

Welcome. My name is Jody Krainer and I'm with the Wisconsin Alzheimer's Institute. I appreciate you joining us today for our webinar, Walking in Their Shoes: Engaging High School Students in Dementia Awareness. We have an expert panel that will be presenting today. I'm excited that they stepped to the plate and volunteered to do this. , very enlightening information that they will be sharing. As they go through the presentation, please feel free to put questions and comments in the chat or you may use your emoji hand to raise it and they'll be able to call on you or just put your camera on and they'll be able to also recognize you. They will take questions as the presentation goes on. However, if we end up getting a little behind in schedule, then we'll defer the remaining questions to an at the end of the presentation. So feel free to start with the chat or the emoji hand or put your camera on. Without further ado, I would love to turn the webinar now over to our panel.

Thank you for having us, Jody. Welcome everybody to Walking in Their Shoes, Engaging High School Students in Dementia Awareness. My name is Sierra Witczak and I am the Dementia Care Specialist in Door County. I've been in my role - It will be four years next week.

I'm Jake Sawyers. I'm the Dementia Care Specialist here in Walworth County. And my name is Ava Schmeeden. I am a Elkhorn High School student. Graduated this year, but I was Elkhorn High School's vice president.

And our final student is... I'm Arya Witczak.. I am an ADRC Door County volunteer. I've been volunteering for about 2 years.

Thank you.

And today, our goal is to provide participants with the tools and inspiration to engage students in dementia education through hands-on experience and community partnership that will offer empathy and real world impact.

Why?The biggest thing is just the idea that the community is going to get a lot of benefits from this as well as the school. So, lots of community collaboration - being able to partner with schools, you are then already kind of creating those intergenerational programs where you can connect with uh you know student orgs like HOSA and so some of the things that we are able to do are already aligning with these student orgs like goals and potential uh service hours that they're trying to do and then it also offers a lot of other kind of flexible learning uh opportunities for the students.

Why do we want to focus on teens? So, this is kind of a mutual question. This was a big goal of mine when I first became a Dementia Care Specialist. I really wanted to make sure we were targeting kind of that next generation as much as we can. When I'm being able to connect with students, I find out that a lot of times I'm the first one introducing kind of the aging boom to them. And letting them know that this is going to be an aspect that their generation is going to have to kind of help surf or navigate, let alone if they're going into the health care field or not. This is just something that they're going to kind of meet. Uh with that growing aging population,

we're going to obviously be talking about the growing need for dementia awareness. Not only is it great for these students to be able to have this dementia awareness as they go on into their futures, but this was a it's a really good vehicle to actually be targeting these students parents who are either already caring or they're going to be the next kind of family caregivers for their parents in the next 5 to 10 years. This helps create community uh awareness which helps reduce that stigma. And another, you know, big thing again when we talk about that future workforce is not only is it potentially planting a seed into you know, a student that wasn't thinking of going into healthcare, uh, but Gen Z is known as being kind of the entrepreneurial generation. And this is a way of getting them to realize the aging population is going to have a lot of different problems. There's a lot of different holes that they potentially could help fix and create a business to help solve. Uh, which is really, really unique.

Multi-generational homes that includes two or more adult generations uh with adults mainly 25 years or older or skip generations which consists of grandparents and grandchildren uh younger than the age of 25 under the same roof. And almost 60 million American households are multigenerational. And for reference, there's estimated to be 131 million households in the United States. While we're giving the presentation, we'll give you some examples of this, but during dementia live, we had - I had- a student that was highly impacted by living in a multi-generational house and being able to care for her grandmother. Uh so among the age group of 25 to 29 year olds there tends to be more men who are living in those multi-generational houses than women. So the statistic of men is uh 37% of those gents are living under a multi-generational household versus the 26% of women.

So, uh, with that being said, there are many youth caregivers. There's estimated to be more than 5 million 8 to 18 year olds that are providing care to an ill family member. Uh, and those youth caregivers are less likely to be able to be involved in extracurricular activities. They're more likely to have lower academic performance and more likely to feel isolated or feel lonely than those non-caregiving peers. So care is more than just hands-on caregiving. This can be where the youth caregivers are involved in socialization, providing transportation, or any other involvement with their person that they're caregiving for.

So we really wanted to highlight the idea of you know youth caregivers and just multigenerational households in general of the acknowledgement that by targeting students and trying to educate them on dementia we are potentially not only like I said that next generation or the next workforce but people who are actually currently in it and maybe just haven't identified it or this is an opportunity for these students to actually identify with their peers that they are facing this uh at home currently. Some other obviously real world student involvements that we're going to discuss is memory cafes, other dementia friendly events, being able to participate and support other activities whether that's in facilities or other kind of senior centers and just again in general intergenerational programming.

The first program we're going to talk about is Dementia Live where we collaborated with the Future Business Leaders of America conference. It all started out with the walk director from the Alzheimer's Association asking if I had any in interest in presenting and I suggested we look at

more of the hands-on approach rather than a passive approach. So, she connected me with the FBLA outreach specialist and that outreach specialist name is Stephanie Jansen. She was pretty amazing with the planning part. So, she took care of a lot of the behind the scenes the sign up. We used Signup Genius to get our student students signed up and interested. And then I also collaborated with additional dementia care specialists in this northeast Wisconsin region. Uh the reason why we focused on that is the conference did take place in Green Bay. So and I also live in that area. So shout out to the other dementia care specialists that were involved and that helped me along the way. And while we were coordinating the event, we structured it with two individuals being a prep coach and two of them being task givers.

Next slide. Thank you. So, like I stated earlier, we focus on that hands-on approach rather than a classroom environment where they're just passively learning by a PowerPoint. and we had participants who we shared where they could engage by altering their senses. So what we did was we had them put headphones on, gloves on, and glasses on and then we tasked them in the experience room to do a variety of tasks. When that experience was complete, uh, the participants came back into a room where they were to share how they were feeling afterwards. So, we really had a great debrief on how this impacted their senses and how this impacted them in general and why somebody with dementia would experience something like this. So, it made for some really meaningful and memorable experiences for these kids.

Some of the quotes from the students during the experience. Uh one of them was I disconnected from everything and it felt so isolating. And then one of my favorite quotes was from a daughter that was caregiving, well actually a granddaughter who was caregiving for her grandma and she said, "It all makes sense to why grandma is just sit sitting there and staring." , and then another time of one of the other students shared that I know how to I'll know how to care for my parents during that time." And it's interesting how we all had different experience. And I really love that one as well because, one person with dementia is one person with dementia and each person's experience is a little bit different....

So, we want to definitely be able to highlight and have Ava give her experience kind of going through the dementia simulation. So Ava, take it away. Ava: yeah, we had the dementia simulation during one of our HOSA meetings and I don't know how I don't remember how many people went through it, but there was a good chunk of us. And I remember talking with everyone afterward and we all kind of had the same feeling of, you know, you learn something new. It's easy to think of dementia as a kind of just a memory loss type thing and people really can be unknowingly ignorant as to how they treat people based on things that they thought they knew. And I think that the simulation with really being put exactly in their shoes and being able to know how complicated things are to do everyday tasks is such a very realistic situation. And you know following this. everyone kind of agreed that it was very, very eye opening and people wanted to kind of take action and I remember collaborating with Jake after this and he had kind of brought up like, how can we fix this? How? You guys want to bring this feeling of we need to help out with these people in more ways after that. But then we had also talked about how you know like parents also don't know this. If we don't know this and we need to talk to our community and to other students and that kind of led to also our learning and living committee which we're gonna

get to that slide. Okay. Yep. Yep. Just the dementia. Thank you. Okay. Yeah. But we all kind of agreed on that that it was something that you really should be taking more awareness to because it was a very eye opening experience that kind of gave us more information about something we completely had no idea about. Wanted to throw out there too for those that are wanting to connect with like school organizations to do the the simulation. U connecting with HOSA was an afterschool and so that way every student that wanted to go through the program kind of was able to. I also do a program with Oak High School that is actually during their it's called AVID and it's during their school day. And because it's during school hours, we had to kind of do the the structure a little bit different. And ... kind of how we do that is we actually only have four or five students go through the simulation itself and the rest of the students are part of the observers and are taking the notes and seeing what's going on. And then afterwards when we do the debrief, we have the students that went through the simulation kind of in a hot seat up front talking through talking about their experience. And then for those that were the observers, you know, were able to highlight kind of again some of the things they noticed, some of the takeaways that they had. Uh, and for some of them, some of the biggest takeaways were seeing their peers who they know don't have dementia now kind of experiencing and showing dementia like symptoms that maybe they've seen with their grandparents or if we have maybe some CNAs in the group that they've actually seen at work. And it was just a really good like rec again what Ava said too is these students are able to interpret it's not just memory loss. You know, when we talk about dementia, we're talking about all sorts of different aspects of cognition, and it's a really good takeaway for them to really understand that. Okay, thank you. Next slide.

Our next opportunity is for students to get involved with memory cafes. I have a couple students that volunteer every summer and they come to memory cafes and it has a big impact not only on the students but also the persons who are affected by dementia. So, this provides a supportive and welcoming space uh for people who have dementia and their caregivers to attend. It's really just a light fun area where people can forget about the stigma related to dementia and come and engage and have a fun time where they engage in the opportunity to socialize with other people. We do a lot of different activities and then have that shared experience with one another. For people with dementia when there is uh kids that are involved a lot of times that brings a lot of curiosity and they really light up inside. So they oftentimes are asking multiple questions. How old are you? Where do you go to school? Do you do any sports? So this brings up a lot of social engagement, different topics. , a lot of times they'll share about when they were younger. It also decreases the isolation. So those people who are living out in the community, it gives them something to do and something to look forward to and it's uplifting for them and stimulating. A lot of times my people look forward to coming to Memory Cafe and it gives them that sense of belonging that they belong to to a group where they are not defined by their diagnosis.

So for our learning and living committee this was kind of started by our president Maya and I'm kind of talking on her behalf today but we are again following the dementia simulation. We really wanted to be able to target people who also kind of had no idea about how this worked and how to take care of it. And we thought that the best way to do that was to target like our parents

specifically. Through this we started with like a survey that asked parents and community members what they specifically needed help with and what they didn't know and how many of them were truly ready to be caregivers for their parents. And it was an overwhelming majority that had no idea what they were doing. Didn't know where to start and didn't know how to work out financials or taking care of their parents, where to put them, how what to get to even like kind of prepare them for the aging process and trying to support their parents through that as well. And we thought that our parents were the easiest way to do that because, you know, we had just gone through this and we felt that we were a good voice to be able to get to our parents and our community members. And so through this, we then had information tables at our school events that really connected with our community and parents as well because there were so many people there. and we had flyers about information that could help out with, you know, how their parents are feeling. , different connections to aging and disability resource centers that they could call for any further information. Just really giving a connection to people who didn't even know where to start because that seemed to be the biggest issues that people really didn't know where to begin in looking forward to something like this. Perfect. Perfect. Next slide. So, what makes memory cafes really powerful is the way that it shifts the focus from the lost to what the presence moments are. So, people with dementia, they usually are defined or they feel defined by their diagnosis and they look at what they can't do. But for memory cafe it provides that opportunity of looking at what they can do and highlighting that and creating those moments based on that. So a lot of times it brings a lot of joy. We see the horrible side of people come out. we are able to be really creative with them and then it also creates these meaningful relationships. like the picture that you're looking at that is Arya who does volunteer like we stated at the memory cafes and oftentimes this brings those extra spark into the person with dementia's life. So Arya if you could share with us how memory cafes have impacted you and what you might have learned from attending memory cafes. Arya: Okay, so like my favorite thing about memory cafes is creating bonds with the people at it. So like throughout the years I've been doing memory cafes, you learn more and more about the people who attend. And many of them had very interesting backstories and had lived exciting lives. Like for example, we had a lady who used to attend memory cafes who would travel for tug-of-war matches, which her stories were very interesting. And so learning about the attendees uh through activities, conversations and stories, they create meaningful like friendships that's genuine and caring almost just like how I would have a friendship with a friend my age. And then what I've learned through them is ...

I've learned patience because it may be easy to like give up or become irritated when people may like struggle to think of a word or a name. However, you learn to give them time and support. Another thing that goes along with that is empathy. It is important to remember that people can also become frustrated at the fact that they cannot remember how to perform a task or think of a word. But you must put into consideration that they are trying their best and you have to remain uplifting throughout that. And finally like I learned how to stand up for the elderly. Many people like especially around my age, because they're kind of young, like to give stereotypes to the elderly and call them out of their mind or even crazy. But voicing my experiences and knowledge can help my classmates, teammates, or even friends change their assumptions and fix mindsets to become more open to understanding and being aware and loving the elderly, especially those with dementia. Thank you, Arya, for sharing. All right, so next

slide, please. So we kind of shared what how Arya felt when engaging with the elderly population in those memory cafes. So this experience does go beyond the textbooks. It does humanize that dementia goes beyond that stereotype or our clinical definitions and that we are able to allow them to communicate with patients. as Arya mentioned flexibility and learning that empathy piece it does challenge the assumption about aging and cognitive decline as well and it allows for those skills to be built so that way uh not only going into future careers you can take these skills with you but just having the awareness of the people around you no matter where you go you're probably going to run into somebody who has dementia or maybe a cognitive impairment. So, just being mindful of that and how you communicate and take patience even if it's somebody putting their card away at Walmart. Next slide, please.

Hey. Yeah. So through the last two years we have kind of worked with Jake and the rest of the aging and disability resource center and we have brought in the same memory cafes and these have been really really beneficial to all of us. It's been like pretty much the same group of people who has gone to every single one. And we kind of start by brainstorming activities that we think would be beneficial for the elderly in whether it's, you know, getting them moving more or to get them to kind of This is like dementia 101. Well, I think it work and to kind of get them to use like more motor skills, which is what we kind of did through our card decorating for Valentine's Day or flower arranging. , either way, we wanted to target activities and things with them that were able to they weren't doing in their regular everyday lives and things that we were able to bond with them over. Like during the flower arranging, we used those flowers for our high school prom the next day. And then during that, we were able to talk with them about their memories and their experiences through high school or through prom. And it was just very very incredible for all of us to like Arya was saying to get to know everyone on such a deeper level because sometimes these people really just need someone to talk to and someone to be there to listen and someone to be able to connect with. And especially for us being the people to talk with everyone there. It was reciprocated in the same way of having someone to listen to and getting to know people on that deeper level. you don't do it everywhere else, which is really nice that we were able to do it with people who really needed it. And from the Memory Cafe facilitator side, it was awesome working with the HOSA group because they took over all of the planning. And I even kind of had them, Ava was awesome in taking over as like the facilitator for the months that the students were there. which was really nice on my end because I could then uh coast a little bit and kind of focus more attention on other things which was awesome. But it was really cool to see the students kind of take action in terms of planning and facilitating and as she said the the flower arrangement and then being able to say that they brought it to prom at that next following memory cafe. the participants were really excited and asking to see the prompt pictures and so some of the students were able to kind of pull up on our screen their prompt pictures and it just made for a really good conversation. next slide.

So just a couple other programs that I do in the Walworth County area. I partner with like Geneva High School through their FCCLA award or which is the family career and community leaders of America. And again the idea that what we created is I asked to just connect with them to do a presentation and then it was offered to them of what do they want to do. Uh, and the students created what would we called the Badger Breakfast Buddies program where we

had a uh kind of a free continental breakfast of sorts that was then encompassed uh and some were tours of the school just so of some of the participants uh hadn't been at the Lakes High School since you know they went to school back in the day. And it was a really cool program to do some different, you know, intergenerational socialization. Uh, and then through FCCLA, , some of the students were able to kind of focus on the actual like foods part. So, they built the menu as it says there, the yogurt the yogurt parfait and some muffins and things. What makes FCCLA and then HOSA and some of the other student orgs really unique is that a lot of times when they do these programs, they then can use these programs as opportunities for the different events that they might have for like these student orgs in the future. So, for example, I can speak on FCCLA's. A student was able to use this breakfast Badger Buddies as like his uh entry piece for the competition and he was able to go through regionals and he was second in state. So, he didn't quite qualify for nationals which is unfortunate but the student himself and again this is that idea of that goal of targeting the workforce. The student's whole plan for career was going to go into computer science. However, after doing this thing he really was excited to think about how he can go into computer science but use that as a leverage to potentially help work with seniors in some capacity. exciting to see if he's able to do that. But you know just the idea that that was a potential goal of his was again just a highlight of this is exactly what we want to do.

Uh, the other program that we do, and this one's with AVID, is the AVID seniors have to do a community service project, uh, before they graduate. And so, uh, I had partnered with them for the last four years to do memory tunes. , what was unique, uh, so memory tunes is our version of music and memory. So, the idea is that the students meet with older adults uh person with dementia, their caregivers, and then have an interview process to then build that personal playlist of music that they then downloaded onto an MP3 player and gifted back to the participants. , in years past, AVID would only have maybe uh you know, 10 to 15 students. This school year, they had 43. and I just didn't have enough participants to make sure that we could participate in memory tunes. And so the students were able to actually pick three different avenues that they could go down. One was the traditional memory tunes. One was I helped be a middleman and connected them to long-term care facilities or the memory cafes that I facilitated. and the students had to plan and coordinate an hour activity at these either locations or the memory cafe. And then the final one was a new intergenerational kind of social program that we're working on called seniors to seniors where uh it was just the seniors were interviewing senior citizens and it was kind of like an oral history project.

So seeing Kathy's question in the chat, uh, when it came to breakfast buddies, do they come on their own or with a caregiver? We had them come with their caregiver. Uh, the first year that we did it, uh, a family that I was working with, the caregiver was unable, but she still wanted her husband to go, so actually he came with me. I was his caregiver to make sure that he still got to attend. And then in different iterations uh we've slowly opened it up not just memory specific uh individuals to seniors just because we are seeing here in Walworth County sometimes when we put memory concern specific kind of communication in our marketing, we don't then get the target audience that we want, especially when we're talking about those earlier staged

individuals because they maybe don't identify with that yet. And so we really have open it up to just older adult or senior and trying to provide that socialization for like all older adults.

So finally what the students can gain uh again for those that are planning on going into or maybe I'm I should rephrase that not planning originally to go into healthcare professions this now gives them that idea of oh this could be something that would be really interesting. Again this is going to increase that empathy and compassion skills as we heard from uh Ava and Arya. Uh definitely better communication skills and reduce the stigma about dementia.

And our community gains the opportunity for the next generation to understand how important it is to really care for your neighbor. And this might give people more interest in caregiving just as the workforce or in other careers because there's a high demand for caregivers. This also provides them with job stability and there again are diverse amount of careers that you can go into where you're going to be impacted by dementia. It also lessens the stigma of dementia and aging in general, as we heard from our students.

I mean to piggyback on the idea of the interest in the caregiving workforce, I can identify the second year I did memory tunes with AVID. One of the students said that she just found it really interesting having that communication interview process with a family. And then next year she ended up coming to one of our memory cafes because she was now a caregiver and she knew about the ADRC and the memory cafes and she brought the person that she was caring for to the cafes which was a really cool full circle.

Wonderful. So we appreciate everybody hanging out with us today. If there are any final questions, we'd be happy to take them at this time.