

**Alzheimer's Talks Edited Transcript
Building Dementia-Friendly Communities
with Olivia Mastry**

November 18, 2014

George Vradenburg: Welcome to [Alzheimer's Talks](#). This is [George Vradenburg](#), the Chairman and Co-Founder of [USAgainstAlzheimer's](#) and the convener of the [Global CEO Initiative on Alzheimer's](#).

Thank you very much for joining today. We have people registered for this call from 38 states and from Canada, Egypt, New Zealand and Japan. This is a monthly teleconference series presented by USAgainstAlzheimer's where we bring you leaders that are working in the research field, drug development fields, regulatory field and in the care field so that you can learn about what is happening now to fight this disease and to address its impact on the American people.

Our guest today is [Olivia Mastry](#) who is the Executive Lead for [Act on Alzheimer's](#) in Minnesota and who is a leader in the effort to develop dementia-friendly communities in Minnesota and also increasingly throughout the country.

We have a special guest today, the United States Senator from Minnesota, [Senator Amy Klobuchar](#). Senator Klobuchar is a leader in the efforts in the Senate, and indeed in Congress, to bring more resource to this field. She's been a leader and strong supporter for medical research and innovation generally, particularly from medical devices. She has also sponsored a resolution with Senator Collins of Maine calling for \$2 Billion in annual funding for NIH for Alzheimer's research - extra funding that we clearly need if we're going to meet our national goal of stopping Alzheimer's by 2025. For those of you on the call who may have been part of our Women's Summit here in Washington as part of [WomenAgainstAlzheimer's](#) you may recognize her as one of the featured speakers.

Senator Klobuchar, thank you for your commitment to this issue, for what you do on behalf of the families in this country who are experiencing Alzheimer's, and those at risk for it, and for the caregivers, and also for joining us today to share a few thoughts.

Senator Klobuchar: Well thanks so much George and thank you to you and Trish for everything you've done to advocate for a cure for Alzheimer's and better treatment. You've just been incredible. And Olivia, we know each other from way back and I'm just so pleased with the great work she's done in Minnesota.

Our state is a state that believes you actually can get things done in government. We have one of the highest voter turnouts again this time and I think it's because people despite all of the problems we have right now in Washington and gridlock and people standing in opposite corners of the boxing ring that our state continues to thrive because of people like Olivia that just don't stop believing that you can move things ahead and make changes, and I know you share that as well George.

I'll tell you what's going on here. I was a bit hesitant to give a report from Washington given everything that's been happening but I'm hopeful we're going to be able to get through the end of the year without another shutdown although there are some people saying that and just so you guys know in the last shutdown I was so angry with what happened with NIH, including the NIH research for Alzheimer's, people were furloughed, put out of work, that I'm the only senator that gave my entire shutdown salary to NIH as a gesture to say we don't just hurt airports and national parks we're also really ruining people's lives and slowing down the effort to get a cure. So I'm hoping that sentiment will carry over.

I think one of the smartest things that the movement has done on Alzheimer's is that you have been bipartisan in how you approach people. Susan and I love working together on it and I think that will continue and you have many Democrats and Republicans. I think we're going to be going into a new year where I believe not all is lost that there are some possibilities to move forward on a budget and do some smart things. And one of the arguments I always like to make at home and particularly with my Republican friends is really a fiscal argument when it comes to Alzheimer's. We obviously have the moral arguments about helping people in need and making people's lives better. And we all know someone who has Alzheimer's or we've lost to Alzheimer's and we know how personal that is and why the issue is so personal. But beyond that we have the numbers, over 5 million Americans living with Alzheimer's, including nearly a hundred thousand people in my state, and we see this increase in numbers coming before us with baby boomers aging. By 2050 an estimated 16 million Americans will be living with the disease - that is a 320% increase over today. And I think we're all blessed that people are living longer, I once called it the "Silver Tsunami" and some seniors got mad at me and now I call it the "Silver Surge" so it's more positive; but we have a lot of people living longer and we're going to see more Alzheimer's with that. So it makes it even more immediate and urgent that we put the money toward a cure.

In 2014, we're going to spend \$214 billion caring for people with Alzheimer's, by 2050, 1.2 trillion. And I think you all know the fact that we just don't have the money we should have in the budget for research. There are amazing institutions all over the world that are doing research in Alzheimer's including Mayo, from my home state, which is also the clinic where the Chair of the [Advisory Council on Alzheimer's Research Care and Services](#) for the country is someone from Mayo, [Ronald Petersen](#), and he's leading Alzheimer's research and we've done incredibly breaking edge research at the University of Minnesota as well.

I always argue that this is about 1) the right thing to do, 2) the long-term economics that we have to cure Alzheimer's and then 3) the research. And doing the research in our country means jobs in our own country, and I've seen it right in my state. So those are the arguments I use. I'm sure you all have your own, but I do believe that we're going to have to do something with NIH funding one, focused on Alzheimer's and then secondly looking at some kind of a trust fund in general for NIH and getting rid of some of the draconian sequestration caps. There are two different bills I'm on that do that and Senator Durbin and Senator Harkin have both been involved in this issue.

Last thing I'd mention is terms of what we need to do going forward, and I always call this the "elephant in the room", and that is the taking care of this increasingly aging population and making sure that those caregivers, particularly caregivers of people with Alzheimer's, are incentivized to continue giving that care with tax credits and other ways and I've introduced and led some bills on this with Senator Mikulski. But I think it is something because we're still dealing with the Obamacare issues and some of the fall-out from that as well as some of the

improvements that can be made, we still haven't gotten to that hard issue of long-term care and how we're going to go into this next few decades in dealing with this in a better way. I know that the group that's on the phone right now will be leaders on that nationally but I think you know at some point that issue is going to hit the ground it already has from our perspective anyone that works in the field or is in a state that has a lot of seniors, we've seen it, we know that's the other thing that we have to work on.

So I continue to reach out to Republicans, I have the desk that Hubert Humphrey once had and he was always the eternal optimist. And he always said that until the end no matter if people considered him a sentimentalist that he believed in this great American experiment in democracy – and that's what I think and I think if there's anything ripe for bipartisan work it's this area of curing Alzheimer's. Thank you.

George Vradenburg: Senator, thank you so very much for joining us. Thank you for your leadership in the Senate and support for NIH and particularly for funding Alzheimer's disease. You're welcome to stay on the call but I think that you may have a few other things...

Senator Klobuchar: Just a few votes coming up and a few things going on but I appreciate that offer George and I'm sure I will see you and Olivia and everyone else soon. Thank you.

George Vradenburg: Thank you.

So today we do have Olivia Mastry on the phone, a constituent of Amy Klobuchar, and a leader in the effort in the country, but her initial work on dementia-friendly communities started in Minnesota. Olivia is the Executive Lead for ACT on Alzheimer's. She combines her training and experience in law, public health and conflict resolution to facilitate cross-sector collaborations. She focuses her work on achieving large-scale systems change through a unique collaborative forum called the [Collective Action Lab](#). And through her efforts, and through collaborative efforts across the state of Minnesota, she is creating dementia-friendly communities across the state.

So just a reminder, if you have a question during the call please press star 3 on your phone by pressing star 3 you'll be placed into a question queue. You'll talk to a member of our staff and we'll try and get you live on the air as soon as possible when we open it up for questions. If you are listening to us online, you can type your question in the box and we will get to as many questions as possible after the opening discussion with Olivia Mastry.

Thank you Olivia for joining us today. I'm really excited to learn more about what you're doing in Minnesota and how you think we might be able to expand the work that you're doing in Minnesota across the states. So take it away.

Olivia Mastry: Thank you George. I appreciate the chance to share Minnesota's work. Alzheimer's is a topic for me where personal and professional life has intersected. So while I've been focused on this work professionally for a number of years, it's really grounded and informed by the fact that my husband's mother had dementia. When she was widowed in 2000, he and I were responsible for her care and support during the last four years of her life: first in her home, then in our home, and finally in assisted living and hospice. All while we had very young children and I ran my own business. So we were a textbook sandwich generation and we learned

firsthand what was and what wasn't available to us in the community to support that journey. So with that background and context, my work with ACT on Alzheimer's was a natural fit.

ACT on Alzheimer's is essentially working to swarm the issue of Alzheimer's disease from many angles by simultaneously focusing on interconnected goals that address the economic, the clinical, the caregiver and the stigma issues surrounding Alzheimer's disease and related dementia.

We knew when we established our goals in 2011 that 70% of people with dementia continue to live in their own homes and they not only need but they want to successfully navigate and be engaged in community life. So we recognized that our impact as a collaborative would depend on our ability to effectively catalyze and equip communities to raise local awareness about dementia and to step up their support for residents who are touched by this disease. And actually whether we realize it or not most of us are touched by this disease, even if only indirectly. So with this concept of community at the critical core of our work we looked to the literature, to studies, to interviews and other information reflecting the lived experience of people with dementia and their caregivers to define what a dementia-friendly community should entail. We also look to the work of other countries and to the [World Health Organization's criteria for age-friendliness](#) because we recognized that dementia-friendly is really just a stepped-up version of age-friendly and it's also a critical element of an inter-generational livable community.

So in one sentence we defined dementia-friendly community as informed, safe, and respectful and that fosters quality of life for people with dementia and their family caregivers. So what might this look like? Everyone fully engaged in community life, as they so choose, without the isolating stigma surrounding those with dementia and with built-in supports and props that enable day-to-day living even when one has cognitive impairment. Now some may say that's just not possible but we actually used to say that's not possible about providing meaningful access to community for people who have physical disabilities. And we have effectively changed the landscape around access to community for people with disabilities that are physical. So we're convinced that we can do the same thing for those who experience cognitive impairment.

Research has already identified many of the programs and services and supports that are helpful to people with dementia and their families as they continue to engage in community. So we actually have the information we need to do this work right at our fingertips. And a prominent theme that emerges out of that research is that each sector of a community can do something to be dementia-friendly, whether that sector is clinical or faith-based or financial or government or business, legal, transportation. So a bus driver or a taxi driver can be dementia-friendly, a beauty salon can be dementia-friendly and your next-door neighbor can be dementia-friendly.

[ACT on Alzheimer's developed a toolkit](#) that could guide community sectors in understanding their unique role in becoming dementia-friendly and foster cross-sector engagement. The toolkit provides two types of support: it provides content support regarding dementia-friendly resources and programs and also process support regarding achieving effective community change. So with respect to content support, what we did was we packaged information that can help community sectors step up to become dementia-friendly. We first developed just a dementia-friendly community visual and that visual synthesizes the principal aspects of dementia-friendliness at the community level. As well as created a one to two page guide or checklist that

identifies how each unique sector can become dementia-friendly using state, national, and international resources that are tailored to that sector. The resources reflect best or promising practices as informed by people living with dementia. So for example, a business can access guidelines for store design, signage, staff training to support people who may become disoriented while in their store or when they're engaged in a transaction. A clinic or a hospital could access information about creating a calm and supportive clinical setting to serve their patients and also access optimal dementia care road maps that can guide them from detecting and diagnosing Alzheimer's disease and related dementias all the way through end-of-life planning for their patients. Another example is faith communities. They can access sermons on living with dementia, faith community support programs for respite and caregiver's support and faith-based awareness and sensitivity training for community faith members. So that's the content support we've developed. And we've also developed that process support about how to move towards dementia-friendly as an entire community. We do this because we know it's not enough just to show communities what to do many communities will need support regarding how to do it effectively without losing traction along the way. Thirty years of research shows us that if communities engage the right leadership, and that means leadership that's reflective of the broader community it's representing, and they organize under a clear structure with shared goals and then they create a shared plan of action, that community will produce more effective and sustainable community change both within as well as across their community sectors.

So using this research we identified four distinct phases that a community would want to move through when seeking dementia-friendliness and throughout all four phases we offer technical assistance through two organizations that have a statewide-reach within Minnesota and that are well-grounded in the content and the process of moving towards dementia-friendliness. Those organizations are our statewide network of Area Agencies on Aging and our Alzheimer's Association Minnesota-North Dakota Chapter. Now community groups often start in their technical assistance process with understanding whether they're ready to act. For example, questions they would ask and answer are: do we have a ready champion and coordinator willing to take this work on? Are there well-networked organizations already among us as well as well-networked people likely to engage in this effort? Have we ever taken anything on sort of like this before, or have we ever tried to address dementia awareness or touched the disease issue in some way? These are all signs that a community may be well-positioned to take on this work. And lastly but most importantly, a community would want to ask is there someone living with dementia in our community who will give voice to this work and provide a guiding conscience for our efforts.

So with that process and that content support in mind, we named the four phases and I'll just tell you a little bit about them. The four phases are: Convene, Assess, Analyze and Act Together. Phase one is Convene and in this phase a community champion or a group of champions convenes key community members to form an action team. This team is absolutely critical to the dementia-friendly community effort and it is the true catalyst for leveraging change, regardless of who else tries to take credit, it is the action team that gets this work done. Ideally the action team is a mirror of the community and at the center are people with dementia and their family caregivers. The broader and more diverse the community action team, the more influential it will be in affecting change. I know that a community is well-positioned to succeed when I walk into an action team kickoff meeting that includes elected officials, sitting by store owners, sitting by local police and emergency responders, sitting by clergy, real estate agents, financial planners, health and social service

providers and local youth and they're all sitting beside a person with dementia and his or her caregiver and their concerned neighbor who lives down the street.

That moves us to phase two which is Assess. Once an action team is convened, the team members take a questionnaire to people throughout the sectors in the broader community, so they expand their reach. This questionnaire is an awareness raising activity in itself and it starts a conversation that's intended to gauge three things for the community. Number one, how aware are we as a community about dementia and its impact on us? Number two, what's our comfort level with effectively interacting with people with dementia and their caregivers? And number three, what do we need to be more dementia-friendly? This process usually results in questions like: gosh, what will happen next? or how can I get involved? or is there something I can specifically do? And so the community engagement process truly takes hold in this assess phase.

That takes us to phase three which is Analyze. And that's when the community analyzes the collective responses they received from the questionnaires across all the sectors of community to identify the areas of need that are beginning to show up as highest priority for community members but perhaps have the lowest activity levels. It might be about general awareness about the disease itself, it might be around special supports for people with Alzheimer's disease or their caregivers such as adult day programs. This analyze process really reveals the sweet spot for that unique community where the community might have great momentum and passion for shared action. Once the community identifies where those priority goals fit, where that sweet spot is, they're then provided with a menu of best practices and programs that we already know exist that match those priority goal areas and the community can choose from that menu or they can create their own unique response to the identified needs.

And that takes us to phase four, Acting Together. And this is really where the community implements one or more priority goals they've selected together that will foster dementia-friendliness at the local level. We have many communities that work right now. Some examples of what they've done in this Act Together phase are designating dementia-friendly businesses, those businesses willing to think about their store layout, their customer service, and how they support and approach their customers who might experience cognitive impairment would be designated as moving towards dementia-friendliness and that would be a sign to local residents that this is a place I can go and continue to interact and enact daily business and it will be okay, it will be safe, it will be respectful. Another community has adopted a program out of the UK called [Dementia Friends](#) and that's really an on the ground, train the average person about how to recognize signs of impairment and how to respond compassionately and in a supportive way rather than turning away for fear of doing the wrong thing. It has spread throughout community so more and more people are more aware of the disease and how best to respond to signs and symptoms of dementia. Another activity that communities are undertaking is to train local emergency responders to recognize cognitive impairment and know how to respond sensitively and appropriately. We're creating memory cafes to offer more engagement opportunities for persons with dementia and their caregiver. We have faith communities that have developed programs to train their clerical team as well as to developed faith-based caregiver support programs. They're even training their youth within their faith communities to understand the impact of the disease on their own families or perhaps their friends' families. And we're also working with some government centers to look at how do public space, transportation and other types of community planning need to incorporate the needs of people who have cognitive impairment.

Currently ACT on Alzheimer's has 32 communities acting across our state from rural to metro, they include geographic communities, cultural communities and faith communities. Each of these communities define their own scope to gauge their needs and they are implementing dementia-friendly changes that best align with their priorities, their culture and their values. We're currently filtering this toolkit through various cultural communities and perspectives and we're going to adjust it as we receive feedback so that it can resonate and have meaning for all cultures. This includes translating key components of the toolkit into other languages, changing terms that may be confusing or lack meaning in some cultures, and ensuring that the toolkit has just enough process to guide a community through the journey but not so much that it hinders the creativity and the unique responses and customization that each community may want to give it. Our toolkit is free, it's available for download by any community from our website actonalz.org. It's not just available for those in Minnesota and while it is somewhat specific to Minnesota resources for the most part it is universal in its approach and it includes national and international resources and programs that are showing promise. The toolkit includes a readiness survey, it has templates for inviting stakeholders, templates for sending out press releases, sample meeting agendas, webinars and short video tutorials to help communities navigate this process rather than to recreate the wheels. Our vision is to ultimately take the toolkit and enhance and automate it so that the resources are available and easier to use by all communities across the U.S.

While this process is designed to enable people with dementia to continue to access and engage in their communities and to support their caregivers, the results of the work will really benefit all of us. Fostering access that helps those with cognitive impairments will help everyone in the same way that fostering access to community for people with physical disabilities has and continues to help us all. Just as the curb cut and the automatic door have helped many people without physical disabilities, better signage, safe walking paths, improved public space design and sensitive, helpful service staff and compassionate neighbors will help all of us whether we have dementia and regardless of age or disease status. This work has really been magical in its ability to strengthen the infrastructure and the support of fabric of local communities. One of our action team members who is living with dementia recently shared through his caregiver that while dementia is not a blessing it can be something from which blessings flow and I have to admit that it certainly feels like the movement towards dementia-friendly communities is one of those blessings. We've learned a lot of lessons along the way in this journey but rather than list them for you now, perhaps it might be best if I stop and take questions and then share those lessons learned as I answer questions.

George Vradenburg: That's terrific, Olivia. Thank you so very much for the clarity not just of this report but also the clarity with which you're conducting your work so that it can be replicated. It does not sound so unique to Minnesota as you've explained it that it couldn't be taken on by other communities.

So let me ask the first question. If you don't have an Olivia Mastry in your community, how do you start this process? I mean where do you look? How does that initial action team get formed and kickoff?

Olivia Mastry: Right. Well they're actually are a lot of Olivia Mastry's out there because there are champions in every community who think about this, who have experienced it personally, and can simply start a conversation with others who might be interested, show them the tools and the process and say, is this something that you'd want to get together and do? And the more you start those conversations the more they'll build on each other and they'll ultimately lead to a kickoff event. One of the reasons we want to make

this a U.S. wide resource is that everybody already has access to the centralized resources but we really want to embed in states local technical assistance support as well. So whether that's area Agencies on Aging, local Alzheimer's Association chapters, or some other vehicle to help communities walk through this journey that could also be available in the next year or two if we're successful in those efforts. But really it just takes that individual who cares, who wants to see change to go to the website, use the resources, and bring others in at the local level.

George Vradenburg: We have an online question here from David Cook. Asking how do caregivers figure into your plan?

Olivia Mastry: Caregivers were integral in helping to develop the toolkit and they're also integral to every action team. We don't have any action teams that don't have caregivers among the working group, constantly informing the process and doing a lot of the legwork. So they're very much a part of shaping the toolkit as it exists today and also implementing it at the local community level.

George Vradenburg: We have a question here from Mike Hellyar from Ohio. Mike, could you ask your question?

Question: Yes, the senator in the opening mentioned something that I've been concerned about and that is caregivers at home. I'm a caregiver for my spouse and some people have to give up careers early or if they intended to continue work they have to give that up, and so there's a tremendous financial burden for which I have not found any tax relief or other assistance and it's troubling me and I could see down the road it's going to be huge issue.

Olivia Mastry: So thank you Mike. I have two passions in my life now, one is around Alzheimer's and the other is around how can we reform our long term service and support financing system so that those who have diseases like Alzheimer's disease and their caregivers get the kind of financial support and help they need and so these are intimately related and there are national efforts afoot right now to take on that very issue and look at what kind of supports can we give caregivers what kind of long-term care service and supports, financing support, can we give people so that they have more flexibility to serve in this important caregiving role. So these two efforts are really quite parallel and very much interrelated.

George Vradenburg: And to add, these are anecdotal and not satisfying to me yet and Mike it won't be to you, but there is an effort with Medicare to think through how it is that a Medicare beneficiary with Alzheimer's can actually get a caregivers support package so that the caregiver is adequately both treated in support and financially to be effective in their "job" to take care of the Medicare beneficiary with Alzheimer's. That's a bit of a strange way to put it, but nevertheless that is a way to shape it so that in fact they can provide support for caregivers who are under 65. The other thing is pending before Congress now is a bill that would give caregivers like yourself who are essentially pretty much full time the equivalent in terms of their social security benefit that they would have earned had they been working in the workforce. That is a bill and it's been supported by quite a few members of Congress it is not a bill that I would say to you will have imminent passage. But there's no question that the caregivers are the front line response to this disease and to the people affected by Alzheimer's and other dementias and that there's increasing attention but only the

beginning of increasing attention to the caregivers who in a sense are secondhand victims of this disease. So thank you for your question and thank you for taking care of your spouse.

We have a question here from Sally Tartre from Maine.

Question: Hi. We are in the middle of working with our community on an age-friendly community. I run a non-profit in town that specifically helps families with Alzheimer's and we're looking to partner with them and I was wondering if Olivia has done this with any other community where you work hand in hand.

Olivia Mastry: When you say when you work hand in hand age-friendly alongside dementia-friendly is that what you're asking?

Question: Yeah, how that looks so we're not double dipping in things so we're getting the same stakeholders around the table, the same process but we're a little more unique as far as the dementia piece.

Olivia Mastry: Yes, so I've seen that happening in local communities that start with age-friendly and then they build on a dementia-friendly focus or lens to their work. For that very reason, it makes so much sense to coordinate efforts the stakeholders are the same. You're really talking about very similar initiatives that complement each other, they don't conflict. And so coming together and identifying where do you have common goals? and how can you move those forward? is really important and that's been happening in at least one community suburb of the Minneapolis area here in Minnesota and it works well when you can combine those two efforts.

Question: Thank you.

George Vradenburg: Thank you for your comments. We have a question here or a comment really from Carol Roberts-Wilson from Florida. Carol?

Question: I am a very skilled speech pathologist for 42 years and I worked with older geriatric people with dementia and Alzheimer's and have done a lot of caregiving during my working years. I just retired last Friday so moving on to help out Brevard Alzheimer's Foundation to see if I can help the community out and build some other information for caregivers.

George Vradenburg: And I think you just printed out Olivia's toolkit. How do you find it?

Question: Yep. Well I went online while we're talking and printed out some information and I know the Brevard Foundation and also I'm working with another organization that's Aging Brevard for Seniors. So I'm moving onto my volunteer work. So I want to thank Olivia for all the information also.

Olivia Mastry: You're welcome. Thank you.

George Vradenburg: And thank you for using Olivia's materials, which are terrific.

I've got a question from Ian Kremer who is the Executive Director of [Leaders Engaged on Alzheimer's Disease](#). A 71 member organization Alzheimer's serving group really the unified voice of the disease or at least those who fight against it. Does ACT on Alzheimer's encourage early detection and diagnosis, and if so how?

Olivia Mastry: Yes it absolutely does. When you look at that dementia-friendly visual that's on our website, there is a clinical dementia-friendly cloud that identifies what does it mean to be dementia-friendly if you're in the healthcare provider world? And it begins with identification as early as possible and detection of Alzheimer's disease and related dementias. And it not just begins with that, but we brought together a group of clinical experts across the state and they have developed both evidence and consensus based tools that will guide the primary care clinic, the healthcare home, the hospital and all other aspects of the continuum from very early stage all the way the through planning for end of life through the disease process. Always using the best practice tools for providing that care and so within best practice is included early screening for the disease and early detection so that early support can be provided as soon as there's detection.

George Vradenburg: Thank you. Again another comment here from Charles Denny online. What should the federal government do that would support and further your community work?

Olivia Mastry: So the federal government has a unique role that it could play in that it could help foster the development of this centralized resource. Taking what ACT on Alzheimer's just created and using it as a foundation but building it out, automating it, and making it U.S. wide so that then anyone could access it and use it and it's more self-directed than it might be today. I think the federal government could have a role in that because it could foster that collaboration that it would require to do that and then it could also support some of those on-going technical assistance vehicles. So for example, area Agencies on Aging have a role in supporting communities through this journey there's such a direct link between their work and for example the Administration on Community Living. So I think taking a partnership role and a developmental role in creating a national resource for dementia-friendly community and making sure it gets implemented across the U.S. would be a great role for the federal government. It really is a private-public effort.

George Vradenburg: We had a question that came in before the call from Barbara Auten from Baton Rouge, Louisiana. How do we get the media involved and reporting on the efforts not just covering it but promoting it?

Olivia Mastry: Sure. The approach we've taken, because sometimes the big media doesn't take this on, but what we found is that at the local community level there's a real interest and a real embracing in fact. Some communities even have local media people on their action teams who will begin to tell the stories around Alzheimer's disease and the impact it's having on community and then begin to tell the stories about what we can do to collectively address some of those impacts and so we created, rather than big splashes and big explosions of media, constant buzz. And that buzz has really collectively come together to tell a much bigger story than any one big media story might. And so that's where I would start is always with that local community taking action, bringing in the local paper to do a quick story, do a quick radio program, get a quick news clip on the local news and that builds up community by community. Our website does have some sample templates that communities can begin to use to start telling those stories with the media audience as a focus.

George Vradenburg: This is just a reminder to people on the call. If you have a question during the call please press star 3 on your phone by pressing star 3 you'll be placed into the question queue. Please have your question ready to share briefly with a member of our staff, or if you're listening to us online type your question in the box provided.

We have a question that was submitted before the call from Kristie Miles in Virginia about the involvement of the faith community and how do we get meaningful worship services for our residents in a memory support unit? I know in fact one of the founding members of our [ClergyAgainstAlzheimer's network](#), Rabbi Esther Adler of Mount Zion Temple in Saint Paul was a test site for your ACT on Alzheimer's efforts. So if you could just talk a bit about the faith community, their role, how they've engaged with your efforts in Minnesota, I'd appreciate it.

Olivia Mastry: Yes, they've really been a very important vehicle for both support but also for learning and growth in this effort and they are a recognized sector within the community that we focused a lot of resource development on so that they can respond in the best ways possible.

From a faith community's perspective, coming into the faith community and what should that look like and how should places of worship be dementia-friendly. But then there's also reaching out to make sure those who can no longer come to faith communities get the outreach and the support they need. So on the coming in, we've coalesced a number of national and international resources that provide for what does even the design of a faith community look like so that people with dementia can continue to take part. Do they have quiet spaces? Are there places that have less stimulus on the walls and where they can worship and continue to be part of the community. We have training processes that allow those who are in the faith community, the actual members of churches or temples to learn what does cognitive impairment look like? How does one respond compassionately and sensitively? How do we continue to welcome people even though they may have cognitive issues? We also provide sermons for clergy to deliver the issue in order to raise awareness and have people think about this disease and think about as a faith community. What are specific programs and supports they can offer to families like caregiver support or respite programs. We also then provide some tools to help those who are going out to make sure that they're finding individuals who may have cognitive impairment who are part of their faith community but can no longer visit that faith community and make sure they're reaching them, they're identifying who their caregivers are, and they're also supporting the caregivers providing them with spiritual support.

George Vradenburg: We have a comment here from Linda Straub. Who says dementia is a disease that's probably already in the second stage when diagnosed. How does the dementia-friendly community respond before the moderate stage? It raises the question for me when you use the analogy of the physical disability community and we developed curb cuts presumably for those with wheelchairs and those who had difficulty stepping off curbs. You can actually see the disease. How does a dementia-friendly community detect the disease and the cognitive impairments and respond appropriately to individuals?

Olivia Mastry: Well first of all I would say that a community doesn't actually try to detect. It is simply equipping itself to address any issue and let's start all the way back before anybody maybe would have dementia and the community can actually start working on brain health initiatives so that the community immediately equips itself with opportunities for all of us, to stay as healthy as we can. And by healthy we just don't mean from the neck down we also mean from the neck up. So that's the starting point for all communities to equip themselves.

Beyond that, if members of a community equip themselves for what does it look like when someone's struggling with a store transaction? Forget whether they have dementia or they don't have dementia. How can I respond as a sensitive customer service staff? How can I respond as a bank teller to make sure that I can prompt rather than hinder that transaction? If we all equip ourselves with better signage, safer walkways, clearer paths and way finding supports, regardless of whether we have dementia or not we will be equipping ourselves to support people with dementia. And then we don't have to worry so much about whether the person we are interacting with does or doesn't have dementia the only people who really need to be thinking about that are families experiencing it and obviously clinical providers who are detecting it. The rest of us can just be supporting each other as we have impairment issues whether they constitute a disease or not. I really think that that's probably the best way to do it, take universal changes - they may be targeted for someone with dementia but they are universal and we equip ourselves to support everyone. So it doesn't matter if you see it or don't see it, you're able to support.

George Vradenburg: And a couple of people who've asked questions about how to access the toolkit and I think you referred to actonalz.org as the website where you can get your toolkit. Is that correct?

Olivia Mastry: That's right and then there's a tab that's titled Dementia-Friendly at the horizontal top of the page. So click on Dementia-Friendly, and that will take you to the [toolkit](#).

George Vradenburg: So we have a question here from Janice Wade-Whitehead from Alzheimer's Tennessee.

Question: Hi Olivia. I was wondering how many cities or communities in Minnesota are currently adopting the dementia-friendly community initiative? And then also is there a benchmark, a tipping point, when there's a percentage of businesses or retails or community-wide where you say, okay we can declare ourselves a dementia-friendly community?

Olivia Mastry: Hi Janice. Great question and one we've asked ourselves. There are 32 communities across the state from as far north, the very tip of the state International Falls, to very south of the state Harmony, Minnesota and everything in between metro, rural, and communities don't just define themselves geographically. We have some communities that are focusing on specific cultural and ethno-racial communities. We have two communities specifically focused in African-American communities, they have the highest rates of dementia and so they are taking some unique approaches and then we have communities also focused in the Latino population, again high incidence in communities there and we have some faith-based communities at work as well. So we're really seeing a little bit of everything.

We don't ever say that we're done, we're dementia-friendly. What we encourage communities to look at is how do we foster dementia-friendliness? How do we work towards it? Like anything we can always be better and so it's always a journey. It's always an improvement process and so we don't really say stop. We try to give some guidelines about what is it you're trying to achieve? What is that you're looking for? What are some general optimal standards you'd hoped to reach? But there's never really a stopping point.

Question: Thank you.

George Vradenburg: Let me ask a follow-up question to Janice's and that is how do you, and if you can, find indicators of progress? A community declaring itself dementia-friendly is one thing another is actually to measure, if you can, how the dementia-friendly community is actually impacting people's lives?

Olivia Mastry: Yeah. We have a short term and a long term approach to that and on the short term which is where we are right now, it's a little bit more process-oriented. We're doing a formative evaluation that's helping us understand this, in the communities that are at work here we're really trying to identify what changes were made as a result of this dementia-friendly work? What new practices were adopted, by whom, and in what sector? Where were there sectors that really you didn't get to respond, that we need to focus on more? Who were the ones who were readily at the table and willing to change their practices? So the first step is around what's actually changing in access points to community and practices of those in community? The longer-term measure is what's it like to live in community with dementia in a community that isn't dementia-friendly versus one that is working towards dementia-friendliness? And has that changed for the person living with the disease? And has that changed for their caregivers? And that's really the long-term effort that we would be focused on by following those living in communities to see what does it feel like now versus earlier. And that's a longer-term measure because it takes a while for those practices to get embedded so that one can actually judge whether life is changing as a result.

George Vradenburg: I've got a question here from John Baber, is your effort based on a 501c3 organizational model?

Olivia Mastry: It really isn't. It's a statewide collaboration and it involves over 60 public and private organizations and hundreds of individuals. We organize in a very disciplined manner with a shared set of goals and we stay very focused on those goals and we have set measures we're trying to achieve in terms of the systems and social change. We do have to act like a legal entity and so to do that we do have a fiscal sponsor that allows us to do that but we purposely chose to stay in a collaborative model because we heard from the leadership, and we really have engaged leadership from all aspects of the state, all sectors of the state, that staying in that collaborative mode has helped everyone feel personally responsible to carry some of this water on this big complex systems-change task we've undertaken. There was some concern or risk that someone might cede responsibility to a single organization when this is an issue we all have to own and carry together.

George Vradenburg: I think our last question is from James Creasey in Englewood, Colorado. James?

Question: Thank you George. Thank you Olivia. I'm very excited to hear the clarity of a vision and your enthusiasm for what you're up to and even better some of the results you've achieved so far. Could you say any more about some of the age-friendly, dementia-friendly, inter-generational things that are in the toolkit?

Olivia Mastry: Sure. So when you start working on dementia-friendly work, you by nature are beginning to address or you are addressing age-friendly needs as well as inter-generational needs in that what will serve someone with dementia is probably the farthest into the spectrum of need and so you've probably already created some supports and prompts for people who are simply aging in community.

Serving people with dementia would include housing that will allow you to adjust and support your changing needs without you having to move necessarily to a next or higher cost setting, that's one change. As we age we

know there are brain function differences. It's not disease pathology but we process differently at age 55 than we do at age 25. We benefit as we age by clearer signage, by safer walkways, by better way finding. So by creating those to help people with dementia, you're actually creating age-friendly supports. We also know the awareness around issues of dementia also raise awareness on what does it mean to age in community and so transforming attitudes about those who have cognitive impairment will help us transform attitudes about what does it mean to even age in our society? And how can aging be a dignified respected process not one that we sort of look away from or deny that we actually go through? So these are the ways they're interconnected. Sometimes people ask, are you duplicating work or is it in conflict with each other? It really isn't. It's a complement. If you're just doing age-friendly not do a few things you would need to do for dementia-friendly, not take it to that next step. So perhaps making sure you have a really good, respite services or memory loss centers, that might not be something you do if you're doing age-friendly but if you want to do dementia-friendly you take it to the next step. So that's really the only differences, where do you have to extend it out a little bit beyond age-friendly.

George Vradenburg: Thank you so very much. [James is a leader in using croquet as an inter-generational tool](#) to involve multiple individuals in the family and communities in a common activity that actually is able to be enjoyed by a person with dementia. So James himself is part of this effort and thank you James for your leadership.

Big thanks to Olivia. You know Olivia you are so clear in your vision and your mechanism of action and the way you've approached the topic that it is extraordinarily helpful I think to all of us as we think through how to begin to adjust our entire society to a more age-friendly and dementia-friendly society. I think we have a lot to learn, clearly in the physical disability community we've made adjustments through laws and policy but also through a huge social change that we've made to be able to better accommodate and respect those who have physical disabilities. The cognitive disabilities are harder to see and harder to respond to but the numbers of people that are being affected is such that we're going to have to make the same kind of societal change for those with cognitive disabilities as we have for those with physical disabilities. So thank you. You are a real leader in this fight and I think that you are going to be a real leader both nationally and internationally in this fight as we begin to articulate with greater clarity how it is we ought to be responding to these demographic adjustments and how it is as a society we ought to articulate how to adjust for a wide variety of mechanisms to make our societies more age-friendly. I really found this a fascinating discussion and I hope a lot of people on this call and those that are going to get the notes and the transcript after this call really take, with the clarity that you've offered, a real means by which they can do this in their community.

Olivia Mastry: Thank you George.

George Vradenburg: And thank you for those online for participating in this Alzheimer's Talks. In about a week we'll have a copy of the recording and a transcript on our website for you to share with your friends. We're so glad that you were able to join the conversation today with Olivia Mastry.

Thank you to everyone who makes these calls and our work possible. And they are supported by a number of individuals these Alzheimer's Talks and I appreciate the support that we do get for putting on these

Alzheimer's Talks call. I find them extraordinarily informative and I think the thousands and thousands of people who participate in these calls do as well.

[Our next call we'll be Thursday, December 4 from 2:00 to 3:00 PM Eastern with Doctor Howard Fillit](#), the founding Executive Director and Chief Science Officer of the [Alzheimer's Drug Discovery Foundation](#). He is going to discuss strategies for Alzheimer's prevention and is going to highlight new exciting therapies that are currently in the pipeline for Alzheimer's disease.

As always please stay on the line if you'd like to leave us a message with a question or comment. We're particularly interested in what you would like to discuss on future calls. So thank you Olivia Mastry for joining us today. We will thank Senator Klobuchar, even in her absence, and thank everyone on this call today for joining us and have a good afternoon.

Olivia Mastry: Thank you.