

Alzheimer's and Related Dementia Across Populations Plenary

September 2, 2015

MARTHA ROHERTY: Thank you for a moment of your attention. We want to ask us to join us in recognizing a second award winner. Those of you who were here yesterday were able to help us congratulate the Julie Beckett award winner, and that was outstanding! We have another award, though and that's the one I want to talk to you about today. We're going to tell you a little bit about this year's Arthur Fleming Award winner, who happens to be Senator Barbara Mikulski. Since 1978, NASUAD has chosen one person to receive the annual Arthur Fleming award. It has a rich history after years of public service, Dr. Flemming completed his tenure as the U.S. Commissioner on Aging in 1978 and joined NASUAD each year after that until his death in 1996 to present the award. He once said, "for far too many people, old age means inadequate income, poor or marginal health, improper housing, isolation from family and friends, and discouragement of being shunned from the mainstream of life."

The core of what is now commonly called the National Aging Network consists of state units on aging, sub state area agencies on aging, and thousands of service providers--all of which grew out of his leadership. He was involved in the planning of the very first White House Conference on Aging, in 1971, and fought throughout his career for the dignity and rights of older adults as well as justice for all persons.

Annually, the NASUAD membership chooses a notable leader whose work has had a positive impact on the lives of our nation's elders. This year NASUAD has chosen Senator Barbara to receive the 2015 Arthur Fleming award, yes, a round of applause, please. Let me tell you a little bit about Senator Mikulski. She served in the U.S. Congress for nearly four decades. In 1967, she won a seat in the U.S. House of Representatives and 10 years later became the first female Democrat to win an election to the senate. She is currently the longest-serving woman

senator in U.S. history. In 2012, she became the first woman and first majority leader to chair the Senate Appropriations Committee on which she served since she arrived in the Senate in 1967. She supports and encourages innovation and research evidenced by her many years as a Chairwoman for the Subcommittee on Commerce, Justice and Science. For the elderly, she authored the Anti-impoerishment Act for Nursing Home Care for Spouses. She is also the dean of women. Earlier this year, she announced that she will retire in 2017. So unfortunately due to her schedule she was unable to join us today however, we will be honoring her as an associate and later this fall we will present her award there on Capital Hill. But again, we just wanted to make sure you aware of our second award winner this year, We are so glad that we could honor her with the 2015 Arthur Fleming Award. And with that, a break, you may continue eating your sandwich and we'll meet back here in about 10 minutes or so, we're going to start with Dr. Petersen, thank you very much for your time and attention.

(Captioner standing by.)

JAY BULOT: Well hello again everyone. Hello hello. Go ahead and find a seat if you would, we're going to now start our next plenary session. I know a few of you have commented on how chilly in here it is. I'm actually pinch hitting and I know you'll be disappointed but I'm pinch hitting for Gary Jessee. Who does not love it when Gary picks up a microphone? but Gary is tied up, so my duty is to quickly and quite joyfully recognize some more of our sponsors, I know you were here yesterday when Gary recognized the first half of sponsors, so if you will bear with me, we want to recognize the very gratefully accepted support. You can find the listing of our sponsors on pages 6 and 7 of our program, so if you would as the day progresses and you see some of our sponsors please join me in telling them thank you, you know this conference would not be what it is without them. Thank you to Kindred at Home, Health: ELT, Loopback Analytics, LG CNS, Outreach Health Services, Pfizer Consulting Group, and Caregiver at Home.

Moving on to our Ruby sponsors: Acces\$, Beacon Health Options, Consumer Direct, Deloitte, Health Management Associates, Independent Living Systems, LeFleur Transportation, Maximus, Mom's Meals, NourishCare, Myers and Stauffer, Phillips Lifeline, Pharma, and SEIU.

[Applause]

And then finally recognition, of our Gold sponsors: Magellan, Complete Care, Marwood Group, Sellers Dorsey, SharedHealth, WellCare Health Plans and Wells Fargo Advisors. A round of applause for our gold sponsors.

[Applause]

JAY BULOT: And while you're hands are now warmed up, a robust round of applause for our Executive Director who is going to come up and introduce our speaker, Dr. Petersen, a round of applause for Martha.

MARTHA ROHERTY: I'm sorry, it took me so long to get up there. So a funny thing happened, you know, I told you that the staff puts on conferences and sometimes states hire us to actually put on their state aging conferences. And a year ago, the state of Hawaii hired us to do a HCBS conference in Hawaii, in December, okay? December in Hawaii, and they gave us a budget to fly everybody over to give presentations and so I invited Dr. Petersen to come over and do a plenary session in Hawaii and in 10 seconds of sending the email, the answer was yes. So it's August, early September in D.C., crickets, no response my invitation in the beginning! I don't blame you, but I do think it's a little ironic. Anyway we're really excited that Dr. Petersen is here. He is a professor of neurology and Alzheimer's research at the Mayo Clinic and he's a distinguished investigator on the board of directors for the National Alzheimer's Association. He's the chair of the Advisory Council on Research Care and Services for the National Alzheimer's Project Act and is on the World Dementia Council. He's the recipient of the 2004 Met Life Award for medical research in Alzheimer's disease, the 2005 Potamkin Prize for

Alzheimer's and related disorders of the American Academy of neurology, he's published over 800 peer reviewed papers and edited 5 books on aging, mild cognitive impairment and Alzheimer's disease. Please join me in welcoming Dr. Petersen.

[Applause]

DR. RON PETERSEN: Boy boy, that makes me sound cheap, doesn't it, a guy from Minnesota who flies in to Hawaii in December but won't come here in the first of September. Martha's pegged me correctly, though, that's the kind of guy I am, so I have to own up to that. Thanks very much Martha for the invitation to participate in this meeting and I must also give thanks to Jane Kelly from ACL who prompted me to come and provided a good deal of the information that I'll be sharing with you today.

I think this is a good opportunity to share with you some information that we live in day in/day out with aging cognitive function and the like. We hear so much about Alzheimer's disease these days, appropriately, but at the end of the day not everybody's headed for Alzheimer's disease so I'll try to put that in a little perspective this afternoon.

On the other hand, it's right after lunch, and if you guys want to take a little snooze, I understand, I mean, you know, although it's chilly in here so you've got to be careful not to doze off for too long, but I won't be offended if you doze off a bit. This is what we're going to talk about, dementia, cognitive aging, and some services that may be relevant for you. These are financial disclosures I put these up all the time. They are not relevant except to say on the bottom there are a bunch of grants from the National Institutes of Health and National Institute on Aging to support our research and then I work were with a variety of companies trying to develop better therapeutic trials for Alzheimer's disease.

So this is where we're going this afternoon, I'm going to talk a little bit about Alzheimer's disease, and then spin it over to cognitive aging, and end up with services and things that may be

of the most importance to you. I'll say at the outset that all of these slides and materials, there will be a bunch of websites on the later slides and those are all available on the website so you can download any of that and use it as you will.

So what are we talking about? Simply, what's dementia, dementia means I'm not thinking as well as I used to, not remembering as well as I used to and that's interfering with my daily function. So whatever your daily function is I'm not doing it quite as well, because my thinking skills are off. It's not my heart disease, it's not my diabetes out of control, it's not my high blood pressure, but it's my thinking skills that compromise my daily living that's the ballpark, if you keep in mind that's what we're talking about. But then what is dementia versus Alzheimer's disease, well, it turns out dementia is sort of the umbrella term as I just described but there are a whole bunch of causes of that dementia. Now, the yellow chunk in this pie diagram is Alzheimer's disease acknowledge them up at the top there you have Alzheimer's disease and vascular dementia, at the bottom, you have Alzheimer's with kind of Parkinson's. You can see Alzheimer's disease is the elephant in the room, but in aging, Alzheimer's is up and away the biggest cause, it's a form of dementia. Common question, what's the difference between dementia and Alzheimer's disease? Dementia is the overarching term and Alzheimer's disease is one form of dementia, albeit, the most common form, especially in aging.

A few years ago the National Institute on Aging and the Alzheimer's Association got together to kind of redefine the criteria for Alzheimer's disease because they hadn't been updated in like 25 years. A series of papers came out with the indication that gee, we know so much more about the biology of the disease now, shouldn't we incorporate that into making the diagnosis? So here's a typical diagram that describes where it is we are in the field with regard to understanding Alzheimer's disease as one of the forms of dementia. On the up and down axis there, we have normal at the bottom, we have abnormal at the top. On the bottom axis we have

cognitive aging, normal cognition, going into MCI, which is mild cognitive impairments, memory impairment, not yet dementia, and then finally we have the dementia stage of these disorders. I want go into detail but there's a variety of curves now that evolve over this landscape. The curves on the left-hand side are sort of a biologic underpinning, it's what's happening in the brain years before people become impaired with symptoms. The right-hand curves are now we're getting forgetful, now we're developing the full dementia syndrome. We've learned so much more about the left-hand part of this curve now that we can make this call much easier and earlier than we formally did. In fact, data from Australia and this country as well, have shown that biologic underpinning for Alzheimer's disease may begin 15, 20 years before people become symptomatic, so before they become forgetful, the substrate is being laid down in the brain. It's like you are getting hardening of the arteries before you get chest pain, the same analogy, the biologic buildup happens years before. The good news is that gives us a 10 to 15, 20 year window to do something about the disease process before people become systematic so that's kind of the thread of the thinking that's going on in the field right now. So this leads to the notion of biomarkers meaning biological indices in the blood, spinal fluid in the brain that are telling us this process is building up, so we have early biomarker, the left-hand curves on that other diagram, we have later biomarkers, sort of the middle curve there.

So what's become a very important part of making the diagnosis and understanding Alzheimer's disease as it evolves are neuro-imaging studies, there are generally 2 or 3 types, structural scan, I mean, what does the brain look like, functional scans meaning what's the brain doing, and then molecular scans meaning-- what's inside the cells in the brain that are the causing the dysfunction, so let's look at these very quickly.

Structural imaging, many of you know about MRI scans, this is a MRI scan. Looking at the person in front on it's like the person is looking at you. The gray stuff there is the brain. The

black stuff, water spaces or spinal fluid spaces that occur normally in the brain but they tend to expand as the brain shrinks, the water spaces increase. So on the left-hand picture there, we have a 70-year-old woman functioning just fine, brain is intact, in the middle skin' scan there, a memory impairment, 72 years of age and you'll note that the water spaces are looking larger now and in the middle bottom part there, I don't have a pointer here, but the middle bottom part there is a memory structure and that's tending to shrink. On the right-hand side, we see the fully developed Alzheimer's disease, dementia. The water spaces are much bigger, because the brain is shrinking. So the nerve cells are dying out it turns out the nerve cells in the memory part go first and nerve cells elsewhere go later. This is not specific for Alzheimer's but very consistent and if we -- oh, you know what, gentleman in the back if you have a cursor, could you ding the bottom of this to see if we can rotate, go down, now start the video.

So there, perfect! So this is -- and we'll do it again so we can set this up. This is a brain, so the left side of the brain and on the left side there, we'll look at the front of the brain, the back of the brain, the red/yellow parts mean those parts of the brain are shrinking earlier than the other part, so this is a depiction that Alzheimer's disease doesn't attack the brain everywhere at the same time but certain structures get involved earlier than others we have a couple more of these later.

So functional imaging, now we can look at the brain and say what's that part of the brain doing? So is the memory part of the brain working? Is the language part of the brain working? And with these color maps we can get very good depictions as to what's going on and we can even get fancy and put numbers on it. Say this part of the brain is functioning normally, this part of the brain is not, same thing here. This is the color part of the brain now that's involved with functional, the color part implies that part of the brain is not functioning well, the inside of the brain here, frontal part of the brain, back part of the brain, very informative but very different

pattern than the shrinkage part and now we do the type of imaging that allows us to look inside the brain cells so here we're looking at cross-sectional scans of the brain. It is a normal person on the left, memory impaired in the middle, Alzheimer's disease dementia on the right and to the extent the scan shows redness, it means that that person has one of the hallmarks of Alzheimer's disease in the brain. So we can tell this in somebodies who 20, 30, 40, 50, 60, and we can see that they're on the road to developing Alzheimer's disease by the pattern on these particular scans. Once again, one more time here, again, now here we see the pattern of the amyloid deposition or this protein, we can spin this brain around, too, this is a more widespread now picture of the deposition of this abnormal protein in the brain. Here it is on the inside of the brain, you see it on the front, and the side. Great, thanks for helping out with that.

So these scans we all put together and the newest kid on the block is another type of scan that looks at another protein in the brain. Alzheimer's disease may have a plaque in tangled disease, when the person passes away we look at the plaque made of amyloid protein and we look for tangles made of the tau protein, a tau scan. The previous one was an amyloid scan, so we can now visualize the two primary causal agents Alzheimer's disease in life early on and that's a major advance for us in terms of understanding the disease.

Now, where we need go of course is link that to therapy and so when you hear about the new drugs that are being developed and new antibodies and new vaccines they're aimed at these very targets in the brain. Because we can now measure how much is there at the beginning of treatment, how much is there at the end of treatment, and determine whether in fact the drug, the vaccine, the amyloid antibody is working or not by measuring it. So we've made great advances and hopefully, therapies are on the horizon.

The other thing when you think about Alzheimer's disease you think someone who is memory impaired, thinking impaired, maybe can't drive any more, that's the person in the bottom

right-hand corner, dementia due to Alzheimer's disease. But as you have just seen, we can pick up the disease now at the MCI, mild cognitive impairment stage, and in the upper left preclinical Alzheimer's disease, again people who are normal but who have the biologic characteristics, so we've expanded the whole spectrum now of what we call Alzheimer's disease to cover people with symptoms and people without symptoms.

So you know all these numbers I won't go over them, but this is a big deal. This is a common problem in aging in this country over 5 million people in this country, 10 to 15 million caregivers, 2 to 3 caregivers for each person, and the numbers will triple by 2050. Then you expand these to the global projections and it becomes absolutely staggering. I won't bother you with the numbers and the dollars figures, but you know they are very, very significant. But the good news is not everybody develops Alzheimer's disease. Some let's turn to the notion then in cognitive aging. Underpinning this is what is normal aging, which sounds like a simple question, but in fact is really quite complex. This is a depiction I use to characterize aging and cognition. Blue lines at the top are the few very few people who really age successfully with no real cognitive impairment over time. The green line is the vast majority of us out there, that is people who are aging typically, meaning I'm not quite as quick as I used to be, I'm having trouble coming up with names of people, cognitive flexibility, how many balls can I keep in the air at one time, that tends to diminish with time, but basically I'm doing okay, I'm getting by, paying the bills, doing taxes, driving, everything is okay. The red line of course is problematic. What we just talked about in the previous set, mild cognitive impairment and dementia but differentiating among those three curves is not trivial, especially the green and red, you know, so how much forgetfulness is too much, at what point does that forgetfulness that you and I have in the grocery store when we unexpectedly run into a guy we used to work with 6 months ago and can't come up with his name, is that sort of the green line or is that the very, very early red line? And the

answer to that is I don't know, maybe, I don't know, you know, and that's the scientific answer. I'm not sure. Call me tomorrow. But these markers that I've outlined earlier are helping source if you've got somebody with a bit of forgetfulness that you're worried about and you do some of those imaging scans and if any of those are positive it doesn't mean you make the diagnosis but you're much more suspicious that that person may be on the unfavorable trajectory there of the red line.

With some of that in mind, the Institute of Medicine paneled a group of experts a year or so ago to look at the issue of cognitive aging, that is not disease but cognitive aging. And this group really tackled a tough question and the tough question is: What is cognitive aging? And they said okay it's Alzheimer's disease or mild cognitive impairment, it's what you and I experience as we age, what are the definition, what are the boundaries, how much is out there? How did we measure it? And what do we do about it? How can we educate people about what cognitive aging is? So what is it? Again, cognition as we outlined earlier are sort of those functions of think, remembering, problem solving, et cetera, cognitive aging is the notion that these change over time, they're quite variable for a variety of reasons: our genetic makeup, oration, et cetera. All of these things can show it's not a disease itself but it continues to change over time and at the same time there's the notion of cognitive health, that is what can we maximize here and how can people in fact enjoy some changes with aging but really maximize the benefit of aging and what we acquire with aging, the nebulous concept of wisdom, what does that mean. I think we all agree that there's sort of wisdom that accumulates over time, that a 65-year-old has things that the 25-year-old may not have, how you measure that and what it means is different, but I think it's a real entity, and we need to recognize that.

So here's a depiction of what is happening with aging, the proportion of people who are 65 and older, the blue bars of the absolute number of people who are becoming 65, 65 and older.

The red line means what proportion of the total population, you can see that's going up. So older people are increasing in the absolute and in the relative proportion of our population. So what do we do about that? It's sort of inherent in aging, everybody is going to age, it changes and it's difficult with regard to an individual over time and it's difficult from individuals to individuals. The variability is significant, and we don't really understand it, to be honest I mean, I think the IOM group did a superb job, but they dodged the issue of what is it. Is it maybe a subclinical disease of one kind or another that's gradually accumulating over time? It's not but say it were vascular disease, say it were the little blood vessels in the brain were starting to close off and were losing cognitive functions. Because of that, that's not the answer but it could be something like that, it could be maybe the mitochondria in the cells of the brain, the mitochondria you remember from science class are the power houses the energy stores of the brains and the cells, maybe those are kind of diminishing over time and dying out and we just don't function properly maybe. But the point being is that we really don't understand the true underlying biology of this. But at the same time, it's so common, happens to virtually everybody, we don't think it's a disease process as we understand it today.

To deviate to one of our own studies up in Minnesota we're doing up in Minnesota to say how common is it for people's recognition regarding age. We're doing a study up there where we randomly sample, we've seen over 5,000 people in our community ages 50 and older, and not demented people, so people who are normal or have a little bit of memory impairment. We bring them in, see them every year and we follow them through and do a bunch of that biomarker stuff because we can do it, we have all that imaging technology so we in fact do that on many, many of these people as they're aging normally. But we also ask them how's memory, how is it compared to what it used to be 3 years ago, 5 years ago and they told us this the dark orange bar on the left are the people that said you know it's fine, I don't notice any change in my memory

and thinking over the years. The yellow bars are gray to not quite what it used to be, most of it is mild, the yellow gray bars are saying it's a little off not quite what it used to be, the bars to the right indicate not really a big deal, it's a big probe so that's not as big. Yet when you look at the numbers it turns out that's something like 79, almost 79%, almost 4 out of 5 people say not what it used to be. My memory has changed so something's going on. We actually took this and said okay, does this mean anything or is this just everybody complaining and we asked the folks how's your memory? We followed them over years to see if they would develop mild cognitive impairment which is thought to be the earliest stage of a dementia process, and basically that just says after you look at things like sex, education, depression, anxiety, a genetic characteristic of Alzheimer's disease, your memory function, your attention, and the bottom thing says how many medical illnesses do you have, you have diabetes, do you have heart disease and all that kind of stuff, it absolutely accounts for all of that. If we take every single stake into account what the person said about their concern about memory, it turned out that that predicted their likelihood of developing mild cognitive impairment in the future so they're telling us something that's real even if you control for all of those factors. So it's a big deal and we don't ignore it when people are getting concerned. Now again it's very common, 4 out of 5 people say "I'm not what I used to be." And here are some data from our project as well, and we're quoted by the IOM saying basically these curves are global cognitive function, the top curve were people who stayed normal for 4, 5, 6 years, the bottom red curve are people who started out normal and then progressed on to cognitive impairment of one degree or another. The point being that cognitive function does decline with aging regardless of how you measure it, it varies with regard to what cognitive function you're talking about but they do decline with age.

So it depends on how you spin it, I think the report struck a nice medium. Yeah it's real but it doesn't have to be a negative message, there are positive aspects of aging with regard to

cognition and again it happens throughout the lifespan and is very individual. But there are activities in which you and I engage in that will actually stall some of the progression. Does it prevent Alzheimer's disease? I don't think so, I don't think we have data that really says if you do this, if you live and do so many cross word puzzles or if you do Sudoku or you do another type of brain game that you won't develop Alzheimer's yet, I don't think we know that but in fact those activities may be somewhat protective at delaying onset and slowing progression.

So from the Iowa Farm Report, I'm going to go over these fairly quickly but they had several salient recommendations we need to incorporate into our planning perhaps going to forward increased research and tools for assessing cognitive aging and cognitive trajectories so we need to be more fine grained with regard to how we measure these cognitive abilities and the course of them. Collect and disseminate population-based data, again, yes, we can get information from universities and medical centers, valuable information, but does that apply to the general population, so we need to do population-based studies with actual samples of people from the general community.

Take actions to reduce risks of cognitive decline in age we do know some risk factor, we do know factors that may in fact contribute to cognitive decline, we need to counsel people on that '.

Increase research on risk and protective factors so instead of just focusing on everything is going to be Alzheimer's disease down the road what can we do to protect our cognitive function? To maintain our cognitive facility over time, we need more research in depth.

Ensure appropriate review, policies, guidelines for products that affect cognitive function and make these outrageous claims. I do some work with the Federal Trade Commission on exactly this. That is there are these products on the market that if you take my pill, it will forestall your cognitive aging, it will improve your memory, most of these are bogus and the

Federal Trade Commission of course is responsible for policing these and pulling them after the market if in fact they are not found to be credible. But it's different than the way the FDA approaches this, the FDA takes the approach that you have to show me before your product gets put on the market, for these non-pharmaceutical regulated compounds, that's not the case, they can put everybody out there but then it's up to the FCC and other agencies to police them and pull them off the market so you have to be careful when you read about these. In fairness to the general public, most of these are not well-documented at all so you have to be very mindful of that.

Develop and implement core competencies and curricula, so I think we need to improve our educational curricula for medical students, nursing, healthcare providers in general with regard to what is cognitive aging what do we expect and what we've shouldn't expect. Along that line, the GSA, impaneled a group of people a couple of years ago to look at what instruments are out there to help the primary care physician to assess cognitive function in the office now that a cognitive assessment in some fashion is part of the Medicare annual wellness routine. So in addition to your blood pressure and blood glucose, they should be looking at your cognitive function as well. That's great, but how do you do it? So the GSA set out to say how can we help the primary care physician? So they did a survey of instruments that are out there, and recall in the process of making some recommendations to help the primary care person. But the point is this is a big step, this is now into the evaluation of people as they age.

Promote cognitive health and wellness at medical visits talk about it, so not only, understanding you've got to exercise, you have to keep your blood sugar down, you shouldn't smoke but what can you do about cognitive health because that's an important aspect of aging as well.

Develop consumer product evaluation criteria and an independent information gateway.

So educate people, allow people to go online to whatever resource they use to try to help them understand what is appropriate and what is inappropriate, expand services related to cognitive health, again, not disease, but cognitive health. We should also expand public communication efforts and promote key messages and action. This about education, getting the information out there. And I must say I think there are several aspects and I'll get to this in just a moment that the federal government is in fact going to get this information out.

So let's turn to the last aspect of the discussion this afternoon with regard to the national plan to address Alzheimer's disease and most importantly, what long-term services and supports are out there. So we've gone through this, cognitive disability among adults what are we talking about? Turns out this is not an uncommon problem so depending on the age, the proportion of the population has some kind of cognitive disability, it's not trivial, and in fact, needs to be recognized as a part of general aging services that not everybody in the population is able to take advantage of this in the same fashion.

So while the majority of people are aging well, it's true that when you're dealing with people who are involved with your services, up to 40% of them have a cognitive disability and up to 50% or more in a variety of care facilities have cognitive impairments. So individuals who require the services that you provide often have some degree of cognitive impairment and that needs to be factored into the overall picture.

So key goals related to cognition for Medicaid beneficiaries promote brain health and maintenance of cognitive abilities across the lifespan and ensure that health and long-term services and supports are dementia capable. We'll get to that in just a moment. There's a movement underway in some states and across the country with regard to dementia awareness, dementia capability and dementia competence in dealing with individuals.

So I mentioned the National Alzheimer's Plan that was signed into law by President

Obama in 2011 and it charged the Secretary of Health and Human Services at that time, Kathleen, with the responsibility of developing the first plan to address Alzheimer's disease in this country. Five goals came out of that plan, listed here the first one is the major one, prevent this disease by 2025. So the plans charged the Secretary with developing the first version which was published in 2012 and updating it annually through to 2025 and by 2025 hoping to make significant progress toward this disease.

2, 4 and 5 then deal with issues of clinical care, service, public awareness and how we're going to measure whether, in fact, we're making progress. Goal number 4, increase awareness and engagement, the brain health as you age has been an important step in the direction of educating people as to what's available, what is healthy age, what is impaired aging and what we can do about it. So ACL and Administration on Aging are, in fact, actively involved in preparing materials and providing options for people with regard to addressing these issues. This is the website again, all of these slides will be available on the website of this particular meeting and this one is particularly informative with regard to much of the material I'm talking about this afternoon, how this information is available to you. So for example, there's the educator guide, this contains slides for a presentation designed to help you discuss these issues with older adults and their caregivers. It tells you what you need to know when and what wishes need to be discussed with them. One important talking point with regard to the various issues we've been talking about this afternoon. The slide presentation, 30 minutes in length it's fairly self-explanatory but all of the materials are there to help you, in fact, discussed these issues in an informed fashion, give the details and some important information on aging, health, normal aging, what's normal, what's abnormal, what can we do about it, what reliable information is out there.

Again, materials for older adults, all available for you that I trust you will avail yourself

of these opportunities. Here's the website again and this is a work in progress, so while these materials are available now and very useful, there will be increasing information available going forward and it's worthwhile keeping in mind because it may be useful in your particular circumstance, or your particular situation.

So let me go back then to the plan on goals 2 and 3, several items here, I'm going through these rather quickly but they're important with regard to improved care and support services that should be available. Here, number one, educate the public. Again, variety of information, sources there of information, URLs that you can use to help you see what the government is doing, some of these are NAH based and have important information regarding brain health.

Number 2, identify people with possible dementia, so keeping your antennae up for the very early signs of cognitive impairment. As we discussed earlier some of these quite subtle signs, some can be normal aging. He's 82, what do you expect, some things are to be expected for a 82-year-old, some things are not to be expected for a 82-year-old, so having those up and at the same time not going overboard in every little instance of forgetfulness is early Alzheimer's disease not necessarily the case at all but these materials will help you differentiate those subtle nuances.

Number 3 ensure appropriate eligibility and resource allocation. So this is important. Who is eligible and who may or may not be aware of that and again, this is an important function that you can serve with regard to your constituents. Provide person and family-centered services so it always comes down to yeah, what are you going to do for me and I think there are some significant options here identifying individuality and how you can in fact support them and I think the more you're able to do this on a one-on-one basis, the more it will be appreciated by them and useful for them again. Several sources of information there.

Educate workers, so this is important as society ages and as the numbers of individuals

who are sort of at risk of developing cognitive impairment increases. The baby boomers are turning age 65 at 10,000 persons a day. You can see the balloon is upon us now and is going to be increasing such that these individuals who are at risk, doesn't mean they all have cognitive impairment or dementia but they're at risk and it's important for us to be able to educate the people around us, the people with whom they will be interfacing as to what's appropriate and what is not appropriate.

Assure quality, again, this is not just an exercise of going out and putting a bunch of materials on a table and trying to tell people what we should and shouldn't be doing, but in fact, we have to put out reliable, valid information. We need to provide them with information that is, in fact, useful for them and at the same time is evidence-based.

Dementia friendly communities is something that's near and dear to my heart, I didn't have anything to do with it, but there was a movement that grew out of Minnesota to develop dementia friendly communities and the state of Minnesota developed a state plan for dementia and Alzheimer's disease around 2011 or so. And again they, like many states, came out with a very nice publication, a white paper saying what we need to be aware of in the state of Minnesota, blah blah blah, and then there was no funding, of course, so, okay, great now what do you do? But in fact, a group of people took on the charge of what the state plan suggested and really took it to heart, developed a volunteer group of individuals, got some of support from a variety of private sources around the state, and developed this concept of dementia-friendly communities. This information is all available on the website, the website there is actually on ALZ.org and all the materials are downloadable. They want them disseminated as broadly as possible because what they also have done is undertaken several steps at developing procedures, information for making dementia friendly communities, to see when you go into the bank, the grocery store or you're visited at home by some service provider that is knowledgeable about

what generally speaking, dementia, cognitive impairment might be and can act appropriately in those situations and if they detect some kind of problem—how to deal with it respectfully. But it's a great program, developed in Minnesota, it's been adopted all over by other states and the plans have suggested including some aspects of this into dementia-friendly America as it is called as it gets expanded to the entire country.

So let me wrap up then by saying that the national plan really provides a variety of opportunities and resources for individuals to take this information to help you function, to provide your services, to provide education for you and your colleagues with regard to degrees of cognitive impairment. There are many, many tools out there available, again, I mentioned Jane Tilly from ACL earlier in the discussion this afternoon, and she and her team have been particularly active in generating and providing these tools that are out there. You don't have to start over, you don't have to reinvent the wheel, but these materials are available to you to use as you see fit.

So let me stop and again, thanks for inviting me to Washington at the end of August, beginning of September and to the 90+ degree weather, it's actually the same up in Minnesota, we're dealing with 90-degree weather as well so it's just fine, thanks again very much and I hope this has been useful to you.

[Applause]

MARTHA ROHERTY: There's another part of our session, we're going to have some consumers come up and share with us some of their thoughts about what their identities are like being a caregiver for somebody with Alzheimer's. I wanted to make one quick plug before we do that. There is a movie screening because you have to have social entertainment in all evening events at NASUAD, so tonight is the Glen Campbell movie screen, you all got a ticket in your bag when you checked in and we hope you will join us. It's going to be shown back in here this

evening and there may even be popcorn, I think it starts at 8:00 back here.

I want to just share with you that what Dr. Petersen was talking about really resonated with me in terms of the science of Alzheimer's. Many of you know that in November of 2011, we shared with the public that my husband was diagnosed with early onset Alzheimer's. The floor neurologist thought it was most likely due to the number of concussions that Brian had in life but we're never going to know for sure. He was really active in public policy and state financing and together we made the decision to be very public with his diagnosis. Brian's here with me today, he's been here all week, and I want to publicly tell him how much I love him, and I value his support he's given me throughout all the years. There have been a lot of challenges in coping with the illness and while I'd like that say that I'm the perfect wife, the truth is at best I'm an impatient caregiver and partner. During one of the most difficult periods it was recommended to me that I call the Alzheimer's association hotline and ask for help. I didn't think I needed help. Hell, I'm the executive director of an aging organization, I know everything about Alzheimer's. I'm a nursing school dropout and I studied all of the brain chemistry, I know it all! I know a lot about the medical side of the disease. A lot more than a lot of the first-year medical students but what I didn't know was how difficult it was going to be to cope with the various significant changes that occur in our relationship, and our relationship with our kids, in our relationship with each other, and my relationship with my work colleagues. So after two years of coping with a lot of salty food, reality television, and wine, a friend said get on the phone to the Alzheimer's Association. And I remember doing it, and sitting in a parking lot the first time I called, I poured my heart out and they gave me some really, really great help and advice. I urge you all to use them, and now it's my pleasure to introduce Randi Chapman of the Alzheimer's Association who is going to take it away for the next panel.

[Applause]

RANDI CHAPMAN: So thank you, Martha, thank you Brian, thank you to all of you for everything that you do every day. I just appreciate it and on behalf of those that we serve with the Alzheimer's Association, I know all of our constituents appreciate what you do. Again, thank you Martha and Brian again for your bravery and courage. It takes a lot to stand up here and talk about real life and what it's really like to live with this disease, so I appreciate that.

So Mary and Karlene, if you all would come on out, so in this portion of our talk today, you will hear from two women that I've had a chance to get to know over the last couple of day whose are absolutely extraordinary, and have wonderful stories to tell, so I'm going to sit down there and get off this podium and we'll hear from Mary Hogan and Karlene Ellsworth.

RANDI CHAPMAN: Okay, good. Sounds like it. So just to give you all something information about our panelist today, Karlene Ellsworth, there to my right is a retired executive, she's been living with multiple sclerosis and is the primary care partner for her husband John who is here today and thank you John for your support. Excuse me. He has been diagnosed with mild cognitive impairment due to Alzheimer's in 2013. 6 years prior to his diagnosis, the couple decided to move into a continuing care retirement community for Karlene's need for support. So Oscar said last night, I guess John got tired of being a caregiver and decided that he would outdo her needing to have a care partner so they have been living there in the CRCC together and taking this journey together. Karlene wants to encourage everyone to pursue every path and opportunity to bring life, joy, and good old fashioned fun into your lives so thank you Karlene. Mary was the primary advocate for her brother Bill who was born with Down's Syndrome and at age 46 Bill was diagnosed with the younger onset Alzheimer's disease. Mary is a special education teacher by training, so she is certainly no stranger to advocating for the rights of those who are experiencing disabilities. She advocated for Bill throughout his life as the third sibling of nine. She's number 3 and Bill was number two. She was the sister and helped him as a

primary caregiver and advocate. After Bill passed away she continued her advocacy work, she currently serves on the Steering Committee on Intellectual Disabilities and Dementia Practices known as NPG, this is an organization that's working to develop an early detection screening tool for dementia and best practices guidelines and staff module, also for the intellectual disability community.

She is also a contributing author of Aging and Down's syndrome, a health and well-being guide book resource which is available through the National Down's Syndrome Society. We also have some copies just in the back by the door, we have a few copies, we don't have a thousand, but there is a sign-up sheet back there so if we are out and you're interested in receiving those please feel free to send in your name and email address and we'll make sure that you get those.

So both of you bring a really unique perspective to the conversation on Alzheimer's disease and it's the intersection between Alzheimer's and Intellectual and other disabilities, and so I want to talk of course about some of the challenges that you all have faced in dealing with that. Mary I'll start with you, of course you've been an advocate and a champion most of your adult life and caring for your brother, what would you say are some of the unique challenges, though, that you face as a caregiver and as an advocate dealing with your brother who had not only intellectual challenges but also cognitive impairment due to Alzheimer's?

MARY HOGAN: Well, I think one of the biggest challenges that we faced was understanding aging for people with an intellectual disability. As Dr. Petersen mentioned, that age is sort of a phenomenon that has, you know, different features for different groups of people, and when one has an intellectual disability, it changes with aging, and they're sometimes discrete and very hard to ascertain what is normal aging for the person and what is abnormal aging for that person – or group of people. People with Down's Syndrome are predisposed to early onset dementia and for us we were aware of that and it was at that time -- the opinion was that everybody with Down's

Syndrome would develop Alzheimer's disease and that indeed is a fallacy that that won't happen. But in our case, my brother did develop Alzheimer's disease and I think it took us a long time to understand what those changes looked like. We didn't connect the dots to know that we were facing a change and we didn't have access to a medical community that understood the discrete changes. The diagnosis came and proceeded to shape our lives after the diagnosis was made. I want to add that, what I experienced or what we experienced, I think is typical of what families across the nation are experiencing around the disability and aging and the unfortunate diagnosis, but many of our family members have very enriched lives and enriched our lives, so that kind of a diagnosis is catastrophic to our families as well as the families in the general population.

RANDI CHAPMAN: Thank you for that. I know one thing you mentioned is the challenge in trying to find the right information and get the care and support you needed as a caregiver and of course inform your family as to what to expect and how to best help Bill as he traveled with this disease. I know that was a challenge.

MARY HOGAN: Right, it was an enormous challenge for us, you know, we had to take some time and distance between living the experience and being here with you today, I think at the time that we were experiencing this, there was not a lot of information for families, it was a topic that wasn't readily talked about, and I think in the course of the last five years, we've made a lot of progress in that regard. But I do think that in our case, we experienced an accelerated end of life and I don't know whether that was because we didn't make the diagnosis in a timely fashion or whether my brother, like some other people with Downs syndrome experienced an accelerated end of life as their disease progresses more rapidly. I think there's a lot of debate about that but for us the end of life was a rapid 15-month period where my brother was no longer able to walk, talk, feed himself, and I felt like we are in a time warp and we couldn't understand what was happening to us. We had few resources to help us understand what it was we were experiencing.

And I think that that's probably very typical of many families that have a diagnosis with their family member that has an unintellectual disability, and there are other forms of dementia but I think the important thing to remember is not all people with Down's Syndrome will develop it but they're looking for biomarkers. There is lots of research on bio markers taking place, there's lots of exploration of the kinds of tools that you would use to develop baseline information and how you would proceed with following a person along over time in order to reach the conclusion that it is, indeed a genetic -- one of the forms of dementia.

RANDI CHAPMAN: Thank you for that. Karlene, I want to turn to you. Now you have managed a debilitating and progressive disease most of your adult life, again, you and John had planned ahead and thought you know here's how we're going to go to this retirement community and have access to care, and then soon thereafter, you find out that the John has this diagnosis. How did you process that? How did you deal with that? And as I asked Mary, what are some of the unique challenges that you all have faced?

KARLENE ELLSWORTH: Yeah, I think John and I are particularly blessed. As you have just said I have been fighting MS for more than 20 years. We made the choice, our house had been completely renovated it was made totally accessible, but the choice was made to move early into a facility where I knew that care would be available if and when a development would come where I needed that. So we made that decision, and we've been there now I guess we're approaching 9 years. It's a wonderful community and we're very blessed to be able to be there. There are very few baby boomers who are in a position where I was. I had an executive position and my husband was in an executive position, we saved money, we happened to have sold our house in 2007, do you remember what happened in 2008, we got very lucky. John began recognizing some of the early signs where he was for getting the names of some plants and some things that were very familiar to him along with for getting people's names, for getting who we

were having dinner with, all of those typical things and it's a retirement community, so we hear a lot of oh, I do that, too. But he was very proactive and he wanted to know more, we were able to arrange for some cognitive neurological cognitive testing and the first year he was tested which was about 3 years ago, maybe 3 and a half years ago, he was found to be gifted. And the person told him, the doctor told him I see the change, it's clear that something is deteriorating, but frankly nobody else is going to notice it just go on with your life. And we did. But John kept feeling it so the following year he had the testing repeated and at that point it was diagnosed with mild cognitive impairment. Because of the connection with that particular community, the geriatrician there was able to get him on to a trial with one of the experimental drugs, so he had the imaging, the MRI, it was determined that he had the amyloid plaque, they did not do the tau test, I don't think that was yet available as part of that trial, but they did the genetic testing, and it was found that with that particular drug, there was a chance of people developing swelling of the brain. So he was taken off that particular trial and he had to wait another year. So he's now just beginning a different drug, and that trial will begin shortly after we return from this.

What we have found is that we are particularly blessed compared to the population that Mary represents and that you all serve, I'm so grateful to be in this room, I feel so honored to be among people like yourselves who work in this field, who dedicate your lives to it. So recognize the tragedy is that the out there in our communities, people don't have savings and the resources that enable them move into a community like ours where they're surrounded by social workers and people who will help with us making our end-of-life decision or our long-term trajectory, where we will live and what that will look like you know, I have people I can talk to there, most of us don't.

So I challenge you to do what can be done, follow our wonderful speak there before lunch Josh, I've forgotten his last name, Linkner look at another way, turn the whole bottle

upside down, find a simple solution that once the diagnosis is made, as quickly as possible, connect the family with resources that are available in the community, make them aware of education. If it's as simple as having a brochure of the Alzheimer's Association in every neurologist's office around the country, in every geriatrician's office, in every primary care physician's office, put of it on channel 12 you know, whatever it is, get the message out that living with this disease really gives us the opportunity to love each other and to learn different ways to be. My husband has made a statement I so admire where he says "well, I used to be this person, I'm not that person any longer but that doesn't mean that I'm not a person. I'm just simply a different person and I want to choose to be as much of that different person as I can be." So thanks to the Alzheimer's Association and the Delaware Valley Chapter specifically, John was recommended to become one of the national advocates, so as a result of him being a national advocate, I was asked to be here today. And I very much appreciate that. He'll be speaking more at other conferences, at other fundraisers, at the walk for memory, putting himself in touch with other people who are getting these early diagnoses and helping them, too, to discover that although they're no longer the person they once were, they are good people, and they are full human beings. And deserve all of our love and respect!

[Applause]

KARLENE ELLSWORTH: Love you!

MARY HOGAN: Thank you, thank you, that was beautiful, thank you. I want to kind of pick up on something that you said and turn it back to you, Mary, we were talking about access to services which I think of course is a huge issue -- yep, it's a huge issue for those -- for everyone in the room, and certainly for this conference as we're focused on certainly home and community-based services. So Mary I know your brother was in a group homes for most of his adult life, can you talk a little bit about how you were able to access services there, some of the

decision-making process about whether to keep him there, or maybe go to a nursing home, and even to the extent that maybe you saw what other families went through and how they were able to access services or not in.

MARY HOGAN: So first of all I'd like to point out that according to the statistics that I am exposed to, through the AIDD and the community, the ARC agency, and the Administration on Community Living, 3 out of 4 people with intellectual disabilities live with their families, so I guess I'm here to help you to put in perspective the kinds of challenges that families experience once a family member is diagnosed with dementia. And many of the families who are sharing a household together are aging so you will find people that have -- that are 60, 70 and 80 and 90 years old taking care of their 50 or 60-year-old family member who is facing this diagnosis. And I think that that's it's really important to understand that that group of people has their biggest challenge in terms of accessing community services, especially if they are no longer able to provide the care to their family member at home, and they've been out of sort of a community, living community, it's very hard for them find the right match for their family member and so I'm hoping that you'll keep in mind and in your hearts the fact that most people are living at home with their family member if they are facing this diagnosis as they age. And I'm not just talking about people well Down's Syndrome but other intellectual disabilities.

In our case my brother was in a group home, we dreamed of aging in place, we didn't dream of aging in place with a diagnosis of Alzheimer's disease, and I know that we worked very hard with our group home in order to provide the kinds of supports that were needed but it was a rather reactive state mind rather than a proactive state of mind, so I think a lot of times we found ourselves in crises that could have avoided had we thought about the progression of the disease. My brother did stay in his group home until very late in the disease process and we did look in nursing homes and he had been in a nursing home before when he had a medical issue, he had a

broken hip so he had some nursing homes experiences that we wished to avoid. But as he needed extra support we were able to work with the group home in which I lived to provide him support until the last 8 months of his life, where he had to make a change to another group home. It was very traumatic, it was traumatic for us as a family, it was traumatic for him and I think it was also traumatic for the community in which he moved who were very unfamiliar with the issues related to Alzheimer's disease. So I think Dr. Petersen had a really good slide up there about training, the importance of providing training to the people who live in their home can access it so that people who live in specialized living facilities have access to trained personnel. I think we did our best in a really difficult situation. I picked up a small book recently, *Balance Moving Your Family Member* by Beth Spencer at the University of Michigan. I think had I known there was that kind of a resource, we would have made a smoother transition, but transitions are very, very difficult to make, and I think it takes a lot of communication, collaboration, and coordination in order for that to happen successfully. My brother died after 8 months in his new group home and you know, I saw the movie *Still Alice*, and I will tell you that I could hardly move out of the theater after the movie ended, because I realized that in ways, I'm not sure we gave access -- provided my brother with the opportunity to try to communicate what he was experiencing and the losses that he encountered, as you can see from the video, he had a really rich life and I think he suffered tremendous losses that we underestimate for people with intellectual disabilities, so if I could relive it, I think I would do that part very differently around supporting him as the disease progressed. So he had wonderful caregivers, people that he considered his staff, but they were really, really wonderful people who supported him until the end of his life and I'm forever grateful for that.

RANDI CHAPMAN: And you know, I will have to say just this to both of you, I think that's your efforts were so important, getting this out, and the uniqueness of your experience, you

touched on at one point the need to have services available for people who are under 60 and we see that and talk about that in the general Alzheimer's community when we are talking about early onset but I think that's particularly important when you're dealing with intellectual disabilities community.

KARLENE ELLSWORTH: And Mary spoke a little bit and touched on being a caregiver and the strain and stress that that brings to the family. One of the things that I have found is that it's kind of like that video you hear on the airline all the time: put the oxygen mask on yourself so that you're available to put the oxygen mask on the other passenger. I really had to take that to heart, when John was diagnosed, I was already in a power chair, I have had this disease for a long time, it came very clear to me if I didn't maximize my own strength and capability, I would never be able to be a caregiver for my husband and I would have to rely on nursing aids and other stuff for support more rapidly. So I did make the choice of going back to rehab and learning how to re-walk, getting into those machines that they have, those wonderful walking machines that got me up and out, and I'm so many grateful for that. I made the choice that eventually, he wasn't going to be able to be the driver so I had to go back and take training on how to drive a vehicle with modifications. We drove from Philadelphia to here to be able to be at this convention, it's that the being able to look forward, it's having the time as we saw in the slide earlier, the disease progresses somewhat slowly at the beginning, so that's giving us time to make some plans. We're in the middle right now of moving from our two bedroom independent apartment into a one bedroom independent living that happens to be located closer to the personal care section of our community so that when the time comes that I can't be the one, but the nurse's aides are right there, they don't have to go so far to get to the apartment where we're located right now. So those sort of planning ahead things that we're able to do, and I'm just so grateful for the time. My son was here, I have two grandchildren living in D.C., we're making

plans to take those kids on an archeological tour, we've want to do that.

RANDI CHAPMAN: Our time has run short, Mary is presenting at a workshop in the Georgetown East room, Understanding Aging for Individuals with Intellectual and Developmental Disabilities. Karlene will be here and kind of hang around for a bit so if any of you all have questions for each of them, you can catch up with them later, so thank you both very much, we appreciate it. Thank you!

[Applause].

MARTHA ROHERTY: You know, I just -- I wanted to say you know Mary, you made a comment as well about thanking us for what we do and you know I think so many of us take for granted having been in this business a long time and it really is through your bravery and your willingness to come tell us what we really need know about systems, what allows us to improve our system, so want to thank you both for being here, thank you so much.

[Applause]

MARTHA ROHERTY: So before you run out, people, by the door, we wanted to remind everyone that we are having a cake before the vendors and in the exhibit hall, and it will be closing at the end of this cake time, so we want to encourage you to make every effort to go back into the exhibit hall and have one last opportunity to thank them for being here. The cake you're going to eat has been brought to us by UnitedHealthcare, so I'm sure it's going to be fat free, sugar free, all of that. The exhibit hall will close at 3:00. Remember the ADA bus will be closing today at 5:00, we are going to start the next round of sessions a little bit late to give you time to have cake, so if you would make your way to the session, around 3:05 and workshops start tomorrow at 8:30 and we plan to see you all then. Thank you so much and thanks again to this panel.

[Applause]

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