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THE COMMONWEALTH OF MASSACHUSETTS
EXECUTIVE OFFICE OF HEALTH AND HUMAN SERVICES

PUBLIC HEARING

INTEGRATING MEDICARE AND MEDICAID FOR DUAL ELIGIBLE INDIVIDUALS, PUBLIC HEARING ON DRAFT DEMONSTRATION PROPOSAL

MODERATED BY: Robin Callahan, Deputy Medicaid Director, MassHealth

BEFORE: Dr. Harris, Medicaid Director
Christine Griffin, Assistant Secretary for Disability Policies & Programs
Secretary Bigby, Secretary for Health and Human Services

DATE: Wednesday, January 4, 2012

AT: Transportation Building
10 Park Plaza
Boston, Massachusetts 02116

TIME: 10:05 a.m.

COPLEY COURT REPORTING
71 Commercial Street, Suite 700
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PROCEEDINGS

MS. CALLAHAN: Welcome, Happy New Year. I'm Robin Callahan, I'm Deputy Medicaid Director and I really welcome you here this morning to talk, to have this public hearing about a proposal to integrate care for dual eligible Medicaid Medicare beneficiaries.

It's truly impressive to see you all sitting here today and I appreciate certainly your interest and your input and look forward to listening to what you have to say today.

We're expecting a few people to join us in this, but I would like to introduce you to Christine Griffin, the Assistant Secretary for Disability Policy, and before Christine starts, we expect to be joined by Secretary Bigby and Dr. Harris who is a Medicaid director, but before we get started, Christine.

MS. GRIFFIN: I just want to echo, is this on? It's not. I just want to thank everyone for coming on behalf of the Secretary who will be here.

We really appreciate you coming this morning and spending the time to tell us what you

think about the proposal, and you know, whether you've read it or not, how things are working for you, what's working, what isn't working.

We really, we really want to hear what you have to say and it will impact the proposal that we put forward, so, again, thanks for coming, thanks for taking the time and we want to get started and there's a lot of people here and hear what you have to say, thank you.

MS. CALLAHAN: Thanks. As you know, this is the second of two public hearings we've had about the proposal that was posted.

We had a session before the holidays in Worcester and the purpose of this hearing is to give members of the public an opportunity to present oral comments and a draft proposal.

MassHealth and EOHHS has held a number of open public hearings over the past several months where we presented information and engaged dialog about the design of a demonstration proposal that we hope to submit to CMS in order to get their involvement and certainly their support financially and otherwise for a program to integrate care for dual eligibles.

The meetings we have had so far have been very productive and have contributed greatly to our efforts. We're going to resume open public meetings in the future but today is a formal public hearing, so, we're really not going to be engaged so much with back and forth, we just are really here to listen.

So, the vast majority of a lot of time will be reserved for testimony by members of the public. We'll be calling names in the order that you signed in on the sign in sheet to speak.

When your name is called, please raise your hand and someone will get a microphone to you. We're going to ask you, understanding we have recordkeeping going on over here, to repeat your name, I might not do a good job at pronouncing it, and also to recognize we want to keep a record.

We are having a transcript made of these proceedings that we would like to, so, please be kind and if you're a particularly fast talker, we'd ask you to make sure our transcribers can keep up with you.

Also, to let you know that we have interpreters available in the room for Spanish, Portuguese and American Sign Language and you can let us know if you would like to take advantage of those services.

Given the number of people who signed up, we're thinking that we probably would appreciate it if you would limit your remarks to three to four minutes if possible. That would give everyone who signed up a chance to speak and as you know, we're expecting a few more people to join the list here.

If you wish to submit written comments today in addition to or in place of oral comments, you may do so at the registration desk. Oral comments today are considered official public comments and will be considered by us in just the same way as written comments.

All comments received by MassHealth during the public comment period will be carefully considered. This is a real attempt to gain input and to make adjustments as necessary to the proposal that we put out there.

The public comment period closes at 5 p.m. on January 10th and the handout that you received at the sign in desk includes E-mail address and a mailing address for submitting written comments.

So, with that we'll get started. Deborah Banda, there's a microphone coming to you.

MS. BANDA: Good morning everyone, and sorry I have my back to some people but I guess that's not going to be important with the current setting.

My name is Debbie Banda and I'm the director of the Massachusetts state office of AARP. AARP is a nonprofit nonpartisan organization that represents people age fifty and over and we have about 37 million members nationwide including about 825,000 here in the Commonwealth.

I thank you for the opportunity to comment on this demonstration proposal to integrate care for dual eligible individuals and we commend the Commonwealth of Massachusetts for being one of the states that chose to pursue this opportunity.

As you all are aware, people eligible for both Medicare and Medicaid are among the poorest, sickest and costliest of all Medicare beneficiaries and that makes them the most vulnerable to receiving inadequate care and to possibly falling through the cracks, and to meet their needs for health care and long-term services and supports, they or their families must navigate between two separate programs and assistance for delivering services, programs that do not have a history of communicating well with each other or coordinating services.

There are many, many improvements for beneficiaries age twenty-one to sixty-four contained in this proposal and AARP has submitted detailed comments in writing and cites in those comments what we think is good about this proposal including the fact that it uses a medical home care model with choice of primary care providers and allows for the involvement of family, informal caregivers, advocates, peers and others in care planning.

However, we also have some serious concerns about several aspects of this proposal

and in the interest of time, I'm going to briefly limit my comments to just a few of those concerns because I know you will all read our written comments as well as those of others in the room in their entirety in detail.

For starters, as to enrollment, AARP supports voluntary enrollment and disenrollment and not a process whereby individuals are placed into a system and then have the option to disenroll if they do not believe it will best meet their needs as is contained in this proposal.

These voluntary features mean individuals are free to continue fee for service arrangements or to disenroll at any time and return to the full services available in traditional Medicare and Medicaid with no interruption of eligibility and no interruption of service.

Bottom line for us, we're concerned that mandatory or passive enrollment as this proposal requires does not provide the greatest amount of consumer protection for dual eligible individuals.

We have concerns about the potential disruption to enrollees and establish relationships and access to their health care

providers.

We also have some concerns about quality of care. AARP believes there should be an expansion of baseline measures of the quality of services provided by the ICO. Now, while the proposal appropriately requires NCQA accreditation for the primary care medical home, it sets no quality standards for the ICO selection of other health and support service providers.

Minimum quality and accreditation standards for all providers within the ICO network must be incorporated; however, an exception should be made for consumer directed care where the ICO would pay for a family and formal caregivers or personal care attendants selected by the consumer.

As to the appeals process, AARP supports the elimination of differences between the time frames for filing and resolving an appeal related to benefits, access to external review, benefits pending appeal and notice of appeal rights.

We believe that it is critical to protecting vulnerable consumers and we support a unified system for grievances and appeals. Where due process and notice of appeals rights diverge,

the ICO should provide the beneficiaries' access to the standard that is most favorable to the individual and to his or her family.

In addition, enrollees should have access to an independent external involvement to assist in the grievance and appeals process.

As to elders and the senior care options program, AARP is pleased the Commonwealth is committed to the continuation of the SCO program in the short term and is not pursuing a change to the SCO enrollment process; however, we have concerns about the future of the SCO program and how it will interface with this proposal over time.

As you are aware, two-thirds of the dual are over the age of sixty-five and 60 percent of them have multiple chronic conditions, so, we intend to monitor this closely.

As to long-term services and supports, we also want to stress that all efforts should incentivize the provision of home and community based services. Any rule, regulation or process which favors institutional care must be revised in our opinion.

In conclusion, AARP applauds the Commonwealth for working to break down barriers between Medicare and Medicaid with the goal of achieving better care for some of our most vulnerable residents; however, as we work through this process, we must be sure that the complex care needs of each individual are met and are coordinated across the entire spectrum including acute rehabilitative, behavioral and long-term care and we're committed to continuing to work with the Commonwealth to get the best proposal and demonstration project possible. Thank you.

MS. CALLAHAN: Thank you very much. We're needing to make a few adjustments for the crowd here I think. Our understanding is folks who need to can't really see the sign language interpreter very well, is that what I'm understanding; is that correct?

MS. CAREY: Right.

MS. CALLAHAN: So, to the extent that the folks in the front are willing and able to sort of readjust and folks who are having difficulty seeing the sign language interpreter want to come up to the front and there are some

empty chairs in the front.

Are we able to communicate this properly to folks? Okay. There are two seats in the front, anybody having trouble seeing if you want to move up. How are we doing here, are we settling down? Thank you very much for making those adjustments, we appreciate it.

Okay, Peter Chronis.

MR. CHRONIS: Good morning, thank you for giving me the opportunity to speak. My name is Peter Chronis and I work at the Boston Center for Independent Living as the senior PCA skills trainer and I also have Boston Community Medical Group as my primary care providers. Anyone else here from Boston Community Medical Group?

THE AUDIENCE: Yeah.

MR. CHRONIS: Yeah, I've been with Boston Community Medical Group for over twenty years and it has been a positive experience for me. The thing I really love about them is that I participate in my care plan, I participate in my needs for durable medical equipment, my doctors and nurse practitioners who are great listening to me, they don't talk around me, they talk to me and

that's very important if you're going to integrate this program for people with Medicare is to make sure that there is a provision in there that ensures that the consumer's voice is heard and is taken seriously.

Not all medical providers do that and I remember when I was growing up, my doctors would talk to everyone except me. It's not like that anymore and we've got to make sure that it stays that way and that consumer control never gets overlooked or undervalued.

Also, I mentioned that I'm on the PCA program as well, personal care assistance. I've been receiving personal care assistance through the Boston Center for Independent Living since 1977, so, give or take a hundred years or so.

And the thing about it that's very important is that again, I have control over how my care is provided by my PCAs. I employ them, I get enough hours to make sure that all my medical needs are met and again, if the PCA program becomes a part of the managed care system, then it's got to be made sure that the providers approve the hours that the consumers need and that

big corporations don't just look at the bottom line as the only thing.

Again, it's all about consumer control, consumer's medical needs being met, and that's pretty much it, thank you very much.

MS. CALLAHAN: Thank you. James Fuccione.

MR. FUCCIONE: Good morning, thanks for the opportunity. My name is James Fuccione from the Home Care Alliance of Massachusetts.

We represent two hundred home care agencies across Massachusetts and one hundred twenty-seven of those are Medicare Medicaid certified and according to MassHealth data provided for this population that this proposal is targeting provided over 13,000 dual eligible care at a total cost to MassHealth of 160 million dollars.

So, given that experience, we believe that home health care agencies have developed kind of an understanding of the needs and challenges of dual eligible individuals and also developed relationships with not just the individuals but with their primary care physicians.

Home health agencies have become the link especially for the dual eligible population over sixty-five, home health agencies have a traditional link in ASAP services.

We just want to come out in support of this proposal and I'll leave a lot of this to my written testimony since there's a lot of people here waiting to speak, but just one thing is that we are looking forward to the potential that this will get rid of the massive billing and case review mess created by third party liability, that issue.

And lastly, we just have one other thing, excuse me, we would like to see in this proposal the regularly scheduled appointments with the care team go beyond E-mail and telephone and include telehealth, our promote patient monitoring capabilities and something a lot of home health agencies have experience with, so, that's something we'd like to see but going back to our experience, we know that we can help make the ICO successful in their goals and we know we have the experience from clinical care management to that possibility if telehealth is properly utilized,

so, we hope to be involved and we hope our experience is properly used. Thank you very much.

MS. CALLAHAN: Thank you. Lee Goldberg.

MS. GOLDBERG: Hi, my name is Lee Goldberg, I work with the Center for Independent Living as a peer specialist and I'm also a dual eligible and what works for me is I get physical therapy, mental health therapy from two different therapists because one of them has a cancer, so, the other one is an interim therapist and they both take Medicare as a fee for service but don't want to be part of ICO, and I'm concerned that when they become Medicare Medicaid managed care, I would lose these therapists and these two therapists is what, what keep me out of the hospital besides my psychopharm and I also get really good care through the Brigham and Women's Women's Health Center and they've been really good to me and I also like the fact I can go anywhere within the Partners Health System and they have electronic medical records and they also know what each other's doing because of the electronic medical records, whether I'm psychiatry hospital

or physical hospital or going for a PCP visit and just I want, I just want the flexibility and also I have hearing aids and I go outside of Partners Health Network to St. E's for the hearing aids because there's no place in Partners for me to get the hearing aids because they're covered by MassHealth but not Medicare and I'm hoping when Medicare Medicaid comes together, they will still cover hearing aids and the batteries and all the other stuff. Thank you.

MS. CALLAHAN: Thank you. Stu Dickson.

MR. DICKSON: Good morning, my name is Stu Dickson, I'm the DDS Chapter President for Local 509 SEIU. Massachusetts must modify its initial proposal to CMS to exempt CMS waivers and DDS, Title 19 service coordination and other public private human services within DDS, DMH, MRC and services for blind and deaf individuals.

Local 509 agrees the need to address needless cost of medical procedures, test reviews, billing and admin redundancies, et cetera. This is profoundly different than the human beings, requires far more of a skill set than being

ensconced in an office wearing headphones and monitoring what, gauging what is within the bottom line and what isn't.

Massachusetts has not properly studied the impact of including DDS, CMS waivers, Title 19, service coordination and public private human service within this proposal. Does Massachusetts have sufficient information regarding the experience of ICO programs providing case management to human services.

Budgets cuts have already achieved whatever savings are intended with the dual eligible's proposal in human services. This makes the dual eligible's proposal unnecessary for human services. Massachusetts must take a more careful approach instead of leaping into this process.

The State of Tennessee has exempted their CMS waivers and Massachusetts should do the same. Please act to explicitly correct this proposal soon. Thank you.

MS. CALLAHAN: Thank you. Toby Fisher, do I have that right? Oh, okay, Toby Fisher.

MR. FISHER: I'm Toby Fisher from the

Service Employees International Union and I'll be very brief. Stu actually represents the DDS folks about disability, the department, the workers there and you heard quite a bit about that. I tend to work more with mental health side, so, that would be the case managers from mental health but the vast majority of our members are in the private sector and also Local 509 has been a strong partner and supporter of the community process and if you look at just over the years going back from the 50's to 20,000 people in institutions to just shortly over 600, we've been an active participant and support that and the only thing we want to say with this proposal is obviously there's a lot of questions and your office has been very open with us and communicating and I know it's an ongoing process to answer some of these questions but we want to make sure the consumers who live in the community, those systems have been built in years.

The Medicaid money for rehab option used in the community has been in years and years of process. The targeted case management money that public case managers utilize have been years in

process, so, the concerns we would have is would a change in the system interrupt very successful thousands, something like 12,000 living successfully in the community and rely partly on the Medicaid funding and the continuity of care, so, our primary care isn't only the workers but also the 12,000 people that are successful in the community. We want to keep them successful.

The system works, you know, community living works and that relies heavily on the Medicaid funding through rehab option, targeted case management and a variety of other sources and if you think about CBS in particular, how would the new system connect with the rehab option which help funds that, and I don't know that anybody can answer that, we've been trying to answer that because it's too complicated right now to try to figure out; however, we just want to ensure and want to make sure there's a process if we should receive forward that people who are successful in the community don't lose one beat and I think the other issue that people, I think most people understand this room is the behavioral health care issues isn't like a broken leg, x-ray, set the

bone, all set.

These can be complicated cases sometimes requiring years of coordinated service and most of these folks, a vast majority are doing enormously well in the community and folks to live independent as they're doing without a loss of service. Thank you.

MS. CALLAHAN: Thank you. Sorry if I'm having a little trouble reading this but I think it's Hang Lee.

MR. LEE: Good afternoon, good morning everybody. Thanks for letting me testify. I will take a seat and speak to you with my paper.

So, my, my name is Hang Lee, I work for the Multicultural Info Center in Boston, Dorchester, Massachusetts. We serve folks with disabilities in the city neighborhoods.

I am here to give you a personal testimony on question, I believe question 2, how important are long-term services and supports for you such as PCAs, peer support and durable medical equipment. What would happen to you if they are reduced.

So, I do have a very visible disability,

it's cerebral palsy; however, my secondary disability, scoliosis that's been causing me physical pain. I may look healthy to everybody but it's very visible once you notice my shoulders. So, basically, the scoliosis, the secondary disability, has been getting progressive and progressively worse, it has given me constant pain and emotional agony.

I find now talking to my best friend who has CP is and who has progressive hypertonia which is tightening of the muscles, the peer support gives us humor and a sense of hope. Peer mentorship is necessary for both of us to continue because it helps with daily productivities.

Secondly, my scoliosis might immobilize me in a few years. By then, I do not want a reduction in services and durable goods because in the long term, I might need a body brace which can cost in the thousands of dollars.

To me a cut in services means a reduction in funding for the brace that I foresee using in a few years. Thank you very much.

MS. CALLAHAN: Thank you. Louise Beach.

MS. BEACH: I'm going to sit here because I'm a senior now. My name is Louise Beach and I'm an outreach coordinator for the Multicultural Independent Living Center in Boston and I'm here because -- and actually, I'm asking about question No. 4.

At age twenty-one, I was legally blind, at age thirty-five, I was almost totally blind, at age forty-five, I was totally blind and conflicts around what services are going to be paid through MassHealth and what are going to be paid through Medicare.

Now I'm sixty-five, my husband is seventy-two and wondering what the dilemma is going to be when we hear about services cut here and there.

I heard the lady talk this morning about AARP, I heard the other young lady about her hearing impairment and Peter and I've heard Hank and as a senior, if young people are trying to decide these decisions about what's going on, well, we have those IL centers, the RFL centers, ASAP, why couldn't we have somebody there who is knowledgeable around what services would take care

of us without having to go all over the United States by phone to see what you need. That's my concern. Why couldn't it be locally right where we are located in the community.

I had a problem with one of my medical services at the hospital. She's telling me well, can you look this up and find this and blah, blah, blah, blah, blah, and I'm saying wait a minute, that's not my job, you get paid for that, you are supposed to provide services for me and I ended up doing most of it myself.

It took us over six weeks or so to find one piece of durable medical equipment for myself to keep me independent in the community but thank God for the ISL center that I work for and ASAP that's here that I was able to find what I needed with no problem because somebody there took the time to assist me.

So, I'm here talking to you today stating that as a senior, I've been on the young road, now I'm a senior, I, my husband is a senior, we work hard, we need to understand, we don't understand what this is all about.

We need somebody in the IL centers and

RSL centers and ASAP to be able to sit down with disabled consumers and seniors who are disabled to explain this is, that is what, this is what you're eligible for.

I'm sick and tired of people on the phone saying hold on, wait a minute, wait a minute, let me connect you to this department, hold on, wait a minute, oh, well, you have to call someplace else.

Well, as of today, Louise Beach of MILCD says find someone in our organization, CCLs organization, RSL and ASAP to be able to service persons with disabilities young and old so they understand what is going on in their State of Massachusetts. Thank you.

MS. CALLAHAN: I just want to make a comment, people are referring to numbers on questions and I want to let everyone know we didn't send anything out with the questions, so, if you don't know what the numbered questions are, neither do we necessarily, so, Karen Bureau.

MS. BUREAU: Thank you, good morning. First of all, I want to thank MassHealth for inviting us affected by the implementation of the dual initiatives here today so we can voice our

concerns to you directly.

I am a dual, also a personal care assistant user and I've been, and I work at Independent Associates in Brockton. One of the fears that I have under the initiative is the vendors who may become responsible for my health care needs and the needs of those of my friends.

One of the things I'm concerned about is unnecessary constraints on how and where I seek my medical and long-term care support. I'm here today to say that it's imperative that consumers who are dual eligible retain choice in the coordination of the supports that we receive.

Unless you are a nurse or a doctor who understands consumer control, you will not be a member of my care team period. Because of my affiliation and experience with independent living centers and ASAP, I feel they would be the most natural providers to coordinate my care.

I want and need to be assured my voice will continue to be heard when it comes around decision making around my health care needs. One of the other concerns I have is automatic enrollment for several reasons.

Within the past two years as a common health, I was enrolled in the MassHealth managed care plan and was told at any time. That's great in theory. After finding out my specialists and my pulmonary doctors weren't covered, I had to switch from one plan to another.

Not a major issue until I was not covered for several days due to a data entry error, on whose part, I don't know. What ended up happening is I had to pay a $200 medical bill that was forwarded to a collection agency because neither MassHealth nor the managed care organization would own up to the fact that a data entry error was made.

So, this and the fact automatic enrollment could mean my current doctors would not be covered. I'm living on the South Shore presently and it was difficult enough for me to find doctors down there wheelchair accessible and actually understood what it was like to work with a person with disability.

Maintaining consumer control must be thought of at every step along the process of the dual initial implementation. Please continue to

ask our input while you roll out the changes. Thank you.

MS. CALLAHAN: Thank you. Maria Serotkin.

MS. SEROTKIN: Good morning, I am the director of the Boston Home representing our ninety-six residents, members of our outpatient wellness program and hundreds of family and friends in our residence, some with progressive neurological that are in need of support wherever they live throughout the Commonwealth.

Margaret Marie and Isley Lamour will be joining me in testifying this morning and they are here as well. Founded in 1881, the Boston Home is a residence center of excellence of adults with advanced neurological disease, primarily multiple sclerosis.

We've always been open to include individuals living in the community through our Be Fit program, day program of wellness and socialization and specialized outpatient rehab services.

We serve as a sort of expert advice on best practices to care for the population through

our annual formal training institute for health professionals across the country. The only facility of its kind in New England, only one of a handful nationwide, the Boston Home touches thousands of lives.

A brief description of the people we serve, 70 percent of the residents of the Boston Home would fall into the category of dual eligible between the ages of twenty-one and sixty-four.

Our residents are significantly physically disabled with most functionally quadriplegic. They are intellectually curious and addressed by care teams. Margaret Marie, a resident of the home, and Isley Lamour, a Be Fit participant, represent their fellow residents in outpatient.

The Boston Home has led the way in implementing an innovative medical model center comprehensive care based in our residential facility. Our internists working with our nurses coordinate primary care, preventive care, specialized services and wellness services.

The progressive nature of these diseases requires timely response to acute conditions as

well as adjustments to seating and wheelchair accessibility. The majority of these services are provided on site. Assistive technology, twenty-four hour technology and assistance with ADLs promote independent and social station.

I encourage the authors of the proposal to consider the following: First, risk adjustment must reflect the needs of the population to be served and can't be based solely on current utilization of services.

For example, how will functional status be incorporated, will participants be able to choose the Boston Home as they do today.

Current Medicaid methodology for determining nursing home rates don't capture the cost of caring for a very disabled population. How will the capitalization rate reflect the huge cost of nursing home care.

As one example, our residents require two staff members to transfer them and those transfers are about 140,000 each year. Medicaid payment for LTSS should be based on meaningful groupings, developing consultation with clinicians and human service providers to ensure that high long-term

care support service users are not grouped with those who are not as disabled.

Second, the electronic health record which I fully support is a critical tool for coordinating care. To my knowledge, few if any entities has a true EHR across the continuum. Funding must be considered for the implementation of such a meaningful EHR.

Third, assistive technology is costly and much delays due to lack of expertise and maintenance. Preferred vendors should be considered with this aspect of service.

Fourth, training is a key component for developing expertise for care for the population. A training coordinator centralized should be considered.

I'm on my last page, and fifth, the core coordinator and community health worker have some overlapping roles, a careful review of these roles should be undertaken.

Finally, No. 6, the ICL should be well capitalized for the inevitable cash flow fluctuations. There is no ICOs, requirements should be flexible to encourage participation by

nonprofits and other provider groups.

So, the Boston Home is prepared to work with the state to accomplish the goals of the proposal while preserving the right of individuals to choose the Boston Home.

The Boston Home and the residents and outpatients join together to achieve independent and socialization, innovative use of technology, staff training, network of specialists who have a track record caring for these adults.

We've been working with dentists and eye care specialists and care coordination and will serve as a pioneering partner within ICO.

ICO should be paid to include the Boston Home in their network. Not only do they have the right to choose Boston Home but also no ICO should be penalized because of that choice.

I thank you very much for your attention. I'll go over to our residents.

MS. CALLAHAN: So, this is Margaret Marie.

MS. MARIE: Good morning, my name is Margaret Marie. I am a resident of the Boston Home in Dorchester, Massachusetts, where I have

been living for the past five years. Is it on now? Okay, I'll start again.

Good morning, my name is Margaret Marie, I am a resident of the Boston Home in Dorchester, Massachusetts, where I have lived for the past five years.

I have multiple sclerosis. I was employed as a social worker before my disability became too difficult to continue to work. I was the first participant in the innovative Boston Home outpatient wellness program prior to my admission.

As you can see, I am unable to walk yet I have independent mobility, a purposeful life with friends and family, comprehensive medical care coordinated by the Boston Home and access to assistive technology that enables me to connect with the world.

The Boston Home medical and nursing staff, direct care staff and rehabilitation staff are experts in all aspects of care for individuals with MS.

The building has doors and elevators and are completely accessible. My life changed when I

moved to the Boston Home from home where my partner was my primary caregiver. We have one daughter.

Since coming to the Boston Home, my relationship with family and friends has changed from caregiving to reestablishing relationships that I enjoyed prior to my disability.

In addition, I have been able to explore and expand interests such as painting and writing. I am here to advocate for EOHHS prioritized providers with experience dealing with people with complex medical and social conditions and not to penalize ICOs that include residents from the Boston Home.

There is little consideration in the proposal for specialized nursing home care. The Boston Home staff have the expertise developed through the 130-year history of this extraordinary organization. Thank you.

MS. CALLAHAN: Thank you, and before we go to the next speaker, I've been informed we now have seventy-five people who want to speak today, so, when I opened up we had more like thirty-five, so, I am going to, you know, if you

could sort of target around two minutes or two and a half or three minutes, that would be great.

We really want to hear from everyone who took the time to come here today, thank you. Next speaking is Isley Lamour.

MS. LAMOUR: Good morning everybody, my name is Isley Lamour and I'm a resident of Boston Home. I have MS. I was employed as a medical assistant before my disability was, became too difficult to function, to work.

I have lived at home with my sister and have a PCA. I am grateful to her because she provide assistance for my daily needs. My internist is medical, my neurologist is in Foxboro. Both of these physicians have provided care for me for many years.

My life improved so much four years ago when I, when I became to attend Be Fit, a daily wellness and socialization program for young adults provided by the Boston Home.

I benefit from participating in an exercise program at the Boston Y. There is continuing for me to have feelings that I would no longer wake up to my sister.

If it was not for the program, I would stare at the walls at home and be very depressed. Be Fit changed my life. Another benefit of Be Fit is my PC who attends with me get a chance to interact with other caregivers and share helpful tips based on additional learning offered by the Boston Home.

I am here to advocate for EOHHS to prioritize providers with experience dealing with people with complex medical and social conditions. The Boston Home and its Be Fit program staff have a special expertise.

Wellness is more than, Be Fit is a lifeline for those of us who live in the community with MS and similar conditions. Thank you.

MS. CALLAHAN: Thank you very much. Robert Park.

MR. PARK: Thank you very much. My name is Robert Park, I work for the Boston Center for Independent Living but I'm here today to talk about my own personal consumer experience.

I was doing some calculation while I was listening to the others speak and I realized this year will be my twentieth year on the PCA program,

my goodness, I feel old.

But I'm here to talk about a consumer directed care without PCAs, I would not be here because I would not be able to get out of bed, I would not be able to brush my teeth, I would not be able to leave my house and I would not be here testifying with you today, to you today.

So, the PCA program allows people to live with dignity in the community controlling their own care, and I was asked to talk about what issues I think are confronting us and I know that we're in a very difficult fiscal time but we need a PCA pay raise, we need health care for PCAs so that people can continue to live in dignity in their own communities. Thank you very much.

MS. CALLAHAN: Thank you. Sarah Kaplan.

MS. KAPLAN: My name is Sarah Kaplan, I also work for the Boston Center for Independent Living and I'm here today to talk about consumer control with your doctors. I'm just going to give a short personal experience.

I love my PCP, I go to Cambridge Health Alliance. I have a really good experience with

her. She believes that my opinion is first and foremost in my care. Unfortunately, my CP doctor at Cambridge Health Alliance didn't feel the same way.

She two years ago wanted to give me, I wear ankle bracelets that just go up to my ankles. She met me for the very first time and within two meetings, she decided that she was going to recommend a full leg brace that went all the way up to my hip.

That's a giant change that would mean that I would have to buy all new clothes and, and learn to function in a completely different way and I was actually physically scared about things like how would I go to the bathroom, what happens if my PCAs don't show up, how do I take my brace off, so, I told her no.

She said, "If you won't take my recommendation, then we can't work together" and we ended our relationship but before we ended our relationship, I asked her for a referral to a doctor outside of network to go talk about Botox injections because my doctor didn't do Botox injections and I met with that doctor and while he

was talking to me about Botox, I said, "Do you think I need a full leg brace?" and he asked me to walk up and down the hallway. He said, "No, I think you need a leg brace up to your knee but I wouldn't put you in a full leg brace."

So, I went back to her and I said, "I had a second opinion outside of network that I happen to agree with," and she goes, "Well then, I think you should work with him" and she hung up the phone.

If I, if dual eligible so that you couldn't decide which doctor you went to, if your doctor, if you didn't agree with your doctor's opinion and your voice wasn't the most important voice in the room, I would be in a full leg brace.

I wouldn't have a job right now, period, I wouldn't be able to pay taxes, I wouldn't be able to pay for my apartment or have a life and that sucks.

So, I'm very, very glad that I'm able to go see my doctor who is outside of network. Unfortunately in the interim because she wouldn't give me another referral, I couldn't see this doctor for about a year.

I went back to him and he said, "I actually can't see you without a referral." She wouldn't give me a referral because she wouldn't work with me anymore, so, I went back to my PCP, explained why I couldn't work with the doctor in network anymore and she gave me a referral but that's only because my doctor believed that I was the most important voice in the room, so, it's very, very important that we are the most important voice in the room and we are taken seriously and that's all I have to say.

(The audience applauded.)

MS. CALLAHAN: Thank you very much. Gail Mitchell, Dale Mitchell.

MR. MITCHELL: I am Dale Mitchell, director of Ethos Aging Services Access Point in Southwest Boston. We've been in business now for almost forty years. My colleague, Linda George, will be speaking more in-depth about the position of MassHealth care around this plan which I will state for the record that Ethos is in complete support of.

I did want to take the opportunity, however, today to speak out on one issue in this

plan or the lack of one issue in this plan which Ethos finds deeply disturbing and that is the absence of an independent conflict free care management entity that is overseeing the provision of long-term support services.

It is somewhat ironic that 2012 is the fortieth anniversary of the state home care system which was founded on three fundamental principles.

One is that the delivery of services be consumer controlled, two is that they be community based and nonprofit, and three, they be independent and conflict free.

This was hailed at the time as a very progressive advance in the delivery of human services that it provided an opportunity for consumer input into the delivery of very important services. It protected the consumer against provider self-dealing and it protected the taxpayers against waste and fraud.

It is a fundamental principle that has since been replicated in the development implementation of the SCO program and has worked very, very well.

I think the absence of an independent

conflict free care management entity in this plan is a very radical departure from the practice of the delivery of human services in the Commonwealth of Massachusetts.

It is very troubling chipping away at consumer control and consumer input in the delivery of services that are essential to their self-determination and a very dangerous shift away from the nonprofit system that has traditionally delivered services, community based nonprofit services entities that have traditionally had services in this state to large multinational systems. Thank you.

MS. CALLAHAN: Thank you. Gerard Plente.

MR. PLENTE: Good morning, did you say there would be opportunity to speak at the other events as well?

MS. CALLAHAN: Yes, we will be resuming our regular open meetings, this is the hearing for the proposal, you will have many opportunities to speak as well.

MR. PLENTE: Okay, because I prepared a three-page outline here today which is rather

comprehensive not only in my own situation but also other individuals and problems within the Medicare system.

So, I've been a dual since 1977 when I turned eighteen years old. I've been living with a spinal injury for thirty-seven years and advocate for people with disabilities and elderly folks since 1980, so, in other words, this is over three decade knowledge of evolution of delivery health care services not only for Medicare but also related to Medicaid which I've been a participant in since 1986 in New York State which is and then when I moved here in 1993.

So, I've seen a number of changes over the years that have been somewhat watered down for the consumer and then some, but also I'd like to say first that the personal care attendant program in the Commonwealth of Massachusetts is over four decades.

It is one of the most successful public policy programs within the Commonwealth of Massachusetts not only because it liberated people with disabilities from oppressive living situations and dreadful institutions as well but

also in the sense that in 2002 or 2003 there was a meeting held here in Boston that brought together a lot of consumers and advocates, executive directors and other nonprofits as well to deal with human services and at that time there was a discussion around the closing of Fernald and I believe at that time there was between 900 and 1,100 residents living at Fernald and the budget for housing the individuals was something like 250 million dollars, so, they served between 900 and 1,100 people and it's an important statistic to keep in mind for a moment.

When we speak about money and saving money, advocates who have been in situations like myself and those doing it longer and then not as long but knows what works because not only do we live with the issues daily and directly involved in the processes that also on behalf of the other individuals as well.

If we look at the program in the Commonwealth of Massachusetts, I'm going by 2002, 2003 numbers, they're around 12,000 consumers who are participating while living in the program and about ten or eleven times more of the numbers of

the people living in Fernald and a bunch of guess what, 250 million dollars, so, serving ten or eleven times more of individuals and paying 250 million dollars for it while at Fernald you had 900 to 1,100 people, so, that's where the cost effectiveness comes in because we all know this is about cost and also, the twelve states that were chosen to be, to start the process to integrate Medicare and Medicaid are looking at as well.

Particularly from what I read too, I did read the report that administrators of the Commonwealth of Massachusetts put together and throughout the report it mentions that it is essential that consumers have a voice in the development and implementation of the integration of Medicare and Medicaid as well, so, I'm hoping to have the opportunity to say more because looking at a comprehensive way and I'll give you two examples about medical care.

One was that I had a broken hip in 1995 and I needed to see an orthopedic surgeon right away, so, I went to this doctor with no spinal injury experience and he said that we needed the surgery within two or three days.

I said well, let me contact the people where I did my spinal rehab which is the world renowned Colorado Craig Hospital and it is the leading researcher to this day in research in spinal injury. They're also affiliated with Boston University Medical Center.

So, anyway, what I always have done over the years is gone to Craig when there is an issue with my injury. So, when I told the original surgeon that we're in the office and when they learned I had Medicare -- first of all, they didn't know people with disabilities, didn't know we were participants in Medicaid, so, lacked knowledge there, and No. 2, when they learned I had Medicare and Medicaid, their eye brightened, so, they saw a lot of dollar signs there.

So, their issue is they wanted me to have the surgery done, they almost insisted on the surgery and I had to have a bit of a debate first and they wanted me to go from his office to the hospital, for example, so, I refused to do that.

They advised me find an ortho surgeon with spinal cord injury experience. Well, when I did do that and the people at Craig also said

people with, we don't do surgery, No. 1, it costs too much money, it puts the person with the spinal injury in a situation where you're after surgery or during surgery, after surgery prone to infection, you're in the hospital for way too long, you don't need the surgery because you're not walking on your legs, so, as long as the bone is in proper alignment, it will fuse on its own and you don't have to worry about the problem.

So, there is the difference between when you look at somebody with Medicare and Medicaid, dual eligible, there in lies one of the problems with this issue, a misalignment.

There are a lot of terms in here that I had questions that need answers to, so, that's one issue there.

The other one is that consumers, we want an insurance company, quote unquote, the outside care team which I read about which doesn't know best what my needs are or consumer's needs, so, it's imperative that the consumer still continue to have control over their daily health care regimen as well.

MS. CALLAHAN: I am going to ask you

to finish there, sir, and again, we will have many opportunities to continue this dialog.

MR. PLENTE: But I'd also like to say I read the text and when you put terms out like the dual eligible are frailer, older, certainly poorer and sicker than the average person, those words spoken by government at Commonwealth Fund and Dr. Maryjane Korn, vice president for Commonwealth Fund Long Term Quality Improvement Program, you know, that's kinds of erroneous because a lot of people that are dual eligibles like myself, we do know the difference between Medicare and Medicaid and another example is a dentist that worked for Medicare, MassHealth earning $88,000 a year of the taxpayer money.

He showed up at a hearing where an individual had dentist repair done and had an infection, and so, he was there to testify on behalf of MassHealth.

When he was there, the mediator, who was a retired magistrate, he asked the doctor if you knew the difference between Medicare and Medicaid and he did not, so, it's very disturbing to know and these are situations that have been going on

for a number of years and one way to involve consumers and is to continue to involve consumers like myself and stakeholders and that sort of thing. I just want to finish briefly if I may and I'll show up at the other meetings.

MS. CALLAHAN: And also please submit your written comments.

MR. PLENTE: Yes, I will, thank you. The conclusion that I have here is that the role of advocates as I said is imperative.

The state, which is the Commonwealth of Massachusetts, lacks the experience administrating the Medicare program and process of both programs and why is that? Because two different coverages providing the same benefit, the state must provide consumers.

The strong oversight, we advocates here and stakeholders, we must hold the state accountable and make sure there is strong oversight of the implementation of dual integration of Medicare and Medicaid to ensure the process success.

Advocates know best what works from years of daily living and advocates also employed by ILC

and other nonprofits, and the one thing we don't want to see is involuntarily enrollment, what we want to see is independent coordinators to oversee the dual eligible program. Thank you.

MS. CALLAHAN: Thank you. David Brickman.

MR. BRICKMAN: Good morning, my name is David Brickman, I'm from Peabody, Massachusetts Pioneer House and first of all, thank you, madam speaker and Dr. Harris and ladies who have given me this opportunity to speak.

I would like to kind of make this on a personal note in regards to us members here and individual patients that have to go through the process.

I'm one of the lucky ones at first because I had a father that was a doctor and many members of my family were doctors, so, obviously I received medical courtesy and I did not have bills left for the leftover 20 percent but now after speaking to members from our clubhouse and also now being out there now where my father has passed away and family members have passed away that have been doctors who I got the medical courtesy.

I'm noticing that there are a lot of doctors that if they take Medicare, they don't take Medicaid, so, we are not paying the 20 percent or that they turn you away because they don't want to deal with Medicaid or Medicare because it's not paying them enough.

When I do end up finding a doctor that will take Medicare, they don't necessarily take Medicaid and I'm left with a substantial bill of 20 percent. When I do find that they take both services, Medicare and Medicaid, what I'm noticing is I'm looked at the low end of the totem pole so to speak and ended up seeing a nurse practitioner.

For a quick sample, when I went to get my medications, I went to see a nurse practitioner and she wasn't able to prescribe the medications that I needed, so, I then had to make a second appointment and go back to a doctor that really didn't want to see me and when he finally did see me, I ended up paying the 20 percent.

Finally, on the last note and difficulties I'm finding is if you need glasses or so forth, other medical equipment, I'm finding out that you have limited choices and you cannot get

quality glasses or find a quality dentist or what have you and again, I'm stuck with a 20 percent or I'm stuck with the fact that I'm getting turned away.

So, thank you very much for the opportunity of allowing me to speak today.

(The audience applauded.)

MS. CALLAHAN: Thank you. Robert Master.

MR. MASTER: Thank you very much for letting me speak for a couple of moments. I am with Commonwealth Care Alliance that I have the privilege of directing and Boston Community Medical Group which I have to say I'm so gratified about to hear all the positive comments both here and in previous hearings and I wanted to talk from that perspective about the voice of this initiative.

First of all, I want to say that this is the most important initiative at least in my professional lifetime to fundamentally improve care and the care experience of people that certainly need it.

The fee for service system is broken,

it's uncoordinated and for decades as a physician I've just seen the ravages of that, so, we have to keep that in mind as we go forward.

The status quo is absolutely unacceptable. As an organization, Commonwealth Care Alliance and Boston Community Medical Group are investing millions this year for statewide expanse.

We plan to move the new Boston Community Medical Group practices, we have to change the name because they won't be in Boston, in other parts of Massachusetts with populations with long-term support needs and we have had for many, many years relationships with really the essential providers, human service providers that have been the guardians of the gate for populations of people with developmental disabilities and serious persistent mental illness and I say that because as we conceptualize the future for this population, it's thinking of new primary care models and new locuses of care that haven't yet been seen before anywhere in the United States and that's going to lead to my recommendation at the end.

A couple of things just to echo what I'm hearing here is really what we've been taught over thirty years of our relationships with Boston Center for Independent Living and with so many of the consumers that we have had the privilege to relate to in our clinical experience and I just want to reiterate these for the design of procurements for populations here and again, I'm reflecting, I'm talking specifically about populations that have heavy, long-term service support needs, that's the population.

First of all, what you heard here if I could summarize it is we have to build the networks and specialists around the people in need of the services.

Boston Community Medical Group for thirty years in a prepaid context has had an open network of specialists and other providers. The question is whose network is it, is it the beneficiaries' network or is it the plan's network, it has to be the beneficiaries' network.

The second is that there really needs to be what you also heard here individualized plans of care, service plans individualized around the

person's needs, durable medical equipment needs, personal assistance needs and speaking of personal assistance, there has to be an essential awareness of the critical importance of personal care assistance, not just for medical needs but for life and independence and maybe we had the privilege of internalizing that because of our long relationship but these all go in to decide.

There really needs to be, and I fully support this, the integration of, we heard independent coordinators and care teams.

In fact, we in our SCO program have had that experience, a positive experience by integrating GSCs, geriatric support coordinating services to determine long-term service supports for homebound elders and we anticipate the best way is to integrate clinicians from independent living centers and providers we'd work with as part of the care fields here, and lastly in the design, there's others but primary care is not going to look like it looks, it doesn't look like it looks for populations in typical networks.

What we're going to see and need to see is multidiscipline teams in different locations

for people with serious persistent mental illness, SCO located perhaps community health centers or essential housing providers with disciplines coming together for people with developmental disabilities.

Critically important is the use of nurse practitioners that we have piloted into the group homes as opposed to the efforts of moving out with all kinds of potential benefits there.

These are some of the ideas of the new models and think about that as you think about some of the prescriptiveness of patient centered medical home. That certainly is an important model but to the typical medical world, there needs to be a more expansive position like that.

So, where am I going with all of this? We have this extraordinary opportunity here in Massachusetts to lead what is an extraordinary opportunity in the United States, to fix something that has cried out for support for decades.

The ACA gives us that opportunity and we have that opportunity but we have to accept that for populations with long-term service support needs, that we, no one has seen what such a system

and network and primary care looks like.

That's different than the other populations. That is really inconsistent with a competitive procurement, it's also inconsistent with passive enrollment or mandatory enrollment but you have to say passive enrollment into what?

We have to create these new models and this is not an excuse not to move forward, we absolutely have to move forward, but my suggestion and plea is think about this population, the 22 percent of under age sixty-five dual beneficiaries differently on their majority counterparts and think about this as a demonstration within a demonstration.

It's going to require a collaborative approach between leadership and state government, CMS, those of us who and others that want to move into this area and most importantly with organizations such as DAR and the consumers in a collaborative approach and if there's one less and from Boston Community Medical Group, the design of those programs that we have had and others validate our successful are those design features didn't come from us as clinicians, we came from a

different head space and different world, it really came from those receiving the services designing the model and I guess we had the good sense to listen many years ago and internalize all of that and I think that's a very, very important lesson that if we're going to do this as a collaborative approach, I think we need to bring this leadership and the key provider entities together and I just want to say I know there's fear.

When I say that, because we have a seven year talking stall experience with SCO. We can get something up for 2013, we can get something on a very substantial scale.

I'd ask the state and colleagues at CMS to think about convening this collaborative approach where we are going to essentially develop entirely new models and entirely new approaches to management of the long-term support services.

What I am afraid of is some of the concerns I'm hearing, keep long-term services out. That essentially would destroy this once in a generation opportunity to integrate and I'd have to say that unlike the other segments of the dual

population, we really need to think very, very seriously about how we're going to move forward and that doesn't have to be the enemy of scale, it really doesn't. Thank you.

MS. CALLAHAN: Thank you.

(The audience applauded.)

MS. CALLAHAN: Lisa Prince.

MS. PRINCE: Hi, my name is Lisa Prince, President of the Massachusetts Council for Adult Family Care. Bob, I'd like to say ditto. There are my comments.

One of my primary concerns while I do understand the proposal, I think it's worthy, I appreciate so much the time and effort that's been put into it, one of the questions that continues to come up today is the basis of the ongoing community supports that are already in place and what role they would play as the providers are identified with a lack of community understanding.

The AFC model is often referred to as one of the best kept secrets in the Commonwealth. I think it's also one of the most progressive programs. Not every state offers it as a state plan service, so, what my hope would be is that as

we move forward with this project, that there's a greater understanding of what the adult family care model is, what the supports are that are available and how the MCO model could incorporate that.

We're often confused with adult day health or group adult foster care. There are very significant differences among those models and I'd hate to see that get lost as we move forward with larger providers not familiar with what the Commonwealth has to offer.

I also would take issue with the automatic enrollment as it's been mentioned many times today. We're talking about a population of people who may not have a good understanding, may not have a strong advocate who could explain it to them.

I loved the example of a person telling me what's going on and explain all the options to me, so, again, bring it back to that community basad case manager, information and resource person or something like that to make sure the information is going out and the options are made clear to all. Thank you very much.

MS. CALLAHAN: Thank you. Laurie Martinelli.

MS. MARTINELLI: Thank you, my name is Laurie Martinelli, Executive Director of NAMI, National Alliance on Mental Illness, and thank you MassHealth and Medicare for putting the proposal together.

NAMI's mission is to improve the quality of life with people with mental illness. We have twenty chapters around the Commonwealth and about 2,500 members.

I want to talk first about the peer specialist and strongly support having them part of the program. We have some questions about whether their role can be increased should the certified peer specialist be a member of the care, coordinator care or clinician team.

How about making sure the peer specialist develops relationships with peer run services in the community. You also mentioned the enrollee customer service and should the peer specialists have a role in that, we think they should.

Other protections are mentioned like the advisory committee or any governing board, I think

the certified peer specialist should be included in all those special protections.

Transportation, transportation, transportation, you mention it slightly in this proposal but it's a huge, huge issue for people with mental illness.

Most people with mental illness don't have cars and rely on public transportation and talking to our chapter in Berkshire County, Pittsfield, very rural, if you can't rely on public transportation, you can't get places and guess what, the Berkshire Regional Authority is cutting services.

So, I think you need to figure this piece out because it's a huge issue for people with mental illness and they do mention timely appointments but that needs to be spelled out.

There needs to be timely appointments but I think the care coordinator needs to get involved in the transportation issue. The role of families needs to be spelled out and emphasized more. That is a huge issue.

The clinical care talks about on page 14 that families, shouldn't they be coached on the

recovery model. They also should be part of the enrollee customer service and also family members should also be part of the advisory or any governing boards that are created.

Outcome measures, you have a very nice chart and a lot of good outcome measures but we were talking at NAMI about the measures that make a difference and here were some of the issues, gainful employment, reduction of services with treaters, is there an opportunity.

The development of self-mastery skills that can be done independently, and lastly is there financial independence, so, I would just include those for consideration.

Communication, my next issue is communication from MassHealth or ICO or whoever is in this new format, but I think we all acknowledge that the notices that currently come out, I'm more familiar with the MassHealth notices than Medicare, they are incomprehensible.

I cannot stress that enough.

(The audience applauded.)

MS. MARTINELLI: So, this whole proposal is to have notices that are

comprehensible and lay people can understand what they say, I can't stress that enough, and lastly, I'd say you mentioned some of the cultural confidence and underserved constituency and you've heard from many of them today but to speak on behalf of people deaf and hard of hearing and people with mental illness, they are truly underserved and the outreach and all of your programs for the deaf and hard of hearing need to be spelled out a little bit more.

Thank you for the opportunity to speak.

MS. CALLAHAN: Thank you. Ruth Kahn.

MS. KAHN: Thank you, my name is Ruth Kahn and I am a graduate student in expressive therapy at Leslie University where my internship is at Boston's Community Medical Group. I've had a relationship with BCMG for about twenty-two years at least.

My husband, Paul Kahn, was one of their patients right from the beginning and without BCMG, my husband would not have had the full life that he did have. Paul used a ventilator for twenty-two years at home and thanks to the wonderful nurse practitioners who came to our home

to change the trach tube, thanks to BCMG advocating for his PCA needs as well as durable medical equipment, housing and all the other complicated needs, Medicare and Medicaid that Paul needed, it was all in his control.

We need to make sure that we do not go back in time. We need to make sure that community based care continues especially for people with complex medical needs and BCMG is a model for the country as far as I'm concerned.

There should be many BCMG's throughout the country truly advocating and being part of the disability community, making those borders go away between medical care and community care. Thank you.

MS. CALLAHAN: Thank you. Gina Farley.

MS. FARLEY: I'm Gina Farley from Independent Living in Framingham, director of human services there. My assistive technology isn't working well so I'll be submitting it.

I wanted to echo what Laurie said. She took my thunder. Most of the time during my day-to-day work at the center, we work on advocacy

issues surrounding health insurance.

Many of the consumers, we only work with people with disabilities and we are almost always working on health insurance, keeping it, acquiring it, whatever together, not that I'm making phone calls and they're sitting around thinking about it, we're doing it together.

It's a major, major advocacy issue at our center and I'm sure I can probably say the same for the other independent living centers that have already spoken, the customer service, the issues that have happened already with the MCOs, people who only have MassHealth has been, I won't use the word nightmare, but in any case, the names of the programs, Commonwealth Care Program are the same almost as the MCO plans that people are put into, et cetera, et cetera.

There's been issues from day one of that. I can take you back even further. I'm very concerned about the opting out issue of not being, voluntarily being able to opt into this program to the PCMH, ICO model mainly because I don't know if you remember this but back in 2006 when Medicare Part D came flying along and the Medicare, dual

eligibles, you oh, all of a sudden, MassHealth isn't helping them with their prescriptions and they have to pick a Medicare Part D program.

Well, they did pick a Part D program, with disregard to their prescriptions completely. It keeps happening, people newly on Medicare who already had MassHealth, same thing keeps happening.

How is this going to go if you really are going to stick with this opting, not opting in but random, is it random, is the person's primary care going to be taken into account or their specialist taken into account.

The vision that Bob has of network in, network out, please take a really good, serious look at that because this is going to be a major issue for consumers.

The other thing is reading the proposal, and I didn't get to the additional benefits until page, I don't know, 57 or something, people have to know why should I stay here now that you've put me here, why should I stay here and what are the benefits.

I want to just say a little bit about

customer service. I get different answers from customer service depending on what day I call and how long I'm on hold. The dual eligibles that I work with have major issues keeping their MassHealth.

What happens when they're in this PCMH and all of a sudden you oh, no, MassHealth for a while because they didn't look at their review form in time and some other left hand, right hand took them out of MassHealth.

It happened to me personally, it's happened to many, many, many, many of my consumers, especially ones with PCAs, all of a sudden, the PCA doesn't get paid and they don't have that PCA anymore and it took me, and I'm an advocate and no, I don't have a hot line and not a personal way to go through MassHealth very well.

I called the director, actually, I didn't get directly to the director the other day for somebody but you can't imagine what we go through. I'm on hold for an hour. Who can do that with a cell phone. I do it at my office and keep working and keep working on my computer.

If the person, my consumer is there, we

keep working on other issues and it's taken months to resolve an actual computer glitch. I won't go on any longer, I have these specific things but please consider one last ditch effort, accessible information, I wanted to laugh when I saw that in your proposal.

Yes, the proposal is quite thorough, tries to answer all my concerns but until MassHealth provides electronic brail and large print forms, ways to submit on line, et cetera for the blind and visually impaired in particular, then maybe you can talk accessible information and clear and concise and nonconfusing information but keep thinking of that MassHealth's infrastructure is going to have to be beefed up big time.

The eligibility department, I barely get through to them. They say they're short-handed, only taking emergencies today, and I say this is an emergency.

I'm sorry, I keep talking, so, please look into beefing up MassHealth's infrastructure, customer service and eligibility department because folks are going to get into really major trouble.

115,000 you're talking about at some point in one year have some issue with MassHealth, I can guarantee that. Thank you very much.

MS. CALLAHAN: Thank you, and just to check in, we've heard from twenty-three folks and we have seventy-five on the list. Christina Allison.

MS. ALLISON: My name is Christina Allison and I am fifty-four years old and I am a dual eligible. I have been in the work force for around the past sixteen years, my disability is retinitis pigmentosis and I've been legally blind since 1984; however, I would like to speak on another issue.

I would like to speak about my health issues and my doctors. I have three doctors, I have a neurologist, cardiologist and my primary care physician.

Now, I've been seeing my neurologist since 1993. I first saw him because I had a migraine induced stroke. Now, that's a pretty rare thing to have happen to somebody. I had a second one in 2006 and third migraine induced stroke July 23rd of 2011.

Now, the thing I'd like to speak on is that my neurologist, cardiologist and my primary care, they all work together. There is not a critical situation I'm in or a blood test, medications or a doctor's visit that I go to where they do not share tests, they share them.

There is, like, a phone call when I'm in an office, I go to an office, my test results are there before I get there. The care I'm receiving from the three doctors altogether is incredible, so, my concern is that when I'm going to be enrolled in a plan or I'm having to choose a plan and my neurologist or primary care or cardiologist is not in that plan, what do I do and given my circumstance of this last migraine induced stroke, I am 98 percent better.

I lost speech, I lost feeling in my right arm and my hand and if not for the care that I'm receiving from these three doctors, I would not be testifying today.

So, I am very, very concerned that I won't be receiving the care because I'm enrolled in a plan and it's basically to me what doctor is more important because one of them or two of them

may not be in the plan, so, it seems to me that I'm not having a choice in my care and we need that choice. Thank you very much.

MS. CALLAHAN: Thanks. Vicky Pulos.

MS. PULOS: I am a health lawyer with the Massachusetts Law Reform Institute. I'll be submitting written comments so I'll keep this brief.

Something I found in my E-mail box when I got back from vacation which I think is a perfect example. A legal aid paralegal consulted me about one of her clients with Medicare and Medicaid, has something called a frozen jaw, suffering from cancer.

The provider had provided a piece of durable medical equipment which would exercise the jaw which would cause him pain and inability to chew, Medicaid would pay but that left cost sharing. MassHealth denied payment.

The paralegal helped with an appeal, MassHealth denied the payment in the spring of 2011. It wasn't until the fall the appeal was favorably resolved and even that wasn't the solution of the problem.

Now, the out of state provider is trying to satisfy MassHealth's credentialing criteria in order to actually get paid for the piece of equipment which the individual has yet to receive, so, someone experiencing pain, inability to chew in large part because of the intersection of two flawed systems.

The integration holds great promise but integrating two flawed systems won't necessarily result in a less flawed system unless there are substantial accountability provisions built into the plan and that's where we would really like to see full consumer participation, full participation by individuals with disabilities and consumer based organizations led by people with disabilities in every aspect of accountability, outreach and enrollment, reviewing the criteria for medical necessary and utilization review, independent coordination of nonmedical long-term services and support, monitoring ADA compliance and not just choke them with one member of a government board but really full, meaningful participation and I will be along with many others including the DAR Coalition submitting comments

with specific recommendations.

We know the concept paper won't have all the details but there needs to be more participation by consumers and accountability to ensure integrating two flawed systems results in a better system, not twice the flaws.

MS. CALLAHAN: Thank you. Nasir Khan.

DR. KHAN: My name is Dr. Nasir Khan, psychiatrist and CEO of Bournewood Hospital. I'm talking today as president of the Massachusetts Association of Behavioral Health System.

This is an organization which treats almost all acute psychiatric patients in Massachusetts who require inpatient care.

As you know, DMH does not do inpatient care by and large. This includes eight freestanding psychiatric hospitals and three other psychiatric hospitals. I'm speaking on their behalf.

Thank you for the opportunity to speak today. The concept of integrated care is excellent because the patients we deal with, the dual eligibles combination of Medicare and

Medicaid have multiple problems, not only mentally ill which is what I'm going to concentrate on but also medical and social needs and we think there will be tremendous savings if there is true integration of care of these patients which has not happened at the moment; however, we have some concerns, which is why I'm here.

On the inpatient basis, two-thirds of our patients are public patients, just over 30 percent are paid by Medicare and 30 percent by Medicaid or MassHealth, so, 66 percent of our public.

So, whenever there's talk about changes to the payment for these patients, we have to be concerned. In fact, our organization is extremely concerned. We're concerned because behavioral health system is economically fragile.

We're concerned that we do not want to jeopardize the viability of inpatient care which could happen and has happened already, psychiatric units have closed. We don't want that to be aggravated because if it is, then access will be a problem, it's a problem right now with patients. We do not want more psychiatric beds closed which will aggravate access.

Getting back to Medicare, Medicare actually from our point of view is not a bad payer, it may not be the best but it is not a bad payer. Their rates are set nationally by CMS, the same rates across the whole country. They came up with the rates after fairly rigorous analysis.

Medicaid paid the state rates and unfortunately, the differential sometimes can be significant. The Medicare rates can be 30 percent higher than Medicaid rates or to put it differently, Medicare rates aren't high, Medicaid rates can be 30 percent lower than Medicare rates and that can be a problem.

So, our organization is really, feels it's very important if these two programs are merged, that the rates paid to providers be at least the Medicare rate and not the Medicaid rate. To all pay to the Medicaid rate, a lot of units will close and that is absolutely a given.

The second thing about the carve out rates, currently in the carve outs which are hired by MassHealth, the carve outs set their rates with no oversight by MassHealth.

We really want whatever rates are set to

be overseen by CMS and MassHealth and not be totally, utterly the prerogative of paying carve out company whether it's a national for profit or whatever. We think that's extremely important.

The savings will come not from cutting rates but from better integration of care and case management. That's where the savings will come and that's why we're in favor of the concept of the integrated care organization but we want it to succeed and it won't succeed unless it's attractive to consumers, attractive to providers and access is good.

If all those happen, then we think it should be good but I do want to, really want to on behalf of my organization, fifty psychiatric units push for the Medicare rate, not the Medicaid rate and not something of a blend. Thank you very much.

By the way, I will be supplying written testimony which will amplify what I've said. Thank you very much.

MS. CALLAHAN: Thank you very much. Mary Margaret Moore.

MS. MOORE: Hi, I'm Mary Margaret

Moore and I have the opportunity to speak with you today, I guess it's almost noon, about how we feel from the North Shore and Cape Ann representing the Independent Living Center of the North Shore and Cape Ann.

One of the things that I've seen in all the work that's been done by you all and the DAR group which I've been paying attention to over the past few months is a lot of concerns regarding the model and the models and the values and I appreciate that you've kept those values of person centeredness, what I would prefer to say is consumer control but I understand why you're using person centeredness and I believe this is an opportunity for us to do something that we haven't been able to do in my lifetime, which is really have a system of access to both medical acute services and long-term services and supports, so, that's why I think we have to jump on this and figure it out.

My worry is I've been involved in lots of these adventures and I don't see in this document what we began with as a principle when the first consent decree happened in this state which is no

more harm and I haven't seen that in here and yet, I hear that question being asked over and over again, that as you're moving forward, what is your ruler to make sure this proposal is going to work and I ask you to put that in as you rule is no more harm is being placed to the consumers, to their service providers, to the Commonwealth in terms of how its system and its cost, so, I suggest that you consider that.

We tried very hard as you know with the whole deinstitution movement and waivers starting way back with the omnibus waiver for our state schools and we've made lots of successes but keep that principle foremost and couple it with that request.

The other one which really is consumer choice. It's in here but it isn't firm and I really ask that you firm that up. Choice to opt in or to opt out, you hear that over and over again.

I don't know if it's cost effective for you to get your ICOs without having a total opt out. I appreciate that but then what's going to make it comfortable, what's going to make it work

for the consumer to get as much as they need right today where their life isn't going to be disrupted and that's where I ask to be put in the no more harm principle factoring whether it's opt in or opt out because that may reflect more on the consumer control and choice which is only sprinkled through here.

I also ask, and Bob, thank you for putting this in, it's not strong enough is flexibility in the models, in the systems, in the ability for folks to need more or less based on what they think with their team of folks.

I didn't see flexibility in here as a driving dynamic and I suggest you look at that aspect because I think it talks to those flexible costers and arrangements of services that get adapted around folks when they need it and the groupings.

The other piece I suggest is local. Having five ICOs or twenty-five ICOs or fifty ICOs or one ICO doesn't matter, to me whose going for the service or you perhaps when you're going for service, what matters is that I go where I am locally comfortable, whether that's a forty-minute

ride into Boston from Salem or from Rockport or it's right down the street there at North Shore Medical Center, I want local so that I know where my folks are and I didn't see localness really built in as a parameter and without that we don't have community based care, we don't have consumer choice.

The last piece that I just remind you of is I'm fairly adept at the system but I've had sixty-three years, I've had sixty-three years of my life and a sister who is nine years older whose been in the mental health world since the age of when she was eighteen, so, we're going back to the early 60's and a son with disabilities and a spouse with disability, never mind working in the field both in government and out but at every moment in time no matter how much I think I know what I'm talking about for myself, I need a guide and I need an advocate.

The fact that I know about where to get those is what gives me the opportunity at times to speak without them, but I don't see it built in here all the way on the road the opportunity for a guide or advocate and I ask that you build those

in as well.

So, thank you on this journey, it's a great opportunity and I hope that this is helpful to you.

MS. CALLAHAN: Thank you. Mr. Raine Newman.

MR. NEWMAN: You'll have to excuse me, I'm a little nervous. My name is Raine Newman, I'm an artist, work in stained glass and photography.

I happen to have post-traumatic stress disorder. I was beaten as a kid and I have a problem with authority figures right now or I have all this time.

I want to bring up just a couple of personal issues and I'll try to stick to the two minutes. My elderly aunt swallowed some food into her lung and she got a bad case of pneumonia.

She was hospitalized for two weeks and medication was so strong with her she kept hallucinating. She went to Hawaii with Elvis for a honeymoon.

Anyway, after the hospital she was too weak to walk so she went into rehab to regain her

strength and she gets home and she finds out from Social Security that her checks are going to be, they were going to deduct money from her checks because MassHealth said they can't pay for both residential hospital and residential at home and she was coming home, she wasn't going to the nursing home to die and so far, her checks have been deducted all summer long which leaves her the last week of the month hungry.

So, I think this issue needs to be addressed by MassHealth, Medicare and Social Security need to have a pow wow because I don't think it's fair and what do they want her to do, get out of rehab to homeless? I mean that's ridiculous. She had to pay her rent and bills and everything else, so, that is my first issue.

The other one is that I want to thank the people of Massachusetts and on behalf of MassHealth for actually saving my life three years ago when I was operated on for a precancerous tumor.

I'm fine now but I have a whole host of medical problems keeping me from walking and everything else. I am using a cane and a chair

because back in 1973, I was sixteen years old and I was in a crosswalk and I got hit by an elderly driver, hit and run, left me in the road for dead, so, I want to encourage MassHealth, MassHealth has been paying all my medical bills ever since, so, let's try to save MassHealth money by working with the State House to campaign for more laws about elderly drivers being tested. I would really appreciate that.

I mean there are needless deaths and injuries and everything else that comes out of these driving accidents.

The other thing I want to quickly say is that I've taken certain medication for my eye drops for the past eight years give or take. I show up at the pharmacy for a refill and they say oh, you now need a PA for that and that can take a whole month.

Well, I went six months with my doctor trying to convince MassHealth that I needed these drops. I'm an artist and I need my eyes more than any other part of my body, so, you shouldn't be finding out about that, you should get a letter in the mail according to what medications you took

and whether or not you need a PA for it before you get to the pharmacy.

I think that's it, I tried to stick to two minutes.

MS. CALLAHAN: Thanks a lot. Brian Rosman.

MR. ROSMAN: I'm Brian Rosman for Health Care For All. We're a health care organization. Everybody needs health insurance coverage and now we had to kind of change our message and now, you know, it was so easy to march under the banner health care for the poor and now we're saying risk adjustment must include functional status, it's another way of looking at things and it's tough and yet it's critical, and that's why we're here to talk about changing the way we think about things, so, I have three quick points to make.

One way we have to change the way we think about things is the medicalization of this program. You know, Medicare and Medicaid are both health care programs and they see their work as bringing doctors and hospitals and nurses to people but the kind of services we're talking

about here go way beyond doctors and nurses and hospitals, so, our first paradigm shift, mental change we have to make is this goes way beyond medical care and demedicalize our thinking and put the focus on the broad range of supports, long range services we've been talking about, and that's No. 1.

Our second change or frame of reference I want to mention is a phrase, I promised myself I would never use this phrase, it's so straight, first do no harm, it's like right time, right place, but I think it's an important concept we have to do which is as we jump into this which we fully support and we stand with DAR and the other groups that are encouraging MassHealth to move forward on this, but we have to really take the steps in a measured way to make sure the capacity is there, the services are there because the harm that could be created by moving too fast or in the wrong direction is so severe.

And finally, the third paradigm shift, third kind of mental shift we have to make is embodied by this meeting and the one in Worcester, so many members of the community, dual eligibles

are here speaking.

We have to keep that up for the next stage. This is not for you guys at the front who know this, this document that we're commenting on today is just the baby step for a much longer process.

MassHealth and CMS are going to be working on over the next eleven, ten, nine months or so a much more detailed protocol document that's going to go into much more greater detail and as we work on that document, we think you need to continue to have the voice of people affected by the program front and center at every stage at every way.

This process has been so good and helpful but only the start, we need input, listening sections and direct involvement by people with disabilities.

I think we all have to be proud in these hearings more than half of the speakers are dual eligibles themselves and we need to keep that going, thank you.

MS. CALLAHAN: Thank you. David Kassel.

MR. KASSEL: My name is David Kassel, I am the communications director for Massachusetts Coalition of Families and Advocates, COFAR. We are a family supported organization that advocates for persons with intellectual disabilities and we advocate for a full range, full continuum of care that includes the community but it also includes institutional care, so, we, you know, I've heard a number of people talk about the need for choice and the need for access and many families have chosen institutional care, many people have chosen community care.

We think all of those things are important and people should not be removed from any of these choices and that's unfortunately what's happening today.

I would just like to add that the situation, the proposal that we're talking about today, the dual eligible proposal, I'd just like to add this also has a risk of a further reduction in choice and access, that's certainly what we've been hearing today.

I think that we agree with the SEIU and others who have said that the services and

supports for people in the waiver in the community and elsewhere should be carved out of this program, out of this proposal because at this point we don't think the proper analysis has yet been done to measure the impacts on people of these proposals.

We're concerned this is another step in privatization of care for people with disabilities and as such it will reduce choice and access. Thank you.

MS. CALLAHAN: Thank you. James Miczeh.

MR. MICZEH: Yes, my name is James Miczeh, I've been a quadriplegic going on forty-five years. I've been with Boston Community Medical Health for somewhere over twenty years. I've seen both sides of the coin and I'm here to support Boston Medical Community Group.

As other people have echoed, the, they speak to you, they are totally, you are the one that came in and you are the one of their focus. They're always there for you. I pick up the phone twenty-four, seven, three hundred sixty-five and I would get a response, so, I know I am safe.

I still get the same attitude from other institutions as far as having other physicians not speak to me, speak to my wife. My wife was hospitalized twice this summer and she is in the stretcher, I am there to be by her side and they're asking me what's the problem, so, and it's happened all the time.

Boston Medical Community Group is preventive medicine and it saves money. I have an MBA from Babson, I can tell you if I had to go in an ambulance to an emergency room and two or three days in the hospital and come back, that would be a lot of money.

So, with a nurse practitioner coming to my house, maybe prescribing some medication, antibiotics, I'm well within five to seven days. I can't say enough about it. Bob Masters, his wife Marie Felton, have just created the most wonderful organization for people like me and others that couldn't really live without them. Thank you.

MS. CALLAHAN: Thank you. Denise Powell.

MS. POWELL: Good afternoon, my name

is Denise Powell, Assistant State Director of Caregiver Homes of Massachusetts. I'm here today to present the testimony of Andrew Marino of Holyoke who could not be with us today in Boston.

Through the MassHealth adult foster care program, Andrew is a paid caregiver for two MassHealth members, at least one of whom would be directly impacted by the dual demonstration.

I appreciate the opportunity to present his testimony and on behalf of MassHealth members to whom Andrew provides critical long-term community based support.

Hello, my name is Andrew Marino of Holyoke, Mass. I'm the caregiver for two of my relatives, Robert, fifty-two, and Marbrielle, twenty-seven. On October 28th, in 2009 Robert went into the hospital for a simple biopsy which left him in a wheelchair.

Marbrielle, my other relative, was in and out of rehab for mental problems for many years. I left my job thirty years ago to take care of both my relatives at home. With help from the adult foster care program, Caregiver Homes of Mass., they both live at home and are doing fine.

Robert is just starting to walk and Marbrielle has not returned to rehab for over a year. Caregiver Homes of Massachusetts is a wonderful and caring program. Having a nurse and a social worker coming to your home is an outstanding factor. These professionals understand my relatives' needs and support all of us.

My relatives look forward to these visits knowing that they are loved and just not another person in a nursing home. Thank you very much.

We know MassHealth has indicated and made available to MassHealth members participating in the dual demonstration. We thought it important, however, to take this opportunity to offer Andrew's testimony to reinforce for MassHealth the potential integrated care organizations the value the AFC provides to MassHealth members and to the state.

As Andrew has indicated, this program helps to support MassHealth members to live in their communities with person centered supports provided by caregivers of the member's choosing and by the interdisciplinary staff of adult foster

care provider agencies.

I thank you again for this opportunity to deliver this testimony.

MS. CALLAHAN: Thank you. Gary Blumenthal.

MR. BLUMENTHAL: In the interest of time, I'm delighted to submit written testimony.

MS. CALLAHAN: Thank you, sir, I appreciate it. Leo Sarkissian.

MR. SARKISSIAN: I'll do the same thing.

MS. CALLAHAN: Thank you. Howard Trechtman.

MR. TRECHTMAN: Thank you, thanks for the opportunity to testify. I also want to say welcome back to Massachusetts, Chris.

MS. GRIFFIN: Thank you, Howard.

MR. TRECHTMAN: We need you here. So, in the interest of time, I just want to discuss a few bullet points. For people that don't know me, I'm a former state hospital ward and been a patient in double digit places facility.

I'm a certified peer specialist and

co-executive director of the Metro Boston Recovery Learning Community and director of the National Greater Boston Consumer Advocacy Network.

One of the first things we did when we opened the Boston Resource Center was to assist people with the newly implemented Medicare Part D plan and we learned that people didn't understand what was going on and needed guidance and because people were randomized to a prescription drug provider without any look at what medications they were currently taking, a lot of work needed to be done to assist people to find a good plan for them and explain to them how things worked.

So, I've always been a big champion in choice in all matters so I applaud MassHealth for providing the opt out option and respecting our choice.

I think a number of the people here have spoken for the need for choices. If you're happy with what's working, you don't want to be forced to have to change it. I'm also a dual eligible myself and a certified peer specialist so we would not want to see randomization to the providers.

Also, consumers I've started to like less

and less, a lot of us have been using the word peer to describe people who identify experience with mental health and addictions treatment and I'm a big champion of peer services in general, so, we thank the Department of Mental Health for funding six recovery learning communities which are completely peer run to service the needs of the local people served.

Our recovery community with our funding was able to operate three recovery centers and a warm line for peer support and a toll free number. We're funded for the Boston area, we've chosen to take callers from all areas and recently able to open up a fourth recovery, the Hope Center at the Lindemann with no new dollars.

We run a variety of support groups, do advocacy and training, getting people back to work, over fifty people back to work and hired ourselves or found peer jobs were very strong in dual recovery for people with addictions and supplemental.

We do not try to tell me not to go to traditional providers that they've been happy with providing the unique work we can do by having

people in their shoes, possibly being locked into seclusion rooms or medication against their will which killed my best friend.

So, we have existing infrastructure that have been operating for three or four years so we're very easily able to leverage new dollars to service new people and expand our offerings.

I'd especially like to be able to provide peer support services. We've had a lot of requests for that but no resources to do so, so, we encourage the vendors to utilize the recovery and educate people about it, potentially fund additional peer run services.

I heard people talk about annual eligibility, that is an issue, have to do it every year. Usually very little has changed but people are getting kicked off, people are in their shelters, not getting their mail, don't understand it, glitches, so, I'd like to revisit the annual eligibility paperwork because it seems it kicks off people and can have trouble with the paperwork.

I applaud the Department of Mental Health for a peer run respite. This is a place people

can go to recover instead of a hospital. The peer run respites around the country, they operate at about the quarter of the cost with better outcomes.

I'd like to see more information about recovery measures for your providers. The certified peer specialist should be providers. Twenty-two other states allow it to be Medicaid billable to deliver services but we don't have that in Massachusetts.

I'm concerned about quality, ditto the comments about transportation. I think the dental care is essential and oral health is essential to overall health. In closing, I think the rates for facility should be significant.

We don't want to lose more beds because people who want hospital services frequently have trouble getting into access but on the same note, I'd also like to see more choice in facility.

I know there can be hours and days waiting for facilities; however, I still believe people should have choice. People have had horrific experiences at facilities and they want to send me somewhere I don't want to be, I'd like

to have the choice not to go there.

I'd also like free market hospitals that have a high level of quality of care, people would care to go to those facilities than hospitals that would suffer the consequences of not treating their patients with dignity and respect.

In the interest of time, I will close and submit written testimony. I thank you very much for the opportunity.

MS. CALLAHAN: Thank you.

(The audience applauded.)

MS. CALLAHAN: Vic DiGravio.

MR. DiGRAVIO: Vic DiGravio, president and CEO of Association of Behavioral Healthcare, statewide association of over eighty community based providers of mental health and addiction services.

We're pleased the draft proposal has its core access to behavioral health services and we share MassHealth's vision of a system that properly identifies and assesses individuals with behavioral health disorders and allows them to access services they need, delivered to live as independently as possible in the community.

There are a few key points I'd like to highlight that we think will contribute to the goal, overall goal of this project.

One, we feel it's important to limit the risk to the integrated care organizations, both the financial risk and the ability to profit financially. We've seen in others funded by MassHealth how they're structured by the Commonwealth really does impact access to services on the ground and that's really important for this population that there be no incentives hidden or otherwise to prevent access to services.

We feel strongly it's important the behavioral health organizations be able to act as medical homes for certain individuals with chronic behavioral health conditions.

Access to health information technology is another key piece. If we're going to have a truly integrated system of care, provider organizations need to be able to access health information technology which is a very expensive proposal for provider organizations.

The outpatient mental health system is a system that each year loses more and more access

to outpatient mental health. Outpatient mental health is the most cost effective way to serve individuals with chronic mental illness and help divert them from more expensive levels of care, so, the health, the outpatient mental health system is very, very important and needs to be a focal point of this project, and the last point we'd like to make is the Department of Mental Health Community Flexible Supports program we are opposed to including CFS services as part of this demonstration project.

The Department of Mental Health has done great work over the past couple of years in implementing a new flexible system of care that meets the needs of individuals with experience.

We feel enrolling CFS into the demonstration project would undercut much of the good work that's happened over the past couple of years. With that, thank you very much for your time. I appreciate the opportunity.

MS. CALLAHAN: Thank you. Ken MacDonald.

MR. MacDONALD: Hello, my name is Ken MacDonald, durable medical equipment provider at

Boston Community Group. I've been in the role for thirteen years, been a wheelchair user for thirty and receiving my medical care from BCMG since probably 1988.

In my opinion, it's the finest medical care model for people with disabilities in the country and as we've heard from other folks earlier.

In our model we have the ability to, we're the payer, we purchase medical equipment supplies, we have an outstanding team of therapists that prescribe equipment working with our members who have a say in what equipment and supplies they're going to receive and although it's not a perfect system, it is much less cumbersome than typically what you would experience with in the dual's population and as we recently started to enroll folks that are dual's, I'm starting to see the disparities in the DME world that I'm sure that many in the room have experienced.

You can have two folks with the same disability or same equipment needs and one can be enrolled in our BCMG paid model and other folks

are in the dual model and I can't get that piece of equipment.

Either it's, you know, it's too soon or they don't meet the exact strict rule based criteria of Medicare or MassHealth, or you know, it's not something they can obtain and it's really frustrating for me in my role to see that and I think I'm real excited, I think this is an exciting time for us to be able to try to expand our model across the street and streamline the whole DME process because I spend probably three-quarters of my day handling the paperwork that is associated with DME and if we can streamline that whole process, get folks the medical equipment supplies they need to allow them to live independently and stay healthy and stay active in the community, thank you.

(The audience applauded.)

MS. CALLAHAN: Thank you. Linda Landry.

THE AUDIENCE: She's going to give Dennis her turn.

MR. HEEPLEY: Robin and Chris, thank you for the opportunity to speak with you again

and folks, I can't tell you how many months and applaud you more for what you're undertaking here.

I'm going to ask us to take a step back. I had an epiphany last week, not talking about how great Boston Community Medical Group is but why it's so great. It's great because it's grown from and embodies independent living movement model.

Last week I was having a test, nurse practitioner came here, checked the person's oxygenation and rather than the person having to go to the emergency room to get an x-ray, the person was streamlined and went straight to the extra room and I waited with the person along with the PCA.

The next day, everyone with all the medical history in this room, I had an allergic reaction and the same thing, thank God the PCA gave me my Benadryl and the epi pen and my nurse practitioner called the emergency room so they were aware I was coming in.

So, rather than being in the hospital for four to six hours or eight hours or overnight as might have happened in the past, I was there for two hours in and out.

So, I'm going to ask, we've heard from folks here today for us to take a step back and look at how we can really make this an innovative demonstration project, particularly folks with complex medical care needs, we need to look at how do we this do this well with a vision in the beginning recognizing it really is a once in a generation opportunity to make changes because right now as the document is currently written, it doesn't promote the independent living.

There are pieces in there but not framed within that context and I think we need to take a step back and do that. I can say a lot of things but I'll just, we'll have further dialog about this but less focus on the medical interventions and focus more on how LTSS can work in the system and independent living and recovery learning community movement can really explain this as opposed to this being an add on or secondary and that's it, thanks.

MS. CALLAHAN: Thank you. Is there another Dennis here, Dennis Cagola?

MR. CAGOLA: What would life be like without health care system without choice? My

name is Dennis Cagola from West Roxbury, certified peer specialist and I'm not a dual eligible but I have mental health experience, schizophrenic disorder.

When I researched the proposal, the impact on me was confliction and frustration. What I see in the state plan for dual eligibles is an initiative to reduce cost for the state at the cost of reducing choice for the dual eligibles.

From my perspective, initial choice for dual eligibles for medical and behavioral care will be subject to the default choice of the provider's decision to stay in the network or not.

Dual eligibles must have the choice first and foremost to stay with the continued providers they so choose. Choosing the right doctor for me is crucial and imperative to my wellness.

A person whose been with the same psychiatrist for four years and while in treatment, treatment where I was able to choose my providers, I completed a twelve month master's degree in teaching with a 3.7 GPA at Northeastern and work full-time and live with roommates and I find my psychiatrist to be very helpful and my

other support system to be helpful in my successes.

So, what I see, what I'd like to see in this model is the modeling of self-determination by adding more funding and resources to the RLCs, recovery learning communities, adding peer support, jobs, increasing salaries for peer support but adding programs and I envision such programs to be personal freedom retreats that teaches person with the stressors about creating lasting change in his or her life.

I feel as a collective we must invest in building the virtue talent and character and not take away their choice in freedom and I'd like to encourage policy makers to enhance the quality of dual eligibles by investing in peer support and also helping them to continue coverage with their current providers to have choice. Thank you.

(The audience applauded.)

MS. CALLAHAN: Thank you. June Cowen.

MS. COWEN: I'm June Cowen, Executive Director of Northeast Community Living Program, peer support manager of our recovery learning

community and I want to talk about one community and the one community is the community of peers and the one community that independent living centers across the Commonwealth, all eleven of us, really focus on is the fact we're one community made up of recovery learning communities, people with mental health disabilities and peers, 100 percent peers, community with people deaf and hard of hearing, independent living needs who peers, peers not only deaf and hard of hearing but part of the wider community in terms of needs being part of our recovery learning peer groups.

We are one community with people with personal care attendant needs, PCA needs who need independence and need peers.

We are one other community that is that community that I want to talk about that is really the heart of long-term support and services and needs, and so, one of the things I want to say, and we're going to submit written testimony so I will make this short, we have many of our consumers here today and staff and I'll give you one example because I think cultural competence, cultural competence is at the heart of services

with the programs and needs of going further with Medicare and Medicaid options and choices for folks. Cultural competence is the difference to unite all of our communities as one.

What I mean cultural competence, I don't think of just the language although that is very critical. It is the culture and deaf and hard of hearing community, our cultural competence needs to mean our medical providers speak ASL, can I say it that way?

Cultural competence that ASL is the language of our deaf and hard of hearing consumers and I'll give you one real example that cuts to the heart of this.

Recently we had one of our deaf and hard of hearing consumers part of our recovery learning community peer group. She's been one of our long-term consumers who has relied on many long-term supports and done very well living in the community; however, when an urgent medical need arose and needed to be sent and go to the hospital in our local Lawrence area, she goes to the hospital with our peer providers, peer support person from our community, our staff, peer

specialist who is there for hours in the medical emergency room with no interpreter services, no interpreter services and our IL specialist.

Our IL specialist comes back to the office and tries to reach the family members, gets the family member and calls the family member to help getting services and help for the consumer. By the time she called back to the hospital, guess what, the consumer wasn't there.

Where was the consumer? We didn't know, no one know, again, no interpreter services. The consumer ended up in a hospital on the South Shore, that's a long way from Lawrence I tell you. Talk about cultural competence.

On the South Shore and again, our IL specialist was the one that was there to happen and get the consumer united with her family.

That's one example of where cultural competence would have made the difference in a very hard and long journey for one of our consumers.

I'll give three bullet points, No. 1, Northeast Independent Program does support wholeheartedly all of the proposals, No. 2, I want

to stress cultural competence which is part of their principles, and No. 3, think about peers on the care team, not just to say it would be nice, no, peers must be on the care team.

As someone said earlier, help navigate and guide when even the most eloquent or most knowledgeable consumer needs that clear voice, and the last thing I would say is the consumer choice voluntary enrollment is important because this is the consumers network, beneficiaries' network so nicely described, not the provider net.

I'll pass this on to Kelly Ann from our recovery learning community.

MS. O'BRIEN: My name is Kelly Ann O'Brien and I work for the Northeast Living Program recovery living community where we are based at ILP and I moved to the Boston area a couple of years ago and come from and worked for the Department of Mental Health from a different state where managed care was the topic of conversation for a couple of years before it was actually implemented statewide.

And so, I come to you with I guess some lessons learned and just reiterating what, a lot

of what you've already heard today but primarily focusing on having an independent quality management organization that is outside, completely outside of the provider network, but in the hopes that quality is thought of up front, not as an afterthought or as where are you in need as an ombudsman or procedure or appeals process but where it's embedded into the services right from the start.

That was a hard lesson learned from people who actually, who were dual eligible in the state I came from who ended up using IL services more often than they had prior to that, so, that was just one lesson I learned being involved in that.

Also, consumer choice is important but why is it important? I think rather than just saying consumer choice, consumer choice, well, why is that so critical? Well, I come from the mental health world.

As they say, I'm a peer person with a diagnosis and I think without at least the thought you're making a personal choice, there is no possibility for recovery because until you can say

for yourself wow, I have this and that means this for me, not from a medical standpoint or a clinical standpoint but what does it mean for me and how does it impact my life, how does it limit my ability to do X, Y and Z, how does it perhaps enhance my other ability to do A, B and C, but until you can see for yourself as a consumer that the choices you make are your life, I mean choice and life kind of go together, without choice, you don't learn things and I think when we talk about creating an ICO or managed care organization on the state leaving for people who are dual eligible, we have to think up front about what quality means and I think we have to also put the question to ourselves, am I receiving quality services now rather than focusing on the mechanism of how things are going to come together, Medicaid and Medicare, what constitutes quality and that's where the consumer voice is pivotal. Thank you.

MS. CALLAHAN: Thank you. So, a little time check here, we have about fifteen minutes left and I've got sort of a lot of people left here, so. Lori Johnstone.

MS. JOHNSTONE: Hi, my name is Lori

Johnstone and I work at Northeast Living Center. I am an IL specialist for deaf and hard of hearing and consumer. For a long time we have struggled for deaf and hard of hearing people. It's been a long struggle.

Finally, we just became peer facilitators and we established a deaf and hard of hearing support group in Lawrence and we have two individuals who are here with us today who participate in that group. They love that group, it's enjoyable for them and they have a sense of belonging.

They're able to go there to ascend, to feel comfortable and belong, and so, please do not cut those services, support those services. There are other issues but I'm going to keep it short for today because I know you have a list but please do take into consideration deaf and hard of hearing services and what we need.

MS. CALLAHAN: Thank you so much. Nanette Goodwin.

MS. GOODWIN: I'll submit testimony.

MS. CALLAHAN: Thank you. William Sanabria.

MR. SANABRIA: Good afternoon everyone, my name is William Sanabria, I work at Northeast Independent Living. I'm also blind and also a dual. The reason why when, I lost everything, my independence, my freedom and I lost my health care, everything. It took me about a year to figure things out but now that I have the choice and I know what it means to regain my independence, I want to keep those choices.

I don't want to be pushed into something, you know, to go into a network that's already filled when I've already built my network around me.

So, I want to maintain that choice, I want to emphasize that, not only for me but for many other consumers out there.

Another one is it affects the quality of life, short-term and long-term. You have people that are dealing with disabilities transitioning into a disability.

The services come up short and nonexistent, and so, I just want you guys to please keep that in mind and have, you know, give people the choice and so they can have the options

to make those choices because it does affect the quality of their life so we can continue on to live well and also the access to information, trying to navigate to try to get information is like looking for a needle in a haystack.

It's not readily accessible. There's many problems with that and with a lack of access to that information, that means we're being restricted because we're not being informed, so, please, if you guys can work on that, not only for myself but many other individuals with all kinds of disability, not just blindness, because information is the key to everything. Thank you.

MS. CALLAHAN: Thank you. Jim Lyons.

MR. LYONS: Hi, good afternoon, I am Jim Lyons, I apologize, I'm Jim Lyons from Northeast Independent Living Program in Lawrence and I'm the community development and advocacy director and it's definitely getting late and most of what I prepared to say has already I think been presented very well.

I really enjoyed the testimonies from people this morning and there were some excellent ones.

I think that consumers such as myself and service providers are pretty well informed by the state at this point and to me looking back that says that we have a high level of transparency at this time and I thank the state for that.

We hope that continues because at some point in the past during the reorganizations of state government, reshuffling and so on of Medicaid, the transparency kind of went away in the past and what happened was basic end run was done on us folks with disabilities and we hope that doesn't happen and as has been said before, the woman from Mass. Law who said that we clearly need substantial accountability features built into this process and really one of them is ADA compliance and I think my colleagues, June Cowen and Kelly Ann, discussed really well and everybody about how sign language interpreters are needed as well as Americans with Disabilities Act compliance and certainly to give an example of cultural competency, we really need the independent living philosophy throughout this in my opinion and it's been discussed by William and just to give an example, I hope I don't hurt anyone's feelings but

when I came here this morning, I came with my colleagues from NILP, Northeast Independent Living Program, and I was with my colleague and friend William and the folks at the registration table asked if he wanted to speak and testify and if you asked me that question, I'll have to tell you you have to ask, I don't know, everybody wants different things and you have to ask people directly.

That's the safe thing to do because if you ask me, I'm going to try and educate you, so, thank you very much.

MS. CALLAHAN: Thank you. Jo Bower.

MS. BOWER: Hi, I'm Jo Bower, also with Northeast Independent Living Programs, Northeast Recovery and Learning Community and I'm only going to speak briefly about the importance of personal choice for people with disabilities, especially those with mental health conditions.

Many of us have searched long and hard to find providers who understand our unique needs and we'd be outraged not to mention poorly served if we were to lose access to the care we have sought for so long and often at great cost.

On another point, neither health insurance companies nor hospitals nor most groups have any expertise in judging the quality nor the efficacy of community programs.

This is one reason why an outside quality assurance party is needed to ensure high quality services in this demonstration. The insurance companies and medical groups 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.

Their worlds are far removed from the realm of community based care. Unfortunately, the insurance companies have generally biased their financial resources to the former and shortchanged the latter.

These efforts to expand the community system are only beginning to make headway. To make these fledgling gains hostage to the community would be terribly short cited and I really support the partnering that we see in the Boston Medical Group's pioneering efforts to partner medical care with independent living and I look forward to more work with them as they see

their practice expanding, expanding statewide.

I'm really excited to hear about that development. Thank you.

(The audience applauded.)

MS. CALLAHAN: Thank you. Robert Duff.

MR. DUFF: I'll pass for now.

MS. CALLAHAN: Okay. Al Knapp.

MR. KNAPP: Hi, I want to be very frank with you, my name is Al Knapp. As was mentioned, I am from NILP as well. I'm asking specifically and directly that there be no cuts to MassHealth or Medicare funds. Thank you very much for the opportunity to speak.

(The audience applauded.)

MS. CALLAHAN: Matt Pellegrino.

MR. PELLEGRINO: Hi, my name is Matt Pellegrino, advocate with Northeast Living Program, also dual eligible. I just want to talk about two examples of how I'm concerned the choice might be affected by this proposal.

One is with durable medical equipment vendors. In my twenty odd years of using a wheelchair, I've yet to find a vendor that

provides what I consider quality services but with the way it works now, I can at least see a vendor that I think is the least terrible.

I'm referring to the new proposal whether organized by area or some other criteria that my choices of vendors will be limited even more or worse, no choice whatsoever and I'll have to accept whatever vendor has a relationship with the ICO and my doctor's office.

Another example is with the doctors I choose to see even, I'm twenty-eight years old, I still see my specialist at Children's Hospital in Boston. I've seen my neurologist literally since I was diagnosed at two months and also see my lung function doctor there and heart specialist at Children's.

These doctors know me well, they know how my muscular dystrophy differs from other types of muscular dystrophy or even people with the same diagnosis as me.

I don't want my health insurance program to tell me, you know, well, Lahey Clinic in Burlington has a heart specialist and it's closer to you and so we think you should go there.

Consumer choice and control needs to be at the center of this new proposal, not service area, cost or any other factor that doesn't have the consumer's best health interest in minds. Thanks.

MS. CALLAHAN: Thank you.

(The audience applauded.)

MS. CALLAHAN: Sybil Feldman.

MS. FELDMAN: Hi (inaudible.)

MS. GRIFFIN: Do you want me to interpret? Okay, I'll try.

MS. FELDMAN: You know me.

MS. GRIFFIN: All right, I know you. Go ahead, start talking, Sybil.

MS. FELDMAN: I was born with cerebral palsy, I'm now seventy-one years old.

MS. GRIFFIN: Wow, I didn't know that, you look pretty good there, Sybil. You don't feel it, huh?

MS. FELDMAN: I have hip problems, a lot of pain, I need my medicine, my personal care.

MS. GRIFFIN: I need my Medicare and my Medicaid, I can't pay all my bills every month, I'm on a budget. I'm missing that.

MS. FELDMAN: I have help on Thursday, Friday and half the day on Saturday half the time.

MS. GRIFFIN: I'm missing the last part.

MS. FELDMAN: I have to pay for bills every month and it's going up. I can't afford that. I need Medicare and Medicaid to help me survive. Thank you very much.

MS. GRIFFIN: Thanks, Sybil.

(The audience applauded.)

MS. CALLAHAN: Thank you very much. So, here is the story, folks, our time is up and the MBTA has a meeting coming into this room at this time, so, I'm very sorry we don't have the luxury or the option of continuing the meeting longer.

It will not be the last time we meet. We will be working hard to consolidate your comments and appreciate it but also that you came down here. If you haven't had a chance to speak and please have written comments or anything that you can send us, we encourage that.

I'm going to ask folks to exit by the front door, the folks from the MBTA will probably be filing in from the back and we'll try to avoid a traffic jam in here. So, again, thank you very much.

(Whereupon, the hearing concluded at 1:00 p.m.)

C E R T I F I C A T E

COMMONWEALTH OF MASSACHUSETTS
SUFFOLK, SS.

I, Julie A. Healey, Certified Shorthand Reporter, Registered Professional Reporter, and Notary Public in and for the Commonwealth of Massachusetts, do hereby certify:

That the testimony that is hereinbefore set forth is a true and accurate record of my stenotype notes taken in the foregoing matter, to the best of my knowledge, skill and ability.

IN WITNESS WHEREOF, I have hereunto set my hand and Notarial Seal this 14th day of January, 2012.

Julie A. Healey
CSR, RPR
Notary Public

My Commission Expires: March 10, 2017