



EPISODE 57: INCLUSIVE HEALTHY COMMUNITIES AND THE ADA

Event Date: June 6, 2018

Presenter: Amy Rauworth, Director of Policy and Public Affairs at Lakeshore Foundation & Associate Director of the National Center on Health, Physical Activity and Disability (NCHPAD)

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VOICE-OVER ANNOUNCER: Blog Talk Radio. (Music) Welcome to WADA ADA Live! Talk radio. Brought to you by the Southeast ADA Center, your leader for information, training and guidance on the Americans with Disabilities Act, and here's your host.

BARRY WHALEY: Good afternoon, and welcome to WADA ADA Live! On behalf of the Southeast ADA Center ADA Live! Center and Burton Blatt Institute and Syracuse University and ADA National Network. I want to welcome you to Episode 57 of ADA Live! My name is Barry Whaley, and I'm the Projector Director of the ADA Live! Southeast ADA Center, and I'm your host for today. Today's Episode on ADA Live!, we're discussing the accessibility of health promotion activity with people with disabilities.

All people have the right to conditions and resources that ensure optimal health. However, engrained in socioeconomic disadvantages and structural programmatic and attitudinal barrier and now is recognized as major contributors to help disparity for people with disabilities. The lack of participation and physical activity is a serious public health concern for all Americans. But even more so for the approximately 56 million Americans who have disability, who are at much greater risk for developing serious health problems associated with a sedentary lifestyle. Before we begin, as a reminder ADA Live! listening audience, you can submit your questions about health communities and design at ADALive.org. It is now my pleasure to introduce today's guest from the National Center on Health, Physical Activity and Disability, otherwise known as NCHPAD, Amy Rauworth, Director of Policy and Public Affairs. Amy, welcome to the show.

AMY RAUWORTH: Thanks so much for having me

BARRY WHALEY: Amy, I'm glad you're here. Amy, let's start with NCHPAD. That's an interesting acronym. What does that mean?

AMY RAUWORTH: It is. We added the H layer so it is silent. But we are one of the national centers for health promotion for people with disabilities that are funded through the Centers for Disease Control, specifically the National Center on birth defects and developmental disabilities.

So our focus is to assist in improving the health and wellness and quality of life for people with disabilities. And we have a variety of resources at NCHPAD.org. And those can benefit people with disabilities across the lifespan. We operate here at Lakeshore Foundation in Birmingham, Alabama as part of the UAB Lakeshore Research Collaborative, and it's a pretty great place to be because here we do activity, research, and advocacy. And I think NCHPAD is the best example of the culmination of all those things put together. So we're really happy to be here and we're happy to translate what sometimes takes so long to get to the community, that specific research or the benefit of evidence-based programs into practice immediately and provide it to the nation.

BARRY WHALEY: Great. I've had the opportunity, the tour of Lakeshore Foundation, you guys do amazing work and you have guys have amazing facility down in Birmingham and I was very impressed. Amy, why is it important for people with disabilities in particular to be active?

AMY RAUWORTH: Well, physical activity is important for everyone. And we know that and it makes it hard. Every day we get up and make a choice of what we're going to eat, if we're going to be active and what we're going to do. And we know it's generally recommended 30 minutes of physical activity a day. But we know that people with disabilities oftentimes are not meeting those guidelines.

In general, adults are only meeting that about 20% of the time. And it's estimated that there are over 300,000 deaths a year due to physical inactivity and poor nutrition. So we know that people with disability are at an even greater health risk due to oftentimes a lack of access and increased prevalence of conditions that are secondary to the primary disability. And even some research shows that persons with disabilities are only getting about half or no physical activity at all that's recommended.

So it's really important for people with disabilities to be active because we know that the research shows us that the chronic condition that we all are likely to experience if we're sedentary are at an increased risk for people with disabilities. And we have to get away from thinking at least in the public health realm and perhaps in the healthcare

environment that having a disability is an outcome. It's absolutely not, disability is a demographic and being healthy and having a disability is not an oxymoron.

BARRY WHALEY: Well put. Amy, you mentioned the recommended amounts of daily activity and the fact that not all of us are getting it. And that's especially true for people who have disabilities. Is it different for people with disabilities in regard to the amount of activity they should get in the day?

AMY RAUWORTH: It absolutely is not different. Physical activity has been stated by people to be the wonder drug. If we had to one thing, being active or avoiding sedentary behavior is one of the most important things you can do to increase your quality of your life and longevity. And physical activity is recommended for all Americans. That's in the details and 75 minutes of vigorous or intense aerobic activity or 150 minutes of moderate aerobic activity. And that's really, really important that the evidence shows that people with disabilities do more harm by being sedentary than by being active.

But what we suggest is that you start where you're at and increase slowly and gradually. If you have concerns or you've been inactive for a long period of time, then perhaps seek advice from your healthcare provider to make sure that you don't have increased risk of some of those chronic diseases that we talked about earlier like heart attack or stroke. But absolutely, the bottom line and the most important message is that people with disabilities should avoid sedentary behavior and should be physically active and try to reach those approximately 30 minutes of physical activity a day if possible.

BARRY WHALEY: I think that's the thing that you point out considering that people may not get the amount of exercise they need or may have very little exercise. It's always a good idea to do this with consultation with a physician or other medical providers, especially, if you have chronic health conditions, right?

AMY RAUWORTH: Right. But absolutely we do not want to put up more barriers for people with disabilities to be active. That's really important. So what we suggest and encourage is actually to look at your risk for those chronic diseases or for active what we call metabolic disorders or orders. So if you're at a high-risk, perhaps you have high cholesterol and you're a smoker and you've been inactive. But this is not a disability or fail of fitness but this can be benefited by being physically active even in small increment of time throughout the day.

BARRY WHALEY: Great. Thank you very much, Amy. Amy, going back to your organization, NCHPAD, what is NCHPAD doing to increase health promoting opportunities for people with disabilities?

AMY RAUWORTH: Oh, goodness. We are really trying to create access and opportunity and increase that for all people, including people with disabilities. So much of our work is based on kind of a two track approach. So we know that at times adaptive programming, for example, when you visited Lakeshore Foundation you saw wheelchair basketball practicing and it's important for children to participate in the school sports. So we look at needs of targeted approach to a specific population like the ADAPT wheelchair basketball. But we also know inclusion is so important to help people and how they're perceived in society and it goes far beyond the physical benefits you receive from being active with a group of your peers.

And, so, NCHPAD is providing adaptive evidence-based programs nationally and we've work on 10 of those to date. Some of those include programs like girls on the run. We also have worked with spark and catch after school programming for youths. And we've worked with the diabetes prevention program. Prevent diabetes for all. Because so much of these evidence-based programs were created without people with disabilities and they have criteria and person with disability is excluded and not part of that cohort.

So we have to go back and look at the barriers that people with disabilities may face in participation. And then we work to address those in in inclusion narrow guidelines and we release that to the public so it gets the support it needs and the inclusion that people with disabilities need in mainstream programming. So if there's a program at your local Y or your after school program, we want it to be inclusive and provide opportunities for all people including people with disabilities. Additionally, NCHPAD recently created a funding opportunity announcement. And we are utilizing the framework of implementation of science framework to see community change. So you'll see and hear that research start. But it's important, we don't do things because we think they work. We use them because we know they're evidence by the research in literature that they do work.

So we utilize that framework in the community action plan and we were able to fund 3 states. We funded Minnesota, South Carolina, and Florida to not only implement adapted programs that we've provided, but also to really look at the whole community and create that community change that we would like to see with technical assistance and support from us, and with very local context to create that change and make it sustainable.

BARRY WHALEY: That sounds like a fantastic project. Thank you for sharing that. And just word on inclusion and the health benefits and social benefits that people have in being part of a team or being part of an exercise cohort is very important for folks.

AMY RAUWORTH: Absolutely. The kids learn from each other. And they actually feel more accepted when they have friends ask them to play. And if the environment is constructed in a way that they can't go out and play with their peers, that's a significant barrier and we really want to address that. And even though ADA has been around for all these years, there are still built-in environment issues. There are programmatic issues. If you need effective communication. And there's also attitudinal issues that perhaps someone may not feel welcome or feel as that program or opportunity or that chance to play in the program is open to them.

BARRY WHALEY: That's great. Thank you, Amy. ADA Live! listening audience, if you have questions about any of our ADA Live! topics, you can submit your questions at any time at our online former at ADALive.org. And I want to pause for a minute for National Center on Health, Physical Activity and Disability NCHPAD.

VOICE-OVER ANNOUNCER: The National Center on Health Physical Activity and Disability, otherwise known as NCHPAD is a public health practice and resource center on health promotion for people with disabilities and other chronic health conditions through physical activity, sports, recreation, advocacy, training, policy, and research. Additionally, NCHPAD conducts national initiatives to educate disability and non-disability service providers in community health inclusion. NCHPAD is creating local level sustainability and inclusion through inclusive health coalition across the United States that promote community and individual behavior change focusing on leadership and planning strategies which the courts really help inclusion. NCHPAD features a variety of resource and services, which can benefit all ages and populations. To learn more, visit their website at www.NCHPAD.org.

BARRY WHALEY: Hi, folks, welcome back to the show. We're having an interesting conversation with Amy Rauworth. She is the Director of Policy and public affairs for the Lakeshore Foundation. And the Associate Director of NCHPAD, the National Center on Health, Physical Activity and Disability. And, so, Amy, I'm curious, what tools can people with disabilities and their allies use to create healthy change in their communities?

AMY RAUWORTH: Well first and foremost I think good advocacy goes a long way. So good advocacy is about representation, mobilization, and empowerment. And absolutely should start with the Disability Community. And, so, Nothing About Us Without Us" should be engrained in all that we do in our outreach. Because if we're working to create change in the community, it's important to involve all community members and specifically for this inclusion of people with disabilities, it has to come from them, it has to be what they want. And, so, we have several different types of tools in NCHPAD.

We have research tools or tools that can assess the environment. So we have a community health inclusion index that looks at how inclusive healthy opportunities are within that community and inclusive coalitions have utilized that tool. And it really gets from a macro to micro-level and can address issues at an organization specifically. So, for example, if you're going to a school system or if you're going to a local fitness center, you can really look at the policies and infrastructure and how it's created to support people with disabilities or perhaps not. And it allows you a place to start and have a conversation.

And, so, much we know about good advocacy is promoting awareness. And, so, the more we can make people aware of the needs and the alterations perhaps and programming of services that people with disabilities need or require, the better those programs can be inclusive. And, so, I mentioned the community health inclusion index, we also have tools that focus on coalition building and CDC has created the community health inclusion sustainable planning guide. That's a mouthful. But we call it CHP for short. And, so, if you want to go join and be part of it, it's profound. Whether or not you're a health professional or providing your experience as a person living with a disability, it's important that disability organizations be at the table when public health initiatives are underway. Specifically, and more importantly around community design, because we know that the community design can be the source of a solution to many issues that people with disabilities face that are either unjust or perhaps increased health disparity.

BARRY WHALEY: That's a very good point. Thank you, Amy. So we've referenced inclusion several times. I'm curious, if you can talk about your definition of inclusion and maybe tie that in with something that I'm aware of and your commit to inclusion campaign.

AMY RAUWORTH: So expectation of inclusion is important because that's where we need to start sometimes is if our expectations are not met, we won't have a good experience. So we pulled together a team of 12 experts nationally to come up with the definition of inclusion and that wasn't an easy feat because there's many disability definitions and also many contextual definitions of inclusion depending on what targeted sector you're coming from in the community. So our specific definition is inclusion means transform communities based on social justice principles and which all people in the community are presumed competent, are recruited and welcomed as value member of their communities and they can fully participate and learn with their peers. And in general, that's what we all want. But I think it's really important to state that in front. What our expectations of inclusion are and define that go really goes a long way.

BARRY WHALEY: Amy, how can we ensure people with disabilities are included in program policies and objectives? I mean, it doesn't just magically happen. There has to be an effort.

AMY RAUWORTH: You're right. You're right. And we created a global campaign actually called "Commit to inclusion." To really address those exclusionary practices and it started out U.S.-based launch and then it went international. And we've reinvigorated it with a partnership for inclusive health. And, so, what we started with was kind of a recipe of much of the foundational research that's been done in disability. We've built upon that and from that we've taken 9 guidelines of disability inclusion. So we really think it's important that all organizations, whether they be government organizations, private or non-profit organizations that they look at these specific areas. And if they do so, they're much more likely to be inclusive of people with disabilities. So in the program development and in the implementation and in the evaluation component, people with disabilities should be included. And it's important that their disability representation be there and have a say at the very beginning. So not that we're serving up an afterthought or checking a box later, it's from the very get-go. And we know access bill should be use by all and socially behavioral and with effective communication.

For example, if an interpreter is required, that's something we need to think about at the forefront at the development of our plans. We also know that the program should address that individual's needs. So it's really important to understand and address the individual. So not everybody is the same regardless of if you've worked with somebody who is blind before, or someone who utilizes a wheelchair. We should really be looking at the individual and in all honesty, that's what you do when you create successful programs. Because you're really looking at the individual level. We also know that there should be an outreach effort. Because we hear so many times, oh, yeah, we put the armor dial meter in the corner over there because we don't have anybody with a disability that comes into our fitness center.

So nobody really uses that. What we would suggest and encourage then is, for example, are you targeting or marketing people with disabilities? So does your flyer, programming materials, in indicate or show a person with a disability utilizing your service or program? So that's really important. We also know that programs should address resource implications at the get-go. If there's training that needs to be provided to the staff, that needs to be thought of at the beginning or the inception of the program. We also know that perhaps sliding fee scale should be available and programs should be affordable for people with disabilities. And then wrapping it all up in the end, we have to have a transparent monitoring process. So we need to have an

open feedback loop with people with disabilities to provide their comments and suggestions on how to improve that program or that service.

And then we need to be able to take that into consideration and understand that in this instance, we're asking the expert, the person with the disability is the expert regardless of how many years I've been in my field, I want to enter that conversation with that understanding knowing they're bringing to me their experience that will only make my program better. And then in the end, we have to make sure the program is addressing outcomes that we want to see happen. So it sounds technical, but it's really what all good programs are -- how all good programs are created.

BARRY WHALEY: So inclusion itself becomes, for lack of a better term, Amy, there's a certain mindfulness to inclusion to make sure our programs or services or things that we provide, the exercise facilities are all geared toward a broad range universally for people to utilize.

AMY RAUWORTH: Absolutely. Universal design is so important. It's important in the community and we know that people with disability and including people who are aging. So from the census data from 2000 to 2030, we know that the number of individuals over the age of 65 will double. And, so, that's a significant number of people who will be over the age of 65. And we know as you age, you get an increased chance of having a mobility limitation. So we really need to think about how we're designing our communities now and what services and programs are providing now so they can be accessible to our entire population and Universal design is really the best approach. For example, why should there be one stall in the restroom that's accessible? Why can't they all be accessible and those are common things. Or a unisex bathroom is accessible for a person who has a caregiver or of the opposite sex. But it's also great for a parent of the child of the opposite sex who needs to change for an activity.

So universal design is really the best way to go. And understanding it doesn't cost more, it just requires some input at the get-go and, it requires feedback loop, and, really, if we can begin to design our communities universally, I think we'll all be better served.

BARRY WHALEY: Well said. Thank you, Amy. Amy, what policy system, environmental change can support inclusive community efforts? Can you give me some examples?

AMY RAUWORTH: Sure. You know, policy sounds like such a daunting thing and we talk a lot of times about big P policy. So that's something actually in either your state or your local Municipality law. Or even little p policies. So what are the policies with organizations and their delivery of service and programs? So there are ways to create

change through policy that doesn't have to take a long time and doesn't have to enter in even to the legislative process. But one example is Complete Streets. So Complete Streets. They really look at usability for everyone. And looking at the safety of not only pedestrians but bicyclist and motorist and it's about creating environments that value all users.

And you'll usually recognize it. If you're in a place and you know there's a great placemaking happening, if there's mix use and stores you can visit and there's people that may live above those stores and there's transit stops that are accessible and you can get to that environment. You want to stay longer. They're designed better and more welcoming and Complete Streets policy is one way to do that. We've seen great success and advocacy efforts on Complete Streets. And many times many places first adopt a resolution. And that just means that they understand and prioritize the design of the community for all people and all users, and not just cars getting from Point A to Point B quickly.

But the next step is to really advocate for those Complete Streets ordinances. They have a little bit more teeth to them so when sidewalks are put in place, or when construction is done, they need to address all users when they do that, because of course we know with ADA it doesn't require sidewalks but if we know we have a Complete Streets ordinance, it prioritize all users which would require sidewalks to be to be put into place. So Complete Streets advocacy is a great thing for people with disability and non-disabilities can participate in.

There's a lot of active transportation going on right now. And disability voices need to be heard in those situations. We've had some successful cases here in Birmingham but it wasn't fast. The resolution began in 2011 for Complete Streets policies in Birmingham. And the resolution, excuse me, began in 2011. And the actual ordinance was passed just this March unanimously. But it really was a lot of individual user groups, a lot of advocacy efforts, and people with disabilities showing up at the city council meetings. And really giving a narrative to the case of what it means to be valued and included in community design, because policies can sometimes feel like it's not something that touches you in your home, or it's not something that touches you on a daily basis. But when we turn that light switch on and people start to see it through the eyes and through the narrative of people experiencing these barriers, it makes a very profound difference.

And I think that's one of the best ways is that narrative storytelling, putting a face to policy, and how it affects you is something that we all need to utilize our voice and advocate for the change that would benefit us.

BARRY WHALEY: Well, yeah. Congratulations on your work in Birmingham in particular. You know, when we talk about Complete Streets, possibly the easiest or the simplest thing we can do for fitness and activity is walking. Public health now is a hot topic. Have you addressed walking and walkable communities within and for the Disability Community?

AMY RAUWORTH: Well, I think term walking sometimes can feel either welcoming or not. And as a result, the recent surgeon general call to action on walking, we heard from the Disability Community. So we heard the voice that is people said, oh, here we go again. Another public health campaign that's not going to include me and going to focus on something perhaps I don't participate in. And we worked with the team that eventually put out the surgeon general's call for action. I encourage you to go look at it and to even listen to the recording that occurred few years ago. It had a very significant inclusive component throughout it. And I think that just the term how I walk, we knew we had to brand that.

So we recreated that by challenging and filing perspective. And this campaign can be found. You can look it up on NCHPAD on "How I walk." And it basically looks to influence perspective on walking. But I encourage the transformation and individual societal attitudes about what does that mean? What does walking mean? I know when I go for a walk with my friends who utilize wheelchairs, we call it walking. We don't say let's rock N roll. So we really wanted to spur that rebranding. And make sure that health promotion providers and walking advocates utilize that term for all of their walking initiatives. And we wanted to inspire advocates and encourage consumers to become their own advocates by sharing the mode of walking through social media activation.

So this is a campaign that's easily useable by anyone. You can utilize the tools. You can push it out. If you're part of a coalition in your community, if you're part of a walking club. If you just want to start one. This is a great way that has educational tools. It creates how to -- it gives you resources on how to create activity friendliness in an area. It talks about community. And it's a great way to start a program and make it more inclusive in the walking environment. So how I walk and how you do that depends on you personally. And we encourage people to share their story about how they walk.

BARRY WHALEY: Thank you, Amy. So beyond rebranding, what are some other things people with disabilities and their allies, what can they do to create healthy communities?

AMY RAUWORTH: Well, I have some great examples. And that's often how we expand and create more opportunities. Looking at what's worked to begin with. And we

partnered with America walk and they provided small amount of money for NCHPAD and Lakeshore Foundation. And it was really to promote that how I walk campaign. But to really take it into the community and utilize the participation of disability organizations in that healthy community design process. Few different ways they did that is we were able to provide funding for access Portsmouth in New Hampshire and what they did is, they actually went out and looked at their entire downtown and utilized Google Map.

So there's great technology out there whether it's Google Maps, or Wheelmap, or accessibility.cloud where you can look up thing all over the world that basically identify access positive and negative issues for people who might use wheelchairs. And they went out and did their entire downtown, and as a result of that, they had even greater community change. We also funded Hanover county department. And it's really about taking that civil action to the next step and looking at walk audits and how you can go out and participate with your city planners or people in power that can make the change in the roads or the infrastructure that you would like to see for people with disabilities and so there's great tools out there for walk audits whether it's AARP tools walk audit.

But I think it's a great way, training people with disabilities to be walk audit leaders and engaging with the community to go out and view the community through the eyes of a person who may utilize a wheelchair. And it makes a powerful impact and connects to perhaps where those funds, if they're limited, can be utilized to create a better healthy community.

BARRY WHALEY: That's really cool. Thank you, Amy. That sounds like a great project. Amy, we're about out of time. And I want to ask you, how can people find out more about health promotion and especially the various activities of NCHPAD after our conversation today?

AMY RAUWORTH: Well, of course, they can go to our website. I know it was mentioned before. It's NCHPAD.org. And we have a toll-free number that's 800 and 900. And we have voice and TTY. You can send an email. And it's email@NCHPAD.org. And you can follow us at Twitter, and Instagram, and YouTube. And we encourage you to let us know what you think. If there is a need, let us know and we'll partner with you. Because we really feel that's the best way to collaborate. And let us know and give us your feedback on how you're living a healthy active lifestyle.

BARRY WHALEY: Wonderful. Thank you for being our guest today, Amy. It's been very informative. I appreciate it. Folks, this Episode and all previous WADA ADA Live! Episodes are available at ADALive.org. Our episodes are archived in a variety of

formats including streamed audio from our website, accessible transcripts of audio, and also available to download is podcast to listen at your convenience. I do want to thank you, our ADA Live! audience tuning in today.

As always, we're thankful for your support and listening to our ADA Live! Broadcast. And remember, you can submit your questions on this or any topic by going to ADALive.org. And I hope you'll join us on July 4, 2018. My favorite holiday for our next Episode of ADA Live! It will be a rebroadcast of our very popular beach access topic. If you have questions about the Americans with Disabilities Act, please contact our center at 800-949-4232 and remember all calls are free and they're confidential. Reminder: You can submit any questions on any of these topics by going to ADALive.org. Join us June 6th for our next episode of ADA Live! We will be talking with representatives from the Accessible Recreational Facilities (Parks). If you have questions about the Americans with Disabilities Act, contact your center at 1 800 949 4232. And remember, all calls are free and they're confidential.

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