

Grassroots Project Webinar August 2024: Expanding Disability Advocacy...

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SUMMARY KEYWORDS

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SPEAKERS

Brittanie Maddox, Noel Martin Rubio, Kate Brady, Alexandra Bonardi, Kimberly Tissot, Jennifer Kucera, Sierra Royster

K Kate Brady 00:00

Okay, we are going to get started. Welcome all for the grassroots project webinar. The grassroots project is administered by the Human Services Research Institute where I work. My name is Kate Brady. I'm the co director of the grassroots project, which is funded by the administration for community living. Today's webinar is expanding disability advocacy by working together successful practices and outcomes in coalition building. We would love it if you would introduce yourself in chat. Some folks are already doing that. Our agenda today is that we'll do intros, welcomes, share some logistics with you, and then we will have presentations from three fabulous coalitions, the Disability Policy Consortium in Massachusetts, the Disability Public Health Task Force, hosted by ABLE South Carolina, and the Ohio Olmstead Task Force. Then we hope you'll stick around for a facilitated discussion that will be fueled in part by the questions that you all share in the Q and A. Before we dive in, some webinar logistics, you will notice that participants are muted. Please do use the chat feature to ask questions and to communicate with the hosts, although you'll also find that there's a Q and A option at the bottom of your screen, and so we would love to collect your questions for examination at the end, any that we don't get to will pass on to the panelists separately from the webinar. The webinar will be live captioned in English and live interpreted in Spanish. Captions can be accessed at the bottom of your screen by clicking the CC button, live Spanish interpretation can be accessed by clicking the interpretation button. At the bottom of your zoom screen, there'll be a world icon, and once in the Spanish channel, you're going to want to silence your original audio. So I'll now read that in Spanish. For those of you listening in Spanish, Se puede acceder a la interpretación en español en vivo haciendo clic en el botón "interpretation" en la parte inferior de la pantalla de Zoom (icono del mundo). Una vez en el canal español, por favor silencie el audio original. with my apologies to any native speakers here. Due to a recent Zoom update, full accessibility, including ASL interpretation may not work if you are participating with us via a mobile device. It seems that when you are on a mobile device, one cannot see ASL slides, sorry, ASL interpretation and the slides at the same time, so you'll need to swipe on your phone or other mobile device to find the ASL interpreter if you need to. We are in direct communication with Zoom about the limitation that this has created

and are doing collective national advocacy to address these systemic accessibility issues. Please do contact us with any questions about other accommodations in the future, at grassroots@hsri.com. Last but not least, this webinar includes polls and evaluation questions, and we would love it if you would be willing to engage in this way by responding to us. So I failed to give a visual description on the screen here you'll see our full team. My name, as I mentioned, is Kate Brady. I'm a white woman in my home office here. I have short brown hair and gray glasses on and a scarf. I'm middle aged, and you she her pronouns, and behind me is some art on the wall, all done by my father Tom Brady. I am joined today by a fabulous team. Our co director, Alex Bernardi, our fabulous project coordinator, Laura bernas, our evaluation partner, Amy Lulinski, and many other contributing staff partners and subcontractors. So this work is an extension of the work that staff at HSRI did to support community members with advocacy related to the HCBS Settings Rule, and we have engaged many organizations, some of whom are probably on the line today. So, I look forward to your hearing from them in the chat and to you connecting with them. We'll go over that just shortly here, regarding feedback and follow up as mentioned and as put in the chat, you are welcome to email us at grassroots@hsri.org. Please know though, that we can't monitor that email during the webinar and ask that anything urgent you direct to Amy Lulinski at A, L, U, L, I, N, S, K, I @hsri.org. We don't officially offer CEUs-continuing education units-but we do provide confirmation of attendance. So if you need that, just know that Zoom will automatically send attendees a confirmation one day after the webinar. You're also going to receive a link to the webinar recording and other materials such as slides and resources one day after and the webinars and associated materials, including a transcript and PowerPoint and plain language summaries, will be archived on the grassroots Project website, and we will share that link with you in the chat. It is also here on the screen. So at this time, we would love to hear from you via the poll that Laura is going to share on the screen about who is joining us today. The first question there is, in what ways do you identify with the disability community? You are welcome to check all answers that apply, if you'll scroll down in that poll. The next question is, what is your gender identity? Also you can check all that apply. The third question is, what age group do you belong to? And we've banded those age groups. Fourth question, are you Hispanic or Latino? Fifth question, what is your race? Of course, check all that apply. And that is the final question there. And I see already that we've got a tremendously diverse group in age and gender and particularly in the myriad of ways that you all relate to the disability community. Glad to see that we have disabled people here, advocates here, people working in disability organizations, caregivers and staff. Looks like everyone is answered, so we'll end that poll and share the results. So you'll see here a wide variety of folks, although a majority of people here today are identifying as women, we have a diversity of age groups and some diversity in racial identity, but a majority of people identifying as white. So we'll stop sharing those results, and I'll keep going so that I can tell you just a little bit about the Grassroots Project. The purpose of the project, which was launched in 2023 is to support national, state and local disability advocacy and action coalitions, as well as individual advocates in building networks to stay informed about the policies that affect people with disabilities, we are also supporting people to come together. To ensure that their perspectives, preferences and priorities are reflected in the systems that provide supports. You'll see on the right hand side of this slide a green, blue and gray circular graphic in which we have individuals with disabilities and others, nested in local advocacy and action coalitions, also nested in state level and advocacy and action coalitions, and ultimately the national advocacy and action coalitions. This is the structure that we're working in. In this project, we have some key partners, a funded national advocacy and Action Coalition, inclusive of the national DD network, the National Independent Living network and a myriad of national advocacy organizations, including the Autistic Self Advocacy Network, the Self Advocates Becoming Empowered group, the Paralysis Resource Center and the National Association of State Head Injury Administrators. We're also supported by an advisory group

aimed at ensuring bi-directional communication so that the project can be informed by state agency membership groups, including the National Association of Medicaid directors, the National Association of State Head Injury administrators, the National Association of State Developmental Disability Directors and Advancing States. And then the folks that you'll hear from today are three, of a cohort of six, supported state and local advocacy and action coalitions. We're taking two approaches in this project, development of structures, processes and relationships necessary to support cross disability, cross generational and culturally diverse leaders within the movement, as well as to connect, grow and strengthen networks of coalitions. On the screen, here is a contrast of capital A and little a. Capital A represents things like advocacy that are direct action, lobbying and such. Our work is happening in the arena of little a advocacy. Those are things like education, information dissemination, preparation and organizing. So lowercase a are the areas that state and local advocacy and action coalitions that are affiliated with the grassroots project can be engaged in. So moving to this webinar today. This is the third webinar hosted by the grassroots project. It brings together state and local advocacy and action coalitions. We will be discussing the best practices for establishing common goals and collaborating to achieve those goals, we are aimed at in the context of these coalitions, ensuring that disabled people are leading the charge to drive change. So we are going to hear from ABLE South Carolina, Disability Policy Consortium in Massachusetts, and the Ohio Olmstead Task Force. Our representatives are Noelle Martin Rubio, Sierra Royster, Kimberly Tissot, Brittanie Maddox, and Jennifer Kucera. And I will turn it over to you, Noel Rubio of the Disability Policy Consortium in Massachusetts. We are so glad to have you with us today, and you're welcome to turn your screen on at this time, and I'll pass it on to you to do visual description. Thanks so much for being here. Noel,

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Noel Martin Rubio 14:42

Thank you so much, Kate and to the whole team at HSRI for putting this webinar together. It's so great to be with you all in community to talk about coalition building strategies, the progress that we've made together and the path forward. My name is Noel Martin Rubio. My pronouns are he, him, his. Yes, I'm proud to serve as the Development and Communications Director at Disability Policy Consortium. We are a statewide disability and civil rights advocacy and research organization based in Boston, operating throughout Massachusetts, and we also conduct several regional and national, and increasingly, international advocacy campaigns with our multiple coalition partners. I'm excited to discuss our history and our why, and I'm also excited to discuss some of the work that we've done in coalition with a broad range of partners in and beyond Massachusetts, and to talk a little bit about what we've learned along the way and what we're excited about in the months and years to come. Next slide, please. And before I move on, I just remembered to give a visual description of myself. I am a late 20s, Filipino American, cisgender man. I have jet black hair and black facial hair. I'm wearing a black sweater and a patterned collared shirt, and behind me is a light blue wall and a black bench. So Disability Policy Consortium was founded in 1996 almost 30 years ago, to bring together the voices of people with disabilities and advocates across the state of Massachusetts, to ensure that the voices of people with disabilities were heard on key issues, to support the health of the community through participatory research and expert policy analysis, and to empower grassroots disability leaders to transform their communities. So you'll see in our mission statement that there are several approaches, and they all operate on different levels of systems change. We have grassroots organizing, community mobilization and policy advocacy, but we also have community based participatory research to engage people with lived experience of disability, to build the evidence base for doing more effective advocacy, and we also have elements of community transformation and systems change that really enable the

disability community to use their voices and to participate fully in the public sphere, so that their voices are represented in the conversation, and they are driving the change that needs to happen in society. Our vision is a redefined role of government in the lives of people with disabilities, resulting in a commonwealth country and world in which equity, access and justice are centered and in which independence, inclusion and empowerment are secured and promoted. For all we very much take a collective liberation approach to our work. We see the disability rights and disability justice movements as parts of an intersectional push towards social justice and as one piece of the puzzle in the fight for racial justice, for environmental justice, for health justice, for climate justice and for all forms of social justice that engage all types of communities around the country and across the globe. We see disability as a key element of diversity that cuts across all axes of society. It cuts across all races, gender identities, sexualities. It cuts across all socioeconomic strata, and it cuts across every element or every aspect of identity. And we are very much a strong proponent of the idea that disability is a major part of diversity, equity, inclusion, access and justice initiatives. Finally, our credo, which really frames a lot of the discussion about Disability Policy Consortium and the work that we do, and it animates our approach to our work and to our partnerships and to everything that drives us is-about us, by us. It's an evolution of the classic Disability Rights phrase, nothing about us without us. It was coined by our late, former executive director, John Winsky, and it is the firm belief that when decisions are made about people with disabilities, people with disabilities must play a leading role in making those decisions and being involved at every stage of the decision making process. On the right of the screen, you will see a picture of our 2023 Paul Spooner, Generational Leadership Summit. It is a relatively new initiative that we have launched in coalition with the Massachusetts Developmental Disabilities Council and the Boston Center for Independent Living to really pass the torch to the next generation of disabled leaders and advocates. I'll be talking a bit more about that in later parts of the presentation, and I'm also happy to discuss more about our upcoming Leadership Summit, which is happening next month in Marlborough, Massachusetts, during the question and answer and open discussion section. Next slide, please. So here you'll see a timeline, an abbreviated timeline of our very kind of kaleidoscopic history as an organization, and you will see that really what the common through line is throughout Disability Policy Consortium's history is that everything that we've done as an organization has really been driven by the grassroots from the ground up, we strive to be an organization that is responsive to the needs of the disabled community, and we do that by building real, meaningful, trust based partnerships and embedding ourselves within the community. A large portion of that is the fact that 75% of our staff and board members identify as people with disabilities, and every member of our senior leadership team is disabled. And so we really, truly believe that in order for us to be an effective civil rights and disability rights advocacy organization, then we must practice what we preach, and we must center the values authentic community representation and community leadership along every axis of our organization. We were founded, as I said, in 1996 by a scrappy group of 240 members of the disability community, representing a variety of different disability identity groups and organizations. They marched on the State House to unite against a proposal that would have cut funding for the state's disability agencies by merging three separate agencies into one and streamlining the budget so that there was only one line item for these agencies instead of separate line items for agencies that served different members of different disability communities. We were successful in defeating that proposal, and that very quickly launched us into the next phase of our development, which was registering and incorporating as an independent 501 c3 organization, which we did at the turn of the century, we eventually got our 501 c3 status in 2002 and from then on, we went on to win a variety of legislative and policy victories, such as securing the right to Clean Air for people with disabilities, securing some landmark reforms to the nursing home industry in Massachusetts and beyond, and also helping to make the city of Boston and other parts of the Commonwealth more physically

accessible for people with mobility disabilities. In 2008 our group of volunteers and employees identified over 500 violations of sidewalks and curbs in the city of Boston alone. And this effort to raise the visibility of the issue of aging infrastructure and infrastructure that was not inclusive and not accessible to every member of the community resulted directly in a \$40 million public investment in sidewalk, ramp repair and construction. That same year, 2008 we also negotiated an agreement to improve accessibility at the State House, which resulted in an annual appropriation of more than \$200,000 for accessibility improvements. Throughout the years that followed, we did a variety of community led initiatives. We hosted town halls to help develop solutions to gaps in home and community based services for elder people and people with disabilities. We formed a coalition known as the Disabled Advocates Advancing Our Health Care Rights, or DAAHR, with the Boston Center for Independent Living that's comprised of over 20 community based organizations, and this is an organization that really helps to ensure Massachusetts place as the first state to implement dual eligible programming for people with disabilities who qualify for both Medicare and Medicaid coverage. In 2016 we contracted with Uber to pilot test an accessible rideshare model in the city of Boston to expand transportation options for people with disabilities in Massachusetts and close the transportation gap, particularly for people in more rural and geographically isolated parts of the Commonwealth. In 2018 we worked with the Boston Center for Independent Living to win an over \$1 million increase to the alternative housing voucher program, which is one of our signature policy initiatives. We founded a group called the Housing Advocacy Leadership team just over 10 years ago, and from that date, from 2014 up to the present, we have been able to increase state funding for affordable and accessible housing for people with disabilities from just over \$3 million in 2014 to now over \$26 million. So an increase of about seven times, seven or eight times over the last 10 years. So much so that we are now in a place where we're getting policy makers to think about expanding the program, because it has been funded so much more than it historically has been to expand beyond just providing vouchers for housing, towards constructing new housing stock, particularly in areas with accessible and affordable housing deserts for members of the disability community across the Commonwealth, and then, I think a lot of our work over the last three decades has really culminated in our advocacy efforts throughout the COVID 19 pandemic, helping to combat healthcare discrimination and protect the rights of nursing home residents, of elder and disabled adults in Massachusetts and beyond, and of all people with immunocompromising conditions, by helping to expand access to the COVID 19 vaccine across the state, helping to disseminate information in culturally and linguistically appropriate ways to reach people who might not otherwise have had access to that information, and also helping to overturn discriminatory crisis standards of care that would have discriminated against people with disabilities in terms of getting them access to ventilators if you know they happened to need them as a result of contracting COVID 19 or for any other reason throughout the pandemic when there was a large nationwide and global ventilator shortage. Next slide, please. Great. So today, we are an organization of almost 30 full and part time employees. We have about 15 community members, most of them disabled, who serve on the Board of Directors. As I said earlier, over 75% of our employees and board directors identify as people with disabilities. Our annual budget is just north of \$2.7 million for the latest fiscal year, we serve about 4000 members who are enrolled in Massachusetts Medicaid program known as MassHealth through our Healthcare Ombudsman Program, which we administer via a state contract that is our largest current program. As an organization, as I said earlier, we managed to increase state funding for the affordable housing voucher program by a factor of about seven to eight over the last decade, and right now, our key legislative issues include protecting and advancing the rights of consumers who use wheelchairs through our work in coalition with the Disability Law Center, the Center for Public Representation, and other legal and service provision groups across Massachusetts to expand our wheelchair warranty and repair efforts and really protect the rights of consumers, wheelchair users and

users of durable medical equipment and assistive technologies, we work with a bunch of other legal advocacy groups to protect the rights of disabled parents in the family and juvenile court system. We work, we have been working on the the issue of Medicaid estate recovery, to really protect the assets and the generational wealth building opportunities of families with members who are disabled and many of whom come from low or middle income situations. And you know, we, we really feel that this is a an economic equity issue, because a lot of times, the only opportunity for these families that are enrolled in Medicaid programs to maintain wealth and to pass it on to future generations is by preserving their house. And so we work on limiting the ability of the states to recover Medicaid or other public health care expenditures from a decedent estate, so that we can protect their assets and their ability to pass those assets, such as their houses, on to members of their family. And we also work on issues of health care and non discrimination, as well as providing comprehensive and responsive Independent Living supports to members of the community across and beyond Massachusetts. Next slide, please. So I really love this graphic because I think it captures the essence of our approach to systems change. It is the image of a river, and it is taking a look at how we engage, through our advocacy, through our research, through our direct services, and through our education and training. Work in systems change at every level, from the downstream individual level to the upstream systems level. So on the individual level, we work with members, individual members of MassHealth, which is our state Medicaid program, to provide healthcare, mediation, patient advocacy and case management services, such as productive referrals to social care and healthcare and other community resource groups for about 4000 Medicaid members each year through the state contract with our state Medicaid agency. At the institutional level, we provide education, training, consulting and technical assistance services that enhance Massachusetts organizations accessibility and inclusivity, really, with an eye towards closing the disability unemployment gap and making employers across the Commonwealth more accessible and inclusive in terms of both physical accessibility, but also workplace culture for people with disabilities who are seeking jobs and looking to build their careers and their chosen professions. At the community level, we conduct participatory research that centers the voices of people with lived experience of disability in order to shed light on key issues facing the disability community. We've done studies funded by the Robert Wood Johnson Foundation to take a look at social determinants of health needs and gaps in Springfield, Massachusetts among the disabled community in the Greater Springfield metro area and other parts of Western Massachusetts. We are currently working with the Institute for Community Inclusion at the University of Massachusetts Boston, as well as Mathematica Policy Research on an ACL funded research study over five years to scale up the evidence base for promoting competitive and integrated employment for persons with disabilities, working with state vocational rehabilitation agencies to scale up the progressive employment model that will place disabled job seekers in work based learning immersion experiences and really help them build the skills and the networks that they need to succeed in their careers and to really gain and maintain upward economic mobility and at the systems level, really the cornerstone of our work, and what got us started in the first place, is our grassroots organizing and advocacy for structural, institutional public policy reform, as well as our intergenerational knowledge transfer efforts through things like the Generational Leadership Summit that we host each fall to develop the next generation of disability rights advocates and community leaders. Next change, please. Next slide, please excuse me. So here is a simplified logic model of what we do and how we achieve what we set out to do so our inputs include our dedicated, representative and effective staff, board and volunteers that really are at the heart and soul of everything that we do and drive and make possible the change that we seek to make happen in and beyond Massachusetts. A lot of our team members, as well as volunteers and members of the community and the coalitions that we, that we work on, have deep subject matter expertise and credibility. We have a strategic, diverse and trust-based network of partners to mobilize stakeholders and drive systemic

change, and that leads to our short term outputs and midterm outcomes and longer term goals, meeting communities where they're at, delivering technical assistance, bolstering and delivering thought leadership to a variety of different stakeholders, improving civic engagement, making institutions more inclusive, raising public awareness of disability policy issues and driving ultimately towards long term goals of independence, inclusion and empowerment for all. Next slide, please. So here are a couple of examples of the coalitions that we've led. I've already touched on a couple of these, such as Disability Advocates Advancing Our Health Care Rights, which actually just won a major victory in convincing the state to withdraw a request for proposals that would have consolidated the ability of independent living centers to conduct independent assessments and evaluations of people with disabilities enrolled in public health insurance programs in order for them to be eligible to access long term services and supports and home and community based services, we were able to maintain the independence of the independent living centers, which are rooted in the communities, to continue to conduct these assessments. And our other partnerships in action include commissions on disability alliance, we work with commissions on disability at the municipal level to really create networks and ability for folks to come together and share resources and make their advocacy more effective and break down some silos. And then finally, here are a couple of examples of our thought leadership publications, such as our annual legislative access agenda and some of the pieces around accessible event organizing and other things that we've put out to really be used by members of the community and making programming more inclusive and accessible. And then here is a collage of some of our partnerships in action, our state house events, our advocacy events with legislators and so on. And I know that we are running short on time, but these slides will be shared out. And so the last slide just showcased a roadmap of where we want to go in the future and what we're most excited about and what our coalition work has really helped to make possible. So thank you very much for your time and your attention. Here is contact information. In case you're interested in learning more and reaching out, you can always feel free to reach me or my colleagues, and we're always happy to have a conversation about the path forward and how to empower, include and raise awareness of our community and the issues and the populations of the groups that we serve. Thank you very much.

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Kate Brady 36:57

Thank you so much. Noel, it's a pleasure to hear from the Disability Policy Consortium. It is my pleasure now to turn it over to Kimberly Tissot and Sierra Royster from ABLE South Carolina. I'll let them introduce themselves and give a visual description as they come on camera. Welcome Sierra and Kimberly.

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Kimberly Tissot 37:28

Hey everyone. I am Kimberly Tissot. I'm the president and CEO of ABLE South Carolina. I'm so happy to be here with you. My pronouns are her and she. And I am a white woman, white middle aged woman with blonde hair past my shoulders, and I'm wearing a black floral shirt, wearing glasses, and I'm in my home office.

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Sierra Royster 37:49

Hi everybody I'm Sierra Royster. I use she, her pronouns. I'm a white woman with brown hair

right below my ears, with gold hoops on today and a tan shirt with flowers. My background is a blanket with some art and crafts on it that is behind me in my home office. And I am the director of capacity building. I'm also a person with an invisible disability, multiple invisible disabilities, that are systemic and neurological. I am going to be dropping in our website in the chat as well since you got to know us, I saw everybody was saying hello, so that's another way to kind of find out more information about our organization.

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Kimberly Tissot 38:35

I forgot to also demonstrate my disability. I'm a very proud disabled woman. I am. I have a physical disability and a lot of healthcare conditions. If I was presenting in person, I'm a woman who has one leg. I had a high level amputation from childhood cancer, and my style of mobility is walking on crutches. I'm also, I know a mom, so I'm a disabled mom who also has a child with an intellectual disability, and so very happy to represent two. And I think parents. I think Disabled Parents are very different from non disabled parents. So one of first, and just real quick, we did not get the memo about making our slides fancy. So our slides will be very simple, not as fancy as Noel's. That was beautiful Noel. But I do want to, before we get going, I do want to just say a little bit about our organization. We are a Center for Independent Living, and we are actually celebrating our 30th anniversary this year. We are a true change agent, disability-led organization, and we're seeking transformational changes in the systems level, communities and individuals. And we provide over 30 programs, that includes one on one services around Independent Living, supports all the way to advocacy. So we provide pretty much anything that people with disabilities are needing. And we have done legislative advocacy as well. Most recently, we eliminated, we led the efforts to eliminate subminimum wage in South Carolina. So we became the 13th state to do that. And then we also passed legislation in 2017 around parents with disabilities. And so that was called the South Carolina Persons with Disabilities Right to Parent Act. Before that act, parents were being discriminated on the basis of disability and even having their children removed and not being able to adopt or foster but now we we've definitely changed that. We are one of three CILs in the state. We have two locations, and we offer services in the Midlands and upstate, which is 23 counties out of 46 counties. But many of our programs are statewide as they provide systems level change, and we also do a lot of national and international work as well. We have nearly 70 staff members and lead the state and systems change regarding disability, and we also elevate and center the voices of people with disabilities. And all that we do, over 86% of our staff are people with disabilities, as well as the majority of our board of directors. So we didn't just live this. We didn't just learn this. We live this every single day. I'm very proud of it. Just to brief our mission, we had to actually create a longer mission because of all the things that we do. But we are an organization of people with disabilities leading the charge to equip people with tools to foster pride and direct their own lives. And so that's through individual services. We serve about 25 individuals a year. We also educate the community to challenge stereotypes and eliminate barriers, and that is through a lot of our community education. We do a lot of speaking engagements, we do architectural and website accessibility testing, and we help with compliance around the Americans with Disabilities Act idea and the Rehabilitation Act of 1973 and then we also advocate, obviously, for access, equity and inclusion on really all levels, and not just in South Carolina as well. And our disability approach has really incorporated and used the motto, nothing about us without us, is why we decided to really jump in on some of the work that we're doing for this project. And so we're going to talk a little bit about that right now. So Sierra,

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Sierra Royster 42:39

Okay, before we get moving into a lot of what we do, we want to introduce you to make sure that you know this language, you're familiar with these acronyms, because it is the core base of a lot of our project, but also our coalition's work. So one thing I'm going to drop into the chat right now is the home and community based services. It's HCBS and as a labor program, it's designed to help provide Medicaid cover services for individuals who would otherwise end up in a nursing home or an institution. So by offering these services, the idea is that the individuals would be able to receive their services in their own home or the community. And the point of the HCBS waiver for people with disabilities is to really promote independence, autonomy, quality of life for eligible individuals. So the piece that it does this with health services and human services, what it provides. So it's going to provide the support to help support medical needs. It's going to help human services to support the daily living needs. So that that's some language that we want to make sure that you have. And then the other one is going to be Early, Periodic, Screening, Diagnostic and Treatment. I say those really slow because it's taken me a long time remember all those words. But that's going to be EPSDT. So that's going to be, your Early is going to be checking and finding and addressing health related issues before they become a barrier. So some of those you might be familiar with of providing physical exams and evaluations at birth or regularly thereafter. Periodically, that's going to be medical or other healthcare visits at regular, scheduled intervals to monitor growth and development that's going to be for infants, monthly and then quarterly checkups for children, adolescents, annual physical examinations and dental cleanings. The Screening is going to be where you're providing physical, mental developmental, dental, hearing, vision and other assessments to identify risk. So you're going to see it does a lot. It covers a lot. And then those screenings are going to include your developmental screenings, your vision screenings, mental health screenings. That Diagnostic, that D, in that acronym, is going to be performing special or specific test to follow up when a risk is identified. So that's going to be your physical exams. You'll get that blood tests, genetic testing, imaging, so EKGs, X rays, developmental testing, hearing, vision, psychological, neurological, all of those things are going to be included into that. And then last so you see the T, it's Treatment. Think about this as services. It's an easier, understandable word that we all know, that the disability community uses quite often, and that's going to be helping reduce health concerns or addressing goals that people may have. So that's going to be your health, mental health interventions, behavior, support, speech, physical and occupational therapy. That's going to be your attendant care. It's going to be autism services. It's going to be inpatient, outpatient services, nursing care, speech language services, a gamut of services that people with disabilities need. So the two reasons we want to make sure you are familiar with that, because this is the crux of our coalition, the work group that is working specifically on this project, and why we brought individuals together. So Kimberly is going to talk more about our South Carolina status and where we're at. So these are going to be acronyms you see in there, and we want to make sure that you know what those mean. So the HCBS is going to be for somebody that's 18 and older. EPSDT is going to be, this is a federally funded, federally mandated Medicaid program that's free to anyone under 21 that receives Medicaid, not just people with disabilities. This is going to be for people that are on Medicaid and all different Medicaid programs. So there's an important piece of that born to 21 but then there's that little overlap, where HCBS, if you're eligible for that, would pick up for the individuals that qualify at either 18 or at 21 when they transfer transition out of the EPSDT services. So as Kimberly's kind of going over some of that, you'll see some of those acronyms and this. And so we wanted to make sure that you had that information as well. So go ahead, Kimberly.

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Kimberly Tissot 47:38

Yeah, thanks, Sierra. So wanted to give you a little bit of a snapshot of South Carolina and kind of why we decided to do some of this, grass works, grassroots work around EPSDT and home and community based services. So we have nearly 57,000 people in South Carolina that are in institutional settings. We recently had a study from the Boston Consulting Group, that our state paid for, and it was published in January of this year, and it really showed that South Carolina has significant gaps. We are the only state among peers where the majority of mental health treatment facilities are operated by the state, which really limits us. And in fact, the state run mental health agency does not serve people with dual diagnoses. So if you're a person with an intellectual disability or developmental disability, they do not serve you, meaning that no one will end up serving them with mental health treatments. And South Carolina has one of the most fragmented Health and Human Services Agency structure versus all other states, and what that looks like in South Carolina is everything is siloed. So these agencies that are supporting people with intellectual disabilities are separate from Department of Mental Health, and our Medicaid system is separate and HHS and so everyone is really siloed and not working together, although they do report all to federal HHS. So in South Carolina in 2023 we had 40, over 41,000 people on the waiting list for home and community based services, which is pretty significant. And in 2022, South Carolina had a little bit over 24,000 people on waiting lists for the home and community based services. So you'll see how it really almost doubled there. And one of the reasons why we're doing this, and we'll tell you a story in a minute, but individuals and families do not know about EPSDT. They do not know what services that their children with disabilities should be getting and the treatment options, and so because EPSDT is a federally mandated program, our state really does not have the option to not provide services. And so we were trying to focus on EPSDT and getting more awareness made about it, but also how people will transition, so how disabled people would transition from EPSDT to home and community based services. And in South Carolina, our state does have home and community based service waivers. As Sierra said, home and community based services are actually optional for states, and so it's not mandated. But in South Carolina, those waivers are really focused around people with intellectual and developmental disabilities, including spinal cord injuries and TBI, so that's where the focus is, and we've got to do a lot of education, but when they do age out of EPSDT, we're wanting to connect them to home and community based services and have that transition be smooth. Our coalition members have really been great with telling us they did not know what their options were after they aged out of children's Medicaid, or they didn't even know what EPSDT was. And so we're trying to build that education. Our worry is that EPSDT is not being provided appropriately in South Carolina, and so that's really limiting the independence of people with disabilities, and then our home and community based service programs are also relatively weak. And so how can we, how can we put people in home and community based services, which are weak when they've never had the services that they were entitled to? So there a lot of times they have significant need. So we will go to really

S

Sierra Royster 51:42

quick before we go to the other slide. Well, we're here, but I just wanted to just give everybody a warning before we go into this conversation or this overview of an actual individual within the institution, and know that this is a real story. There is graphic detail and horrific details that are hard for some to hear. It's hard for everybody to hear, but it may be very triggering for some. So if you need to step away to take care of yourself and just come back when we head on to the next slide, that is completely okay, put us on mute and wait for the next slide. But it is

important that we share these stories, because if people don't know the truth of what really is happening, then the need for the services is not as important and pressing. And so we did think it was very valuable, because if you're not familiar with these things, we want you to be familiar with what's happening in your state, and the condition of people with disabilities in your state are actually living in it, if you don't know.

K

Kimberly Tissot 52:40

And so this is the why. It's absolutely the people, we hear these stories. We're disability led. We've experienced these issues as well, and so they, the issues, is what really drives a lot of our services and program design. So I'm going to tell you a little bit about Alex. We did change his name just for confidentiality reasons. He is an autistic teenager with also a significant seizure disability and suffered severe abuse and neglect at a residential facility. Initially, 90% able to independently use the bathroom, Alex regressed to needing to wear adult incontinence pull ups 24/7 so when he entered the facility, he was completely able to use the toilet independently. And so there was a lot of regression, because that is not where he was when we pulled him out, he went over five years without necessary ankle foot orthotics, and leading to severe physical deterioration, with the point where he was unable to climb stairs, was unable to really walk very far when he was able to do that before, with his ankle braces still today, his ankles turn inward to the point that he practically walks on them, and that's because of some of the growing that he had done in the facility, and so he was there starting at 12 years old, and we got him out just a couple years ago. So when he was 17, he also suffered from numerous injuries, bites, lacerations, falls, really, truly, neglect, which resulted in the needs. One even resulted in the need for staples to his head, a broken collarbone and a nail that was bitten off, which resulted in a dismissal of a member of a person of personnel and a lifetime ban on working with children. Alex was also taken to the hospital for treatment. The mother of Alex called every single state agency in South Carolina, and no one was really listening to her, and no one was doing anything about the situation. She got a hold of ABLE South Carolina, and we really started doing everything that we can to really advocate for him. We got him out of the institution, he is now, that institution is now closed. He's living at home with EPSDT services. He just turned 18, but he is still receiving EPSDT services in the home. So that is a home, home and community based type of service EPSDT is but after months in the hospital, the medical bills reached over a million dollars, and so home and community based services via the EPSDT would have allowed Alex to live with his family originally, rather the lack of options, which resulted in a really dramatic and more costly health care system, but Alex's quality of life and so this is the stories that we keep hearing, is that there are no services in South Carolina and really limiting people's ability to be successful and independent. I will say that Alex is home. He is receiving home and community based services and excelling and doing really, really well. He is back to using the toilet independently, and so he's really been able to to catch up, fortunately, so, but, but that's the type of fight we really had. We had a pool in the governor's office. We had to do a lot of advocacy to make sure that he was receiving the services that he is entitled to, and the state is federally mandated to provide. So I want to talk a little bit about the coalition that we, we run. We, South Carolina, ABLE South Carolina has created, and we lead, a number of coalitions, some around employment, some around public health, emergency, disasters, a number of different programs. We also run the state's advocacy day for access and independence, where we take a needs assessment from people with disabilities and their results, and create barrier removals to to the issues. And so we advocate for that annually. But in 2023 ABLE South Carolina, with support from ACL and South Carolina Assisted Technology Program that's housed in our UCEDD, we established the South Carolina Disability Public Health Task Force, and we have a number of goals that we're working on, including, you

know, redoing the policy around medical rationing, because right now that our state's medical rationing policy is discriminatory against people with disabilities, but the group is made up of 45 members of advocates with disabilities, advocacy organization allies and state agencies, including the main state agencies, so Department of Public Health, Health and Human Services, Department of Social Services, RDD agencies and the University of South Carolina, just to say a few. And our work really, truly centers around the issues that impact people with disabilities regarding public health. We saw public health disasters in our state. And I know this was not just South Carolina when COVID hit. Just lack of healthcare access, the medical rationing issue, lack of education for public health entities to even serve people with disabilities. And so the program we are working on with the Grassroots Project, we are going to talk a little bit about that now, but this is we, we created a work group within the coalition made up of people with disabilities, majority, and some parents, like Alex's mother, to be able to provide input to the project that we're doing. So Sierra, do you want to tell everybody about the project?

S

Sierra Royster 58:46

Yeah so, we have three goals, three deliverables that we're hoping to work towards by the end of this project. And one is the letter to the South Carolina Department of Health and Human Services from the disability community. So that work group that Kimberly just described will be helping craft this letter, along with our attorney consultant, and they, we will be listing out concerns and the barriers that individuals have been experiencing, and demand for the improvement, a demand for the services to be accessed by the disability community, and that this information is shared with them. The other thing that we're working on is...because that's going to be the systemic change that we're hoping to see it just by saying, hey, we know this is something you're required to do. You need to be carrying this out. But we also want to empower and educate families that may not know about these services. So we're creating a tool for families, and I can, we even see it working beyond that of doctors and clinics and social workers and everybody involved in service providing and those that are receiving those services to educate them about EPSDT and HCBS. What are those qualifications? How to access those and how to make sure that you're getting the services you need to meet those goals that you have, and that you're also able to transition, if you're eligible, to HCBS, so that you can that young people are living in their communities and receiving services, and that once they hit adulthood, they are still remaining in the community of their choice, and with their families and friends and not being sent to other states or not being sent elsewhere, to institutions, where they have the right and South Carolina needs provide the services to keep them there. So we're hoping to create advocates of family members and people with disabilities are really going to know these are my rights, and we want to speak up for this. So we're working on that tool as well. We're also going to be doing a media press release that will also increase the knowledge of the general community to know about these services and continue the conversation further. So here's our contact information. This was a mouthful of information, and we know sometimes it might be new to you. Please feel free to reach out. We may not know everything about it, but we can definitely get you in contact if you need help navigating the different ropes. And Kimberly, do you have anything else?

K

Kimberly Tissot 1:01:17

I guess, yeah, I don't. And please feel free to reach out to us. We only had 10 minutes, and I think we may have went over that a little bit, but we can talk strategies. We can talk how we are doing all of this work to be able to pull people with disabilities together too and center their

voices and truly, really elevate their voices to make sure that our state is hearing from the disability community and making change. Thank you.

K

Kate Brady 1:01:43

Thank you, Sierra and Kimberly, great to hear about ABLE South Carolina and all that you're doing. So it's my pleasure now to invite Jennifer Kucera and Brittany Maddox to come on screen and share with us a bit about the work of the Ohio Olmstead Task Force. Thank you both for being here.

J

Jennifer Kucera 1:02:08

Hi everybody. My name is Jennifer Kucera. I'm a white woman in my mid 50s. I was born with a developmental disability. I am the chair of the Ohio Olmstead Task Force. I also work at the Center for Independent Living in Columbus, Ohio, and I use the pronouns she, her. I have a purple background, and my hair is kind of pulled back today. Brittanie?

B

Brittanie Maddox 1:02:36

Good afternoon, everyone, or good morning wherever you may be joining us from. My name is Brittany Maddox. I use she, her pronouns. I am a 35 year old white woman with long brown hair. Today, I have on a black shirt and a black headset. My background is some long vertical blinds and a tan wall. And I am the vice chair of the Ohio Olmsted Task Force, also known as the acronym O, O, T, F. So I will start off our presentation. This first slide states our name, who we are, what we do, and why it matters, and the left part of the screen is the state of Ohio in blue, and it says Ohio Olmsted Task Force in white throughout the state. Next slide, okay, so this slide depicts the Ohio State House on the left hand side, and on the right side, it has words that state, what is the Ohio Olmstead Task Force, and it depicts that we are a statewide grassroots coalition of Ohioans with disabilities, of all ages, family members, advocates and organizations advocating for the right to live, work and participate in their communities. We were founded in 2002. It consists of both individuals and others who represent various organizations across the state. OOTF works closely with various departments in Ohio state agencies, the Centers for Independent Living, disability rights organizations, lawmakers and many others, to advocate and facilitate change. Next slide. This slide has three different colors of blue. On the left hand side, it's the mission and vision. And so on the right hand side, there are two columns. One is OOTF mission statement, which again, is to advocate, educate and support change for all people with disabilities, ensuring their rights to participate in a thriving community life and our vision statement on the far right side of the slide is Ohioans with disabilities shall have access to inclusive, integrated and person-centered services and supports tailored to their individual needs, to live independently in the community. Next slide. So, our structure is on this slide, and at the top right, it's again our logo, which is the blue Ohio State with Ohio Olmstead Task Force in white. Our officers are Chair, Vice Chair, treasurer and secretary. We have both voting members and non-voting members at large, and we have various subcommittees and ad hoc committees. So we do have the steering committee, which is made up of the hosts or CO hosts of the standing committees, and Jennifer and myself and our treasurer and secretary as well, we meet twice a month to discuss various issues and things that keep us running and going together. Each month our standing committees, we have

a legislative committee that works to review public comments that are up in Ohio, they also look at the various bills that are coming out. How do they impact people with disabilities? And we usually will write testimony as well and submit that to the State House. We also have a public relations or PR committee that runs our website, creates documents for us, helps us out, makes things look pretty, and our Finance Committee, which keeps all of our money together. So we love our finance people, Our ad hoc committee-so this means that we did not have to vote to create these committees. That's the direct care workforce crisis committee, housing advocacy, and voting advocacy. Next slide. So this slide on the left, it says, What are the OOTF subcommittees? And on the right, it gives more description, what I stated about each various committee and what they do. So I will not, I will not go over that again. We can go to the next slide and I'll turn it to Jennifer.

J

Jennifer Kucera 1:07:11

Thanks, Brittanie. If we could just go back to the last slide a little bit. I wanted to speak to our ad hoc committees. We have the direct care workforce that works on everything to support our direct care workers in the home and community based service. We have several different waivers throughout our state. There are nursing home level of care waivers along with IDD waivers or developmental disability waivers. I think all told, we have 11 waivers throughout our state. So the direct care workforce work group works on issues, again, surrounding our direct care workforce. We've, we'll talk more about this, but we've had legislative days to try and raise the wages of the direct care workforce, and most recently, we're going to talk about some of the abuse that's happening on the IDD side with folks that live at their homes. And we kind of want to learn more about how that system works and what we could do to advocate for change. And we also started, recently, the housing advocacy work group. There's a lot of grassroots advocacy involving housing going on across Ohio, and so we joined people together, mostly from the Centers of Independent Living, along with people in the Medicaid department, some of the managed care organizations, and we are working on some state level issues right now. So everything that we do, we try to remain statewide focused. Go ahead, next slide. So the history of OOTF, how did, how did we do this? We actually started in 2002 and we are still very much grassroots. I say this because if we can do this, any state can do this. Um, they really started by meeting in libraries. It was the one of the centers of independent living, the Ability Center in Toledo, Ohio, and the University of Toledo that got together and we at the time, this was before Medicaid expansion and Money Follows the Person, we had not accepted either one of those in our state yet. And literally, people were sick of being in nursing homes, and some people obviously were able to live in the community, but it, our state was not doing enough, so they met in libraries, and little by little, they created the Ohio Olmstead Task Force. They work with the Medicaid department. They even stay at the state house-they sit in, where the-what is that organization, Brittany, that I'm thinking of? Adapt? Yes, thank you. I'm sorry. Adapt. They came to Ohio and they helped organize a sit in at our state office until the Medicaid director would listen to them and again, slowly but surely, Medicaid expansion did happen in Ohio. They brought the Money Follows the Person program here. So initially we got funding through our Ohio Department of Medicaid with the Money Follows the Person program to start OOTF. The money was initially housed at Medicaid, and then it ended up going over to the DD Council, where they kept our money. But when the Money Follows the Person program, it did not end. But we didn't have a contract with Medicaid anymore to perform any service. Initially we did a housing I um, not a retreat, but a housing conference, and we did not want anybody else to close our money anymore. So that is why we ended up becoming a 501, c3, so that we could manage our own funds. Um, and we are different than a lot of other grassroots groups, as far as we know, because we do provide mileage and reimbursement to caregivers so that

advocates can attend various events. We are all volunteer at the moment. So I mean, it's really a great group, and to think about all the things that we do and being volunteer at the same time. It's pretty amazing. Next slide. So to increase our membership again, we start out with very, very small numbers, back in 2002 and slowly but surely, we have developed a very great, we have very great participation from our centers of independent living and the Ohio Statewide Independent Living Council. There is a great group of advocates from across our state. We have many, many regions in Ohio that are represented. As far as disability advocates go, we are still looking to increase our numbers, so we're doing a lot of outreach through open houses and participating in events to get the word out that we exist. But we also have members from the state, state departments like the Ohio Department of Medicaid, Ohio Department of Aging. We have the aging committee organizations represented. They're called the triple A's in Ohio area, agencies on aging, COHHIO, the homeless organization is involved with us. I'm sure I'm missing a few, but there are a pretty broad range of organizations that are involved. Along with the disability advocates we are and will always remain, disability run and led, that will never change, even though we do have partners that do not have disabilities, but they advocate on behalf of people with disabilities. Next slide, please. Some of the things that we have accomplished within the last two years. We had a care event at our state house, in part to educate legislators. We gave out awards for caregivers. We talked about the direct care workforce in our state. There was even a video that one of the folks, that one of the independent living centers created, where they interviewed several folks with disabilities about the direct care workers that they have and the system that we have in Ohio. So we had a lot of laughter, but we also had tears. We had a lot of...it was really just a great event, and we hope to be doing this again next year, either at the state house, or we're even thinking about doing it regional now, so every year we'll have a different care event in different parts of our state. We've provided public comment on various different rules. The waiver changes. Self direction is being added to two of our nursing home level of care waivers. We've commented on that. We even have partnerships with the Ohio Department of Aging and Medicaid to work on self direction in our state and to get more waiver alignment across at least the nursing home level of care waivers. We do a lot of speaking like ABLE mentioned. Two things recently: we've talked about housing at two or three, the Ohio Housing Finance Agency and the homeless organization COHHIO. So we've done speeches or talked about accessible affordable housing, and we participated in a disabled woman making art event, and it was literally a celebration of the Olmsted decision, where we ended that we had everybody in the room draw in the style of Lotus Curtis. So they had to draw a self portrait of themselves or somebody sitting next to them, and it was, again, really well received. Next slide. So these are some of the other accomplishments. Most recently, we got REV UP funding from the American Association of People with Disabilities, AAPD, to discuss voting at the various youth leadership forums across our state. The Independent Living Centers host these leadership forums to encourage youth and advocacy. So we've participated in a number of those events. We are also leading a statewide voting training coming up in September, middle September, and like I mentioned, where we always work on policy, self direction. We've made many comments at the state house around various laws, and we, we definitely meet with legislators on a regular basis, either with Advocacy Days right at the State House, where we encourage people with disabilities to attend, and again, we pay all their expenses so that there's nothing that they have to work out of pocket for, to be there with us at the State House, and we are currently also working on ending sub minimum wage. So the 14 C certificates, we're having an advocacy day again in the middle of September to encourage our legislation to help us end the sub minimum wage. So the idea that we're doing with the the Grassroots Project is an HCBS Home and Community Based Services Advocacy Retreat and in the photo-and I apologize for not doing the other photos, sometimes I'm so passionate, I get carried away, so I deeply apologize-but there's an African American lady holding a sign, it says "our homes, not nursing homes".

And there's other people doing a rally or a protest in the background of the photo. So we have noticed that there's a lot of pockets of grassroots advocacy going on across our state, and some of it we are involved in, and some of it we are not. So what we wanted to do is host a fun but working event for all of us to get together, because all of us get zoom fatigue at one time or another. So we thought this would be great to do this in person. It's going to be a two day all expenses paid advocacy retreat at a local Columbus, near Columbus, Ohio, towards the end of September. And some of the topics-at the beginning topic, we are going to imagine an HCBS, home and community based system, if we forget the system that we currently have in place, and we're going to recreate what would be our ideal system. So that's going to be kind of our icebreaker, our beginning thoughts and discussion, and then we will go on from there and based in reality. And hope to come away with some things like budgetary asks, so that we can do more advocacy surrounding the budget next year, like we did last year where we did get a, I think it was a \$3 increase in direct care workforce for all the our direct care workers. So we're really, really excited about this retreat. Um, and here is the ways to get a hold of me or Brittanie. We have some social media accounts and also our website. Thank you so very much.

K

Kate Brady 1:19:05

Thank you, Jennifer and Brittanie, if we can invite all panelists to come on screen, the excellent and brilliant Alixe Bonardi, co-director of the Grassroots Project, is going to lead a Q and A and I'm going to pull these slides down. Thanks again, all.

A

Alexandra Bonardi 1:19:29

Thank you, everyone. And this has been a tremendous set of information that each of you have presented. And it's, I've been standing here just paying attention to all of the passion that each of you is doing, as Kate mentioned just a little bit ago, we are. We're going to move into what is kind of a lightning round conversation at this point, given where we are with time, I'll do a brief introduction of myself. I am a white woman with dark frame glasses. I am in my home office with a bunch of books behind me. I have shoulder length, grayish, brownish hair, and I use she, her pronouns. I want to pick up on all of the presentations that you all did, and I guess you started, each of you, at some point in your conversation, talked about the origin stories of your organization, describing events and situations in your own state that were the catalysts for creating the mighty disability advocacy organizations that you're working with, and, oh my goodness, what a list of projects you have underway, including the work that you're doing through this grassroots advocacy group. I have a question for each of you, and I'm going to start actually just picking it up with you, Jennifer, since you were last here. So Jennifer and Brittanie, I was curious if you could describe in your experience, what are the best approaches to build and maintain momentum for your advocacy work. And really, this is a sharing kind of thing, so love to hear that from each of you, the best approaches that you see to build and maintain momentum for this advocacy work.

J

Jennifer Kucera 1:21:05

One of the things I can speak to is that you need to meet a lot, to keep everybody focused and on task and on point, and bring up new ideas too, and talk with other organizations across your state to get ideas of what they're doing and we try to do that all the time,

A Alexandra Bonardi 1:21:26
Meetings. It is a it is an important fact of life. People need to connect, don't they

J Jennifer Kucera 1:21:31
Absolutely.

B Brittanie Maddox 1:21:34
The other thing I would say is I feel like part of what my role, I do work at Disability Rights Ohio, but I think part of my role is really connecting with advocates. And what I try to do is do a lot of presentations, like if I can, and trainings on just getting people comfortable and feeling like I have the information that I need, even if I don't know what 100% I feel confident that I know who I can reach out to. I can practice it with you. I can give you tips and tricks on how to engage legislators, what you could do, how to get a meeting right? Like, how do you stay connected to everyone? And I feel like we do. I feel like we do a good job in our group of really making sure that everyone has time to have discussions, and they never feel like they couldn't email or call us and say, hey, I really need to talk to you, I have this question. It's a really, it's an open door policy. So I feel like, as we keep you know, we give people information, we give them talking points, and that helps reassure them, but they also feel supported by us too. We're always engaging.

A Alexandra Bonardi 1:22:42
Engaging, meetings, relationships, wonderful. Thank you both, Jennifer and Brittanie. Sierra and Kimberly-I'd like to turn to you then with the same question about the best approaches in your experience to build and maintain momentum for this advocacy work.

K Kimberly Tissot 1:22:59
Yeah, I think it's a lot of having the coalition be a part of the solutions to the barriers, and then also elevating that disability pride, like we can make changes. Nothing about us without us, and we're bringing that alive. And so I think those are two points that we really use within our organization, and then for the partner agencies to, you know, bring different speakers to the table, like recently, we had OCR and ACL come and present about the the revisions of the Rehabilitation Act of 1973 and so, you know, going over those and bringing new information to people. I think they're hungry for it, and I think they're also hungry for disability representation.

S Sierra Royster 1:23:46
I agree with everything that's been said. I was just going to add one thing, one thing we saw with our one of the work groups out of the coalition was thinking big ideas. So how do we change the world? How do we change everything? How do we get services happening today

and letting them know all these things can be addressed, but there has, it has to be done in an order, and we're hearing you. Let's come up with a timeline. Let's come up with a plan with how these things can be addressed, because unfortunately, we can't take everything on at one time, even though we want to. So I think just not dismissing that idea, but then laying out with them-okay, what do we feel like is a priority? Where do we want to focus first? That way, everybody's voice is being heard and they can see that the work can be done. It just maybe isn't done overnight, so that would be along with everybody else's...

A

Alexandra Bonardi 1:24:45

Thank you. So I heard disability leadership, lots of good information, big ideas and tangible action plans to get the work done. Wonderful. And thank you. Noel, same question to you. Your experience, and the best approach is to build and maintain momentum in this work

N

Noel Martin Rubio 1:25:06

Abosultely. Well, I think momentum is incredibly important. And I think the best way to do that is to continue to communicate, you know, the progress that has been made so far through the work that you've done with your various coalitions, to keep folks engaged and informed about what's happened and what still needs to happen. And I think, as folks have said, provide opportunities for folks to come together regularly to discuss what the future state should look like and what still needs to be done, you know. And I think really putting it into the context of, you know, public discussions about things like, for example, state budgets and you know, what are, what are some initiatives that are happening that you know either represent opportunities to grow funding and investment for you know, whatever it is you're advocating for, or what are opportunities to oppose proposals that might threaten the progress that has made so far? I think, you know, it's just a matter of, of, you know, playing the long game and making sure that you're communicating, you know, to folks what has been done, what still needs to happen, and kind of, what is the broader context in which we're operating, what's at stake, and how can you get involved, providing, you know, multiple opportunities for people, multiple touch points, for people in the community to get involved and to make their voices heard and giving them the resources to do that. You know, I think a big part of our work, and I didn't get the chance to touch on this is, you know, enabling people in the community to fully participate in the public policy making process by, you know, training them to identify and contact their representatives, participate in public hearings by developing and delivering effective testimony and really making the case that, you know, every voice matters and every perspective is valuable, and that, you know, if these are decisions that are being made about the lives of the livelihoods of people with disabilities, then you know it is imperative that people with lived experience of those disabilities be at the forefront of the conversation about how resources are allocated and how policies are structured in order to really be represented in the design and the rollout and the evaluation of programs that affect their everyday lives.

A

Alexandra Bonardi 1:27:33

Fantastic. Thank you. Thank you, Noel, and we really heard about all of the opportunities to build people's connections with these important policy activities. Thank you, Laura for bringing up our final slide. This is, if you scan that QR code or you go to the link that will be in chat, this

is a brief survey we are asking you to provide, just to give us some feedback on this presentation and I do want to particularly thank our panelists who joined us today to share so much information. I feel like hopefully everybody who has been here today has gotten a good introduction to these and some other groups we heard about in chat. And finally, I would like to say the question and answer section has been open, and I see that our panelists have been answering it as they could. They still, there still are a few unanswered questions. And what we will do with both the answered and unanswered questions is bring them together, see if we can get answers for the broadest swath of questions, and also post those, make those available to people who attended this when we do follow up email. So once again, thank you, everyone for your participation. This has been a full conversation, and if you have a moment before you move on to the rest of your day to complete that survey, we would very, very much like to hear from you. Please keep in touch through our email address, grassroots@hsri.org. There will be more to come, and keep on the lookout for that. With much appreciation, enjoy the rest of your day, everyone. Thank you.