to me those concerns. Therefore, community-based organization are integral and absolutely necessary to provide truly recovery-oriented

care and support for these duals who have had these diagnoses of serious mental illness. That population is close to forty thousand of the duals.

Considering the incredibly large number of that population, we would like to request capacity building funding as part of this initiative to raise capacity of the recovery learning communities and other peer support organizations in the communities to help serve these forty thousand people and to promote recovery.

It is also imperative to have an independent consumer board overseeing the ICO services and an independent care coordinator available for every consumer who wishes to have one on their team and true consumer choice of every provider on their team. Thank you.

(Applause)

MR. HEMMING: I am Bill Hemming from the Boston Center for Independent Living and DAR, and I want to thank you for holding this public hearing. I think it's great that you are sitting and listening to the healthcare

concerns, the access concerns of people with disabilities. We really appreciate that.

I think the reason DAR has been so involved in this is probably two reasons. One is there is the unavoidable reality that here's this huge proposal to remake the healthcare system and to remake the healthcare system is on the horizon in every state. It's a big topic down in Washington. A lot of the remake may come through slashing programs. If certain people get full control of our government that will happen. We know that will be nasty, it will be horrible. So the idea of being engaged in the discussion is critical, and we appreciate the opportunity.

I think we are also here and DAR has been involved because we can see the potential for an integrated system. We know, the people here know what they've said has underscored it with great emphasis that if you focus on long-term services and support you get better health, you get wellness, you get independence, you get integration, maybe you get employment, and that's good. But what we've

also said, and you've heard it I'm sure quite a bit, is that the consumer voice is imperative in that it not be the medical voice that controls things. We can't say enough.

This thing can change healthcare positively through integrated model, but if that consumer voice is not at the table of the decisions with long-term services coordinators, with oversight entities that involve disability organizations or if it's seniors with ASAPs, it will fail ultimately. The tidal wave of change is coming, but the tidal wave of big health will be very hard to stop.

We look in Massachusetts and we see Partners growing in corner after corner of our communities. We now see Steward Healthcare coming in. No one even heard of them barely two years ago. They now own ten community hospitals, they may be bidding on a rehab. They are a strong reality.

Our constituency, people with disabilities, with intricate healthcare needs, it is utterly woven with the independence picture, and that voice in all of it is

essential, and I hope that will be considered as this plan moves forward, but I would also like to say there is so many things we could speak on, but conditioning any program on compliance with the ADA, as a few folks have said and as Bill Allen has said, is essential. That is a new and necessary move forward.

I would just like to ask people to raise their hands. How many people here have had difficulty getting on an exam table? A quick dozen, including the assistant secretary.

MS. GRIFFIN: Absolutely.

MR. HEMMING: We heard issues with interpreters. We know of the issues of access and problems in emergency rooms for people with mental illness. It's not a throwaway line. I am not saying anyone thought it would be in this proposal, but it can be the test for any provider that's really serious about serving people with disabilities as well. So I hope that gets as much consideration as how long-term services are set up, how the PCA program is set up. Vital, vital things. Thank you.

(Applause)

ATTENDEE: I am a PCA consumer, dual eligible. A couple of years ago I had a rotary cuff surgery, spent nine months in a nursing home, and if this PCA program is cut, guess where I'm going? And I will be damned if I go back there. I have people that currently communicate with me. I would say something and they would do what they wanted to do, not what I needed. So it's very critical to keep this program going, and I have a second idea regarding the DME. I get a new wheelchair two years ago, and it just broke last month. Now because of the regulations, I'm not due for another one for three years. What do I do? Thank you.

(Applause)

MS. CALLAHAN: Thank you very much. Anybody else who hasn't spoken?

ATTENDEE: My name is Ruthie Poole, and I am a person with a mental health condition who has the privilege to both be familiar with recovery learning communities and independent living programs, and they both saved my life and other people's lives as well.

Too often those of us with psychiatric diagnoses are really given the medical model only, "Yes, you are depressed." What I have been told is "Yes, you are depressed. Take these drugs for the rest of your life and don't add stress to your life." That's basically what I got out of the medical model, but out of independent living centers and recovery learning communities they've really provided me and others with a lot of hope for recovery, and I'm really afraid that -- I just picture big insurance companies trying to run peer support, and I just want to cry. The number of times that people say to folks at recovery learning communities or independent living centers, "Wow, you are the first person who really gets it. Have you been there yourself?" And it makes all the difference, and I just really don't think insurance companies or big providers can do this.

So I really, really urge you to require that kind of contracting for long-term support services and independent care coordination because I think those of us with

disabilities, mental health conditions, those of us who are deaf really do understand in a whole different way.

The other thing I want to talk about is the choice of providers. I know there is stuff in the proposal about continuity of care, but I always worry about that. I had a situation about a year and a half ago where I am I'm not a dual eligible. I have insurance through one of the large HMOs in Massachusetts, through Tufts, actually, and I had finally found a therapist and I had been working with her for about seven years at that point, and I really felt like with her support, with community support, my life was really coming together, and that's when we had Blue Cross and that's when we switched to -- we had HMO Blue and we switched to Tufts, and Tufts said "Oh, no. You are in Arlington. There is a lot of therapists in Arlington," and I said, "Well, you know, I have this really long-term relationship, and other people really haven't helped me in this way and, you know, there may be others in the community, but that really shouldn't make a difference,"

and they said "No. Sorry. We can't add someone else to our plan." And I know a lot of people have had this experience.

So I've also had the experience in the early HMOs having my psychiatric records mixed with my physical health records. So I have had the opportunity of being treated for a physical illness as someone who is totally crazy and breathe in this bag because you are hyperventilating. I have had that experience. So when my therapist asked me "I can write stuff that's very, very strong, but it will be in your record." I told her "Tell them I am on the bridge with a gun to my head and you are the only one who can talk me down." And so she wrote some stuff that not everybody would want in their permanent psychiatric record, and believe it or not, they denied it.

So I just really wanted you to look at choice of providers and choice outside of network, but I was lucky enough that she then let me -- she really slid her scale down and let me private pay for very little money because we had such a good relationship, but that's going

to happen to thousands of people. Thank you.

MS. SHAW: I am Janet Shaw from Stavros Center for Independent Living. I want to talk about the insurance companies in part, and I don't think that there is any one single person here that has had any kind of insurance, whether it be Medicaid or Blue Cross Blue Shield, that if they need anything more than a Band-Aid that they don't have to go through a hellacious appeal process to get the goods and services that they need, but my big point is I feel as if there is some sort of political pressure here to push this through and if we don't take the time to make sure that this really happens in a way that is fair for people with disabilities, then we are just asking for more economic trouble down the road.

I know there is a great push in the country and in the State to save revenues or to not spend them anyway, but we can't do this at the expense of those who really need to have the services. And also the point of having a choice in who your healthcare provider is is absolutely essential, and I think it's important

also to remember that the medical people that have become familiar with the processes or with the concerns or health issues of people with disabilities have largely been taught by those people with disabilities, and you can't forget that, we are not just people, we are people with disabilities, with brains, and I just don't want to see us get railroaded or steamrolled economically for the sake of political reasons. Thank you.

MS. CALLAHAN: Anyone else who hasn't spoken and would like to? Anybody who would like to speak some more?

MS. STONE: I am Laurie Stone, and I just want to add an experience that I had. I am at Northeast Independent Living Consortium. I was talking with someone who was depressed and she wanted to get some help. I brought her to the hospital, and she was being evaluated. We asked for an interpreter, and she wasn't provided one, and I was there from 9:30 until 9:30 at night, and the doctors had told us you cannot stay for the night because they cannot find a bed. So they told us to go home, and we

went home. The next morning we went back to the hospital. I continued to look for my advocate. She wasn't there. She was transported to a hospital way down south, and there was no communication. That hospital had no idea how to provide services to that patient, so they had to call me, and I told them about how to communicate with a deaf person.

So that's just an example of an interpreter not being there makes it pretty difficult.

MS. CALLAHAN: If everyone has spoken who wants to speak, we can start the process of wrapping up, and I am going to hand it over to our executive for the moment. I just want to say that on behalf of the folks on the project team that this has been an incredibly valuable experience for us to hear from you. I do want to say also that no matter what happens, we will be continuing to have -- in addition to the hearing that we have on the 4th of January, we will have at least roughly more open meetings. I encourage you all to keep your eye on our web site and please, please come.

To the extent this might have been the first time you attended a meeting around this project, I hope it's not your last time. This has been incredibly valuable. I think it's taught me that there is a couple of things that we will focus on. One is, as I told you, that we will be spending a good amount of time reviewing the comments that we are hearing in these sessions, along with written testimony, along with e-mails of any communications that we get after the comment period closes down so we can really understand the themes and understand what types of changes we might need to make in the proposal that addresses the concerns that we're hearing.

Beyond that, it is a big project and there are a lot of details to it, and I think that there are certain areas that I'm hearing that we haven't been as clear about as we could have been. I think I heard some concerns that I think we can address even now. I think there is other sets of concerns that we need to work on to sort of make sure we are really working with folks to craft a response

to. And I would also expect that you will be seeing a revision to this after we've gone through the process of really sitting down and trying to get through the comments that we've heard and working with various people to try to reconcile certain areas of the proposal.

So this will be an ongoing process. The open meetings that we will continue to have will be interactive in nature, except for the next meeting will be another public hearing like there. So as we change things or as we evolve we really want to have a conversation about whether or not we are going in the right direction.

So with that, I am going to turn it over to Doctor Harris.

DOCTOR HARRIS: (Julien Harris) This has been, as Robin has noted, I think of incredible value and a powerful experience for all of us who have had a number of different kinds of conversations. I look around the room and I see a number of familiar faces, but I also see a lot of new faces, and I just want to echo what Robin has said, that every person in here

who spoke and told us their story had something that was unique and that was powerful to say and that will form the way that we think about doing this work, and I know that people have all kind of challenges, transportation challenges, work, family, and other kinds of challenges, but I would say that if you haven't had the opportunity to be a part of this process and you are interested in being a part of this process, we really do invite you to continue to come to join us at our other meetings. We will continue to make sure that we're not just having meetings in Boston, but we are also having opportunities for people in other parts of the State. We will only get this right if we are able to hear your perspectives.

I think that folks who have had a chance to read the proposal and were involved at the beginning have been involved along the way, you will see, and I think folks had mentioned some of the things that people are really excited about, and that really come directly from the conversations that we've had with some folks who are in the room and other folks who

weren't able to make it today.

So I think the people had a lot of concerns and there was a lot of conversation about things being cut or withheld, and I think one of the things that I hope comes across is that we really are seeing this as an opportunity to look at the system that we have today, and I know that a lot of people talked about the parts of the system that they have today that they like and are working and that they value, but people did also talk about things that they think are broken, that are fragmented, and we know from other conversations that we have had, we know from focus groups that we've held, we know from a number of other kinds of interactions, that there are many ways that our current system is not working for people or is not working as well as it could, the fragmentation between what Medicare pays for and what Medicaid pays for doesn't often work for people, it creates particular kinds of gaps.

So some of the innovations in this proposal that the people mentioned today really are in the proposal because we heard from people

about those gaps, that we have an incomplete spectrum of behavioral health services, and it's important to actually enhance the offerings and to try and complete that spectrum, that there are opportunities to think about some additional behavioral health diversionary services, about some additional community-based, long-term services and supports, but we have also heard that there are ways that we can be more rigorous and more robust about emphasizing the important role that I think we all really do believe and want to see community-based organizations play in this initiative, and I think that has come across.

I think that on the accessibility side, being very clear that we need more detail, and again, I think maybe before I got here there may have been some conversation that people are talking about a proposal, and a proposal is something that captures a lot of what we hope to do, but the next phase of this to approve would be to develop something called a RFP or a Request for Proposals, and that is really sort of the contract where a lot of

details that would shape how these organizations would be structured and how they would work would be outlined in a great deal of specificity.

I think a number of the concerns that people raised today really are ones that will be even more important as we consider what that process would look like, and one that I heard very clearly is we need to be very descriptive about the ways that we think about accessibility, not sort of encouraging people to think about "the letter of the law," but really what does that mean, what will that mean for those who need interpreter services, what will it mean for people who need to ensure that they have access are receiving care from providers who are providing that care in settings that are truly physically accessible for people. So those were some important themes that came across.

I think that we heard that the traditional behavioral health model, the sort of medicalized behavioral health model, is at best incomplete and really is not as informed as it

needs to be by the recovery perspective. So how do we make sure that that is a model that traditional organizations are accustomed to operating under, and how do we make sure that they have opportunities for training and for capacity building and retooling to ensure that they are again partners with us and with all of you and ensuring that it's a complete spectrum, that it's not just about medications or sort of traditional services in a traditional setting, but that there is this recovery really movement that has transformed people's lives and I think transformed the lives of a number of people in this room. So you want to make sure that other people have access to that kind of transformation.

I think we have heard a lot about the fact that this has to be more than the traditional medicalized model, but I also think that we heard that it's not enough to just say it's a long-term services and support model but that it needs to be an integrated model, that it's not enough just to have a robust long-term services and support system but that people do

really need medical services and people really do need behavioral health services and how do we actually ensure that people who are not receiving those services in silos, that there is integration, how do we ensure that the care team is not just composed of people who understand and know how to refer to the medical services but don't really understand the full spectrum of community-based, long-term services and support and don't fully understand the full range of behavioral health services, including services that are focused on recovery.

I think we heard a lot about independence and of the kinds of ways that different kinds of services promote independence, and if you think about the values in addition to the services but the values that this initiative has to promote, I think that consumer voice and independence have to be absolutely at the core, but people were more specific because they talked about what kind of services support independence, and we heard just how important people's PCA services are and how important it is for people to feel like they

have control over their PCA services, and those services are a match for them in the way that they're hoping to live full and independent lives, and that interpreter access is also an important part of independence.

I think a big thing that came through, and people said it explicitly and it was often said implicitly, is that even if people recognize the ways in which the status quo may be broken or may be fragmented, any departure from what you know is scarey, and more than one person explicitly used the word "scarey," "this is scarey," and I am hoping we can get to a place where people are actually excited about the possibility of seeing a complete spectrum, not seeing this status quo of a medicalized model on the one hand and an LTS model on the other and a behavioral health model on the other hand, each of those being incomplete in their own ways without coordination and breaking across those services and with some key gaps filled in, with some rationalizing of DME, for example. That was another big thing that came through.

I also want people to have a clear sense that we are not interested in a cut and paste, generic managed care model, that we are actually trying to push the model of what it means to provide integrated services. We are trying to push it in one way by saying that this can be a provider-centered and provider being broadly defined, including independent living centers and ASAPs and recovery learning communities, that these can be provider-centric organizations, groups of providers that come together. That's not something that you're seeing in every state's approach, but we are saying that providers who are actually closer to the members, who know them better, who have nurses and care coordinators and other team members who know them better may provide a different model; but even in the model that an approach that may be taken in other states, we are actually trying to do something that is different and that's innovative, and I want to be transparent.

I recognize that people see that the stakes are very high and that the hope is

that if we are able to do something, especially the folks who have been involved in this for a long time, if we are actually able to do something that is really innovative here in Massachusetts, there is always the hope that maybe we can show that there is a best practice that can be generalized to other people. And I think that that is absolutely a hope that we share. I think it's been part of the reason why that I think that if you look at the approach and some of the services we are talking about adding in the ways that we're trying to ensure that it's not a medicalized model, but that it is a model that really promotes independence. We're trying to do something that I think is very different from the way that these conversations are happening in a lot of the other parts of the country.

It's clear that we still have work to do. That's what this process is about. There will be another public hearing. We are going to go over all the transcripts, but there is also an opportunity to receive written comments or e-mails, as Robin mentioned, so when

you get home and say "I wish I had said this," send us a note, send us an e-mail, and all of those things will be taken into consideration as we work on the next phase.

I would say please keep working with us. Nothing this transformative and this complex will be perfect and will perfectly satisfy every need and concern, but we are going to do the best that we can, and when we have a proposal and when we move to an RFP, we are going to need you to continue to work with us to make sure that we are really clear about some of the areas that you have concerns about, their specificity and things that are broad in the proposal, and when we move to the RFP we are having the kind of specificity that people need to recognize what they're hoping to see in these systems and organization in the future.

I want to thank everybody, and I want to thank all the people in your lives who support you and who make it possible for you all to come and participate and contribute, and we look forward to ongoing conversations, and I'll say one more time that if you are not often a

part of these conversations, your voice is very important to us. What you say really is shaping, has shaped, and will continue to shape the way we implement this. So, please, if you have the opportunity, continue to come and continue to be a part of this conversation. Thank you.

(Applause)

MS. GRIFFIN: On behalf of the Secretary who couldn't be here today and wanted to be, just thank you all for coming, and I would just echo what Doctor Harris said. Stay involved. Your voices are critical in shaping a better system for all of us. So we look forward to continuing to work with you.

(Applause)

(Hearing concluded at 3:00 p.m.)

C E R T I F I C A T E

I, Cynthia C. Henderson, a Certified Shorthand Reporter and Notary Public within and for the Commonwealth of Massachusetts, do hereby certify that the foregoing testimony by the attendees of the public hearing on Integrating Medicare and Medicaid is a true reflection of the hearing on December 16, 2011.

IN WITNESS WHEREOF, I have hereunto set my hand and affixed my notarial seal this day of , 2011.

Cynthia C. Henderson
Notary Public

My commission expires
July 14, 2017