Moderator Rachel Breidster: Hello, and welcome to "Public Health Live," celebrating 20 years of exemplary education for the public health workforce. I’m Rachel Breidster, and I’ll be your moderator today. Before we get started, I would like to ask you please fill out your online evaluation at the end of the webcast. Continuing education credits are available for a limited time after you take our short posttest and your feedback is helpful planning future programs. I also want to let you know our planners and presenters of Public Health Live do not have any financial arrangements or affiliations with any commercial entities whose products, research or services may be discussed in this activity. And no commercial funding has been accepted for this activity. As for today's program, we will be taking your questions throughout the hour by phone at 1-518-402-0330 or via e-mail at phlive.ny@gmail.com. Today’s program is entitled “New York State’s Public Health Approach to Alzheimer’s Disease.” Our guests today are Dr. Mary Gallant, the senior associate dean for academic affairs and professor of health policy management and behavior at the University at Albany School of Public Health. And Ms. Meghan Fadel, director of the evaluation and collaborative projects in the bureau of community integration and Alzheimer’s disease at the New York State Department of Health. Thank you for joining us.

Moderator: So good morning, thank you both so much for joining us.

Dr. Gallant & Meghan Fadel: Good morning. Happy to be here.

Moderator: Excellent. Megan, would you get us started today by reviewing what the objectives are we have for today's program?

Meghan Fadel: Absolutely. Today leaners will be able to describe the New York Alzheimer’s Disease Care Support Initiative, they will be able to list emergency findings from the evaluation of the initiative, and also be able to discuss policies relevant to Alzheimer’s disease and caregiving in New York State.

Moderator: Excellent, thank you so much. The title of today's program is New York State's Public Health Approach to Alzheimer’s Disease. Can you tell us why you see this as a public approach issue and why this approach is so necessary?

Meghan Fadel: Absolutely. So traditionally Alzheimer’s disease has often been seen as primarily an aging issue but really over the past couple decades, we've seen that transform. And there's a few big-picture ways that's been happening. Number one has been the rollout of a
national plan for Alzheimer’s disease and along with that, the rollout of state plans across the country in public health departments. We've also seen the recent release of the third edition of the Healthy Brain Initiative Public Health Roadmap, and that's a publication that's jointly issued by the Alzheimer’s Association and the CDC and really targeted to health departments and giving them concrete ways to try to make an impact in addressing this disease. And last but not least, the Healthy People 2020, which is -- for anyone unfamiliar, it is a set of goals or objectives we set for the nation on a variety of health issues. That recently has started including a couple of measures focused on dementia. It's really exciting to see us thinking about this disease not only from a clinician's view or community support view, but also from the population health standpoint.

Moderator: Excellent. Now, I understand that Alzheimer’s disease that's really a tremendous impact. Can you tell us more about the scope of the disease?

Meghan Fadel: Absolutely. So we see the prevalence of Alzheimer’s increasing and right now it's actually the sixth leading cause of death in the United States. So it certainly has a huge impact on our communities here in New York State. We also see the cost as tremendous and growing. So annually the total payments for Alzheimer’s disease in terms of health care amount to $277 billion dollars. And we actually expect by the year 2050, that will grow to over $1 trillion and that includes things like Medicare, Medicaid, as well as hospice and out of payment costs, we all see that growing tremendously.

Moderator: Those numbers you shared are national numbers. Can you talk about some of the Alzheimer’s figures for New York State?

Meghan Fadel: Absolutely. Here in New York State we have an estimated 400,000 people who are living with dementia today. And we certainly expect that to increase as well. There are also some very real challenges in the field and one of those we've seen, due to looking at the behavioral risk factor surveillance system, which is an annual survey that focuses on a variety of health issues. But we found from that, that over half the people who are experiencing memory changes in themselves have not brought that up to their physician. So we see there's real opportunity to be able to change the course of the kinds of -- not only diagnosis but care and support people with dementia receive. There's certainly some barriers, I think one being stigma and fear, but also people often don't realize there are so many benefits to getting that diagnosis. So we really want to change that.

Moderator: Sure. So let's talk about not only the person him or herself impacted by Alzheimer’s disease but the caregivers. I imagine they're a really big part of this equation.
Meghan Fadel: Absolutely, they're huge. And caregivers actually often don't even realize they're caregivers. Caregivers include maybe people who are providing hands-on support but also people who provide financial support or go to doctors' visits, prepare meals, all of those encompass what caregiving can be. In New York State we have over 1 million people who are caregivers for people with dementia and they provide a tremendous amount of support, valued at over $14 billion dollars. And that's a lot of care our health care system couldn't provide on its own, so they're valuable not only to the person with dementia, but also to our larger systems.

Moderator: Absolutely. I can see the impact in New York State is huge. What has the public health been thus far to address it? And how do we get to where we are now?

Meghan Fadel: One great thing is New York State has really been a leader in this area, and some of the actions focused on Alzheimer’s disease and other dementias has real dated back to the '80s. The 80's is when we saw a creation of a blue ribbon panel of experts who informed policy recommendations for what action the state should take. And it also saw the creation of a couple of service programs, one being Alzheimer’s disease community assistance program, as well as the Alzheimer’s disease assistance centers. Since that time, we've really seen an evolution. In 2007, more recently we saw the creation of the New York State coordinating council for services related to Alzheimer’s disease and that is a panel of experts that again really help inform us. It's been fabulous to be able to have community partners helping guide the direction that we take, and 2015 really is the beginning of what we're here to talk about today, which is the New York State Alzheimer’s disease caregivers support initiative. This was an infusion of funds, $27.5 million on an annual basis, to really expand the infrastructure of support available to caregivers and people with dementia.

Moderator: It really is exciting to see all of the progress that has occurred in New York from the '80s until now. And from what you've told us, it sounds like supporting the caregivers is really an important part of this whole process.

Meghan Fadel: It’s essential. Really the caregivers and person with dementia. There's a wonderful quote from a caregiver in New York State where she says, “I love my mother and want to keep her with me, and now I’m realizing that if I want to continue, I need help in order to stay healthy myself.” I really see this quote as being so valuable for a couple of reasons. One being that it really highlights the desire to remain in the community, which is such a common sentiment, and also it highlights the need to support caregivers, both of which are essential. What we see are the majority of people with dementia do live in the community. Certainly not always the case. And not always in every situation would be the right place for that individual but when it is with the right supports, we really want to be able to enable that. And that’s something we’ve really seen transforming across the country in terms of how we deliver long-
term care, that there's a shift to providing more and more possibilities for care how we give care in the community setting.

**Moderator:** Excellent. If that support is so important, what should it look like? What kinds of supports are effective?

**Meghan Fadel:** Well the great thing is, there’s a growing body of evidence on interventions that are effective. And a great starting place to learn more about those is a white paper published in 2012 called *Translating Innovation to Impact*. This highlights 44 different caregiver interventions that span in terms of the types of caregiver support they survive and that evidence, too, is growing, has grown tremendously since that time. So it's exciting to see there are effective ways to make an impact. And there are some key commonalities that effective programs have. For one, family caregivers are actively involved. They're not just passively taking information in but really involved in the decision making and planning process. We also see that those programs are tailored and flexible to meet the changing needs over the course of a disease and that the intervention meets the needs of both the caregiver and person with dementia. One other point I’ll make about the evidence base too is there have been a growing number of studies focused on the cost savings as well. Not only is it supporting the caregiver and person with dementia, but there actually are a number now that have been shown to have cost savings in terms of health care utilization. So it's powerful for both our health care systems and families impacted.

**Moderator:** Excellent. With that evidence base in mind you can talk about, what does the caregiver support initiative look like here in New York State?

**Meghan Fadel:** So this is an initiative that's again based on that evidence, and it really takes a scalable public health approach to implementing the evidence base. We have, it’s a two-pronged effort. On the one hand there's community support and education and on the other hand diagnostics and professional training. The way we've gone about it too, is to invest in a series of grant projects so we’re really tapping into the infrastructure that’s already in place and really just enhancing it rather than starting from the ground up. And we've also been really excited to partner with the School of Public Health at SUNY Albany to be able to do an evaluation and really understand the effect this is having statewide.

**Moderator:** Excellent. Can you tell us more about the services offered under those grants?

**Meghan Fadel:** Absolutely. So there are a series of core services, and these are again, common to much of the evidence base I spoke to earlier. For one there’s care consultations. This is more individual support, whether an individual or family setting where they can really talk to an expert and plan and problem solve and really discuss whatever challenges they're facing in that...
moment, and for the future. We also offer education, so really designed to enhance the knowledge that the caregiver has about the disease and what to expect. Support groups offer a peer network where caregivers can come together and strategize about how to provide that care and really be able to talk about issues they're facing. As well as respite, which is so important. Respite is designed to give caregivers a break from that caregiving role. And also provide engagement for that person with dementia. We do also have a 24-hour help line to make sure that caregivers are able receive support any time of day or night. And those are just the core services, there are many more beyond that as well.

**Moderator:** Certainly sounds very comprehensive. Since education can be a really valuable resource to help caregivers better understand the disease and build skills of caregivers, we recently visited the Alzheimer’s Association to learn more about a program that builds awareness about the latest research on brain health and wellness. Let's take a look.

**Shannon Lawler:** Hi, everyone! Thanks for coming. This program is healthy living for your brain and body and it's tips from the latest research. There's a lot of great evidence out there in research to promote healthy aging of our brains and our bodies. By the end of this program, you're going to be able to identify the reasons for taking care of yourself as you age. We're going to give you some materials and get you to really start thinking about making a plan and starting today to make healthy choices that can have a greater impact in the future. What we know about aging is it's affected by a lot of different things, our genes, also the environment and lifestyle choices. But we do know lifestyle choices may help keep our brain and body healthy. These are the four areas we're going to talk about today. We're really going to talk about that cognitive stimulation that we can learn at all different ages. You may not have gone to school and got the formal education but you're continuously learning in other areas of your life. Those things we know have protective factors and really help our brain age well.

**Moderator:** So talk to me a bit about what kinds of services are offered through the centers of excellence?

**Meghan Fadel:** Absolutely. There are ten centers of excellence across the state and they offer of assessment and diagnostic services, that's huge. Because over half the people with dementia actually don't have a diagnosis. That's something we want to change. They also offer care management, as well as medical and health care provider training. We really want them to help infuse and really enhance the workforce that's available to offer health care and medical services across the board. And last but not least, they are also tasked with the promotion of clinical trials to make sure caregivers are connected with available options.

**Moderator:** Terrific. Now, how can people access these different services?
**Meghan Fadel:** I would encourage anyone who's interested in accessing services for themselves or to refer clients or patients to visit the website. The New York State Department of Health website on Alzheimer’s disease. If you click on a link focused on ‘where can I get help’, there's actually an interactive map where people can click on the region that they're located in and find out a listing of all of the services available there, as well as contact information for those organizations.

**Moderator:** Thank you so much. Now, Mary, let me turn to you for a minute. I understand that you've really been enlisted as the person to evaluate the impact of the care giver support initiative. What are some of the things you're hoping to learn by the evaluation?

**Dr. Gallant:** Well, the evaluation has quite a few parts but there are key questions we hope to answer when all is said and done. First, we like to get a clear understanding of exactly what services are being delivered across the state as parts of this initiative. And what those services look like and what kinds of barriers and facilitators the service providers encounter when trying to deliver those services. Second, we really want to get a good understanding of who's being reached by this initiative and are these services reaching people all across the state and reaching people most in need of the services? Third, we really want to gain a good understanding of how this initiative is impacting people with dementia and their caregivers, especially in terms of those key outcomes that Megan mentioned like caregiver health and wellbeing and unnecessary hospitalizations and delayed nursing home placement. And finally, we want to be able to describe how this initiative over time is changing the infrastructure in New York State that's available to provide dementia support services. So we want to see how the network of service providers is being strengthened as a result of this initiative.

**Moderator:** Terrific. Now, I have to pause for a moment and just remind the audience if you have questions for our speakers, you may e-mail them to us at any time during the webcast to phlive.ny@gmail.com or call us at 1-518-402-0330. So Mary, Megan said we're really right in the middle of this initiative so I understand the evaluation process is ongoing but can you talk about some of the things you have learned thus far?

**Dr. Gallant:** Sure. Right, the evaluation results won't be able until the initiative is over at the end of five years, but we really learned a great deal so far. For example, we've been able to document really extensive service delivery across the state just in the first two years of the initiative, both in terms of the availability of services, increased availability of services and the utilization of those services. For example, each year, each of the core services that Megan described reach anywhere between 5,000 and 20,000 individuals, and the individual goals that the contractors have set in terms of service delivery and participation in those services has been met or exceeded pretty much in all cases. In addition the extent to which these services are already available to people all across the state in every county is really notable.
**Moderator:** Terrific. Can you put some of those numbers into perspective for us?

**Dr. Gallant:** Sure. So this graphic indicates -- sort of illustrates the community support and education services that have been provided across the state in the first two years of the initiative. Both in terms of the number of those services that have been delivered and number of people that have received those services. So as you can see, these numbers give you a little bit of sense of the scope of this initiative and how large it is. Because there was a fair amount of ramp-up needed in the first year in order to start delivering these services on such a wide scale, we've seen really big increases in year two in the number of services being delivered. So for example the number of care consultations in year two was twice as many as year one. Three times as many caregivers received that service in year two. Similarly twice as many people received education in year two as in year one.

**Moderator:** Certainly impressive numbers. What about the services on the clinical side, can you tell us anything about those services?

**Dr. Gallant:** Sure. As Meghan described, the centers for excellence provide a variety of diagnostic and training services. In the first two years of the initiative, we've seen that they performed over 12,000 diagnostic assessments for individuals with cognitive symptoms and memory problems. They've also trained over 36,000 medical and health care professionals in terms of dementia care and management and including training primary care providers on screening and early diagnosis, as Meghan mentioned. Since one of the goals of the initiative is strengthen the links between the clinical service providers in the state and community providers that are providing more supportive services, it's really nice to see that over 45,000 -- or almost 45,000 referrals have been made by the centers of excellence to community support providers.

**Moderator:** Again, very impressive numbers. Just the sheer scope of people reached by this is very impressive to me. Do we have any data about the coverage across the state?

**Dr. Gallant:** Sure, yes, we have. We've been able to demonstrate for pretty much all of the services that Meghan described that people in every county in the state have been receiving those services. For example, this picture just illustrates in terms of diagnostic assessments, that even though the centers of excellence are mostly concentrated in sort of, larger population areas, urban areas in the state, people from just about every single county in the state have received diagnostic assessments through that service.

**Moderator:** Terrific. So talk to us a little bit about what you have learned so far about the experience of implementing and delivering these services.
Dr. Gallant: Sure. Our contractors and their partners across the state have really had terrific success in implementing this huge variety of services that they're offering. Sometimes these are new services these organizations are offering. Our findings have sort of confirmed and highlighted some of the known challenges in delivering these type of services. For example, as Meghan alluded to, caregivers often don't self-identify as caregivers. And so sometimes recruiting caregivers to participate in these services is a little bit of a barrier. In addition, sometimes there's a little bit of a lack of understanding of what these services are or how they might benefit someone. For example, sometimes it's unclear what respite is or what a care consultation is and why it might be of value to someone. In addition we know caregiving, because of the variety of demands caregivers face, they have a lot of competing priorities so they're probably a lot of times where there are services they would like to utilize but they just can't fit it into their schedule. So that's another challenge. And also our contractors have needed to find strategies to deal with staff shortages. So in the first year of the initiative, about a third of the contractors reported that they had difficulty in recruiting and retaining staff that had experience in dementia, in the types of services they needed to offer. Also shortages in the respite provider work force are well known nationally. On the flip side, some of the things we've found that are really facilitators of contractors being able to successfully deliver service relate to the skillfulness of staff in relating to and really developing rapport and engaging with caregivers. That's really a key aspect of delivering these type of services successfully. As well as contractors have learned they really need to be quite flexible in how they schedule these services in offering programs on weekends and sometimes in the caregiver's homes and things like that.

Moderator: Really try to meet the person where they are in terms of delivering the services that are needed.

Dr. Gallant: That's right.

Moderator: So did the data tell us anything about the people who are being reached by these services, by this initiative?

Dr. Gallant: Yes. So as I mentioned before, the services are being provided all across the state. And even more importantly, we've been able to demonstrate that the proportion of people sort of being served in each region of the state is similar to the proportion of the total New York State population within each region. So in other words, the reach of this initiative is pretty equitably distributed across the state, which is an important thing to be able to demonstrate.

Moderator: Absolutely. So how does this relate to specific populations that the initiative is specifically trying to reach?
Dr. Gallant: One objective of this initiative is to reach populations that have been traditionally underserved by caregiver support services. For example, rural areas are traditionally an underserved population. This initiative has been really successful to date in providing services in rural areas. For example, this graph sort of illustrates that the percent of rural caregivers that have received services in each area is sort of equal or exceeds the percent of rural people living in rural areas in each region of the state. Our providers have also been really successfully reaching lower income caregivers as part of this initiative.

Moderator: Excellent. Again the numbers, the statistics are all very impressive what you have talked about so far. This next video shows an example of the service offered in the home. The Alzheimer’s disease caregivers support anywhere initiative increased access to a variety of service including rural counties with transportation can be a barrier accessing services. In this video a caregiver will share her own experiences with an array of services to educate herself and to find support for her and her husband.

Stacey Barcomb: Today we're going to talk about finding meaningful activities, I know we discussed earlier things you can be doing with Bob. I know he's had changes and there's still so much more you two can do together.

Suzanne Merrell: I had been noticing that he was forgetting things. He was working as a carpenter after he retired and he’d have to keep coming back to get the tools and all, and then his cousin came to visit and he said, so there's a big difference in him. You need to get help.

Stacey Barcomb: Knowledge is power when you are dealing with something new and something that can be frightening and something that can break your heart. My role is that I present in community based settings, public settings with professionals, and privately with caregivers through a variety of topics about caregiving.

Suzanne Merrell: I started going to the Alzheimer’s meetings, met some people that we later joined together to form a support group and just tried to adapt. And that's one of the trainers here and she took us through all of the facts and figures but we still had to kind of work out the daily routine. A friend told me about the aide I have now she's been caring for someone for five years and the woman had gone to a nursing home, and I should call her. So I did. It was magic. She suggested the moving chair at the kitchen table. She has found toys for him.

Stacey Barcomb: We’re able at any time. So if somebody comes up with a question later, they can reach back out. We’re constantly creating new programs based on caregiver need or different considerations from the public. And we're all over. I also facilitate all of our memory cafes so I have one in Hamilton County and one in Washington. And I also facilitate support groups as well.
Suzanne Merrell: We started using the services and going to the memory cafe. That was another huge help to us all. I could even get an overnight away. One of the best things that has happened to me is my daughter brings me up for Pilates. I'm two years in now and I’m strong and I feel strong physically and mentally because of it.

Stacey Barcomb: My role is giving people power, giving them power to make those legal decisions, make those financial decisions, and guide them to the center for excellence for Alzheimer’s disease.

Suzanne Merrell: I had this awful feeling that I thought I would go down into the abyss with him but he's been on this very good plain now where he's just so agreeable with everything and smiles. There’s an intimacy that my daughter said, I think you love Dad now better now than you have loved him in the past.

Moderator: Such an important program. I wonder if you have any other thoughts or feelings that you would like to share on what we just watched.

Meghan Fadel: I think it's a great example of a caregiver reaching out for support, not only terms of education, which is power when it comes to this disease, really understanding what you're facing and what kind of services you can access. I think it's also a great example of the ways that some of our programs have been, very creative in terms of meeting a need in the community. So, for example, transportation can be such a barrier, not only rural counties but really across the board. So this is a unique example of the way they were able to bring some services into the home. And it's been exciting to see all of the creativity many programs have taken in terms of trying to address the challenges caregivers and people with dementia face.

Moderator: Excellent. Mary, are there other underserved or minority populations targeted by this?

Dr. Gallant: Yes, there are, reaching racial and ethnic minority populations is also a priority of this initiative because they're impacted by dementia pretty much twice the rate of white populations. For the most part, caregivers that have been served under this initiative have been largely representative of the New York State population as a whole in terms of racial and ethnic groups, with some room for improvement in certain groups and regions of the state. For example, in New York City we've been very successful as sort of the population of caregivers being served under this initiative, kind of mirrors the population of New York City in terms of race and ethnicity distribution.
Moderator: Okay terrific. So what can you tell us about the caregivers themselves that have been reached through this initiative? Is there insight into the caregiving situation?

Dr. Gallant: Yes, well what we have learned so far is the caregivers served by this initiative seem to be, seem to have been providing care for a longer period of time and at greater intensity. And report sort of experiencing more stress in your caregiving role than a national sample of caregivers. And this tells us that these services are really reaching the caregivers in New York State that are most in need of the services. So that's been a good finding.

Moderator: Absolutely. Since this evaluation aims to describe the impact of the initiative on caregivers and their families, can you tell us what you're learning about the impact thus far?

Dr. Gallant: Sure, ultimately we're interested in knowing whether this initiative translates to beneficial outcomes for people with dementia and their families. And as Megan indicated, the evidence behind this initiative indicates that these services translate into reduced health care utilizations, particularly in terms of less unnecessary hospitalizations both for people with dementia and their caregivers. The evidence base also indicates that these types of services help families keep their loved ones at home when they desire to for as long as possible, so delaying that nursing home placement. And these services lead to, you know, better outcomes for caregivers in terms of reduced stress and in terms of increased confidence and feelings of competence as a caregiver. So those are the type of impacts we especially will be looking at. And I should say we're currently in the process of systematically collecting data to document some of these outcomes. We don't have numbers to share yet but we do have some preliminary indications that these services are leading to these types of impacts based on some qualitative data we have from participants.

Moderator: Which is really terrific. I wonder if you could share, in doing your evaluation, I'm sure you heard particular stories that maybe have resonated with you or told you something about the program.

Dr. Gallant: Absolutely. Here I have a couple quotes to share to give you a little flavor, I think, of the kind of impact these services can have on caregivers' feelings of self-confidence and competence about their role as a caregiver. So for example, one of our participants said, “It’s so nice to have a professional tell me that I’m on track. I want to do the absolute best job I can do as my mother’s care partner. With the help of your organization and information you’ve shared, I feel like I’m prepared to face the progression of her disease and I don’t have to do it alone.” Similarly, another caregiver shared, “It's been reassuring to hear that much of the behavior we’ve been witnessing is common among those suffering from dementia. We're getting better at handling her misdirected anger, confusion and fear. Talking with you about our trials, successes and failures has been extremely helpful.” I think the second quote is a really good
illustration that caregiving really requires a lot of unique skills and that people may not have had experience with before. So these services can really help individuals feel much more competent in that role and much more confident about taking it on and doing a good job.

Moderator: Yes, I would imagine even having that network to talk to, that person said knowing this is common, this is what to expect, I would imagine even having that would provide such a tremendous sense of relief.

Dr. Gallant: That’s right.

Moderator: Do you have other caregiver stories that you’d like to share that exemplifies sort of a key finding in the work that’s been being done so far?

Dr. Gallant: Yes, one of the real difficulties or one of the things that leads to some of the negative outcomes for caregivers and their families have to do with the stress and burden of being a caregiver. So a key impact is that these services can really help caregivers feel less stressed, less burdened. I think this quote is a great illustration of that, “I woke up for the first time in a long time with a calm and a plan. You already have made a great difference in our lives and our parent’s lives by giving us the lay of the land and the ‘permission’ to look at her as a unique person and case in figuring out what is the best way to move forward.”

Moderator: I think that's a very telling quote in and of itself. It doesn't really need much elaboration but just really, really powerful to hear someone say that as a result of the work that’s being done.

Dr. Gallant: That's right, yep.

Moderator: Have you heard anyone else comment on the impacts of the program?

Dr. Gallant: Yes, as Megan said, a lot of times families, one of their goals is keep their loved one at home with them for as long as possible. We're going to be looking at nursing home placement and being able to delay or avoid that as one of the key outcomes. I think this quote really illustrates that, one of the participants shared, “I was so glad she was home when she died. My husband and my goal was to not have her in a nursing home and to take care of her at home. We accomplished this. I want to thank you for being a part of a program that is so important to caregivers and for all of your help and understanding.” Just a key illustration that the key outcome was achieved for this individual and it was important to her and her family.

Moderator: Absolutely. And in a disease that's so prevalent and complex to have that one good thing to hold on to, that you're able to accomplish that goal, must be a really tremendous sense
of success. So in this next video, a caregiver shares her story of how a diagnosis and engagement in support services has benefited her and her family.

Christine: My first thought when David was diagnosed January 6, 2014, was oh, my poor, sweet David. And my second thought was, I will survive this. It all started in 2007 when he was 54 years old. He had younger onset of Alzheimer’s disease. As his father did before him. He knew –I mean, I remember one of the worst days of my life was the summer of 2013 where he said to me, you know what we're talking about here, we're talking about the long good-bye. Things progressed. We got further along. He was missing things. He was getting lost. He was getting very frustrated. He ended up with a psychiatrist because he had so much anxiety. David, I loved him, he loved him, he started to put it together. He said Christine, you realize what you're talking about? You're talking about cognitive problems. He was tested in December of 2013 with a neuro psychologist. It all came out. He was much, much more progressed, and that report said likely Alzheimer’s disease. It's best to know what you're dealing with. It's very important that people are diagnosed appropriately both for the person and for the caregiver. Because what it does, is the diagnosis can inform the progress of the disease. I signed up for the savvy caregiver program that said two things very early on that I have found to be truisms. You can't bargain and you can't reason. And, boy, if that isn't a true statement. And the other thing they said is as a caregiver that everybody needs, every person with this disease needs at least two caregivers. And you have to get somebody involved very early on, besides yourself. Then I also got involved with what the Alzheimer’s association calls their Ease Program. It's another –I think it's eight or ten-week course and you go as a couple and you talk and then you split up into support groups. There's a support group for both the caregiver and for the person with Alzheimer’s. I also used the respite grant program through the department of health, through the eddy. One of the biggest services that both the Alzheimer’s association and the eddy do, is they validate the caregiver's experience and they are actually people who listen to you, which is invaluable. Nobody ever says to you – and I think this should happen almost in the first conversation where somebody says to you -- there will be a time, caregiver, where you will not be able to take care of this person. And you've got to recognize when that time is.

Moderator: Again, such a powerful video, and it makes me wonder if you have any thoughts or feelings you would like to share after reflecting on that.

Meghan Fadel: I think her points on the value of a diagnosis are huge. So many caregivers and people with dementia and caregivers find it a relief to find out what they're facing and it also allows them to access treatment earlier in the disease process as soon as they're able to get that diagnosis. There's also a whole host of benefits in terms of the social supports they can then tap into once they know what they're dealing with. There's tremendous benefits to that diagnosis. I also really love the points she made about not needing, nor should you do this alone, that there
is help available and accessing it is the first step. That's why we're so happy to have these services available in New York.

**Moderator:** Sure. Now Mary, you've talked a lot about how this work impacts individuals. Can you talk for a bit about the impact this has had on New York State as a whole?

**Dr. Gallant:** Sure, I would be happy too. We've already been able to show because of this initiative, even though we're only halfway through it, New York State is better equipped in a whole host of ways actually, to address the problem of Alzheimer’s disease. One of the goals of the evaluation is to document the ways this initiative causes sustainable change in New York State. We're already seeing some of that in some cases, organizations that have never provided dementia services are now providing services in this area. Over a third of our funded contractors have leveraged the funds they received from the state to help them receive funds from other sources, to provide even more services in the dementia area. And so those are some examples that we are already being able to illustrate that the infrastructure for addressing Alzheimer’s disease is changing permanently and being strengthened in the state. The initiative has also contributed to the expansion of the state's dementia capable workforce, both by investing in dementia specific service provider positions as part of this initiative but also through the emphasis on provider and staff training that many of the funded contractors have built into their work. So just as a little example in the first year of this initiative, 186 new staff positions were created at organizations around the state. And many organizations have made staff training and professional development a routine part of their operation, and so that the workforce specific to dementia is really being strengthened. On the clinical side, as I’ve already mentioned, a large number of health care providers have received training on screening and early diagnosis and the preliminary evaluations we have done of those trainings indicate the majority of the providers intend to implement changes in their practice based on what they have learned. That's a really nice thing to see. We're also seeing much more coordination among different types of dementia support providers, which means that the network of providers around the state, both clinical and community support providers, is really being strengthened. For example, just as a result of this initiative, almost all of the community support providers receiving funding through this initiative reported that they developed new informal partnerships with other organizations. Almost two thirds reported that they developed some sort of formal partnerships with other organizations. These organizational partnerships are very important because they allow organizations to realize efficiencies in the way they deliver services or they allow organizations to reach new populations because they're now connected with other organizations. And they allow organizations to sort of share talent and take advantage of others' resources and expertise in order to deliver services most successfully. So that's really exciting to see that kind of coordinated provider network. As the initiative goes on, we will be looking to document ways the infrastructure in the state has permanently changed going forward as a result of this investment that the state has made.
Moderator: Well it certainly sounds like everything you shared, even though we're only halfway into the initiative that terrific changes are happening both on an individual level and statewide picture. Thank you so much for all of the information you’ve shared about the evaluation process. Now Megan, it's exciting to hear this, right, to hear the impact the initiative has had. What other action is the state taking to support caregivers and folks who have dementia?

Meghan Fadel: You’re absolutely right, it's huge to see this expansion of the infrastructure. It really is. And I think when we think about it in context of other action that's been taken, it's really exciting to see progress being made. So a few examples of that include the Caregiver Advise, Record, and Enable act, the CARE act. That requires hospitals to identify a caregiver and provide information about discharge and post discharge care. We've also seen the rollout of the paid family leave act. And that's a really important policy that enables paid time off to caregivers to be able to provide care for a family member. In addition, there's a new program called the New York State Assisted Living Voucher program, and this really aims to prevent the transfer to a nursing home due to inability to pay. Last but not least, the Respite Education and Support Tools Program, which is really designed to train more individuals to be able to provide respite and really strengthen the availability of respite care in our communities. So these are just a few of the large actions that are being taken but relates to caregiving not only for people with dementia but beyond as well. And we're really excited to see progress being made.

Moderator: Terrific. It sounds like New York State is really investing quite a bit in such an important issue and such an important situation that’s occurring with the increasing prevalence of the disease. It's been really great to hear from both of you about the initiative and how successful it's been to date. We're going to spend some time taking questions that have come in from our audience. Bear with me one moment while I pull up the first one we have here. The first question is what are the next steps for the evaluation? Will I be able to see a report?

Dr. Gallant: One of the immediate next steps is to utilize survey data of people who are participating in these services to really drill down and look at some of those outcomes we were talking about in terms of health care utilization and perceptions with stress and burden as well as self-reported benefits of participating in these services. So that's one of the next things. And we're also going to be using some of the data available in the state to try to estimate some of the cost savings that these services are realizing for the state. So those are two of the next steps. In terms of reports, we do put out and Megan can offer more details about that, but we put out intermediate evaluation reports that once they're finalized are available to the public.
Meghan Fadel: We actually do have one available on our website that we would be happy to share with anyone who's interested in reading more. Certainly we want this to be an experience that we can share with other states as well, who may be interested in implementing something similar. Hopefully what we see happening here can just expand support elsewhere as well. So excited to share some of results and certainly there will be more information forthcoming too.

Moderator: It’s interesting you say that about sharing with other states. The next question we got in is what advice would you give to states who want to support something similar to the caregivers support initiative?

Meghan Fadel: I have are a few thoughts on that. Mary, please feel free to chime in as well. Number one something that's been very valuable is really tapping into the infrastructure that already exists. Really utilizing those community partners and infusing that infrastructure rather than replicate or create it from scratch. That's been one I think really important aspect of our approach.

Mary Gallant: I think what we found in the evaluation just seconds that. Because this initiative sort of was a little bit of a combination of funding at higher levels, organizations that already had a long history of providing services in this area as well as funding organizations that were new to this area and in terms of their year one experience clearly and not surprisingly, the organizations that needed to ramp up had to spend a lot more time getting ready and try out these services. So I would echo that suggestion.

Meghan Fadel: Definitely. Another thought too is use the evidence base that exists. I imagine it's out there, a big part of how we justify this program is really being able to show a similar array of services has been shown to have positive impacts on caregiver outcomes, both in terms of mental and physical health, and also in terms of the cost savings to the state as well, which is important when we want to think about sustainability of our health system. Reducing hospitalization, unnecessary hospitalizations, delaying or even potentially avoiding nursing home placements, all of this, there's evidence out there. It's not just an experiment we're doing here. So tapping into that too is something we would be happy to help people access as well if there's interest.

Moderator: Terrific. And it's interesting some of the things you're saying, they are similar themes that I hear on show after show about utilizing existing resources, existing relationships that are already in place. That's something we hear with every successful initiative that we talk about on this show. It's great to hear that echoed. We have another question that asks, what resources are you using to train health care professionals?
Meghan Fadel: So there's a number of resources out there, number of curriculums that have actually been developed, nationwide that are available, and certainly a lot of our community partners are really experts in the field and have developed a number of different training offerings, everything spanning from with the centers of excellence focused on diagnosis, focused on how to assess, how to refer, and how to provide that quality care management. And our community partners train on everything from legal and financial planning for the future to caregiving tasks, how to approach caregiving to ideas about self-care and caregiver wellness. There's really a span in terms of the types of trainings offerings we have. But it's exciting to not only see training offerings for health care professionals but also for unpaid caregivers for families who are facing this disease as well.

Moderator: Thank you. Another question, what are the first things that a caregiver is usually looking for when they connect to these support services to help them with the person with dementia they're caring for? Has evaluation given us any insight into the staging or sequence of services? You mentioned flexibility.

Meghan Fadel: I love that question. A couple of thoughts just in terms of service delivery, people tend to reach out, it really varies. Everyone's situation is unique. But oftentimes people do tend to reach out in moments of crisis. And unfortunately there's still that tendency to wait until you're in that crisis rather than planning for the future. One huge goal across the board is really try to encourage people to tap into the existing supports and try to prevent or reduce the impacts of those crises down the line. There's where, again, I can't emphasize enough how important that early diagnosis is so you can try to plan and really prepare yourself for the future, get that care team in place. Identify who your supports are going to be for yourself as a caregiver and for the person you're caring for.

Dr. Gallant: And I think the evaluation has just illustrated what Megan said in terms of the huge variety in how caregivers access and initiate access with these services. There isn't one -- there isn't one thing we found that oh, this is the sequence of services that caregivers utilize. And so, the recommendation that sort of comes from that is to provide a variety of services because we're noticing that the contractors are finding success in different ways. For some people who are in crisis reaching out, you know, this one-on-one care consultation might be the first step that gets them into a variety of services. But for other caregivers it might be a support group or it might be an education program in the community or it might be one of these joint enrichment programs. The contractors have been really creative in the types of services they're offering, and there's a huge variety in which ones sort of, you know, pique someone's interest and gets them connected with an organization where then they explore more services.

Moderator: Sure.
**Meghan Fadel:** And for people who may be unfamiliar with joint enrichment and what that means too, this could be anything from visiting an art gallery, for example, that includes both the caregiver and person with dementia and gives them a community of support that helps reduce isolation. And gives them kind of a safe place to be able to be comfortable. I think there are still is a lot of stigma about the disease. And so it really gives them a place to be able to share and be comfortable and be social without the focus being all about the disease but against the offering that community of support.

**Moderator:** Excellent. So we have another question, what efforts are being made to do outreach in many rural areas of the state? The areas of low persons of numbered served. This is somebody representing Fulton, Montgomery, and Herkimer counties.

**Meghan Fadel:** I think some of the data Mary shared really speaks to the way this initiative has been successful in reaching rural populations. Traditionally this is a population that don't have a ton of access to services and support so it's been great to expand these more and more to the rural counties. Certainly, there are barriers that exist, transportation being one of them. But I think there's a lot of potential to do more and we're excited about the progress that has been made in that realm.

**Dr. Gallant:** And actually, to date, the evaluation findings are showing the services are sort of reaching rural populations kind of in proportion to the kind of prevalence of those populations in the state. And so at least the findings to date indicate that the services are being sort of equitably distributed across the state and are being pretty successful at reaching rural populations.

**Meghan Fadel:** Some of the strategies that can help in these situations is really tapping into the local community organizations as well as kind of the trust of the people in that community, so making sure our organizations are really making those connections. And also being creative about how services are delivered. We saw a great example earlier about an in-home education offering. There's certainly many examples of that across the state. So those are just a few.

**Moderator:** We have time for one more question. This is someone who wants to know what a memory cafe is.

**Dr. Gallant:** Great question.

**Moderator:** That was mentioned I think in one of the roll-ins in the video clip. Can one of you explain that?
**Meghan Fadel:** That's a great question and a perfect example of a joint enrichment program. Memory cafes are designed to bring together caregivers and people with dementia in a safe setting where they can bond and connect with others in a similar situation. They engage in a variety of different activities to really help just provide social support.

**Moderator:** Terrific. That sounds like an excellent experience, both again for the person with the disease and caregivers. I’ve certainly learned so much with everything you both have shared on this show. I want to thank you both very much for being here, for your work in reaching this population and building infrastructure in New York State to really address what is a growing issue that we need to be planning for. Thank you both very much for your work and for sharing it with me and with our audience this morning.

**Meghan Fadel:** Thank you.

**Dr. Gallant:** Thank you so much for having us.

**Moderator:** I would also like to thank you very much for joining us today. Please remember to fill out your evaluations online. Your feedback is always helpful to the development of our programs and continuing education credits are available for today's program for a limited time. To obtain CNE, CME, CHES, or social work continuing education hours, learners must visit www.phlive.org and complete and evaluation and posttest for today's offering. This webcast will be available on demand on our website within two weeks of today's show. Our next webcast on March 21 is focused on facilitating independent living through accurate completion of MDS section Q. And there's a special edition of *Public Health Live* on March 28th focused on maternal mortality. Upcoming topics are available at phlive.org. Information on public health live and relevant public health topics can be found on our CPHCE Facebook page and twitter feed. Don't forget to like us on Facebook to stay up to date. You can also let us know how you use public health live by taking a brief survey at phlive.org. I'm Rachel Breidster. Thank you for joining us on *Public Health Live*. 