Kickstarting Brain Health Conversations with LGBTQ+ Older Adults

Applications from the GSA KAER Toolkit for Primary Care Teams

Momentum Discussions Podcast from the Gerontological Society of America

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Announcer:
The Gerontological Society of America, meaningful lives as we age.

Jen Pettis:
Welcome to this GSA Momentum Discussion podcast addressing Kickstarting Brain Health Conversations with LGBTQ+ Older Adults. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Genentech, Lilly, Eisai, and Otsuka for their support of the GSA KAER Toolkit for Brain Health and today's program. My name is Jen Pettis. I'm the Director of Strategic Alliances at the Gerontological Society of America, and I'm delighted to serve as the host for today's Momentum Discussion podcast episode. Joining me is our friend and colleague, Dan Stewart, the Associate Director of the Aging Equality Project at the Human Rights Campaign (HRC Foundation). He is the HRC Foundation Lead for the Long-Term Care Equality Index. We're recording this podcast at the GSA podcast booth in Tampa, Florida during GSA 2023. Dan, thanks so much for joining us here in Tampa, for taking time out of your busy schedule to be part of GSA's Annual Scientific Meeting, and for sharing your insights around Kickstarting Brain Health Conversations with LGBTQ+ Older Adults.

Dan Stewart:
Thanks for having me. It's great to be here.

Jen Pettis:
Before we get started with talking about conversations around brain health, I'd like to find out a little about your work. I think our listeners would be very interested to learn a bit about the Human Rights Campaign Foundation and the Aging Equality Project. Could you share a bit?

Dan Stewart:
The HRC Foundation is the educational arm of the country's largest lesbian, gay, bisexual, transgender, and queer advocacy organization. Since 1984, with 11 programs, we've been working to identify the problems that LGBTQ people face. Through a tried method of building understanding, shaping the public conversation around LGBTQ folks through public education and research. We change policies and help organizations review their policies for inclusion using our benchmarking tools. We empower our strategic partnerships to really leverage their relationships and advocate for LGBTQ inclusion. Our Aging Equality Project, which is part of our Health and Aging Program, strives to ensure that all older adults can age with dignity and respect regardless of who they are, who they love, or where they live. We do this through education, through our equality indices as well as strategic partnerships with organizations like the Alzheimer's Association.

Jen Pettis:
Tell me a little bit about the indices that you mentioned.

Dan Stewart:
We have several indices. Our oldest one is our Corporate Equality Index that we've been doing for over 20 years. Our Corporate Equality Index works to shape the workforce within the United States and ensuring that there are protections for LGBTQ Americans. We started that initiative 20 years ago but have recognized that there are other areas that LGBTQ people face challenges with healthcare one of the number one challenges that we face. We started the Healthcare Equality Index 16 years ago, which works with about a thousand hospitals across the nation. Essentially, it's the first national benchmarking tool of LGBTQ inclusion made up of 30+ best practices. Unlike other initiatives, we validate every single policy as well as how do they communicate that policy. Our latest, which I have the pleasure of overseeing, is our Long-Term Care Quality Index that specifically looks at inclusion at the intersection of senior living and long-term care. Our LGBTQ elders unfortunately experience high disparities and a lot of chronic conditions as they age and need that extra support. As we see that in long-term care, how can we best support those providers to ensure that they're an inclusive space, not just for their residents, but also for their employees and the visitors.

Jen Pettis:
I did have the opportunity to spend some time on your website and look at all the rich resources, but I also noted there that LGBTQ people face worse health outcomes than their non-LGBTQ peers in just about every category. These disparities are even greater for LGBTQ people of color, older adults, and people living in poverty from the LGBTQ+ community. Can you share some insights into these disparities and why they exist?

Dan Stewart:
LGBTQ people are in every community, every profession, every culture, yet face enormous obstacles. Those obstacles often result in them having a higher likelihood of health disparities and chronic illnesses. It's important to look at this population, especially at the intersection of aging from a life course perspective.

Dan Stewart:
We recognize historically that there has been a history of stigma and legal discrimination as well as pathologizing identities. As we look at the older adult population that identify as LGBTQ+ who lived through a period of the 1950s, the 1970s where homosexuality was considered a mental illness; in terms of the Lavender Scare and having federal employees fired for being thought to be LGBTQ happening. We had the Stonewall riots in the 60s and the AIDS epidemic in the 80s. There have been historical periods of time where there has been a great need and then also a lack of response governmentally within the systems that are there to support. What we see unfortunately is because of that stigma and discrimination, a greater fear of accessing care, a less likelihood to access preventative care. As you can imagine, if we're not taking care of things as they come along, often that can compile towards the end of individuals' lives, almost having an accelerated aging process in comparison to their non-LGBTQ peers simply because of that stigma and discrimination, pathologizing, and lack of access to care.

Jen Pettis:
With those challenges, what are some unique challenges to consider around brain health dementia in aging for individuals in the LGBTQ+ community?

Dan Stewart:
For years, we expected a higher likelihood of developing chronic conditions such as dementia or other cognitive concerns. Now we're seeing the data that affirms that. Dr. Jason Flat has some research that speaks to the higher likelihood of mild cognitive impairment and cognitive concerns. When we break down that LGBTQ population, those that are transgender and non-binary have even worse outcomes related to that. First, recognizing that there's a higher risk in this population, and then we compound that with a less likelihood of accessing services. Ensuring that individuals understand that this is a population that needs extended outreach; outreach that is culturally inclusive informed and that also recognizes the unique family structures that is often found within LGBTQ populations. Many of us, as we age, may have children or a partner to help care for us, but this is a population that is twice as likely to not have children, to age alone, and to have a dwindling social network so often are relying on family of choice. Recognizing that especially in in situations where an individual may become unable to make decisions for themselves, that we also are bringing up advanced directives and recognizing that the family structures or families of choice may not be recognized legally or by blood. In turn, that does necessitate some extra steps to ensure that their voice and wishes are heard.

Jen Pettis:
When you are assessing organizations as part of the Equality Project, how do you look at family in those organizations? I'm curious about questions and things that you identify on that.

Dan Stewart:
With our indices, we have four key pillars. The first is our foundational policies and non-discrimination and staff training. This is not just for the patients or the clients, but also the employees and the visitors. Ensuring that there's an equal visitation policy that recognizes person of choice, not necessarily related by blood. In addition to that, through our patient services and support section intake forms, we get an idea of who's important to people rather than having pre-prescribed or assumption of your husband or wife. Even changing the question to who's important to you to have something that's more open-ended.

Dan Stewart:
We also ensure the employees' aspect because we firmly believe in creating an equitable space for the client, patient, and employee. It's a holistic environment that everyone really should be part of, what it means to be inclusive.

This also involves, in terms of employees, an extended definition of family. When we talk about family medical leave, we include people that are not your blood relatives. This is also the case for non-LGBTQ people. There are many people that are in long-term relationships that aren't married or have an aunt or a cousin who may be like their mom, but based on current FMLA practices, those people may not fit under that umbrella of who you can take and have protected leave for. This includes extending that to the policies for the employees to create a more inclusive environment.

Jen Pettis:
What would you like primary care teams and others who work with older adults who have dementia to know about stigma and the combined challenges of being LGBTQ+ and having dementia?

Dan Stewart:
I think it's important to recognize that life course perspective of understanding that while the individual in front of you may not be experiencing that stigma and discrimination, they still carry that in their history. As a result, there will probably be a greater likelihood of individuals being more closeted or less forthcoming about their identity. Taking the steps to be outwardly open and welcoming is critical to create that space where people feel comfortable. Recognizing that a families of choice dynamic of the language that we're utilizing to create space for that elder to speak, and then also ensuring that, that we trust people in saying who they are. It's been very interesting to do this work, especially in the light of dementia and brain health.

Several questions have come up from folks, although there's maybe one or two instances in the literature that this has happened, but there have been concerns. What if a transgender individual develops dementia? As they age and as they progress through the disease, they no longer remember who they are and they say that they're their former name or their former gender presentation, and then there's all this concern of what to do. But really the simplest answer is what you do with anyone with dementia or really anyone that we're working with. It's just meeting them where they're at and honoring that person as they show themselves to be in that moment. I think there's just a strong desire to ensure that we're following best practices and what the, the policy says, but also recognizing the human aspect behind all those policies, which is ultimately what we're getting at is person-centered, person-directed care and really seeing that person for who they are. Giving folks the space to really share who they are is critical just for overall quality of care. Also recognizing that by doing that, you are also shifting the narrative of what this population has gone through historically, where perhaps they have never been out about their identity, but because you've created inclusive space, they now feel comfortable to.

Jen Pettis:
Dan, you shared a bit about the Health Equality Index and the Long-Term Care Index as well, but I'd love to hear some success stories associated with it. How have you seen actions on the ground that have improved lives for individuals?

Dan Stewart:
It's amazing to see the extent that these institutions are really diving into difficult conversations. I have the pleasure of working within the senior healthcare industry. I'm a gerontologist. I got my start in long-term care. Historically, because of invisibility, that's a keynote, there really hasn't been that much identification of LGBTQ+ elders or active outreach. However, as the conversation opens publicly, we see more elders come out later in life. We've been working with an institution in Colorado that took on the call to welcome this transgender woman who had been denied care at multiple communities across the state. The social worker was calling community after community and they were saying, no, we won't. This community decided to take it on not knowing what the best policies were, not knowing other than we want to provide the best patient-centered care that we can, but through working through the Long-Term Care Equality Index and technical assistance, being able to formalize these best practices of ensuring that that person's name was being used, ensuring that care was continuing, to ensuring that she was placed in a room that aligned with her own gender identity, really helping this organization formalize that so that it was ready for this resident, but also for residents to come.

We've seen great work. Watermark is one of our largest system sign-ons who have been doing LGBTQ work for several years. We want to help those that have even been on this journey for a while to sharpen their resources and communication. We have seen LGBTQ elders who think they have to move to the coasts, or they have to spend a lot of money, when in reality there might be communities in their own backyard that are doing this work. These communities may not realize how important it's to share that through marketing, community outreach, and even touring, to let the community know that there are safe options in their own local hometown that they can attend.

Jen Pettis:
Can you share about the partnership you mentioned with the Alzheimer's Association?

Dan Stewart:
It's really been a lovely connection. I started volunteering with Alzheimer's Association, Missouri Chapter when I was a grad student doing dementia-related research. through that had the experience of joining their DEI Council and now moving to a national organization to really extend that relationship on a national level that's really focused in on educating our LGBTQ community at large about brain health, about ensuring their cognitive health as they age, as well as ensuring that they recognize the signs of dementia. As LGBTQ people we're also more likely to be caregivers. Having an emphasis on what caregivers can do and how they can take care of themselves in the process of caregiving for LGBTQ loved ones. We've done several webinars, and we published an article within Alzheimer's Association specifically on working with transgender elders with dementia as well as our equality magazine, highlighting a volunteer, both our organizations who cared for her partner for 14 years with dementia and now is an outspoken individual sharing the message and running a LGBTQ support group for caregivers of those with dementia.

I think a key component, especially now that we're in the era of treatment, is early detection and with a history of barriers to care as well as being fearful to access care, there is that much more of a need then for organizations such as HRC to have these conversations with our constituents.

Dan Stewart:
We began in 1980 and now have over 3 million members at HRC. The reality is that many of our members have aged with us. Recognizing now that to sustain and care for ourselves throughout the lifespan that includes our brain health and recognizing how that is a key thing to be prepared for.

Jen Pettis:
Tell us a little about what individuals who are providers or just part of care teams, what could they find on your organization's website to help them move the dial and to provide more inclusive care?

Dan Stewart:
HRC Foundation is our homepage where you'll find a variety of resources. As I said, we have 11 programs. Our health and aging team oversee the hospital scape as well as long-term care, residential senior living. We also are in spaces of our All Children - All Families Program working in child welfare services, our HBCU Program working with the students there, Corporate Equality Index, our global team, a wide range of resources for folks who may work in the field and are looking for resources on how to provide best practices as well as initiate institutional change on a level in their organization. In addition, the LEI houses several resources specifically for those in the intersection of aging and LGBTQ care. Our work really centers on the long-term care sector, but really that expands to home and community-based services. Many of those best practices and educational material will be relevant too.

Jen Pettis:
Thank you so much for taking the time with us here in Tampa and for joining me for the podcast. Let me know if there's any final word you want to leave our listeners with.

Dan Stewart:
I want to thank GSA for the opportunity to be here, as well as the response that GSA has had to the light of anti-LGBTQ legislation that has happened in our country. I think it's important to really recognize in which ways that we can stand up and support individuals that have historically been marginalized. Thankfully, now we have the research best practices and success stories to show the next steps that we can take, and I am happy to be there during the process.

Jen Pettis:
Thanks again for joining me, and it's been a wonderful conversation.

Announcer:
The Gerontological Society of America was founded in 1945 to cultivate excellence in interdisciplinary aging research and education to advance innovations in practice and policy. For more information about GSA, visit geron.org.