Transcript of the Health Yeah! Podcast

"Health Yeah! With Dr. Shannon Griffin Blake"

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JOSEPH RHODES:

Hello, and welcome to Health Yeah!, brought to you by the National Association of Chronic Disease Directors, promoting health and preventing disease. You can find more information about NACDD at chronicdisease.org. As always, I'm Joseph Rhodes, your friendly podcast producer.

Hello, everybody, and welcome to another episode of Health Yeah! Today's guest is Dr. Shannon Griffin Blake, and she works for the CDC's National Center on Birth Defects and Developmental Disabilities. And she talks today about the resources they make available to professionals at large. So you're not going to want to miss this.

PAIGE ROHE:

Hello, and welcome to Health Yeah!, a podcast series provided by the National Association of Chronic Disease Directors. I am Paige Rohe, Director of Communications at NACDD, and I'm very pleased to have joining me today Dr. Shannon Griffin Blake, the branch chief for the disability and health branch within the Division of Human Development and Disability at CDC's National Center on Birth Defects and Developmental Disabilities. Thank you for joining me today, Dr. Griffin Blake.

DR. SHANNON GRIFFIN BLAKE:

Hello, Paige. It's my pleasure to be talking with you today.

MS. ROHE:

So we are very pleased to have you with us today because we're very excited to talk about some of the innovative work in data presentation that you all have been doing in recent months. We have done a couple of webinars with you which are available on our website to talk about that. But I first wanted to get into a little bit of an introduction. Could you tell us about CDC's work in disability and chronic disease prevention? Why is it important?

DR. GRIFFIN BLAKE:

Sure. I'd first like to share that the Centers for Disease Control and Prevention has been involved in disability and health activities since 1988, and it was at that time our work was mainly focused on primary prevention. And the way I always explain that is we were protecting healthy people from developing a disability in the first place. But after 1990 when the Americans With Disability Act, better known as the ADA, was enacted, providing legal protections to millions of Americans with disabilities, our work really began to evolve and we moved from primary prevention to secondary prevention where our work was defined by helping people with disabilities achieve optimal health and protect them from health problems such cardiovascular disease, diabetes, and obesity.

But today, we have a laser focus on making sure that people with disabilities have access and are included in public health programs and healthcare services that can improve their health and overall well-being. So when I talk about inclusion, it involves more than just simply encouraging people with disabilities to be involved. It requires making sure that sufficient policies and practices are in place and implemented within a community. These policies and practices should be designed to identify and remove barriers, whether these barriers could be physical or communication or attitudinal barriers, that hamper an individual's ability to be respected or involved and fully participate in society the same as people without disabilities.

Specifically, the Disability Health branch, our mission is to promote the health and full participation in society by people with disabilities across their life span. The branch monitors the health of people with and without disabilities to identify how health issues affect people in different ways and why some people are at higher risk for certain diseases and conditions. Studies have shown that people with disabilities are more likely to have poor overall health, less access to adequate healthcare, and increased risk for preventable health problems.

But to give you just a couple of examples here, adults with disabilities are three times more likely to have heart disease, stroke, diabetes, or cancer than adults without disabilities. So these statistics are very important in identifying barriers, the ones I just mentioned, to achieve good health but also to design prevention and health promotion programs aimed at reducing health disparities and improving the health of people with disabilities.

Now, the branch has multiple functions and has informed our structure and priority. We conduct disability research and evaluation. We improve disability surveillance. We provide programmatic oversight to a variety of cooperative agreements, all while disseminating public health science and program successes with a variety of partners. We are ultimately striving to meet the needs of our partners and stakeholders while, of course, serving people with disabilities and their caregivers at every part of our work. At CDC, we know we don't work in a vacuum. We work with a variety of internal and external partners, including other federal agencies, local and state governments, universities, non-governmental organizations, and disability advocates to understand unique needs of

people with disabilities, share research ideas, brainstorm state-level and community strategies, and amplify research efforts at improving the health of people with disabilities.

DR. GRIFFIN BLAKE:

I would like to add that much of our programmatic and research activities are framed by the socioecological model, and that's about achieving multi-level changes such as increasing healthy behaviors, decreasing the prevalence of chronic disease risk factors such as smoking, obesity, physical inactivity, improving sustainability of programmatic policy systems and environmental improvement, and lastly, improving the availability of effective health promotion programs for people with disabilities. The public health interventions that we promote will achieve greater impact when changing the environmental context so that individuals with disabilities can easily take healthy actions in the normal course of their lives. But I'll probably just include as well that it's important to understand that disability does not equal poor health. Anyone can be born with a disability or develop one at any point in his or her life, whether it's through conditions present at birth, injury, chronic conditions. Really, disability is part of the normal human experience and it's our responsibility to make sure that the needs and engagement of people with disabilities are recognized so that everyone can have the same opportunity to participate in all aspects of life to the best of his or her abilities and desires.

MS. ROHE:

Wow. I can see why this is such an important topic for our listeners. And just hearing you break down so succinctly all of the many reasons why our members, chronic disease professionals, really ought to be looking at how they can be more inclusive of people with disabilities in their work. I mean, you've mentioned them being at three times greater risk for certain cardiovascular—preventable cardiovascular events. You've mentioned the fact that disabilities do not necessarily equal poor health, that it's part of the human experience. I love that phrase because I think so many of our members are focused on concepts like health equity. Right?

DR. GRIFFIN BLAKE:

Mm-hmm.

[Overlapping]

MS. ROHE:

…How health systems are created and may be creating inadvertently or advertently some health inequities. And considering that disability is a part of the human experience, and as public health professionals plan from cradle to grave, how they will be addressing different community needs, it's important to think about disability perhaps maybe, in some cases, as a life stage, or in some cases, as an added area of opportunity for health equity.

So, so much of what you said, I think will resonate so well with our members. And it's wonderful to hear that you're celebrating your 30th anniversary at CDC doing this important work as well. So happy birthday.

DR. GRIFFIN BLAKE:

[Laughter]. Thank you.

MS. ROHE:

I think it's interesting that NACDD started in 1988 as well; the National Center for Chronic Disease Prevention and Health Promotion started in '89. And, of course, your disabilities work, the disabilities work that you do, started in '88. So it seems like not too long ago there was sort of a real focus on addressing some of these great challenges. So it's exciting to see how far we all have come since then.

DR. GRIFFIN BLAKE:

Absolutely. That is exciting.

MS. ROHE:

And, speaking of sort of your work with other organizations, and, I think a point that our members will really appreciate is the concept of integration. I think you would, maybe you would, agree that when we think about disabilities inclusion work, it isn't about necessarily creating separate things. It's about—or separate activities or actions—it's about thinking how to be more inclusive in the activities that are already being planned. And in that sense, I'm wondering in what ways have you worked with NACDD on some of these priorities, knowing that we do disabilities inclusion work but we also do chronic disease prevention work.

DR. GRIFFIN BLAKE:

Absolutely. I totally agree with you, Paige. There is a lot of overlap in our work. Of course, we're all striving to improve healthy behaviors for our work, definitely around people with disabilities, and also addressing health disparities. So both of these are obviously focal on outcomes for us. And it's really exciting that the Disability and Health branch and NACDD has developed a collaborative project together to promote disability inclusion strategies to make healthier choices the easier choices for all people, whether they may—where they live, where they learn, where they work, where they play. Our project is entitled Reaching People With Disabilities Through Healthy Communities, and this project really bridges state disability health efforts and community engagement by improving disability inclusion at the local level. And it's the engagement of community coalitions and infusing state-level disability expertise and resources to accelerate local

improvement, whether it's addressing physical inactivity or poor nutrition or tobacco use and exposure.

What I think is also exciting is that CDC and NACDD also partnered with one of our key partners, which is the National Center on Health, Physical Activity, and Disability, sometimes known as NCHPAD, to provide some additional support and overlay access to disability inclusive tools that can be used, again, at the local level, to identify and address health disparities in an equity space by people with disabilities. So this project is focused in on five state programs that are funded by the Disability and Health branch, who applied for this project. And then each state identifies two local communities to participate through a competitive application process. I do just want to highlight that the five state disability and health programs include Iowa, Montana, New York, Ohio, and Oregon. And over the last two years, NACDD has done an excellent job working with these communities to bring public health and disability and health advocates together in many ways for this one of a kind project. It's using a multi-phase model that these communities completed a local assessment.

And, again, I love the fact that they're creating this data-driven process to develop community action plans and implement community level improvements to promote accessibility and inclusion for their residents. We've already seen a number of successes that we've been able to document. And I would like to encourage anyone who's listening to go to our disability health website. I'll be giving the website name towards the end of the podcast. But if you're interested in learning more about this project, the type of successes that have been able to be documented, and view several videos from our communities, I want to encourage you to go to this disability health website and check it out.

MS. ROHE:

That's excellent. I know that you have a lot of material on your site as well, and there are a number of great videos on YouTube showing how these communities have worked together to do things like make a street a little bit more walkable, to make a park that's been funded by the city include opportunities for people with disabilities to enjoy the park more actively, to, I think, even, you know, looking at community gardens and all sorts of things like that. And just help make environment more accessible, as you said, to make the healthy choice the easy choice. And you've just been great. You study these cases for other communities who are looking to do something to really see it doesn't require that much investment to make a real appreciable difference in inclusion.

DR. GRIFFIN BLAKE:

Absolutely, Paige. And I think what's really exciting about these videos is that it really is able to bring to life the type of adaptations that can be completed within communities that can create accessibility for all members. And so, again, these videos, I think, are really

helpful tools to be able to understand, again, the type of strategies that other communities can try to include in their own environment.

MS. ROHE:

Absolutely. And taking a 50,000-foot step back, we know that people with disabilities are at higher risk for certain preventable serious chronic conditions. We know that many Americans will experience a disability in their lifetime. And we also know that there are, as you said, very simple interventions and ways to include people with disabilities to make the healthy choice the easy choice. But it all comes back to looking at the prevalence of disability in communities overall. And, as my old mentor used to say you, you cannot measure what you cannot count. In other words, getting a sense of how many people have disabilities in a community, in some cases, what those disabilities may be, how—whether they're more prevalent in certain communities in a state than others. These can all help state health programs, and our members in particular, better understand where they really need to be thinking especially about inclusion in certain programs and activities they do. And this leads me to talking a little bit about your disability and health data system. I know you guys have put so much work and energy into this and it is such an important tool. So I'm hoping you can tell us a little bit about it. What is it, and why was it created?

DR. GRIFFIN BLAKE:

Sure. I'd be glad to talk about the disability health data system but I just wanna echo something that you just said, which is, you know, data is a very powerful tool in making sure that programs that are being developed are congruent with actual needs. And I would probably add another evaluation quote, which is: What gets measured is what gets done. So this disability and health data system is what we hope to be a very powerful tool for stakeholders and partners who are working at the state level.

As I've already mentioned, adults with disabilities experience significant health disparities compared to adults without disabilities. So to improve the health of this population, we know that state epidemiologists, researchers, public health professionals, need access to both accurate, as well as timely data to inform their state's health promotion activities. So at CDC, we created the disability health data system, and you'll hear me call it DHDS, using the acronym, to provide quick and easy access to data on demographics and health information for adults with disabilities.

DHDS is an online source of state-level data on adults with disabilities, and users can access information on six functional disability types. And I'd like just to maybe walk through these six. The first is cognition, defined as serious difficulty concentrating, remembering, or making decisions. The second is hearing, defined as serious difficulty hearing, or deafness. Followed by mobility or serious difficulty walking or climbing stairs. Vision, defined as serious difficulty seeing, or blindness. The fifth is self-care, defined as

difficulty dressing or bathing. And the sixth and final disability type is independent living, which is defined as difficulty doing errands alone.

What's exciting about DHDS is that there are data on approximately 30 different health topics. And I really want to encourage anyone who's listening to go to the DHDS site and explore it. And they'll notice there are a number of different health topics that may be of interest. Again, the smoking, obesity, heart disease, and diabetes. Users can also customize data maps, charts, and tables, making it very easy to see information about their state or even their region. They can identify health differences adults with and without disabilities overall, but then also dive a little bit deeper and stratify by age or sex or race and ethnicity. Data can be used in presentations or reports. We know that, again, some users have used it for grant applications or even to inform dialogue with decision-makers and other types of partners.

What might be helpful, though, is just to give a couple of examples of questions that we know have been answered by other previous users who've explored DHDS. And maybe I'll just give a handful or so. So one question that can be answered is, what is the percentage of adults with disabilities in my state? What is the percentage of adults with a particular disability type in my state or states in the surrounding areas? A third question may be, how does my state percentage compare with national percentages or even neighboring state percentages? And a final example of a type of question that can be answered would be, does the percentage of adults with a particular health indicator—and again, it can pulled up by obesity, physical activity, or smoking—vary among adults with and without disabilities? So DHDS is a very useful data tool that can be used to answer, really, some key public health questions at the state level.

MS. ROHE:

That's an excellent introduction. And, I think something that maybe has been left a little unsaid is, in thinking about the chronic disease programming and activities that our members are doing, you might find that there's a tremendous opportunity to reduce the burden of chronic disease by explicitly focusing on disability inclusion. So I just want to throw that out there in the sense that there may be populations that without—in the absence of having access to this data to be able to see—you might find that maybe a large group of the people that you really need to focus on are those with disabilities in your communities once you're able to kind of compare and contrast that data. I don't know if that's accurate or if you want to add to anything related to that.

DR. GRIFFIN BLAKE:

Well, probably what I would add, and I've shared this many times with colleagues is that we will never be able to reach our public health goals without meeting the needs of people with disabilities.

MS. ROHE:

So, Dr. Griffin Blake, would you share with us then some statistics that you found in digging deep into this data that might be very compelling for some of our listeners to really be convinced that they must and they really are encouraged to include disabilities work as part of their work to achieve their goals.

DR. GRIFFIN BLAKE:

Absolutely. And these statistics really are diving into some of the major findings that we have found when updating the disability and health data system with the 2016 BRFSS data. And probably as just a quick caveat, I really want to encourage anyone who would like to learn more about these statistics to go and check out our morbidity and mortality weekly report that was published on August 17th, and that MMWR was entitled "Prevalence of Disabilities in Healthcare Access by Disability Status and Type Among Adults, United States 2016," because where we really had some "aha" moments as we were exploring the 2016 BRFSS data, or the Behavior Risk Factor Surveillance System data, was that these new data from 2017 indicated that one in four adults in the United States live with a disability. And by including all six disability questions within the 2017 data, we were able to see also the number of people reporting serious difficulty hearing, and we did not have that hearing question previously asked before the 2016 survey went out. But by including it and being able to collect and report based off the Behavior Risk Factor Surveillance System 2016 data, what we found is that an earlier estimate that was one in five adults had a disability, then moved to one in four adults reporting a disability, which, to me, highlights the importance of surveillance. It highlights the importance of having appropriate questions being asked so that we can have the most accurate numbers.

I think a second key finding is that all disability types were more often reported by women, with the exceptions of serious difficulty hearing, which was most often reported by men, and then self-care, which was equally reported by both men and women. But I want to give you a handful of statistics, to me, that really highlight how adults with disabilities continue to face health disparities compared to people without disabilities. So, for example, approximately 38% of adults with a disability are obese while 26% of adults without a disability are obese. Now, if you think—as we explore smoking, 28% of adults with a disability smoke, compared to only 13% of adults without a disability smoke. We also see similarities around our statistics with, with heart disease and diabetes. For example, 12% of adults with a disability have heart disease compared to 4% of adults without a disability have heart disease. And then, finally, 16% of adults with a disability have diabetes, while only 7% of adults without a disability have diabetes. We also see health disparities around access to healthcare for adults with disabilities, so that remains a challenge. And I'll maybe just throw out one statistic here, which is 26% of adults with disabilities could not see a doctor due to cost in the last 12 months compared to only 10% of adults without disabilities.

So I think I just wanted to share a few statistics here that we learned while we were exploring the 2016 Behavior Risk Factor Surveillance System data and how there's some really interesting data points at the national level but I really want to encourage everyone to go to the DHDS site and explore state-level data. And I think they may be really surprised by the disparities that they find.

MS. ROHE:

That's some really compelling data. And I think some of the things that I'm hearing from the program side would be, "Wow, you know, if we—if my community, in particular, happens to have, a higher or, a significant rate of people with hearing concerns, then maybe telephonic delivery of certain educational messages might not be the right way to go, or I might need to consider that." If so many of my community in my address of pre-diabetes awareness I may want to focus that more—in my community if I know that there are more people with disabilities in certain areas where I'm targeting, I might want to think about access to being able to attend a meeting to learn more about pre-diabetes or whatever it is. So I think it goes to not just looking at, you know, maybe where the burden of disease is, but also in those brass tacks when you're staring to plan a program, being able to use data like DHDS to really help you think about how you're creating that program, and what considerations you may need to put in place to make sure you're reaching individuals who may otherwise be left out because they can't maybe listen as easily on the telephone or because maybe they can't as easily get to where they need to be to participate in the screening fair or other things like that. So that's sort of one of the key takeaways that I've heard from this conversation.

So I know that we don't have that much more time left in our conversation. I feel like we could probably go into this for a lot longer. There's so much wealth of data to talk about but I wanted to give you some time at the very end of our time together to talk about other resources that you really think our members should take a look at. We know that there's the DHDS website. NACDD did a couple of webinars on how to use that, that include some case studies of other states that have used this data to help them plan more integrated chronic disease prevention work. But would you give us some resources that you'd like to direct our audience to?

DR. GRIFFIN BLAKE:

Absolutely. And I definitely think you already began to share a few, but, just to highlight again, there are a number of resources available and we hope that they're gonna be useful to anyone wanting to use and explore DHDS. There is a Getting Started guide that's an excellent resource that people can find on the DHDS website. This is a step-by-step guide that can help a user navigate the site and find the information he or she is looking for. We have a Frequently Asked Questions page that, hopefully, will provide answers around this data source, the methodology, usability, and other general questions about DHDS.

DR. GRIFFIN BLAKE:

As you noted, Paige, we do have some training tools available as well, specifically, two webinars that occurred in June of 2018. The first webinar happened on June 21st, which was really entitled around A Beginner's Guide to DHDS and was to help users who wanted to learn the basics around this data tool and to be able to find health differences between adults with and without disabilities. The second webinar took place on June 16th, entitled DHDS Beyond the Basics, and that training really was around helping users who wanted to explore more advanced features of DHDS and learn tips on how to utilize the data in the system. There are recordings of these webinars. There are PowerPoint slides. There are transcripts. And we hope these will serve as a resource to anyone wanting to use DHDS.

And, again, all of these resources are available on the Disability Health website. I did want to finally give that website to everyone listening, which is www.cdc.gov/disabilities, which is plural. I would just probably add that there's a DHDS fact sheet, which, of course, is easily printable and can be shared with colleagues or other stakeholders that may be interested in understanding and learning about DHDS. And then also state profiles. We have used DHDS to create state profiles that can be easily printed and be used to educate partners and stakeholders, again, about the disparities for people with disabilities in each state. And if you go to the DHDS website, these state profiles can be found under Data and Statistics.

Probably a final note I wanna add about these resources is that we know, for many of the state disability health programs that we work with, that DHDS has been very useful. It's been a data source for fact sheets that they're developing, data briefs. It gives them timely data at their fingertips to help educate, again, decision-makers and other types of stakeholders about the disparities faced by people with disabilities. I would note, though, that, again, whether it's developing a social media presence and developing tweets using key statistics about people with disabilities, whether it's developing emails and newsletters where, again, individuals working at the state level want to frame the importance of their programmatic work and how this work is being used to address the unique disparities faced by people with disabilities, or even developing a state improvement plan and then trying to include people with disabilities as a focal population. I hope that our disability health data system is a key resource for any user who wants to create that platform for their work and will be able to be a useful tool for them.

MS. ROHE:

So, Dr. Griffin Blake, are there any other resources or, you've listed a, a great number of things. Are there any other resources that our members should be aware of? Are there any opportunities for them to provide feedback?

DR. GRIFFIN BLAKE:

I think a final resource, just to highlight, is as anyone goes to the DHDS site and begins to explore the data that is available, we really want to encourage anyone on the site to go and complete the online survey. There is a link on that site. And, again, this helps us to understand who is going to the DHDS site and the utility of these data. So any feedback, any information that you can provide always helps us to improve the site and the data that we're able to provide to you, and to our future users. So that would be wonderful.

MS. ROHE:

Excellent. Well, again, as we all said earlier, you cannot measure what you do not count. And for those who are making use of the data, please do return the favor and provide some data back on how the tool has worked well for you or the team. Well, I really appreciate sharing those resources. And, some of the data that we have from our members suggested this really well. In a pulse survey that we did in July of this year of chronic disease directors, we found that 58% did not feel they had enough information at the time, or were working to get more information to help address the disparities that people with disabilities face in their community. So, again, for those of our members who are listening, these are some really great resources to support those efforts that, again, are continuing to be refined and looked at. And we know that this is such a priority for so many of our chronic disease directors as well. You know, 57% said that addressing the needs of people with disabilities in their communities was a high or medium priority for their work. So, again, for those of our members who are listening, we really encourage you to go to the cdc.gov/disabilities website to get access to these absolutely critical tools in your work to help you address these priorities and to meet these information gaps and needs that you have.

So with that, I'll add, if there's anything else that you would like to share with us?

DR. GRIFFIN BLAKE:

I would just say, Paige, thank you so much for the opportunity to talk a little bit about CDC's disability and health work. We hope, again, that the disability health data system will be a key resource and we look forward to future collaborations with you at NACDD and your partners.

MS. ROHE:

Thank you so much for joining us at Health Yeah!, our podcast for the National Association of Chronic Disease Directors, Dr. Shannon Griffin Blake. We look forward to continuing conversations with you and with all of our members to hear their thoughts on this and the other podcasts available at our website chronicdisease.org. Thank you again for joining us, and until next time.

MR. RHODES:

Well, that's a lot of great resources. So for more information, go to www.cdc.gov/disabilities. And, hey, while you're there, take the survey to help them enrich the data they have available. And, as always, if you want more Health Yeah! or more information on NACDD, go to chronicdisease.org.

And, finally, one small correction from our guest. Earlier in the podcast, Dr. Griffin Blake refers to 2016 Behavioral Risk Factor Surveillance System of BRFSS data as 2017 data. All the data included in the disability and health data system or DHDS are 2016 BRFSS data.

Well, that's gonna wrap up another episode of Health Yeah! I hope you found it informative and entertaining like I did. On behalf of the NACDD, thank you very much for listening.

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