

Grassroots Project_June 20th W...ng One's Advocacy Community...

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SPEAKERS


Alixé Bonardi, Eric Washington, Laura Bernas, Kate Brady, Santa Perez, Lola Kernell, Dr. Jennifer Johnson, Cody Drinkwater, Cody, Allilsa Fernandez




Kate Brady 00:00

Kate, welcome to the grassroots project, engage, connect, advocate, our inaugural webinar. My name is Kate Brady. I am co director of this project that is administered by the Human Services Research Institute where the project team works. We are funded by the Administration for Community Living. A brief visual description of me is that I'm sitting in my office with art on the wall behind me. I am a white, middle aged woman with short, curly hair, and I am wearing a bright orange scarf, and I'm going to speak up a bit. Thank you for that. Cue. Today's webinar is finding one's advocacy community stories and insights from the disability community. We would love for you to introduce yourself in chat and get connected with other people who have joined today, we'd like to share with you some webinar logistics. Participants will be muted during this webinar, and please use the chat feature if you have urgent individual concerns. You can direct those to alaminsky@hsri.org and that email is available also in the chat towards the end of the webinar, panelists will have an opportunity to respond to questions that have been entered into the chat. So we'd love for you to be thinking and dynamically responding as we move through this webinar. The webinar is live captioned in English and live interpreted in Spanish. Live captions can be accessed by clicking the CC button at the bottom of your zoom screen. Live interpretation can be accessed by clicking the interpretation button at the bottom of your zoom screen. It's a world icon. Once in the Spanish channel, please silence the original audio, and now I will say that in Spanish. So I am not a native Spanish speaker. [Spanish Interpretation] Due to a recent zoom update, full accessibility, including ASL interpretation may not work if you are joining with a mobile device. ASL interpretation and slides can no longer be viewed simultaneously via phone or tablet. If you are on a mobile device, you can swipe sometimes on a mobile device to find the ASL interpreter if you need to this live webinar includes polls and evaluation questions, and we'd appreciate if you would be prepared to interact during the polls. So regarding feedback and follow up, we would love to hear your feedback about the webinar itself, and you can email us at the grassroots project, at grassroots@hsri.org that email will not be monitored during the webinar, so that's for general feedback and for urgent matters, please email alainski. We are not officially approved for continuing education units. However, we can provide you with confirmation of attendance, in

case an organization wishes to use that and zoom will also automatically send attendees a confirmation of attendance. One day after the webinar, you'll also receive a link to the webinar recording and other materials such as slides and resources one day after the webinar and grassroots project and webinars and other associated materials, such as plain language summaries and transcripts will be archived on our website at the link you see on the screen there, and where else of. In that image. So at this time, we'd like to introduce the first poll so that we can get a sense of who is here today. And the first question in the poll you may need to scroll down in this box asks, In what ways do you identify with the disability community? You are very welcome to check more than one box, and I already see that we've got a great variety of folks here. The options include person with a disability or disabled person advocate, family member or loved one of a person with a disability, a person working in a disability organization. There are great many folks here and caregivers. The second question, if you scroll down, asks, What is your gender identity? And you can if you're willing provide that information, and you're welcome to check more than one box if multiple categories apply to you. We're also asking what age group you can select from a variety of options, and whether you identify as Hispanic or Latino, the fifth question is, what is your race? There are a number of options there, and that concludes the poll. And we really appreciate your response to those questions. It helps us understand the breadth of the community that we are reaching. So we can leave that pull up for another second or so lower, and then we'll pull it down and carry on. Looks like we've got pretty good participation. I'm going to keep going.

 Cody 07:10
Okay,

 Kate Brady 07:12
let's carry on. Thank you all very much for your response. So the purpose and goal of the ACL grassroots project, which launched this year with the goal of supporting a national, state and local disability advocate coalition to build networks and grow advocacy leadership with the intention of driving disability policy and supports to serve disabled people and communities robustly and wholly. In this first national webinar, we seek to learn from disability advocates and hold a conversation about how advocates stay informed, work together and mobilize to make change in their community and service systems. We are very glad that this webinar provides a chance to hear from advocates about the steps they took in finding their disability advocacy community, the trials and tribulations they have found along the way and any tips they have for success, and ultimately, how they see disability advocates maintaining a sense of connection in their work together. Our agenda today is that we'll we'll do introductions from our funder, the Administration for Community Living, and our team will provide you with a project overview. We'll introduce the panelists, and then we'll have a facilitated discussion. So here on the screen, you'll see pictures of just a small subset core of the grassroots project team. This work is supported by many brilliant folks at the Human Services Research Institute who aren't pictured here, and some phenomenal national partners, but you'll see here our co director Alex Bernardi and our fabulous project coordinator Laura Barnes. At this time, it is my pleasure to introduce Dr Jennifer Johnson, Acting Commissioner of the administration on disabilities. Dr Jennifer Johnson is at the Administration on disabilities, part of the US, Department of Health and Human Services, the Administration for Community Living. Aods mission is to equip individuals with disabilities of all ages to lead lives. Of their choice in their community, its

programs are working to create change and improve the lives of the estimated 61 million individuals with disabilities living in the US by advancing opportunities for inclusion and participation in the community, employment and financial well being and independence and self determination. Dr Johnson previously served as the Deputy Commissioner since September 2019 with a focus on improving the quality and accountability and evidence base of AOD programs and initiatives. She supports planning and oversight of AOD \$355 million budget that funds a number of disability programs and projects across the US and territories. Her 30 year career in government, academia, national organizations, local school systems, all demonstrate a clear commitment to improving opportunities for people with disabilities to lead full lives in the community, with emphasis on diversity inclusion and advancing a diverse array of programs for underserved and unserved individuals and communities. It is my pleasure to introduce to you. Dr. Jennifer Johnson,

S

Santa Perez 11:34

okay,

D

Dr. Jennifer Johnson 11:35

my video looks like it's on and my audio is working.

K

Kate Brady 11:43

It is working. Well, yeah, great.

D

Dr. Jennifer Johnson 11:45

Thank you. Well, hello and thank you for that. You to this national webinar, and I want to thank you for joining us. As was said, I am Jennifer Johnson, and I am a middle aged white woman with long hair that's right now pulled up into a high bun. My hair is salt and pepper Gray, and I'm wearing a white long sleeve top with a V neck, and I have on a turquoise blue necklace that's made of very large beads. I'm sitting right now, and behind me is a big desk and some other objects, I guess, behind me in my room, I go by the pronouns she and her. I also have both personal and professional experience with disabilities. I have both ADHD and generalized anxiety disorder. I also have children with disabilities, and as was shared in my bio earlier, I've had a very long and very wonderful career in the disability field. I'm going to just share a little bit about the project that we have funded, the grassroots project. This is a very important project for the administration on disabilities, or AOD and I know in my bio there's a little bit of information about AOD, but in case those are, there people on who are not familiar with us. We are a part of the Administration for Community Living, or ACL, which is part of the US Department of Health and Human Services. Within ACL, we focus on both people with disabilities and older adults, and our core mission is to ensure that all people, regardless of age, their level of support need, their needs, in terms of community living, that they are getting the supports they need to be able to live very active and full lives in the community where they're valued members of their community, as was mentioned. We within AOD, but also across ACL, we fund both disability and aging programs at both the state and local level, and these

programs are carrying out a variety of activities that include direct services, both to people with disabilities and some to older adults, to programs that provide legal advocacy, and then to programs that also are working To change systems to make them better. We also fund research and training on disability and independent living. So in terms of the grassroots project, the idea behind this project is really to make sure that people with disabilities have the tools and. Resources and the connections that they need to each other, to have their voices heard and their perspectives included where it's needed to inform decisions that are being made. It made about services and supports, and it's really based on the power that we all know and appreciate of people having their voices and their perspectives included, and the importance of making sure they can get information that is needed to be able to do that, it's also based on the strength of getting connected to like minded people so they can use that power to call for change where it is needed, or when it's needed or when no change is needed, and that we need to maintain the services and supports that are needed to live in the community, whatever it may be, the importance of connecting with peers to be able to advocate for what is needed. So we at AOD understand that for people to be engaged in that way, they need a resource for them designed by them to meet their advocacy needs. With this grassroots project, we are really creating something new, and I think something really innovative. It's something unique that we have never really done before, and while we have certainly supported self advocacy and leadership development, and we continue to do that. We've done that for years, and we are continuing to do that through some of our grants, but also through many of our programs that we fund. This grassroots project really brings things to a new level. And so not only is this about building and growing and strengthening grassroots advocates, people at the ground level who are advocating for services and supports, we are also building and growing and strengthening what we call an infrastructure for grassroots advocacy, especially in places where it does not exist, and then also to strengthen it in places where it does. And by infrastructure, what I mean is that we are building the connections of organizations and people and of resources for grassroots advocacy and and so what we are doing is bringing different groups to the table to create strong connections at the national level for supporting grassroots advocacy. And we want to be able to support the same kind of connections at the state level and the local level. And we are also creating connections across all those levels. So our national partners that are involved with the grassroots project are supporting state partners that they are engaged with and connected connected to, and then the state partners supporting local grassroots coalitions. And that's what I mean by creating that infrastructure. And so it's these connections are not only going to be supporting seasoned grassroots advocates, but we also want it to bring in new people into grassroots advocacy, helping them to understand how complex systems of support work and how their voice really matters and making sure those systems are working for them, and that's what many, if not all of us, are aiming for, and why we do this work now. We all envision a world where people with disabilities are treated with dignity and are appreciated for their individuality and allowed to live their lives without people making assumptions about what they can do and cannot do just because they have a disability. Our work at AOD is about that and about the people who on a daily basis, have to fight to get a job, have to get education, have to fight, to get into the playground, to play with their peers, to get onto an exam table at the doctor's office, to get personal care at home, whatever we it may be, we know that there are people with disabilities out there on a daily basis who are having to fight and advocate to Get what they are entitled to. So this grassroots project really aims to give people the tools they need to educate others about their disability experience and what is effective for them to achieve their life goals. It is also aims to give people with disabilities again the information and resources they need to understand how complex systems work, so they know where to go when they need to advocate. Today, we have some amazing grassroots advocates who are going to share about their experiences. They are going to share how they as grassroots advocates, stay informed, work with others and connect to make. Change in their

community and the systems that support them and their peers. They're also going to share how they got involved in their disability advocacy community, what worked, what didn't work, even what might not be working now, or what is working now for them. And they're going to share their thoughts and wisdom on what they think is needed to not only keep these connections, but also, how do we build off of the connections that currently exist? So these amazing grassroots have figured many things out in terms of how to get connected and how to advocate, and they really found their way into grassroots advocacy, and they certainly have a story that we can learn from, so that we can harness that knowledge and experience to grow this effort and bring more people into grassroots advocacy. We know many of you connecting today have to a story to tell, so we encourage you to share your advocacy story through the chat feature that was mentioned earlier. You can also use the chat feature to ask questions. So that's it for me. I think we really want to get to what counts, and that is the speakers today who will be sharing their experiences with us. So again, thank you for being on with us. I hope you keep track of our project and the work that we're doing and that you get connected through it.

K

Kate Brady 21:24

Thank you. Thank you very much. Dr Johnson, great to hear from AOD, and we're so glad to have the project supported in this way. I'm going to share my screen, folks. This is Kate. Back to speaking again, and we'll just quickly provide you with a little more detail about the grassroots project. Though I think you've heard a great deal about the vision for the work. We are aiming to position the next generation of cross disability, cross generational and culturally different streets advocates as leaders. Our aim is to support catalysts of systems change and to lead a national effort to support grassroots advocacy three partnership. We'll share a bit with you about the other partners that are engaged in this work. You see here on your screen an image, a round image, of nested layers of effort, and at the center there, of course, is individual disabled people, right, who are working locally in their communities to advance their life and the lives of others. And then we are engaged in supporting both state and local level advocacy and action coalitions. So those are grassroots coalitions of advocates, sometimes already working cross issue, already working cross population, sometimes with the support of state organizations and all making change in their work. And then we're partnered with a national level advocacy and Action Coalition that will share a bit with you about so our project approaches are twofold. We're aiming to develop structures and processes that that underpin and hold up a cross disability, class, generational, culturally diverse group of folks within the advocacy movement, and then to strengthen, grow and support the existing coalitions, of which there are so many around the country, by providing support To grow skills, providing resources and information, all with the aim of improving community living. Some of the key activities that we'll be engaged in are the production of an environmental scan in which we've looked at what the gaps in advocacy may be, what the existing resources are for the support of the advocacy. We'll also be hosting webinars like this one monthly. We'll create an advocacy resource hub that will be publicly available to show those resources that already exist to support disability advocacy, and we'll generate a toolkit to present examples of innovation in advocacy. This project works across all six ACL focus areas. Those are pictured on your screen there, and they include person centered planning, consumer direction and self direction. The caregiver crisis, health and safety and community living, the HCBS rule, civil rights and community integration. So we'll see work in a variety of areas next. We just wanted to give you a sense of some of the immediate outcomes we anticipate through this project, you've heard about the formation of new advocacy partnerships, an increased number of state and local policies that advance issues of importance to the disability community, an increased number of grassroots advocates who engage in training their peers and others, and an increase in

people's ability to engage in state level system advocacy right, which can be varied and complex, also pictured, there are some other details around increases in knowledge, increases in diversity of people engaged, and increases in the numbers of coalition and peer networks. We also wanted to share with you some of the intermediate outcomes. So things that we envision will happen longer term as we continue the development of the grassroots project, and so we anticipate Danes in knowledge of state systems of services, understanding of how to leverage state and other resources to create new coalitions and understanding and how state services are funded and and then we anticipate that there will be some autonomous organizing that happens nationally. We are committed to establishing and supporting the creation of processes and structures that support advocacy. We have also formed a number of state and national coalitions, and have within our strategic plan the explicit aim of working in a cross disability, cross issue manner, some of our key partners are the NAAC, which is the national advocacy and Action Coalition and advisory group called the state agency partnership group, and then a number of supported state and local advocacy and action coalitions on the screen. Here is a list of national advocacy and action coalitions, including nacdd, the National Association of councils on Developmental Disabilities and National Disability Rights Network, the Association of University Centers on Disabilities, or AUCD, the Autistic Self Advocacy Network, the self advocacy resource and Technical Assistance Center, the Association of programs for rural independent Living, the National Council on Independent Living, the National Paralysis Resource Center and the National Association of State head injury administrators. As you see, we are in partnership with the National DD network, the National Independent Living network and a number of other leading national organizations all equally committed to advancing disability advocacy. When we say advocacy, what do we mean? There are lots of kinds of advocacy. There's direct action, lobbying, there's educating, organizing, preparing and in the context of this project, we are focused on the blue little advocacy, providing education, supporting information dissemination, helping people prepare for their advocacy goals and supporting organizing, recruiting new folks, identifying new allies. Our state agency partnership group is a phenomenal advisory group that provides us support to ensure the effectiveness of the project. They are committed to improving the systems that support community living for disabled people, and we are glad to have their advice. They include the National Association of State Directors of Developmental Disability Services, advancing states the National Association of State. Head Injury administrators and the National Association of Medicaid directors. I am so pleased now to move us to the part of the webinar in which we will hear from the panelists. And at this stage, I'll introduce them in alphabetical order, and we'll take the slide deck down, and you'll hear from them just a one minute self introduction. If you find that you want more detailed information, the bios are available in the slide deck, which will be available on our website. So at this point, it is my pleasure to introduce a Julisa Fernandez, if you'd like to come on camera, we'd love to hear from you about the issues, what issues are most important to you? And then just an introduction with a visual description. Thanks so much.

A

Allilsa Fernandez 31:10

Hi everyone. My name is Julisa Fernandez. My pronouns are he, she, they interchangeably, which means to switch it up. I'm a person of color. I have short hair, black short hair, brown skin, and I'm wearing a colorful shirt. In the background, you'll see an AC and white walls. A little bit about me. I am an advocate activist, a pet parent of two dogs and a guinea pig, and I live openly with psychosis. I have worked with companies such as Lionsgate, Facebook and Verizon, to name a few, around mental health matters and my work surrounds disability justice and mental health. Justice. It is a pleasure to be here with you all today. Thank you, Angela.

K Kate Brady 32:09

at this time, you can turn your camera off, and I will welcome Cody Drinkwater. Cody, we're glad to have you here, if you would give a visual description and tell us a bit about the issues that you're working on. Thank you.

C Cody Drinkwater 32:25

Hi, yeah, so I am. I am a Caucasian male with glasses, brown hair and kind of a little beard and and, yeah, so I am on autism spectrum, and I had been, of all involved with disability Advocacy, probably since like 2018 although I've certainly been advocating for parts of my life for, like, a lot longer, and I have, I have ADHD and anxiety disorder, probably generalized anxiety disorder. So I have a few things, a few things going on, um, and, yeah, I'm, I'm really passionate about advocacy and passionate about helping people, um, and I'm very happy to be here with you today. Thank you.

K Kate Brady 33:40

great to have you with us. We look forward to talking with you more. You're welcome to turn your camera off at this time, and it is my pleasure to welcome Eric Washington, Eric, we'd love to have a visual description and hear about the issues that are most important to you. Thank you.

E Eric Washington 33:59

My name is, I need my government name. My name is Eric James, Washington. I'm from Detroit, Michigan, um, African American. Bald head, big beard, salt and pepper beard, go t thing. Um, as far as the disabilities that I kind of suffer from. It's wide on the spectrum. It is. I broke my neck playing football, so I have a spinal cord injury. I deal with multiple cognitive and mental health issues, so I take enough medicine to calm a storm. I have cancer, two different types, so I'm just an advocate for all types of things. Some of the areas that I've worked in, I've worked in the DEI area, I've worked in brain injury area, I've done a lot. Stuff with peer to peer, just helping people learn how to tell their story. Yeah, that's me a nutshell.

K Kate Brady 35:09

Thank you, Eric. We're so glad you're with us at this time, you're welcome. Yep, you've already done it to turn your camera and we will welcome. Lola Cornell, Lola, I'm going to share your slides, and it will be great for us to hear a visual description of you, and then I'll be happy to advance the slides if you're just saying it Okay.

L Lola Kernell 35:32

Hello. My name is Lola Cornell, a peacemaker and advocate. I am a young white woman with Down syndrome, long, dark blonde hair, glasses, and wearing a light blue shirt. Behind

Down syndrome, long, dark blonde hair, glasses and wearing a light blue shirt. Behind me, you see a brown buffet style cabinet, and in the dining room that I'm sitting in, I am the Advocacy Coordinator on the Kansas Council on Developmental Disabilities, issues that are important to me are competitive, integrated employment and all rights of people with diverse abilities. I will be leading the new change agent program, which will support and train new self advocates in Kansas. This program will launch in September to prep for 2025, legislative session. I'll go into that a little bit later, but first, let's talk about me. I'm 19 years old and graduated last month from bitumen age High School, one of the many ways I like to express myself creatively is through theater, and I'm involved in the American heritage girls. I work for the Chiefs the Royals, and on my first day of working on the council, I had a job coach who has helped me get started. I know I don't need that help anymore. This is a photo of my siblings and my sister in law. Next slide, please. This is a picture of us celebrating World Down Syndrome Day at the Kansas capital ever since I learned that I had Down syndrome, Down Syndrome Innovations has always been there for me, and I was honored to be invited to be part of the Down Syndrome innovations in Kcd employment roundtable. That was where I spoke with Kansas legislators, Kansas vocational rehabilitation services, employers and other organizations to talk about my employment background at a Kansas registered apprenticeship in partnership with Down syndrome innovations, the Kansas Department of Commerce and Down Syndrome innovations work together to create more inclusive opportunities for people with diverse abilities. It is important to have those skill building opportunities integrated in community. Next slide, please, like I said, I am the Advocacy Coordinator at Kcd. I'll be leading the change agent Program, also known as cap, a new training program to support individuals with IDD as they become self advocates and share their experiences with Kansas legislators to drive change. The Change Agent program is launched in September of this year. Next slide, please. These are some of the issues that the council and I have been working on together. Kansas has the largest historic way list in our state's history. It has a wait list of 5200 people waiting to 10 years or more for services, we successfully secured funding for 500 new waiver slots, allowing for 500 new families to receive services. We have been advocating for increased funding to eliminate our IDD waitlist and address workforce issues such as the DSP shortage. When I was in DC in April, I met with members of Congress to discuss a federal bill that would help recognize the role of DSPs. And through that increased competitive we we have also, we have also worked towards increasing competitive, integrated employment for IDD community. Through that, Kathy's Bill has been passed. For those who don't know, it is the hiring preference preference for individuals with with IDD i. Some minimum wage has been eliminated, has been eliminated at federal level via transition to competitive and unemployment act. And at state level, we are working toward eliminating some minimum wage through a new grant program so you, which is a new grassroots advocacy program called the Kcd change agent program to recruit and empower self advocates and advocates around Kansas to be more effective advocates. I got the opportunity to introduce Governor Kelly with our Executive Director, Sarah Hart Weir at a council meeting. Next slide, please. It takes courage to be a sub advocate. You may be taking a risk. Disagree with others, share something personal, feel like you are being judged and be afraid of getting in trouble. I want to empower individuals like me with diverse abilities to become strong self advocates. Next slide, please. You.

K

Kate Brady 41:24

All right, thank you, Lola, we're so glad to have you with us. It is clear what a powerhouse advocate you are in Kansas, and we look forward to hearing more from you at this time you can turn your camera off, and we will welcome Santa Perez, we're glad to have you here, Santa. We'd love to have a visual description and hear about the issues that are important to you.

S

Santa Perez 42:03

I can't put my camera on. I Hi. My name is Santa Perez. My pronouns are her, slash she. I am a Hispanic woman with brown hair tied back in a ponytail. I'm wearing purple glasses and I'm in my office with a white bookcase behind me. I have been living in Las Vegas with my friend Tim and our son Noah, for 25 years. Excuse the beeps I used to switches to use Morse code to access my computer. Some people might say that I am nonverbal, but I am definitely not. I am a talker, and my passion is advocating for people with developmental disabilities and intellectual disabilities, dd, slash, IDD, sometimes people can understand me, but other times I need to use my computer to talk. I rather have someone relay what I say. It's faster, but I'm fine with both ways you Thank you.

K

Kate Brady 44:11

Thank you, Lola, and you're welcome to leave your I'm sorry, Santa, thank you, Santa. You're welcome to leave your camera on, and at this time, I'd love to invite all panelists to join us with Video on for our facilitated discussion. Welcome. Okay, I'm glad we're all here. So at this time, we'll present some questions to you folks, and we'll continue to use the alphabetical order, just for the sake of being. Organized, and so I'll pass it to you, Laura for the first question.

L

Laura Bernas 45:05

Hi everyone. I'm Laura bernas. I'm the project coordinator at hsri, working on the grassroots project. I use she her pronouns. I am a white woman with long brown hair. I am sitting against a dark gray chair wearing a navy blue dress with white flowers on it, and behind me is a light blue wall and a cabinet with some Mardi Gras headdresses on it. We're so happy to have all of you here today for this first part of our panel discussion, we're really interested in getting to hear from you the ways in which you're advocating and how it's going for you right now. So the first question that we have is, What is going well in your advocacy currently? And Julisa, we'd love for you to start us off.

A

Allilsa Fernandez 46:04

Thank you. This is Julisa. For me, I think that what's going well in my advocacy is providing the community resources and education. I specifically advocate on disability justice and mental health justice, most of it is on mental health, and in that work, a lot of the things that I do is provide folks with resources and education on APA Olmstead how to apply for SSI, and oftentimes The community doesn't know that a lot of these disability laws applies to mental health disabilities, so that's mostly what's working for me currently, just educating The community and providing resources. Wonderful. Thank

L

Laura Bernas 46:59

you. Cody?

C

Cody Drinkwater 47:02

Um, yeah. So currently, uh, I am in a process of creating an advocacy group that focuses on transportation on Eastern Shore. Um, because, uh, it's transportation in general. I know in Maryland, this is a rural issue. Uh, or can be a role issue. And Eastern Shore, it's, it's pretty bad. We don't we only have like, two bosses, and they only have, like, very limited routes. So me and another person from people in the Gulf of Maryland are, has have this idea of creating kind of a transportation advocacy group. We have a like interest meeting. Well, we have two, so July 8 and July 10, and so we're trying to, like advertise, just to get a sense of who's interested and, you know, and attending. And then when we do that, then we, we probably will wind up like pushing legislators to try to take it seriously. Um, I'm kind of, you know, I don't have a clear idea entirely of how we are going to achieve some of the stuff, but we want to like we want to find a group of like minded people to meet and to discuss it and hopefully find a solution to it. So yeah, that's that's currently what's going on with advocacy with me in my area.

L

Laura Bernas 48:45

Great. Thank you, Cody, yeah, transportation is something that we've heard really consistently from all the different advocates that we've spoken to over the course of the project thus far, as a real, a real need that and a real barrier for a lot of people as well. Thank you. Yeah, Eric,

E

Eric Washington 49:03

I think what's probably going well with my advocacy work now is being able to be the guinea pig for the stuff that I'm fighting for now. I think because, you know, going through a lot of stuff with cancer and surgeries and, you know, cognitive ability, you know, different things that I deal with, and then to not have case management. That's why I see it be more of a need to argue this at, you know, at the higher levels. Because, I mean, I remember my grandmother, you know, back in the day, it was like, when the doctor said they were going to call you, you just waited by the phone until they called, and then eventually that person just, you know, kicks the bucket or something, and that's it. They're like, Well, why didn't they ever call? They're like, well, that's you. We don't want to bother them, you know. And now it's more of a, you know, my doctor just retired. You. Is the reason why, you know, my cancer kind of slowed down. So now I'll have to go find another doctor, and new doctors present new case management or new case studies and new ideas, and that may potentially spiral this out of control. So I'm just pretty much using myself as a, like, I said the lab rat, just to say, like, you know, this is why I think some of these things need to be happening. And look at me. So I'm using some of my bad stories to be able to, you know, push people in the right direction and really help out everyone that needs to be helped. You know,

L

Laura Bernas 50:37

thank you for sharing that, Eric, yeah, I'm someone with complex chronic disease and and I think this is something that I hear from people all the time, is the complexity of trying to coordinate our own care, the energy that's required to do that. And there's definitely seeming

now sort of a groundswell of people wanting more and more advocacy in those areas. So that's that's awesome to hear that you're working on that.

K Kate Brady 51:07
Lola,

L Lola Kernell 51:09
Hello, I am. This is Lola speaking. I just graduated from high school, and I'm excited to start a couple of classes at the local community college, including interpersonal communications, which I think would I, I think will help my advocacy skills. I love my new job at Kcd, and was honored to be the capital when Governor Kelly signed bill SB 15 to hopefully eliminate sheltered workshops in Kansas. I even got to keep the pen she used to sign that bill. I also really love acting in theater. It was just in the world premiere of a play called Rubik about autism featuring self advocates. It's important to have accurate representation everywhere.

L Laura Bernas 52:00
Thank you, Lola, that's wonderful to hear about. Love hearing you know how other fields can also take up the mantle and do work that's coordinating with the disability rights and justice movement through arts representation. Wonderful. Thank you, Santa.

S Santa Perez 52:23
Mrs. Santa, I am a member of the President's many People intellectual disabilities. I am co chair. Living, living. Oh. We are? We are working. We are working on, we are working on the community we put for the final report it will be out in the fall, and tell everybody that about a lot of advocates have been speaking out, and we have, we are encouraged. We have, we are we have heard and it would be, oh, Santa's second military to have her for advocate, and it will be on the final report.

L Laura Bernas 54:41
That's amazing, Santa. Thank you for updating us on that work and the important work that the committee continues to do. It's wonderful to hear how that's progressing forward. So our next question is around energy and capacity. So where do you find. That you were able to build the energy and capacity necessary to do your advocacy work. Are there people who support that, or different environments that have really helped you build energy and capacity, and how do you maintain that? And Julisa, love for you to start us off.

A Allilsa Fernandez 55:21
This is Julisa. So several parts to that, the energy, the motivation that keeps me going is

specifically for people of color. The system is problematic, extensively versus white counterparts. So the injustice that exists in the space just motivates me to keep going, to keep advocating for Disability Justice, mental health justice, and looking at from the lens of a multi marginalized person, but also community and so that, in itself, keeps me motivated. But in conjunction with that, having folks who also have lived experience and are also living in the spaces of injustice, that also keeps me going, having conversation and community, keeping the conversation going, that continuously motivates me, but also being mindful, and I think that this is the important part of rest, to rest, that it's okay to rest, because advocacy can burn you out, especially when you're speaking about advocating in the cap like Capitol Hill policy terms changing changes of laws and so forth, it is exhausting, and laws, as we know, don't change overnight. It's not like changing policy within the workspace or within the community. It's more daunting. So just taking time to rest. And some, often times I've had to do that for the past year. I took time to just rest, to just be, to just exist, and knowing that that's okay, that although we see injustice and we experience justice, that it is okay to also take time to nourish our bodies, our mind, or spirits, whatever that may look like, because it's diverse for different people. And just be able to rest, especially in our disabled bodies, to be able to take time to care for our disabled bodies is so important. And so it's both having community, living in community, knowing this injustice, but also being able to rest. And I think all that together is what keeps me going in this work. Wonderful. Thank

L

Laura Bernas 57:50

you for sharing that. Julisa, I'm so glad you brought up rest and how it works, in conjunction with everything else that we see, and balancing that between wanting to fight, you know, for against these injustices, but also needing to take care of ourselves, to maintain sustainability throughout our lives, in advocacy as well. Thank you, Cody. Love to hear from you.

C

Cody Drinkwater 58:16

Yeah, definitely. So for me on so I feel like that. My sense of capacity and energy to do advocacy comes from my lived experience and drive towards justice. I feel like that, just generally speaking, maybe it's because I'm on autism spectrum, I tend to have a very good idea of what is right and wrong, and I feel like that, you know, especially getting into the field and becoming more and more aware of stigma and the ableism that exists in a society, um, I feel like that sense of that need to so provide justice drives my um, my focus, um. And, you know, sometimes it can definitely give me energy, especially if I feel like, you know, something needs to be done, or especially when we're able to achieve, you know, a victory. And yeah, I mean, you know, but I also agree that, you know, it can be exhausted, too, because, I mean, I work with, you know, a legislative advocacy groups for people to go and, you know, we promote, like a lot of bills that you. Know, try to help people with disabilities, and we also, like, oppose a number of bills that could hurt people with disabilities. And, you know, I mean, it's not so much that the bills that will hurt people get passed because they usually don't, but it's also that the bills that will try to help people also don't get passed. So it can be kind of very frustrating sometimes when you're trying to propose or promote kind of a common sense legislation, and, you know, it gets, you know, it gets, it fails, you know, and you're like, yeah, and probably a lot of it is budgetary reasons, you know, but that could be very frustrating and discouraging, but like, at the same time, I would say it doesn't really kill my overall like, desire, you know, towards kind of like, that kind of disability justice. So, you know, and you know, my, my energy, it definitely, like it definitely fluctuates, because, as people who are all an autism

spectrum, or know, you know, our, our energy towards things on a regular basis, gets taken up quite easy and quite frequently, and you kind of have to like work on dedicating yourself to certain tasks. But I will say that, you know, for at least advocacy, even though I get tired. I'm pretty much, like, just always naturally focused on doing that, primarily because it's, you know, it's also a part of my life. It's not just a job. So, yeah, that would be quite sure.

L Laura Bernas 1:01:55

Thank you, Cody, yeah, I feel like I'm hearing, you know, the through line of finding the balance of what works for you individually, based on, you know, all of our different lived experiences, our desires, but that through line of really understanding injustices and wanting to work towards changing those Thank you, Eric,

E Eric Washington 1:02:19

I don't know. I mean, where my energy comes from. I've always said that I feel like I'm solar powered, you know, like, as long as they're sent outside the sun, you know, as long as they're sun out, I got energy to go do what I need to do. And a lot of times, what I do is I use a lot of my issues, like PTSD or insomnia. I use that as, like, a reason to do something. Like, I'll stay up for, I'm staying up for two, three days at the time before, and it's like, okay, cool. Well, I wanted to read this book, or I wanted to study this, and I just use it to my advantage. And when I crash, I just crash. I don't really make a lot of excuses for why I'm doing what I'm doing. Um, where I think a lot of my energy comes from is, I think it's, it was kind of, I was born into it like my mom. I remember when I talked to my cancer doctor maybe three years ago, he said I had six months to live. And he was like, So what do you want to do? My mom was like, shoot. He ain't got no choice. What? What do we got to do? What he got to do to be here? And it was like, that's just the makeup of my life. You know, I never I wasn't born with a towel to throw in. You know, it was like it's all or nothing. When I say something, it has to happen. I'm the past version of myself that was homeless, that didn't, you know, take his meds, or didn't know that there was meds available, or didn't understand what a brain injury was. That was the system failing me. This version of myself is when the system works. So this version is when all of the you know, the systems come together and they talk to each other and to help each other out and advocacy. That's this version that you see now. So that's something good for other people to see. To say, Wow, if we do wrap around services, we might get an Eric, or we might get a Asia, or a Lola, you know, or Santa. We may get a Cody. You know, that's what it is when a person understands what they're going through and, you know, give themselves some type of grace. You know, for a long time I felt like just growing up. I don't know what you all know about Detroit, Michigan, but it's a paradise. No, it's actually terrible. But back in the day, it was terrible, but then at the same time it was you didn't get to complain, get up, don't cry. You can't go through this. You You only gonna be you. You be in jail or football player. Which one you want to be? You know, you had just these devastating options, so you didn't have time to even deal with reality of life. But now, as you get a little older, it's acceptable to, you know, to express yourself, to take some time to cry, just to take a nap in the middle of the day. You know, as long as you get back going to you don't park the car. You know, you it's okay to be a neutral. You just can't park and then you keep on going. So. That's where I think a lot of my advocacy, my energy comes from. My energy comes from there's tons of people that aren't getting the help that they deserve. And when I was sitting in the car thinking about this is my final days, I didn't want anyone to feel like that. And the only gift that I felt like, you know, we

can give to God is by making this world a better place while we're here. That's the only gift I can give. So when my days are done, if they keep saying my name and he did this, then I did what I was put in to do. So that's why, that's where my energy comes from.

L Laura Bernas 1:05:32

Thank you for sharing that. Eric, very powerful. Um, I love what you said. You know, this is what people can experience. This is what the world can look like when we have wraparound services. This is the actual reality when people are collaborating, when services are coordinating, when there's communication, when we're working together, when people are being heard and seen. This is like. This is what can the powerful, positive, wonderful things that can occur and embodying that in the world, and allowing people to see your transformation, you know, from what you experienced before to what you're experiencing now, and just showing up. I think it's a it's a really powerful example of just existing actually can be really powerful for other people to witness. So that's thank you for sharing that. Lola, I'd love to hear from you.

L Lola Kernell 1:06:22

This is, this is my passion, because I have Down syndrome, I have always had to work hard to accomplish my goals. So I'm used to working hard, and know something good will come of it, if I just keep going. Thank you. Lola, yeah,

L Laura Bernas 1:06:41

I love that passion, the dedication, you know, working through and the positive energy, really awesome. Thank you for sharing, Santa,

S Santa Perez 1:06:57

my energy. I want me. Wanting society better for people disabilities and it takes time and people from all walks alive make change. All people need to come table and have their voices heard. I hope to encourage new advocates by going we have come so far in our right mountains to climb, I would like to see more people with disabilities In the

L Laura Bernas 1:08:40

There we go. Thank you, Santa. Yeah, I think something we've seen in our environmental scan thus far as well, too, is wanting to see more people with disabilities leading developing younger generations of leaders, which is a core component of the work of the grassroots project as well, and wanting to be able to encourage and really pass that torch of leadership and work as as time goes on. Thank you. So the last question that I'm going to ask is, Who or What helped you figure out where to do your advocacy, advocacy, how to do your advocacy. You know, were there specific organizations, systems, people that you feel really helped you kind of get your start, and provided you assistance along the way? Julisa,

A

Allilsa Fernandez 1:09:36

this is Julisa. That's an interesting question, because I did not have anyone teach me how to advocate or how to manage advocacy, because it is a management so I'm going to try to summarize it as short as possible, but I came into advocacy and activism all at the same time via some injustices that was happening in Stony Brook University. If folks want to learn more, you can Google it. You'll see a few articles, but there was a lot of things going around that it was against the ADA, such as the ADA button networking, not having ramps, or the ramps were covered in snow, kicking out students with mental health disabilities off campus because, quote, they were a liability. So countless of things, and so countless of students came together to host conversation on campus around this, and it was just I had to learn. On the go, I was leading a movement, except I didn't know how to lead it. And so there was a lot of trial and errors, a lot of things that did work and didn't work, and just learning. And one of the things I did do was reach out to community leaders and try to learn, how do you lead a protest? How do you lead conversations and community, just learning how to carry some of this work. But fortunately, not everyone is willing to teach, but some folks are so just taking what you can learn and applying it. And so that's how I got into advocacy and activism, and then kind of learn as I went along.

L

Laura Bernas 1:11:31

That's awesome. Thank you. Yeah, learning by doing can be a fast way to get into it. But also, you know, I think sometimes what we've heard too, is, I think people can be so hesitant to start because they feel like, Oh, I'm not ready. I'm not prepared. I don't have the tools. But sometimes we'll never feel ready, and that just getting into it and then figuring out as we go can be just as important and really useful as as kind of having some sort of formalized education to start, and I love that you, you know, along the way, reached out to community leaders to get their advice and see what what other people were doing. That's awesome. Cody,

C

Cody Drinkwater 1:12:13

yeah, so similar to I'll choose I'm the hope I'm not butchered name if I'm sorry. Yeah, it is alchessa, right, it's alchessa, yes, okay, okay, all right, similar to what to what you said, I feel like that, you know, I it, you know, also just kind of got into advocacy, like, it was kind of just an evolution, like, and a lot of ways, I'm so sort of figuring out certain parts of it, like, I don't feel like I have everything completely together. I'm learning as I go in a lot of ways, but I And sorry, I'm looking at the list of questions. I kind of got lost.

L

Laura Bernas 1:13:14

I apologize. It's you know, were there people or organizations, what helped you be able to find which kind of advocacy you wanted to do, and kind of helped you get your start in being able to do it Okay, right?

C

Cody Drinkwater 1:13:31

So, yeah, so there were definitely a number of people who supported me, like my parents, my family. But, I mean, my mom, pretty much, was the one that pushed me to, sort of like, get into services, because I was only diagnosed as being on the autism spectrum, and, like, 2016 and, so I'm like, I'm like, 36 now, so I don't know I was like, not sure how long ago that was. This is only several years. But so I got, basically, I got diagnosed as being on a spectrum, and then from there, was trying to get supports for myself through doors, which was like, not, not great to be honest. You know, doors is the deficient of real rehabilitation services in Maryland, and I got, like, I got some job coaches, but I would only last a job for like, six months at a time. And so went from there. And then finally, I. It was like a number of things. It was a combination of, like, the fact that the CCS, because once I got we were meeting to kind of get into services with DDA and like, to this day, I kind of thank the CCS, because I feel like that they may have kind of like I have been told in a lot of ways that, you know, people my age trying to get into services just doesn't happen because I'm told so I sort of feel as if, like that CCS might have, like, done some stuff to make me getting quicker that probably normally nowadays, just would not have happened if the process had been kind of more like, you know, done, quote, unquote, correctly. So whatever they did, if they did do anything. I don't know. I don't know for certain, but, you know, I really appreciate it. So I got, I got into the services, and then it was also around that time too, that my job coach, basically, I applied to become an advocacy specialist working for DDA and so, and that was a combination, too, of also, like just having your connections. I would volunteer at the library, and one of the people that interviewed me actually, like, would go into library and knew the person I was volunteering with, so that I think helped. So it was a number of things. So I sort of feel like, even to this day, like there was just everything lined up correctly. And a lot of it almost kind of seems like more like luck, you know, because which I'm grateful for. But, you know, I just feel like that. I didn't really know that this was my calling until I stumbled into it. Um, so, you know, although I think people supported me, uh, ultimately, I felt like that. It was the only end was my interest and passion that made me an advocate. And it was one of those things where I realized I'd always, kind of, in some level, been raised, been advocating. I just didn't have a name for it. I didn't have a name for my disability. So it's kind of, you know, looking back in retrospect over the years, I see that, you know, the same qualities and skills and things I've been doing like I've always been doing it, but I just didn't have, like, an awareness to call it what it was. So, yeah, I mean, I kind of just feel like it's not like I came in and I was like, Oh, I'm going to be this, this specific person with a specific job. And it was more like, Okay, well, I have a job. I think this will be cool. And then the more I started kind of getting involved and talking to people, I was like, oh, like, this is this impactful? And then it was like, went from there to like, Okay, what more can I do? And now I'm with people to go and work with legislation. And so it's kind of just this evolution. So it wasn't really planned at all. It wasn't a sense of like, you know, I didn't really have a clear idea for a career path when I started it. That's

L

Laura Bernas 1:18:31

great. Cody, that's wonderful. Thank you. Yeah. It's so great to hear these different perspectives and the different paths that people have taken. Thank you.

E

Eric Washington 1:18:50

So, Eric, all right, sure, um, so, I guess I'll give you a Mount Rushmore of the ladies who did this. So my mom, obviously, who birthed at me, put this in me, because, I mean, you have to, when you come from an underserved population and things of that nature. minority status. you

naturally have to advocate for yourself, to either a try to convince someone why you deserve something, or to try to get equal privileges to something. So that's just naturally, just in you. Um, so my mom was number one. Number two. It was a lady that when I was homeless in Kansas City. Her name was Paula Laney, where she proud me, and I didn't know I had a brain injury or anything like that. I just kind of just knew something was off. I went for having good grade, so I couldn't think, couldn't remember, she presented me to this other lady that pretty much was like, Eric is one of the most broken individuals. He has a lot of potential, but something's off, so I think he needs some help. That's number two. Then she took me to a person where I met. Her name was Jennifer Braun, where I spoke at a brand. Injury conference when I was actually homeless, I was on a panel like this, everyone had like, five minutes or something like that, so I said something about just what I was going through. And Jennifer said, hey, it would be cool if you can come to Washington, DC and say that to Congress. And I was homeless, and I'm like, crap, I'm staying in my van. It don't matter where I go. So I just went, you know, like two, three days later, spoke in DC. Then after that, this kind of happened. Then the last person, which she's on one of these calls. Her name is Bevin. She kind of, you know, always would just be sending me information about, you know, I think you should talk to these people. Or I met her with end caps and stuff like that. And eventually it kind of was like this, you know, four headed monster to kind of put this, I guess, put the fuel in this missile. So now it kind of, I just do whatever needs to be done. So those are the people that are, can, you know, account for that made this beat.

L Laura Bernas 1:20:56

That's awesome. Thank you for sharing that. Eric, so cool to hear these kind of, you know, events that just come up, and how things lead from one thing to another to a path. Very cool. Lola, Hello,

L Lola Kernell 1:21:08

yes. When I was in sixth grade, I saw a group, a group of boys bullying another boy who went to stand up for himself. I stepped in and told them to stop and realized that my voice matters. Down Syndrome Innovations has helped me in so many ways. For example, Amanda, who is the Employment Coordinator there, helped me with employment and asked me to speak and at an employment roundtable. Out of that, I got an internship with Kcd, I'm learning to make an impact more broadly in my current job with my coworkers at the council, they are very supportive and give me good guidance, and my parents and family have always been there for me.

L Laura Bernas 1:21:58

Thank you, Lola, so cool to hear about, you know, these personal experiences that then spur action, and the people supporting you and and how people see things in other people and are wanting to uplift them. It's really great to hear about Santa,

S Santa Perez 1:22:20

most of all, the people that are, can, you know, account for that made this beat.

first of all, I'm an old advocate. I haven't had a lot of people help me in my advocacy. I think one of the reasons, no, I think one of the people is, oh, the DD, a DD Council in Nevada,

E Eric Washington 1:23:06
a healthy on

S Santa Perez 1:23:10
my first Not for mine, they have helped me, mean better. A better advocate, but I believe, I believe that everybody needs to be an advocate. It would help, it will help you, and it will help other people.

L Laura Bernas 1:23:54
Thank you, Santa. Yeah, I completely agree. I think we all not only have the power to do so, but it is so advantageous for us to advocate for ourselves, for our communities, and really create some transformational changes that we want to see. All right, everyone. So this is the end of our panel discussion portion. So panelists, feel free to turn your videos off, and we will be moving into very, very brief Q A, and wrap up of the webinar.

C Cody Drinkwater 1:24:30
Um, so I just wanted to, like I saw that there's, like, two more questions about what's challenging about advocating. Are we not doing that?

K Kate Brady 1:24:41
Thanks, Cody, we are at the just final minutes. Okay, so we're going to skip some questions. Okay, that's why our co director, Alex Bernardi, to come on screen. Okay, close us out. Thanks so much.

A Alixe Bonardi 1:25:03
Alex, so Good day, everyone. My name is Alex, and I thank you, Kate, and to this tremendous panel. I am a middle aged white woman with shoulder length light brown hair and dark frame glasses, and I'm sitting in my home office with books behind me. I I've been monitoring chat in the background, and there has been a tremendous set of conversations. And I cannot even reflect everything that had that came up in chat, but several questions came through, and I'm grouping them kind of into different categories. One is focusing on people starting to share community resources and education, some additional conversations around community living, advocacy. And then there was a theme that came up. And I think we have time for one quick question. And this is a question for all you panelists, so if you can listen in this is a question that I'd love to have at least one person be able to reflect on a number of people were talking about

partnering, partnering particular disability populations, and then how people connect and grow as disability leaders in their own space and And we have a few questions, specifically talking about connecting with and among people who are mental health system survivors, with other groups, with deaf people and and I'd love to hear from from our panelists, if anyone would like to do this, to speak, if you could speak to what you see as your role in connecting with people across disability advocacy groups emphasizing Disability Justice work while still representing the particular issues that you that that most relate to you or to a particular population. And I see I see Santa that you are on camera. So if you have something you wanted to add, I'd love to turn to you.

S

Santa Perez 1:27:13

I think part of the problem is we only have we only talk to This disability community, and we have to our house about we have to be upon community. That means open, no, it means going out of your community, and meaning, yeah, other people who may not have, may not have a disability, But this can be, can be, could be an opportunity to open community.

A

Alixé Bonardi 1:28:53

Thank you. That's such important and powerful advice, Santa, and we are hoping to do that and support more of that through the grassroots project. Eric, did you have something you wanted to comment on? We've got about a minute, so this will probably be the last one.

E

Eric Washington 1:29:08

Yeah, I was just commenting on that. It's a lot of disabilities that might not get the attention that, you know, that they deserve. You know, it's like they're a minority of something that's already a minority, such as, like a brain injury, or, you know, the deaf population. But I think that what needs to happen is, whether you have a disability or not, or you have that specific disability, we all kind of need to stick together, like Santa was saying, as far as being a, you know, community, you know, we're still a disabilities community, you know. And I think that once you have a place at the table, like me and some of the other panelists, you kind of, you know, you have an obligation that, once you get in some of these rooms, to also speak for those that might not be at the table yet, you know. Because, as you know, as time goes on. You know, with, you know, racial incidences, or, you know, ADA things, whatever gets the media's attention is kind of where we go with our money, where we go with our thought process. And that's always, we always leaving somebody behind. So I think that is, you know, our responsibility, you know, as advocates, to advocate for everyone that you know that don't have you know. I think that that's just really important, even when the grassroots situation you know. So yeah,

A

Alixé Bonardi 1:30:34

Thanks, Eric. And I think you really summed that up really well. This has been a rich conversation, and as as we've seen in chat, this will be this is being recorded and will be posted publicly in a few weeks, as as folks are winding down, and before you all leave, we we would

very much appreciate if People would take a moment to respond to the survey that has come up on your screen this. This helps us understand how this is working for you and and how we can continue to build, build on this, this conversation. Thank you, everyone. This has been wonderful to be with you in this place together today, and I wish you a good rest of your day. You.