

Age-Friendly Public Health: The Podcast

The Intersections Between Disability and Aging Policy

Guest: Alison Barkoff, Associate Professor of Health, Law, and Policy at The George Washington University Milken Institute School of Public Health

Host: Dr. J. Nadine Gracia, President and CEO, Trust for America's Health (TFAH)

[00:00:04] **Ms. Barkoff:** We're at a moment in time where there is a lot of change happening in the public health system and the healthcare system, and I think the partnerships and the collaborations across aging and disability are more important now than ever. The time is now to really lean in on our commonalities to build new relationships, to have a big tent.

[00:00:30] **Dr. Garcia:** That's Alison Barkoff, associate Professor of Health, Law and Policy at the Milken Institute School of Public Health. Hello, and welcome to this new episode of Age-Friendly Public Health, the podcast. I'm your host, Dr. Nadine Gracia, president and CEO of Trust for America's Health, also known as TFAH. Welcome to the sixth episode of Age-Friendly Public Health, the podcast, a production of the Age-Friendly Public Health Systems Initiative.

Our guest today is Alison Barkov, the Harold and Jane Hirsch Associate Professor of Health, Law and Policy at the Milken Institute School of Public Health at the George Washington University. She also serves as director of the Hirsch Health Law and Policy Program at GW. Prior to joining the George Washington University faculty in October 2024, Professor Barkov led the Administration for Community Living or ACL at the US Department of Health and Human Services, serving in the role of ACL Administrator and Assistant Secretary for Aging from January 2021 to October 2024. She was the advisor to the HHS Secretary on Aging and Disability Policy. Oversaw national Disability and aging programs and LED cross-agency initiatives related to long-term services and supports, civil rights, housing, workforce, family caregiving, healthy aging, and public health.

Alison, welcome.

[00:01:54] **Ms. Barkoff:** Thank you so much for having me today. It's a privilege to be here.

[00:01:58] **Dr. Garcia:** Well, Allison, let's jump right into our conversation today. You know, I'd love for you to talk a little bit more about your background and interest, specifically in disability policy.

[00:02:08] **Ms. Barkoff:** Sure. I have been involved in disability issues. I, for most of my entire life, like many people, I have entered into this policy conversation through my own lived experience.

I'm a sibling of a now adult brother with intellectual and developmental disabilities who was born at a time when people like my brother were, in general, placed in institutional settings. There was no such thing as home and community-based services and. My brother and my family really were on the edge of starting to think about how to create opportunities to include people with disabilities in the community, working to create inclusion in schools in, the broader community, and changing.

The Medicaid system and at the same time part of a civil rights movement that eventually led to civil rights laws like the Americans with Disabilities Act. That turned into, of course, a professional passion. I am a civil rights lawyer by training and been involved in both legal and policy advocacy, really focused around community living, and that's how I really entered into.

The intersections of aging and disability in so many of these common areas. and shared goals around increasing access to community supports that help people of all ages and people with and without disabilities to be able to participate and be included in their communities. And so. For my entire career, I have either been in government or in nonprofit advocacy, or now in academia, really looking to advance aging and disability policies using legal and policy tools.

[00:03:58] **Dr. Garcia:** Thank you, Allison. Thanks for sharing your personal connection to to this important issue as well as your professional journey and passion as it relates to to disability policy. We talk a lot about this in terms of there are also intersections, right? between aging and disability.

Can you share some of your thoughts around these intersections and why those intersections are important?

[00:04:21] **Ms. Barkoff:** Sure. You know, I've really done a lot of thinking about this, and most importantly, for people who aren't familiar, the agency that I had the privilege of leading the administration for community living.

Brought together aging disability programs and policy from all across the Department of Health and Human Services into a single agency, really focused on those intersections and commonalities, and particularly around the desire of the majority of older adults and people with disabilities to live and participate in their own community.

So, lemme talk about just a couple ways that I think there are such important intersections. The first is, in many ways, these are overlapping populations. People might not think of them as overlapping, but actually more than a third of people who are 65 or older report having different types of disabilities or functional impairments.



think about mobility or hearing or vision, or cognitive disabilities like dementia or limitations with activities of daily living. And so even though people who are older might not think of those as disabilities, they actually are and. Fall under many of the civil rights protections in terms of disability.

And of course, the percentage of older adults who have what are considered disabilities increases with age. And so, we have more older adults who have disabilities, particularly as people are fortunately living longer. In fact, the largest subpopulation when we look at it of people with disabilities is actually older adults.

And then, of course, there are many people with disabilities who have had disabilities their entire lives, who are living longer and aging with their disabilities. So, we often talk about this overlapping as people aging with and into disability. The second place, and I think this is really what the foundation of ACL was about, is about some of these overlapping priorities and common goals that the aging and disability communities have.

The first, as I mentioned, is really about the goals of helping people be able to access the supports and services that help them. Age in their own homes and communities and fully participate as part of their community life. What some people may call home and community-based services. Both communities are very interested in supporting the 53 million family caregivers who really, in many ways, provide much of those services and supports that help a family member who's older or has a disability be able to stay in their own homes and communities.

Other common issues include accessible and affordable housing, which for many, both older adults and people with disabilities, really becomes a barrier to being able to stay in the community. And just to provide one other example of overlapping priorities is some of the stereotypes, bias, and even discrimination that both older adults and people with disabilities face.

Kind of terms like ageism, which, you know, really has been a, an important conversation happening, in the aging space, ableism, and the discrimination that people with disabilities face. And as we'll talk about, I'm sure later in our conversation, this discrimination happens in so many ways, whether we're talking about the discrimination that older adults or people with disabilities might face.

Accessing healthcare and in the healthcare system or in workplaces. and really in, in so many barriers like accessibility of transportation and places in the community. So those are just some of the many places where collaboration across aging and disability makes so much sense because of these common goals.

[00:08:35] **Dr. Garcia:** Yeah. I really appreciate you talking about those common goals and that those common goals and the the common issues right between aging and disability is, actually, an opportunity. You know, there are barriers that are there and there are challenges that are posed, but they actually can then present themselves, as you're saying, as opportunity and.

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For us, you know, certainly as we think about the field of public health at TFAH, there are really some key considerations that can be made as it relates to disability policy from your vantage point. What are those considerations that really are important, specifically to disability policy for the field of public health?

[00:09:09] **Ms. Barkoff:** I think one thing that is so important and critical is that public health systems really understand the unique needs of people with disabilities who live in their community, learn and about those needs, connect with the disability community itself, and really have people with disabilities. At the table to help public health systems affirmatively plan for meeting those needs.

I was privileged to lead the administration for community living in 2021 and 2022, when we were really at the peak of the COVID pandemic. And I think what we often saw early in the pandemic and public health systems was that despite people with disabilities as well as older adults being at highest risk, and really, I think some of the populations that the public health system really wanted to be able to serve best, we saw a lot of barriers.

Things like inaccessible information, maybe to people who are blind or deaf barriers in getting vaccines because sites were inaccessible or websites were inaccessible and a lack of transportation or sometimes even in terms of thinking about people with disabilities and older adults, people, all, people often think, oh, most people are in nursing homes or other institutional settings.

And really don't realize that the vast, vast majority of people are in their own homes. And so that was really, I think, an important time. To have the disability community as well as the aging community really partner to help bring in strategies. And this, of course, is not unique to COVID. We've seen these, this type of, maybe not understanding the needs and barriers of people with disabilities in all different types of emergencies, which is why inclusive planning and response has really become such a priority.

I'd say the second thing that is really important is. Public health is so focused, and it is so good that they focus on kind of health equity and really thinking about historically underserved populations and how to address those inequities. And too often, at least historically, we have seen disability is not a consideration yet.

If we look at health outcomes and access, people with disabilities really have. Significant disparities, you know, poor health outcomes that are due to a lack of access and ableism. You know, people who are unable to access preventative healthcare, higher rates of preventable health conditions, shorter lifespans, and more chronic disease and.

If we're using an intersectional lens, disability is actually higher in many underserved communities, like Native American communities and communities of color. And one thing that I think was really important, and I hope some of these lessons will really kind of impact the lens of public health, is during the Biden-Harris administration, the National Institutes for Health.



Actually, looked at this issue of health disparities for people with disabilities and designated disabled people as a health disparities population. And I think this really has given momentum to, with intentionality, thinking about disability in health equity work. So, I think those are really two examples of how public health can really think about [00:16:20] building disability into some of the.

Core important work that they do and that they lead on.

[00:12:58] **Dr. Garcia:** I appreciate those, really, those two critical points that you made, Allison? both in terms of the importance of assuring that public health is, is integrating and really partnering with the disability community and and giving the examples from the pandemic to the secondly, the point around.

Disparities and having that focus and centrality of health equity as we really work to assure optimal health for everyone. You know, you contributed an article to the special edition of the Generations Journal for in spring 2025, and I encourage our listeners, if you haven't yet, checked out that special edition, please do.

It is filled with so much great information, and you specifically talk about the importance of these types of partnerships and the multi-sectoral nature of it. One of the challenges we often see, for example, is sometimes those partnerships happen during the time of an emergency, and you talked about COVID, the COVID-19 pandemic specifically.

What do you think are some of the lessons learned and, and ways in which public health and other sectors can sustain those types of partnerships? and ensuring that the disability community really is a critical partner, not only during times of emergency, but also in non-emergency times.

[00:14:09] **Ms. Barkoff:** Yeah I, I really believe in what I love about public health is really thinking about who is at the table and making sure communities are there.

I agree with you, the best time to kind of build relationships is not in the middle of an emergency. The best time is really to kind of build into your tables and your planning, and really all the work that you do. Thinking about those communities and the disability community, there is a saying nothing about us without us.

And I think that's really important. It's, it's about making sure disabled people and advocates and people from the community are at the table. One thing I was really proud that we were able to do, and I. I very much like you wanted to think about how not just to build relationships that were very needed in the moment in this crisis, but how to think about building those moving forward.

And when there was funding as part of the COVID-19 supplemental funding that was passed by Congress. There actually was funding that went out through ACL and the aging and



disability networks, specifically called Public Health Workforce Funding, and it was about Building long-term relationships with the public health system.

And the goal of that was really to plant seeds, not just to respond to what was going on immediately in COVID, but really to create infrastructure for ongoing collaboration between those networks and public health. I have seen that play out in many places and, and the relationships that were forged, both networks saw the value of each other.

You know, we don't need to recreate a wheel in the public health system to have, you know. Every single public health person deeply becomes an expert on aging or disability. What they need to do is have the right partners and know the right partners to work with. And so that was really, I think, an important strategy.

I, I hope that we continue to see both the aging and disability communities as essential to our public health goals. And again, from the get-go in planning and in everything that we're doing in public health, as we pull communities together, ensuring that we have both communities at the table is really important.

[00:16:42] **Dr. Garcia:** Yes, excellent points. And in particular, you know, noting that, that those types of partnerships, it takes the efforts of doing it and knowing that you'll actually have a better understanding of what the assets are, what the needs are of the communities that you are serving. And, and as you said, that's a key role for.

For public health. And I'm hearing you also talk about many other sectors, even in your, your earlier responses about other sectors that play a role and, and that's critical to the age-friendly ecosystem, that there are many sectors that have a role to play in assuring and helping to promote optimal health for older adults.

Can you speak more to where there are opportunities for collaboration among sectors in the age-friendly ecosystem? Programs, for example, that are supporting older people as well as programs that support people with disabilities.

[00:17:32] **Ms. Barkoff:** When I look at the age-friendly ecosystem, and, and again, thank you for mentioning the article that I wrote.

My observation was, so many shared goals, and really, the disability community is a critical partner if people really wanna take age-friendly ecosystems to the next level. And when I look at all of the components, virtually every component, there really is a role. For collaboration and in some ways, some places where even the disability community may have additional tools and strategies that could be adopted by the aging community.

Just to give a couple examples from the sectors and initiatives. You know, we've talked a little bit about the shared goals around home and community-based services, which is one of the pillars there, and just. All of the shared advocacy and really at the state and local levels,

the collaboration happening around expanding access to community services and strengthening the workforce that provides those services, and supporting family caregivers.

A second place is about the healthcare system, and I think this is really about addressing barriers to access and discrimination in healthcare that many older adults and people with disabilities. Both face and a real commonality. Again, even if an older adult who may have some of these functional limitations, doesn't think of themselves as disabled, if they can't get in the door or get on the table because it's not accessible, if they can't use a kiosk or a website, or if they literally are denied, you know, lifesaving treatment based on stereotypes and ageism.

Ableism, when we're thinking about allocating resources, a really important tool actually is disability rights legislation and, and particularly disability rights laws like the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. And we have seen some incredible collaborations, both in terms of.

Educating the medical profession, but also using disability rights laws, for systems change and really moving forward some of those laws that require accessibility and prohibit discrimination. One other example that I'd like to give is around cities and communities and states and, and some of the livable communities, which at its core, you know, has a key aspect of accessibility.

You know, think about curb cuts as ensuring public places like restaurants are accessible. Think about making sure community programs are accessible. Those things actually are happening because of. Disability rights laws. And so that partnership from a community that has worked a lot around those types of accessibility, I think is, you know another great example.

And then as we talked about, a few moments ago in public health, there just has been, such great partnerships over the last couple years, whether it's educating people, you know, about preventative healthcare, about, accessing [vaccines, about emergency response and really building off those strong partnerships that were so successful in the pandemic.

So, I really think almost everything about age-friendly ecosystems. Has a lens where bringing in the disability community as a partner would benefit everyone.

[00:21:15] **Dr. Garcia:** And I really appreciate you pointing that out about, you know, this, it benefits absolutely, of course. people with disabilities it, it benefits the people who are older adults, and those who, you know, age with or into disability.

And your last point that it, it actually also benefits everyone, just as you talked about the curb cuts, for example, that it, there's a benefit to everyone and, and really focusing on that, that framework of, of, of accessibility. As an example, you know you, you mentioned earlier, in, in highlighted for example, in the context of the the pandemic, that as we think about those structural barriers for people with disabilities or, or older adults, that.

Facing some of those structural barriers that they're still within those communities, individuals who face even greater risk of those types of, of barriers. You pointed out Native Americans, people of color. What advice would you give for example to address those types of disparities, especially as you're talking about the intersections between aging and disability, to, to understand that there are individuals who face an even greater when it comes to those types of structural barriers,

[00:22:21] **Ms. Barkoff:** Yeah, I think it's really important that we recognize, for both people with disabilities and older adults, I. People cut across all communities, and so we have disabled people who, you know, may be LGBTQ, may be a person of color, may not speak English as a first language, may live in a rural area.

Of course, the same with older adults, and that we need to not think about kind of aging or disability as a monolith. We need to think about the fact that many people have intersected. Disabilities or intersecting identities that, that need to be addressed. I think it's important that we make sure we have the diversity of those communities when we bring the disability or aging community to the table.

It cannot just be a white male, wealthy, you know, older adult or person with a disability. We need to make sure we are having representation of people who can really share their lived experience of the compounding barriers that people often face. So, I think it's really important to understand that within each of those identities and barriers. As I mentioned, my background is really as a civil rights lawyer, and we really have tried to be intentional to think about both barriers and discrimination can be not because of one thing, but because of the way multiple things come together. And in fact, the way that the,

Civil rights provision in the Affordable Care Act called Section 1557 is written, actually covers the fact that people in the healthcare system may experience discrimination based on a combination of disability or race or ethnicity, or age, among a host of things. So, the public health system, and again, its focus on equity, on health disparities, on addressing barriers has been really good in thinking about those barriers. But I would just encourage people, when you add in this additional lens of disability and aging, I think having to do it in a really nuanced way to make sure people understand how people experience disability may be different in different communities.

And of course, the same with aging.

[00:24:45] **Dr. Garcia:** Thank you, Allison. So many, so many lessons in that and, and advice that our listeners certainly can learn from. And I appreciate you too, elevating, for example, rural communities, and understanding that there's so many factors that influence our ability to be able to have good health and, and access.

The resources that are needed for optimal health. So, thank you for, for sharing that perspective. I would love to hear you share some of the innovative programs or initiatives that individuals with disabilities, that the public health and aging sectors, should consider for replication that you've, that you've seen, that you're familiar with.

[00:25:22] **Ms. Barkoff:** Sure. I'll just pick a couple that I, I think are really exciting. You know, I, I talked earlier on really the, ways that it, it's, it's about understanding needs and if we are waiting until we are in the middle of a disaster to think about barriers that people face and people's unique needs, it is way too late and.

I think the disability community has certainly post-Katrina, but frankly, it has been a top priority for a very long time to think about inclusive disaster preparedness and response and recovery. They have worked a lot with Congress on legislation with federal agencies like FEMA and across HHS and at the state and local levels, really ensuring that disability, uh.

The disability community is a partner at the table. And what I would say is, you know, historically, and maybe COVID will change this, this hasn't been quite as much of a focus for the aging sector. And part of what we were trying to do in the pandemic and then afterwards is really support.

Both the aging and disability networks to collaborate together and to collaborate with their state and local public health and emergency response system. So, I think that is one thing. I have seen that in a number of places, really picking up steam in the last couple years. I think that is an important innovation, and, and really excited and, and hope that continues to pick up more speed. As I mentioned, the kind of changing the paradigm about who the public health workforce is was something that was really exciting to be able to, you know, give some funding to the aging and disability networks, which not only helped build partnerships with public health, but I think there was this and "Aha" moment for the public health systems of really the aging and disability networks are kind of extenders and can help us reach our public health goals. And I've been really excited as I've kept in touch with local aging and disability organizations that receive this funding to hear how this is continuing to blossom in a lot of different ways, in the public health system.

And then I think the last area where I think public health and aging could really learn from. Disability and, and maybe model and, and take some of the work that they have done forward is around addressing ageism, ableism. You know, I think forever, the disability community has been very rights focused, working very hard from, as I shared in my own personal background.

Passing civil rights laws that the community has really used for systems change and to address stereotypes and barriers, and discrimination. And it's been really exciting to see over the last several years. A real robust conversation in the aging community, thinking about ageism, and thinking about them a little bit more through a rights-based lens.

It's been great to see the reframing aging initiative gaining momentum and I'm starting to see that and TFAs been a real leader and bringing that into public health communities. And I think looking to how the disability community has taken it, from kind of reshaping the way that you. Think about disability, which, of course, is an important first step to translating it to concrete change in policies and practice in our public health and healthcare system.



So, I think that's a really rich area for collaboration and an important way that I think the aging community can advance some key goals that it has and, and some really exciting new initiatives.

[00:29:23] **Dr. Garcia:** Those are indeed some exciting new initiatives and, and as you noted, really, what can be gleaned in terms of addressing ageism and addressing ableism and, and leading to that kind of systems and policy change, right?

Then that really creates those conditions in which all people and people with disabilities, people who are older, have the opportunity and the resources and access that you were describing, because this is, it permeates right through every sector. So, I really appreciate that, certainly as a resource as well.

Allison, in closing, is there anything else you'd like to share with our listeners?

[00:29:59] **Ms. Barkoff:** I just wanna share that I really appreciate TFAH and others having this conversation. We're at a moment in time where there is a lot of change happening in the public health system and the healthcare system, and I think the. Partnerships and collaborations across aging and disability are more important now than ever as we are, you know, working to make sure that we are preserving the important gains that we've made, the, the ways that we are working to together to fight against proposed cuts that we know will hurt the communities that we represent. The time is now to really lean in on our commonalities, to build new relationships, to have a big tent. And I appreciate the leadership of TFAH and others in broadening the tent and really supporting the [00:35:20] collaborations and relationships across the aging and disability communities.

So, thank you for your leadership, and thank you so much for having me here to talk about this important conversation.

[00:31:05] **Dr. Garcia:** Well, thank you, Allison. Thank you for sharing such great advice, perspective, resources that our listeners can be using, and as you said, to really meet this moment and the importance of partnerships collectively to be able to meet this moment so that we can continue to make progress.

It's really been a pleasure speaking with you today.

[00:31:26] **Ms. Barkoff:** Thank you again.

[00:31:27] **Dr. Garcia:** Absolutely. For our listeners, please feel free to share this segment on your social media channels and look for an announcement of our next segment, which will be released in the next few months. And we also invite you to explore a new age-friendly public health systems resource called the Six Cs Training and Implementation Guide.

This guide is designed to increase your understanding of public health's role in improving and supporting older adult health, and you can access the six Cs training and implementation

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guide and learn more. About the age-friendly public health systems initiative on our website, which is afphs.org.

That's afphs.org. Thank you.