NWX-HHS-AOA-1

Moderator: Greg Case
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1:00 pm CT

Coordinator: Welcome and thank you for standing by. All participants will be in a listen-only mode until the question-and-answer session of today's conference call. At that time please press star 1 on your touch-tone phone to ask your question.

Today's call is being recorded. If anyone has any objections, you may disconnect at this time and now I would like to turn the call over to your host, Dr. Jane Tilly from the Department of Health and Human Services. Dr. Tilly, you may begin.

Jane Tilly: Thank you very much. Good afternoon, everyone. Thank you for joining us on this Webinar which is targeted to explaining what the National Alzheimer's plan is and the role of the Aging Network in implementing it across the country.

If you go to the second slide - I can see that it's up, sorry about that - on the agenda you'll see that we're going to be talking about the impact of Alzheimer's Disease itself, the national plan that I just referred to as well as the implementation activities related to that plan that are already underway at the Administration for Community Living.

And as I mentioned, we'll be talking about state and local implementation and then we'll have some time for questions and discussion at the end of the presentation. You're going to hear from a number of us today.

I'm going to be beginning with some of the introductory material and then you'll hear from a number of other people as we go along and we'll introduce them when it's time for them to tell you about the exciting activities they have underway.

So right now you should be seeing a graphic that comes from the National Institute on Aging and it should be life course of dementia compared to normal aging and what you'll see in the yellow line is that there is some small amount of memory loss that are a part of normal aging and that usually involves a loss of short-term memory related skills.

The brain has a way of compensating for that by improving its - the way that the brain - processes information globally so you don't see a whole lot of loss of function due to normal age-related memory loss.

The second line that you see is a combination. There's a green portion of the line that indicates mild cognitive impairment and people who get mild cognitive impairment, not all of the go on to get Alzheimer's Disease but roughly 40 to 50% do.

What happens is that mild cognitive impairment will be things like just again things with short-term memory loss, some loss in what's called executive function and that's basically the skills you use to manage your life on a day-to-day basis, things like managing your checkbook, working, that sort of thing.

People can still hold down jobs with mild cognitive impairment. Sometimes that mild cognitive impairment is due to other things besides dementia, for example, depression can contribute to that and people can go in and out of mild cognitive impairment.

When people get a diagnosis of Alzheimer’s Disease it’s usually after the age of 65 and what happens is that Alzheimer’s Disease is a progressive illness - a progressive brain disease - where you steadily lose the ability to function independently and it is a fatal illness. It will result in death if people don’t die of another disease in the interim.

And Alzheimer’s Disease is characterized first by things like if you forget your keys, that’s like a short-term memory issue that isn’t an Alzheimer’s Disease but if you forget what keys are for, that’s an example of the kind of impact that Alzheimer’s Disease might have in the beginning.

Quite often people discover they have it when their loved ones find that they’re having difficulty managing their finances. That’s often an early indicator of the disease and so it’s those initial executive function issues that come up that become indicators of the beginning stages of the disease.

At the end of the disease, people are totally dependent on others for all of their basic activities including eating, bathing, dressing. At the very last stages, people have difficulty swallowing and eventually deteriorate completely and die.

So it’s a very serious illness and as many as 5.1 million Americans may currently have the disease and the prevalence of mild cognitive impairment that we were discussing earlier is higher than that.

The estimates of the number of people with Alzheimer’s Disease vary. We don’t have a firm national estimate. The estimates range from 2.4 million to 5.1 and the 5.1 million includes people with the mild stages of dementia. The 2.4 million is more likely to be people in the moderate to final stages of the disease who are dependent on others for their daily activities.

And as you all know, the baby boomer generation is aging. The first of us hit 65 within the last few years and so because aging is a risk factor for the disease, the prevalence is going to increase dramatically over time as the U.S. population ages.

And you can see in the next slide that Alzheimer’s Disease - when I use the term dementia - that’s a global term for a number of different kinds of illness that cause progressive brain disease and Alzheimer’s is responsible for 60 to 80% of all dementia cases.

And it has steadily been climbing as a leading cause of death in the United States. It’s now the sixth-leading cause of death in the U.S. among people of all ages and the fifth-leading cause among Americans aged 65 and older.

And it’s important to note that why this is obviously an important issue for the Aging Network because the aging population is most at risk for the disease but it’s also the people that use the network services are much more likely to have some form of cognitive impairment or dementia.

So for example about 60% of people using the National Family Caregiver support program, those people participate in that program, about 60% of them are caring for someone with Alzheimer’s Disease or a memory-related illness and prevalence of Alzheimer’s in institutions is about half, half of those in institutions have Alzheimer’s or some form of memory impairment.

And the two figures I just gave you, one is a program estimate and the other is a national estimate for the percentage of people in institutions, there are studies that show that about 40% of people that participate in Medicaid home and community-based services (flavors) also have Alzheimer’s or some other form of cognitive impairment.

So a large proportion of the folks you’re serving have this disease and it’s important to know a little bit about the disease and its prognosis as well as the symptoms associated with it.

As we’ve already talked about, age is the strongest risk factor for dementia but there are people who are diagnosed with Alzheimer’s Disease before the age of 60 and that is referred to as early onset Alzheimer’s Disease or young onset Alzheimer’s Disease.

So you could find people sometimes as young as 35 although that’s very rare and usually that’s with there’s a family propensity for dementia for people who acquire the disease before the age of 60 but it’s important to understand that that does occur.

And as people age, the risk of having Alzheimer’s - the rate of new occurrences of Alzheimer’s Disease - doubles approximately every five years after age 65 so that by the time you hit 80 or the population hits 80 or 90, about 40% of people in that age group will have some form of dementia.

There have been a number of studies to date that have tried to sort out the causes and factors associated with dementia and there are a number of theories about risk factors and the only and so some of the evidence around risk factors associated with Alzheimer's Disease are the same things that are associated with risk of cardiovascular disease so and these are just correlations.

This doesn't mean that what I'm talking about is a cause of Alzheimer's Disease. It just means that people who have risk factors like high cholesterol, high blood pressure, lack of exercise, obesity or diabetes, these are all things that are correlated with a risk of having Alzheimer's Disease.

It doesn't mean that anyone has proof that this causes Alzheimer's but there are lower risks of Alzheimer's for example for people who exercise regularly and keep their weight within normal ranges.

And I should mention that there are no known drug therapies at this point in time that are able to prevent or decrease the decline in function that occurs with Alzheimer's Disease. There are some therapies that help deal with some of the symptoms of the disease.

There have been some estimates of the costs of Alzheimer's Disease to society and the cost estimate that the National Institute of Aging uses is that Alzheimer's Disease and other dementia costs Medicare and Medicaid more than $148 billion in the U.S. annually.

This cost estimate does not take into account - oh, I'm sorry - the cost is that includes costs related to Medicare and Medicaid and some of the costs that are also associated with the disease, other things like the cost of support, lost wages and other kinds of things.

So for example a person who gets early onset Alzheimer's Disease and can no longer do their job as an engineer, their lost wages associated with having to retire early for example and those kinds of costs are in that estimate that I just gave you.

And it’s not just an estimate of the impact of Alzheimer’s Disease on those who have it. There are significant costs associated with Alzheimer’s Disease for caregivers in terms of their own lost wages, lost pension benefits.

Caregivers of people with Alzheimer’s Disease experience more stress and physical and emotional hardship than people who take care of folks with physical disabilities so caregivers also experience those kinds of issues.

And the reason for that is that Alzheimer’s is a brain disease - the brain deteriorates - in a global fashion so that it’s not just a person’s physical functioning but also their ability to remember to understand what’s happening to them.

So and an illustration of this is someone in the moderate stages of the disease may every afternoon go - if they’re in a facility of some sort, say an assisted living facility - they may go to the door every afternoon around 3:00 and try to get out to go and get their son or daughter from school.

So that they’ve forgotten that was an important role for them as they were raising their children and that’s what they but they don’t remember where they are or the fact that their children or grown so that can cause - that example - might be an example of wandering.

Another example of a behavioral symptom of Alzheimer’s Disease is quite often people with the disease if they need to be clean and well-kept but they may not understand why a stranger - someone they perceive to be a stranger -

is helping them undress in preparation for a bath and they resist that because to them it feels like an assault.

It doesn’t feel like somebody’s helping them take care of themselves so there’s a lot of another thing that’s associated with Alzheimer’s Disease is quite often there is unrecognized pain.

People might be crying or screaming not because they’ve got untreated pain so there’s a lot of different things associated with Alzheimer’s Disease that make that kind of care - caring for someone with that disease - very difficult.

So now we’re going to turn to what we’re doing at the national level and what you all are I know many states already have state Alzheimer’s plans of their own but I’m going to be talking about the national Alzheimer’s plan which was set into motion by Congressional passage of the National Alzheimer’s Project Act.

The President signed it into law early in 2011. You can see in this slide, there’s a number of things that the Act requires the Secretary of Health and Human Services to do. One is to create and maintain a national plan to ensure coordination of research and services.

One of the major goals is to accelerate the development of treatments that would have an impact on the disease, improve early diagnosis and coordination of care, and the early diagnosis is really important.

Some estimates are that about half of those with Alzheimer’s Disease don’t actually have a diagnosis and so it’s important - getting a diagnosis - is important early on because it helps people plan for the course of the disease.

Also coordination of care and treatment for the disease and any co-occurring illnesses so for example most people with Alzheimer's Disease will also have some other kind of chronic condition like diabetes or a heart condition and the management of those co-occurring illnesses is complicated by the fact that the person with dementia will have difficulty managing their medications and their treatment plan so they need a lot of assistance with that.

Another part of the act is designed to improve outcomes for ethnic and racial minorities and also folks with Down's Syndrome. All three of these groups are at a higher risk than the general population of acquiring Alzheimer's Disease.

Another part of the Act requires international coordination and then creation of an advisory council that is to review and comment on the national plan of the Secretary of Health and Human Services.

This advisory council also has a role in reviewing and commenting on the implementation of the plan itself. On the next slide you'll see President Obama's vision statement for implementation of the National Alzheimer's Project Act.

In it he recognizes the especially heartbreaking struggle that people with the disease and their caregivers experience as Alzheimer's as they get a diagnosis and live with the disease and he recognizes the burden that this can represent for the nation's elders and their families.

And he made a $156 million investment early last year during federal Fiscal Years '12 and '13 to attack this disease aggressively even before the national plan was released in May and this investment was designed to take immediate action on Alzheimer's Disease and to support the national plan.

The first thing that was done was to divert about $50 million in research funding from the National Institutes of Health into Alzheimer’s Disease. That was $50 million more than was originally planned for Fiscal Year ’12 and that funding has in fact gone to several research projects that would not have received funding from NIH otherwise.

In the President’s Fiscal 2013 budget, he has proposed $80 million in new Alzheimer’s Disease research funding but research isn’t the only thing he’s made an investment in.

He’s also made an investment of $26 million in Fiscal Years 2012 and 2013 related to education and outreach to increase the public’s understanding of Alzheimer’s Disease and you can see that that’s about $8 million over the two fiscal years and that effort is housed within ACL, the Administration for Community Living.

There is also outreach to educate healthcare providers. That funding went to the Health Resources and Services Administration and that is being used to educate healthcare providers through their geriatric education centers about Alzheimer’s Disease.

In Fiscal ’13 there is $10.5 million proposed as part of the President’s budget to expand supports for people with the disease and their caregivers in the community and finally there’s an effort to improve data collection and analysis to better understand the impact of Alzheimer’s Disease.

So for example we don’t have firm counts at this point in time about how many people have Alzheimer’s Disease and Medicare and Medicaid. We have estimates but we also don’t know the amount of money that Medicaid - have precise estimates and precise figures - on the amount of funding that is going for this disease so the improved data collection should help sharpen the data that we currently have.

The Secretary of Health and Human Services appointed the advisory council on Alzheimer's research, care and services towards the middle of 2011. The chair and it's composed of 11 members who are non-federal people who represent the various key stakeholders in the Alzheimer's community and that is they're representatives of people with the disease, their caregivers, the providers who serve them, state and local government and researchers.

The chair of that advisory is Dr. Ronald Peterson. He is with the Mayo Clinic and is an eminent research in Alzheimer's Disease and has a great command of all of the issues associated with the disease.

On the federal departments that are members of the advisory council are of course the Department of Health and Human Services, (Don Moals), whose picture you see on the slide there is the lead staff person in HHS who is on the advisory council.

We also have representatives from the Department of Defense, National Science Foundation and the Department of Veterans Affairs and many agencies within Health and Human Services including a representative from ACL serves on that council. The development of and just recall that I mentioned that this council is the role is to review and comment on the National Alzheimer's Plan.

The way the plan developed was even before the council was named, the Secretary formed a federal interagency workgroup on Alzheimer's Disease which included a number of different across basically the departments that you saw listed in the previous slide as well as many of the agencies within HHS.

We formed three subgroups related to research, clinical care and long-term services and support. There are quarterly meetings of the advisory council and ad hoc meetings of workgroups and subcommittees. The final plan was released on May 15th of this year and you can see the Website where you can get a copy of that plan if you’d like to do that.

The National Alzheimer’s Plan has five goals. The first is to prevent and effectively treat Alzheimer’s Disease by the year 2025. Another is to make sure that we make the best use of our resources by optimizing care quality and efficiency in current and future government programs.

A third goal is to expand supports for people with the disease and their families, to enhance public awareness and engagement and to track progress in implementing the plan’s goals and drive improvement throughout the government.

In terms of implementing the national plan, if you at some point get a chance to go and look at the National Alzheimer’s Plan at that Website that you saw in the previous slide, you’ll see that Appendix 4 has an implementation plan for the National Alzheimer’s Plan.

And that implementation in Appendix 4 contains the five goals that I just described to you as well as quite a number of associated goals and strategies. Each one of those strategies and action steps have lead agencies and their partners identified.

And we've already begun to implement the plan as, you know, even before I think even before the plan had been released, we were beginning to - we certainly were identifying things - action steps we could take immediately as well as those over the next few years so that you'll see that many of the things that are in that plan are underway as we speak.

We also have to report progress to the advisory council on a semi-annual basis and it's important to note that the National Alzheimer's Plan is not a fixed document, it's a living document. It's being updated annually and that process will start getting underway this fall.

So I'm going to turn to ACL's role in the implementation of the plan so we'll be focusing primarily on Goals 2, 3 and 4. We do have some role in research but it's circumscribed. The lead on that is with the National Institutes on Aging.

We have some partnerships with them and we'll describe a little bit about that but primarily we're involved in improving the services for people with Alzheimer's and their caregivers so we - some of the capacity - that we have in place for dealing with the special needs of people with Alzheimer's and their caregivers is AoA's Office of Supportive and Caregiver Services has a lot to offer in terms of technical assistance.

We have the Administration on Intellectual and Developmental Disabilities which is now part of ACL with special expertise on the needs of folks with Down's Syndrome almost all of whom if they live long enough will acquire Alzheimer's Disease and there's intergovernmental coordination opportunities too that are available.

Some of the current resources we have involve the National Alzheimer's Call Center. You can see that number there. That 800 number is something that is supported in part by the Administration on Aging. We'll hear more about that from Amy Wiatr in a little bit.

That number is a 24/7 help line for people with Alzheimer's - with the disease - and their caregivers. We also have a new Alzheimer's Website, alzheimers.gov which links people to a number of different resources and information about the disease and where to get help and finally many of you may be familiar with the Alzheimer's Disease supportive services program.

There's a Website associated with that and that program basically translates evidenced-based interventions to help caregivers as well as trying out new innovations to help improve the service delivery to this group.

The main focus of the kind of umbrella for ACL's approach to implementing the plan is under the theme of dementia capability and for those of you who don't know it, dementia-capable it simply means that those services are tailored to the unique needs of persons with dementia and their caregivers.

I spent a fair amount of time early on talking about some of the behavioral symptoms. That's one example of the special needs of this population. Dementia-capable - the ideal dementia-capable - service system would be able to readily identify those with dementia and provide services to them using staff with special training or knowledge of the disease.

Those staff would understand how best to communicate with the persons with dementia and their family caregivers and ensure that people with dementia are supported in their decision-making about their services in involving family caregivers where necessary.

Quite often what happens is that people have dementia and if they are counseled early in the stage of the disease and even fairly far into the moderate stages, people with dementia can make decisions about their services and about their preferences.

But as the disease progresses, people with dementia have to rely more and more on family caregivers and people who understand their preferences and can help them make decisions and, you know, why this focus on dementia capability in the network?

Basically people with dementia and their caregivers have additional support needs as I've already talked about and I also mentioned already that really 40 to 50% of the folks you see on a day-to-day basis in your service systems are going to have some form of dementia or cognitive impairment.

So it's not possible to create a special system just for them. They are your system. They are part of your system and so the general system itself needs to be capable of meeting the special needs. ACL has made some recent investments in dementia capability.

There's an issue brief explaining a lot more about what we mean by this and what a dementia-capable system looks like and in addition to this issue brief, there is a very good toolkit that gives examples - well the issue brief and the toolkit itself - both of them give examples of how states have implemented various aspect of dementia capability.

Another investment we made last year was grants called systems integration grants and four states got grants in two parts. One was a grant called Part A. It was designed to help states integrate their general - their LTSS - systems but Part B was specifically designed to help make those states dementia-capable.

So we're looking to - those are three-year grants - we're looking to see how those states implement them to see what we can learn over time and make those learnings available to other states and localities.

We also through the Alzheimer's Disease Supportive Services Program have had innovative programs such as the grant to Massachusetts that helped it make its LTSS system dementia-capable.

So this has been a theme of our work for quite some time and it's being given special emphasis and priority because of the National Alzheimer's Plan and also in those states where they have their own state Alzheimer's plans.

We're about ready to talk about the awareness campaign. Hunter, are you on the line? Okay, well I guess Hunter couldn't join us so we'll go ahead and turn it over to Kate Gordon who can talk with us about the implementation of the awareness campaign.

Kate Gordon: Thank you, Jane. My name is Kate Gordon and I work with the National Resource Center for the Alzheimer's Disease Supportive Services Program and also support the Administration for Community Living and the implementation of their activities for the national plan.

Typically joining us would be Hunter who helps the Administration for Community Living implement the full outreach and awareness plan. There are two main components to fulfilling the activities within the national plan for awareness and outreach and one of them is very specific.

You can conduct a national outreach specifically for caregivers of persons with Alzheimer's Disease and the Website as Jane mentioned earlier alzheimers.gov launched just a few months ago in its prototype.

It's been updated since its launch and will continue to be updated as national experts are consulted as well as feedback from caregivers themselves that are using this Website. We'll talk about the Website just a little bit in a moment.

The second part of the awareness and outreach was to expand materials on an existing resource that was funding through the Administration on Aging called longtermcare.gov. It's an awareness campaign.

It's a Website for the awareness campaign that's been in existence for several years now focused specifically on baby boomers and what they can do to prepare for their futures. The purpose of the outreach campaign itself was to connect caregivers with currently available public and private resources.

That's to say that it's not just diverting people to government resources but it's looking at organizations like the Alzheimer's Association, the Alzheimer's Foundation of America as well as internally within the federal government different areas of the government who focus on Alzheimer's Disease.

So the Administration on Aging, the National Institutes on Aging and others that had resources prior to the launch of the National Alzheimer's Plan but the messaging itself specific to this outreach program for caregivers is to let them know that you don't have to go it alone.

So the basic messaging is caregivers, you are not alone. You don't have to go it alone. Here are some resources that you can connect to online today. The resources that we had financially to launch this effort, there was a budget, immediate funding at $4 million for FY ’12.

We developed this entire program. It launched on may 15th and until he time when many of you have seen our television ads for the campaign, it was about eight weeks into development so from the time of funding to launch to actual live Website as well as print and other media, it was eight weeks.

What we really tried to focus on were some key elements, first and foremost making sure that as individuals accessed these resources that they were in plain language which is a government-wide effort to make sure that we’re not using our own acronyms and making sure that it’s a reading level that is accessible to most.

And again the Number 1 focus of this resource specifically alzheimers.gov is to acknowledge caregivers the roles that they fulfill and some of the strategies and services that they can access as they go this road. You’ll see in front of you now a screenshot.

It’s not today’s screenshot but a recent screenshot of alzheimers.gov. As I said this is really an evolving Website. What we’re looking at here is specifically again what resources can we provide to caregivers today? Each one of these links gives you some text but it also as I said links you to other resources off-site of the alzheimers.gov site.

The next screenshot that you see is for our print media. This is part of the campaign is that we recognize that it doesn’t matter where a caregiver is, if they’re at work, if they’re out in the garden, they’re constantly thinking about their caregiving role and what they can do to make the life of the person that they’re caring for easier and more fulfilling.

So the visuals that you see on the campaign itself, you'll notice the question marks going around this individual's mind, she's just thinking about not just about her daily life and how to get from Point A to Point B but how is she going to cope with the rest of the day.

So when someone in your life has Alzheimer's, the questions keep coming. The answers start here, alzheimers.gov is the message so we're into the implementation and constant evaluation of this effort.

We want to make sure that people who are coming to these resources have an opportunity to tell us how to get them information that they really want so as part of for example the Website we have a pop-up survey that comes up to ask the individuals what more information were you looking for?

Did we fulfill the needs that you had today? How did you get to us so we're going to be asking the consumers themselves how to improve not just our Website but the other resources that we offer through the government.

We're going to be using a number of techniques and market analytics to really improve both what you see online, what we offer offline and then spreading our outreach further than where our dollars have taken us thus far.

As I mentioned we spent about $4 million on the campaign in Fiscal Year 2012. We have about $4.2 million proposed in the President's budget for FY '13. We're going to take that and so as much as we can with those dollars but really counting on individuals like yourself out in the field to really press this message farther than we at the federal government can go.

Our next steps as I mentioned are to update and improve this Website. We have on hand a committee of subject matter experts including as Jane mentioned earlier some resources specific to individuals with intellectual disabilities and the Down's community.

Everything on this site is going to be updated on a periodic basis based on feedback except for that Down's Syndrome page which is going to be focused specifically on what's provided by subject matter experts.

As I said we spent the money that we have. Most of it, that $4 million but we're going to continue with what we have at the moment to expand into social media, hopefully to use Facebook and Twitter to our best advantage. We're going to be doing some outreach to bloggers.

We're going to make better use of earned media. I know we've already had a question come through in our chat line about how can we make the materials available on a national basis? We really want to get together with you guys as local individuals to talk to local journalists, local bloggers to really spread our message farther than we've gone so far.

And last but certainly not least we're going to cooperate, coordinate and partner with you all to identify existing networks and ways that we can spread this message farther.

Jane Tilly: And next we're going to hear from (Mettie Patterson) who's going to talk with us about the specific populations area of our work.

(Mettie Peterson): Thank you, Jane and thank you or inviting me to be part of this discussion. I am with ACL, I'm with the Administration on Intellectual and Developmental Disabilities there and we've been charged with others in Health and Human

Services to look at some specific populations that are disproportionately affected by Alzheimer's Disease and those include people of racial and ethnic minorities, people with Down's Syndrome and other intellectual disabilities and those experiencing younger onset Alzheimer's Disease.

And with that our task is literally form a task force, a federal task force on these specific populations and we'll be undertaking in the next few months development of a plan to address the unique needs of this underserved population or disproportionately-affected population.

The focus of the task force will be the accurate and timely diagnosis of people within these groups, their need for access of care, education for practitioners who typically do not work with an Alzheimer's population and other specific unique considerations of these populations.

As a plan is developed, our next task then will be to identify barriers and make recommendations to the advisory council that Jane talked about and Health and Human Services Secretary Sebelius as to how barriers can be addressed.

Our task is to be completed by next June and with the task force work to be finished by the end of January. As Kate mentioned, there will be a specific presence on the Website around Down's Syndrome and the unique and disproportional effect of Alzheimer's Disease on that population as well.

Jane Tilly: Thank you very much, (Mettie). We're going to hear from Amy Wiatr next about the Aging Network education efforts we have underway.

Amy Wiatr: Great, thank you so much, Jane. I'm very glad to be able to be on this Webinar. One of my responsibilities at AoA ACL is being Project Officer for our National Alzheimer's Call Center grant which Jane mentioned earlier.

The grantee for that is the National Alzheimer's Association and the grants that we provide help support their 24/7 phone and online support for caregivers and people with dementia.

And in the course of working on that grant to try to better coordinate those activities with the work of NIA, NIH and their 30 funded Alzheimer's Disease research centers throughout the country, the National Alzheimer's Plan was also being developed.

And so we took advantage of those synergies to work on coming up with some education for the broad Aging Network in the form of an AoA-NIH co-sponsored Webinar series. Some of you who are on today's call may have been a part of that three-part Webinar series.

We feel it was very successful. We had over 500 participants registered for each of the three sessions. The first was back in May and the first was on Alzheimer's and other dementias.

We had a variety of speakers that talked about the latest in diagnosing dementia, providing research updates and giving more information on both Alzheimer's Disease as well as other dementias. The second Webinar was back in June and that focused on the online tools and resources available to assist again individuals with dementia as well as caregivers.

And the three sites that we focused on in that Webinar included the National Alzheimer's Call Center so the Alzheimer's Association's services they provide through that as well as their Website with lots of tools on looking at caregiver stress, looking at the different fact sheets about different aspects of

Alzheimer’s, dementia, caring for somebody with dementia, online learning modules and more.

The second resource we focused on was the Eldercare locator which again many of you are familiar hopefully with eldercare.gov and being able to find local resources, area agencies on aging and other programs to assist people in their caregiving activities.

And then the third was the ADEAR Center which is the Alzheimer’s Disease Education and Referral Center which is sponsored by NIA, the National Institute on Aging and the focus there on the latest in research-based information to address dementia, Alzheimer’s Disease and caregiving for persons with Alzheimer’s and other dementias.

The third Webinar was on connecting the Aging Network individuals with dementia and caregivers with research opportunities and this was held in July. That Webinar focused on the 30 NIA-funded Alzheimer’s Disease research centers and the services that can be provided through them.

As well as where people can find other information about the clinical trials that are available such as on clinicaltrials.gov or finding out if their kind of profile characteristics, what they were interested in, what they were able to do, how that might match-up with the trials currently available such as through something trialmatch.org.

All of those Webinars, all of those three Webinars are archived at the Website that’s shown on the slide along with a if you go to that link you can also find a detailed agenda list and speakers list for each of these 90-minute Webinars.

We're going to be reconvening the planning group and looking at next steps such, you know, to kind of incorporate some of the other things that we've identified as areas to assist the Aging Network such as, you know, dementia and people with intellectual and developmental disabilities, crisis and emergency situations and people with Alzheimer's and dementia and things like that.

So we hope you'll stay tuned and be on the lookout for those as well as to please share any suggestions that you have with us to make sure that we can, you know, provide the resources and information to help you do the work that you do out in the field.

Jane Tilly: Thank you very much, Amy. We're now going to turn it over to Kate Gordon to talk about the legal assistance efforts we have underway.

Kate Gordon: Thank you Jane so again within the national plan itself, there's a very specific requirement that the federal government provide education for legal professionals about working with individuals with Alzheimer's Disease and there are two ways in which the Administration for Community Living is really moving forward with this effort through the Administration on Aging.

One is through a grant program called Model Approaches to Legal Resource Development and that is a grant program that's been going on for several years and they're moving into a new grant phase, Phase 2.

The program announcement that's going to be released for Fiscal Year 2013 will include dementia capability as a component of building your model legal resources for individuals for the elderly so it's an Administration on Aging-specific grant program. There will be dementia-capability components built into that.

If you are going to apply for this grant, you are going to be looking at how do you make your legal services dementia-capable? The second and I think more tangible for all of us on the line will be a set of trainings this fall working on legal issues in Alzheimer's Disease.

There will be three Webinars, two for legal services professionals or lawyers specifically talking about how is serving a client with Alzheimer's Disease or a related dementia different looking at issues of guardianship in Alzheimer's Disease, looking at financial issues in Alzheimer's Disease.

And then there's going to be another Webinar specifically for the Aging Network looking at what legal resources are available through the Aging Network that are related to Alzheimer's Disease but also how to look at the dementia capability of the resources that you currently refer people to.

So that is going to be a more hands-on Webinar that talks again about what are the legal resources available but again how to look at the dementia capability of the resources that you're using today.

Jane Tilly: And this is Jane again. Thanks, Kate. Another item that we have had underway is related to the National Alzheimer's Plan is related to two of the strategies.

And what we did is we had a meeting in mid-June, the Alliance for Aging Research in partnership with AoA put together a day-long meeting about translating innovations into - about the best ways to - that about the, - I'm sorry, I'm getting my words mixed-up here - about translating evidence-based interventions into community programs.

And that day-long meeting was funded by the MetLife Foundation and what we did is we heard from researchers who originated the interventions as well as folks who had implemented their interventions, many of whom were funded by the Alzheimer's Disease Supportive Services program.

We heard about these interventions and their results or implementation, the ability to sustain these interventions financially in three different areas. One was programs targeted to folks with early stages of dementia.

Remember I talked about those being stages of dementia being where people have difficulty with executive function. The second set of interventions was around the most effective means of supporting caregivers as they're taking care of their loved ones in the community.

And the third is around care transitions, those being transitions from hospital to home or hospital to nursing home and this fall we will have available a white paper on this day-long meeting that will talk about the results of that and its implications for the Aging Network. Next we're going to hear about partnerships that ACL has underway from Becky Kurtz.

Becky Kurtz: Hi, I'm Becky Kurtz. I'm the Director of the Office of Long-Term Care Ombudsman Programs here at ACL and I wanted to say a little bit about what CMS is doing and what we are doing in partnership with them.

CMS has a national partnership to improve dementia care and an important goal of that partnership is to reduce the inappropriate use of antipsychotics in nursing facilities. Antipsychotic drugs when they're prescribed for elders with dementia can have serious medical implications.

They can cause confusion, injury from falls and even death. In fact, the Food and Drug Administration black box warnings state that anti-psychotics greatly increase the risk of death in persons with dementia.

Nationally 23.9% of long-stay nursing home residents received an anti-psychotic last year and so CMS is seeking to reduce that national average by 15% by the end of this calendar year so that's just a few months away.

To assist in meeting this goal, CMS is developing a program called Hand in Hand to train nursing home direct-care workers on dementia care practices. We've been involved in commenting on that and as they were designing that program and we together with our funding for the National Ombudsman Resource Center and through states' long-term care ombudsman programs have been working to support CMS' to reduce the misuse of antipsychotics.

We've especially been focusing on education of nursing home residents and their families as well as through ombudsman promotion of care planning that meets the needs and goals of individual residents with dementia.

Jane Tilly: Thank you, Becky. We're going to turn to Kate to talk about the research inventory that has been conducted at the National Institutes of Health.

Kate Gordon: Thanks Jane and as we mentioned earlier, the two items that we're talking about now - the CMS partnership and this NIH partnership - these are things that the Administration for Community Living is partnering on. We're not necessarily leading them but we have a lot of work that we've been doing as part of intergovernmental workgroups.

The National Institutes of Health and specifically the National Institute of Aging has been looking across all federal agencies and asking for input on what are the different types of evidence-based projects that we have been funding, looking at both biomedical research that's been going on as well as non-pharmacological approaches to dementia.

The reason that they're putting this inventory together is really to look at where have investments been made? How do we learn from research that's already gone on? How do we reduce duplication of efforts across different federal agencies and that is called the CADRO which stands for the Common Alzheimer's Disease Research Ontology.

It's available online now. You can see the link below in orange. What the National Institute on Aging is really looking to do is to move this ontology - this inventory - beyond the federal government and ask for input from organizations as well as the international community.

And it's important to note that this inventory originally was a partnership between the National Institutes of Aging and the Alzheimer's Association so those two entities were the first groups to add the research that has been done with funding through NIH as well as the Alzheimer's Association.

So the future of this research inventory is that it's going to go international and we hope that those of you on the call who are involved in the research community will add your projects to really build this inventory out.

Jane Tilly: And so the last part of our presentation is going to deal with the Aging and Disabilities Network roles in relationship to the goals of the National Alzheimer's Plan, the first one being preventing and effectively treating Alzheimer's Disease. Kate?

Kate Gordon: So we’re just going to start off and go goal-by-goal with some ideas that we’ve heard from people in the field as well as what has come through the development of the national plan itself starting off with Goal 1 which is to prevent and effectively treat Alzheimer’s Disease by 2025.

I’ll reference what we heard earlier from Amy Wiatr-Rodriguez from the Administration for Community Living and really looking at how can we as networks increase enrollment in clinical trials through our own community outreach so this may be as Amy mentioned partnering with your Alzheimer’s Disease research center.

It may be working with your local universities and talking about either individuals with the disease, caregivers or even healthy individuals getting them involved in research projects that are going on locally.

Really where we see a dearth of participation is within the racial and ethnic minority communities. Either they don’t know that research is available or don’t know the importance of their role within research. As many of you can surmise, most of the research that’s gone on in the United States has been in the Caucasian community, predominantly male.

So we’re really looking to branch out from that and using strategies that you all are doing in outreach for other projects whether you’re home or community-based services can be used to enroll people and promote participation in political trial and other research.

We also want to make sure that we’re putting into our local newsletters information about the latest research findings. You can easily find information about pharmacological or non-pharmacological interventions as Amy mentioned through the ADEAR Website, that's the Alzheimer's Disease Education and Referral Website.

They have a daily log of new and exciting research that's going on in Alzheimer's Disease but you can also promote best practices and evidence-based practices within your own organization.

So if you're currently using a model of caregiver intervention that perhaps you've been using for 15 or 20 years, you might look at doing a pilot of one of the new evidenced-based models promoted through the National Institutes of Health or through the Administration on Aging.

Jane Tilly: And we're going to talk about Goal 2 now which is to enhance the care quality and efficiency of service delivery so we all have the network in conjunction with its partners has a wealth of programs that provide vital services to people with all sorts of disabilities.

And there is a way to make that vital and valuable service network be more dementia-capable and it starts with building a workforce with the skills to provide quality care and it goes back to the theme that I talked about earlier about dementia capability.

I'm not going to repeat all of that but it's important that anyone who is going to be interacting with a person with dementia or their caregiver know at least a little bit about what the disease means, how to identify that person and how to help them most effectively and that ranges from people that do information and referral all the way to folks that do care transitions under special programs that many in the network have.

Another way to develop dementia capability is through training folks that are doing options counseling and the folks in aging and disability resource centers and as we heard from Becky, it’s important to link the ombudsman program to dementia-specific training and resources because many nursing home residents as she mentioned many residents with dementia are being subject to antipsychotics which damage their health and can in fact cause their death.

Going on to the next slide, I mentioned earlier that probably about half of the folks with dementia don’t actually have a diagnosis and it’s not just that it’s underdiagnosed. There also could be an overdiagnosis issue.

It’s important to keep that in mind so for example someone who has chronic depression and isn’t receiving medication or therapy for that can actually seem like they have a lot of symptoms that might with just a quick diagnosis might be diagnosed as Alzheimer’s Disease but in fact it’s untreated depression. Likewise there can be drug interactions.

Older people process pharmaceuticals differently than younger people do and there are some pharmaceuticals aren’t appropriate for the older population but they get prescribed anyway so it’s very important to get an accurate diagnosis and that’s something linking people to experts in diagnosis and clinical management of Alzheimer’s Disease is critically important as we’ve mentioned a number of times.

It’s also important to make sure that healthcare provides know about how to help the people that they serve access long-term services and support so there’s affirmative, proactive educational opportunities for working with providers to help people with dementia and their caregivers.

And also turning to the planning, that's another theme that we've talked about several times today, making sure that people when they do get a diagnosis engage in the kinds of early planning around management of financial issues, management of services over the course of the disease while the person with dementia still can communicate most effectively their preferences around care and planning for their future. Next we're going to turn back to Kate for discussion of Goal 3.

Kate Gordon: And our Goal 3 is to expand support for people with Alzheimer's Disease and their families and a few of the efforts that publicly we're going to call on for input include the following, first of all to ensure the receipt of culturally-sensitive education training and support materials.

Part of the national plan calls for those materials to be collected and disseminated. The specifics of that are not worked out at this time but we will be asking publicly so please keep an eye out for a call for materials that can be utilized through the Aging Network.

I know that we currently have many of our resource centers have these materials and we're going to be looking at how do we better disseminate those, make them available either via our Websites or through additional workshops and Webinars like we're doing today.

We recognize that you all will continue to provide care to caregivers that will help them to maintain their own health and well-being. As I mentioned earlier, we're looking to you all to continue to adopt those evidenced-based interventions that are going through randomized clinical trials are getting more evidence base behind them.

There will be information coming out from the Administration on Aging on best practices for caregiver assessment. That will be coming out within the next couple of months and we'll again provide information to you all about how to use the resources available and adopt them locally.

In addition we wanted to be able to provide you with tools to support caregivers in crisis and emergency situations as we had on our slide deck earlier, the 24/7 call line that's available to any caregiver anywhere in the United States 24 hours a day, seven days a week.

That's a call line that any of us can promote and make sure that our caregivers have access to who are dealing especially with individuals in the middle stages of the disease and in addition we're going to be doing some training calls on how to work with individuals in emergency situations.

So there are some resources that are going to come again through the Administration for Community Living specific to these two areas of crisis and emergency situations. We'd like your assistance in promoting the long-term care awareness campaign. Again it's via our Website longtermcare.gov.

If you haven't been on there or haven't promoted these materials previously, there are tools available for you to promote this campaign locally and it's really again to assist families specifically baby boomers in planning for their future care needs.

There will be materials on longtermcare.gov that are specific to Alzheimer's Disease but this is really for planning in advance of even knowing that there is a diagnosis so what are some of the advanced care plans that you need to have in place and how to go about setting yourself up for those future decisions.

And again maintaining the dignity, safety and rights of people with Alzheimer's Disease is a specific action in the national plan. As I mentioned earlier, we're going to have some Webinars to educate legal professionals and the network about the legal services that are available and how to look at dementia capability of legal service professionals.

And we'd like you to support the implementation of the activities through the national partnership to improve dementia care so for example promoting the training materials through Hand in Hand, those creating this curricula will be out - going to be put - on the market soon and has not yet been released but when it does, you'll know. It'll come through the entire Aging Network just as we promote other resources available.

Jane Tilly: And Goal 4 is to enhance public awareness and engagement as Kate mentioned spreading awareness of longtermcare.gov. Likewise we would like you to help us spread awareness of alzheimers.gov.

So for example in alzheimers.gov folks can go there to get basic information but they can also go there to get links to places where they can find out about clinical trials and links to the new - the Spanish language - page for example and other kinds of resources there.

It's important also for the network to work with state, tribal and local governments to improve coordination and to advance Alzheimer's Disease awareness across levels of government so it could be at the state level.

For example, if you have I think more than half the states have Alzheimer's plans, looking to the national plan, seeing how it relates to your state's plan and making sure that everybody in your state is aware of these plans, the resource available.

And maybe there are some ways that there can be leadership at the state, local and tribal level to for example make people aware of the resources available through the Websites we've mentioned, also through geriatric education centers. I mean, there's a wealth of efforts out there that people need to be aware of so they can take advantage of them.

And it's very important that in addition to spreading the word, implementing innovations and evidence-based programs, making sure that your networks are dementia-capable, it's also important for us to hear from you about what we can learn from you about serving people with Alzheimer's Disease and there are a number of different ways to have input into the national plan for example.

There as I mentioned this fall the advisory council is going to be making recommendations to the Secretary. The Secretary is going to be developing her plan. There will be open comment periods - periodic open comment periods - and people can send comments at any time to napa@hhs.gov, that's N-A-P-A at hhs.gov.

You will hear if you join the list-serve you will hear about those opportunities for comments on the plan and on other things that come out of the advisory council and this slide gives you instructions about how to be added to that list-serve. I would encourage you to do that. We also publicize opportunities for the Aging Network through ACL's various communication mechanisms too.

There are a couple of additional resources in addition to those we've mentioned earlier. One is that you can as I mentioned the advisory council has quarterly meetings.

At the Website you see there, you can get the agenda, the meeting summaries and the slides and videos are all available for each of the advisory council meetings. In addition every advisory council meeting has a public comment period and you can hear folks' public comments also at that Website.

Kate Gordon: And the second resource that you see is just an example of how at the state level we've looked towards expanding knowledge and information about the national plan. The University at Albany School of Public Health created an actual broadcast online that's focused on the public health perspective towards the national plan and how to implement it locally.

And the link that you see at the bottom or if you just want to Google the University at Albany School of Public Health, they have a public health live broadcast that's a frequent broadcast and it goes out to their entire public health network so I'd aim you towards that.

One of the participants in that is a member of the National Alzheimer's Plan advisory council and it's just a different perspective than what you heard from on today's call.

Jane Tilly: And operator, I think it's time for questions now so if you could give folks instructions on how to queue-up for that.

Coordinator: Thank you. If you would like to ask a question, please press star 1 on your touch-tone phone. Please unmute your line and state your name clearly so that I may announce you and to withdraw your question, please press star 2. Once again if you would like to ask a question, please press star 1. One moment for the first question. (Judy Michon), you may ask your question.

(Judy Michon): Okay, can you hear me all right?

Jane Tilly: Yes, thank you. Go ahead.

(Judy Michon): Yes, I'm from Hawaii. We're working on the Hawaii state plan out of the Executive Office on Aging and it's going to be presented to the 2014 legislature.

We have a workgroup that involves public awareness and we noticed on television and radio and print the national, you know, awareness campaign and we were wondering if there was a kit that would be given to the states or to the local Alzheimer's associations so that people could align with that public education messaging.

Kate Gordon: And that's a fantastic question and I apologize that we - this is Kate Gordon - that we didn't get to it as you put it on our online piece so (Judy) the answer to that question is yes, there is going to be outreach to states and we will be working to develop ways to reach out and specifically as I said earlier to do earned media together.

So working with the different states that have Alzheimer's Disease plans or who are in development now so we will follow-up with you directly and if others are looking for ways to connect, go ahead and use that NAPA e-mail address and we will connect you to the resources available but for certain there will be outreach to states that already have plans in existence or that we know are developing them.

(Judy Michon): Thank you very much.

Jane Tilly: And congratulations on developing a plan. That's great to hear.

Coordinator: Christopher Nadeau from New York Memory Center, you may ask your question.

Christopher Nadeau: Yes, is there a role for the National Endowment for the Arts in the NAPA plan particularly related to informing practice changes in long-term care settings?

Jane Tilly: Sure. I think I know that there are various forms of assistance for people with dementia that makes use of various art media, to music, therapy, has proven effects in helping folks with dementia and I know there are various other forms of more, you know, visual arts so I'd be happy to hear from you about that, about those opportunities.

Christopher Nadeau: Is there an opportunity for NEA to be - I noticed in the executive branch agencies - that are part of the planning process and in terms of weighing-in on NAPA, that NEA was not listed as an executive branch agency that was weighing-in on the NAPA plan. Will that be something that will change?

Jane Tilly: I believe some of the requirements around who participates on the advisory council are in statute but I think that's something that could be considered and certainly if not on the advisory council itself, participating in subgroup discussions.

Amy Wiatr: But overall, every federal agency has the opportunity to participate in the planning process itself and providing input to the advisory council.

Jane Tilly: Yes, so there's multiple ways that can occur.

Coordinator: Eric Sokol of the Alzheimer's Foundation of America, you may ask your question.

Eric Sokol: Yes, hi, it's Eric Sokol with the Alzheimer's Foundation of America. Thank you very much for this presentation and for really making some meaningful progress on the strategies and goals of the NAPA plan. It's great that we're only a couple of months out and we have some real tangibles moving forward.

I want to know how is it possible to reach out to some of these groups that are being formed like the interagency task force so that we might be able to partner and provide some training materials and some data and research that might be helpful with that group and the group on the legal training as well moving forward?

(Mettie Patterson): Hi, this is (Mettie) and thanks for that question and one that we have had discussions with both internally and with external experts. Part of our charge is to engage expertise from outside of the federal government as well in terms of developing the plan and we do have a plan to do that.

One of the constraints we have within the federal government is that we are not able to have a joint task force because of the federal legislation and requirement around those groups being formed.

But we have already actively sought input from a variety of advocates and also experts with information around providing services for people specifically with intellectual disability. I'm going to see if Jane has anything to add to that.

Jane Tilly: Yes, I think Eric you were also talking about input into the legal services training. I think the best way for anybody to make available so for example if you know of a training that has been done previously with legal services representatives, you know, use the NAPA Website - you can use the NAPA e-mail address - napa@hhs.gov.

And that mailbox is reviewed fairly frequently so we'll be able to make sure that as those suggestions come in that we get them to the people that are dealing with the various trainings and Websites and things that we've been talking about today.

Eric Sokol: Will do. Thanks, Jane.

Jane Tilly: Thank you.

Coordinator: Once again if you would like to ask a question, please press star 1. One moment, please. I'm showing no further questions at this time.

Kate Gordon: Okay, we have - thanks (Diane) - we have some that have come in via our chat function in our question-and-answer. One question is how can - can you tell us a little bit more Jane - about how that $10.5 million in additional funding in 2013 is going to be used to support family caregivers?

Jane Tilly: Yes, that as I mentioned is part of the President's budget and the idea behind that would be to have an agency within state government that would help lead an effort on dementia capability and providing evidence-based services to caregivers and people with the disease.

We don't have a lot of the specifics available right now. As I mentioned, it's a budgetary proposal and should that budget be passed and we have those funds available, there would be as we always do at ACL a grant announcement through our various media and then opportunities for people to compete for grants. Any other questions?

Kate Gordon: A few questions have come in related to the Hand in Hand training program that Becky Kurtz had talked about earlier which is the training for direct service workers in nursing facilities and just to clarify that that curriculum has not yet been released.

When it is released, it's coming from the Centers for Medicare and Medicaid Services CMS and we will through the Aging Network be releasing information about that through the ombudsman program but also through all of our outlets so that you guys will have access to it but it will be available on CMS' Website.

Jane Tilly: Anyone on the line have any questions?

Coordinator: We have no further questions but once again if you would like to ask a question, please press star 1. One moment, please.

Kate Gordon: Jane, I do have an additional question.

Jane Tilly: Okay.

Kate Gordon: The question is will the additional funding for 2013 focus on the translational research to expand community support for people living with the disease and their caregivers that focus on specifically dealing with burden and depression, the translation of evidence-based programs?

Jane Tilly: Yes, I think the plans are to have that kind of focus but a lot depends on, you know, as you know the budget process dictates the parameters of what we're able to do and I really don't have any more specific information than what I gave you earlier.

I have what - the brief description - that's available in the President's budget but beyond that I don't have any definitive information and that's something that has to pass Congress too.

Coordinator: I'm showing no further questions from the audio portion, ma'am.

Kate Gordon: All right, and we have two more that have come in through the chat function. Jane, could you tell us what was the percentage of individuals in nursing homes who have dementia?

Jane Tilly: So the percentages of persons in nursing homes who have dementia is around 50% and those are people with a diagnosis. I just saw a figure today for residential care facilities and that would be - and that is - 42% and that's based on a national survey.

There are some (Oscar) data, no one else - I don't know if people will know what that is - but that's basically a database that's kept at CMS and they show that nursing home residents with cognitive impairment are roughly half of the people in the facilities but as I mentioned, there tends to be underdiagnosis of the condition.

Kate Gordon: We have an additional question, very clearly stated. In this fiscally challenging times Jane, we see the need for growing and budgets just drying up. How can local government agencies receive funding to increase supply and to deal with that demand?

Jane Tilly: I don't have a good answer to that one. I do know that there are opportunities within Medicaid for example to serve people more effectively and efficiently through various types of waivers. There are multiple opportunities under the

Affordable Care Act for states to receive increased match if they serve more people in the home and community.

There are opportunities to help people who want to do so to leave nursing homes and live in the communities so I would encourage folks to really take a good look at the opportunities under the Affordable Care Act that are out there many of which ACL has had a number of Webinars about some of those opportunities.

And seeing how you might be able to make sure that those opportunities when you take advantage of them, making sure that your general system is dementia-capable in the ways we've talked about. Anything else?

Kate Gordon: Another specific question to that $10.5 million. A lot of questions have come through about how the dollars are going to be used including will they be used to pay for example for adult day services? Will they be used for evidence-based services for caregivers and will that be through a program such as ADSSP?

Jane Tilly: I do not have the specific answers to those questions as I have given you about as much information as I have. I wish I could be more specific but I can't be because I don't know what's going to happen with the Fiscal '13 budget. Now recall that this is not a Fiscal '12 opportunity.

If it is in the final version of the Fiscal '13 budget or appropriations, then we'll be able to be more specific then when once we get instructions from Congress and the Secretary.

Kate Gordon: (Diane), are there any additional questions on the line waiting for us?

Coordinator: We have no further questions from the audio portion.

Jane Tilly: All right. Thank you everybody for joining us and for the good questions and we're very much looking forward to working with you as we work to implement the National Alzheimer's Plan and to connect implementation of that plan with your plans at the state and local levels. Thank you and stay tuned. There will be more to come.

Coordinator: Thank you for your participation. Your call has concluded. You may disconnect at this time.

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