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OLIVIA WILLIAMS:

Welcome to the Disability & Philanthropy Forum's Disability Equity Series. My name is Olivia Williams. My pronouns are she/her, and I am the senior program and communications associate for the Disability & Philanthropy Forum. I'm joining you today from the Land of the Missouri, Oto, Kansa, Osage, Shawnee and Delaware, also known as Kansas City. Today's webinar is brought to you in partnership with our co-sponsor, The Care for All with Respect and Equity Fund. As part of our commitment to accessibility, our panelists and I will each provide an audio description of ourselves. I am a Black woman with low-cut curly hair, wearing a dark blue blazer with a pink top underneath. And my background is a glass wall. A few housekeeping items. There are two ways to access our live captions today. Use the CC button at the bottom of your screen or to access the captions in a separate window, see the link to the external caption viewer in the chat.

Today, only our moderators and panelists will be on camera. You'll be muted throughout the event. This webinar is being recorded and you'll receive a link to the recording in the next few weeks. Although we will be using the chat to share links with you, it will not be available for you to communicate out. Instead, please use the Q&A button at the bottom of your screen to share your questions at any time during the session. We'll try to integrate them into the discussion and we will also make time for questions at the end. If the Q&A is not accessible to you, please feel free to send your questions to communications@disabilityphilanthropy.org. We have a poll question to help set the context for our conversation today. Please answer it now via the box that just popped up on your screen, if you don't mind multitasking a bit while I talk.

If the poll is not accessible to you, please feel free to email communications@disabilityphilanthropy.org or respond in the Q&A. I will read the question and choices now. Please indicate your personal connections to care and select all that apply. I'm currently caring for a child, parent, or loved one. I have a family member, loved one or friend who is a caregiver. I have a child, parent, or loved one who is receiving care from a family member, loved one or care professional, or I am currently receiving care from a family member, loved one or care professional. To moderate our panel, I'm delighted to introduce Anna Shireen Wadia, executive director of the Care for All with Respect and Equity Fund. Anna is joined on the panel by two disabled leaders with knowledge and lived experience in care work and disability rights advocacy.

You can learn more about the panelists from their bios that are linked in the chat. And before we start, if we can close the poll, we'll take a look at our poll responses and it looks as though many of us are currently caring for a child, parent, or loved one. So that means a lot of us here in this room have personal experience with care work, that's about 33% of us. And then 27% of us have a family member, loved one or friend who is a caregiver. So you'll hear more from our panelists about the many people involved in the care movement. And as we can see here, that includes you. Anna, take it away.

ANNA SHIREEN WADIA:

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Wonderful. Thank you so much, Olivia. And thank you very much to the Disability & Philanthropy Forum, and our speakers who I'll be introducing soon. My name is Anna Wadia and I'm the executive director of the Care for All with Respect and Equity Fund or the CARE Fund. I'm a woman with light brown skin and brown and some gray hair, and I'm wearing a floral shirt. And behind me is a yellow background with a CARE Fund logo. I use she and her pronouns and my apartment building in New York City is on traditional unceded Mohican and Lenape lands. I've really been looking forward to this conversation today because it is so integral to the DNA of the CARE Fund. We are a unique collaboration among foundations and individuals, pooling resources at scale to build the cohesion, capacity and power of the care movement. We all come together across our differences as funders because we know that we will only win transformative change in our care systems if we build power together.

As long as we are divided, we will be conquered. As long as we allow the politics of austerity to pit consumers of care, care workers, and family caregivers against each other, we will never build the powerful, energized base to win public resources at scale for transformative change. And this is especially important for people with disabilities because people with disabilities play all of these roles. Many people with disabilities employ personal assistants so that they can thrive in their communities and workplaces. They also build networks of friends and family to navigate independent living and care needs, and they themselves are caregivers for their children, their parents, and other loved ones. So this is why the CARE Fund, from the very beginning, has been committed to supporting disability rights and justice organizations and highlighting the perspectives of the disability community on care in forums like this one today.

So I'm thrilled to welcome two amazing advocates to share their perspectives and wisdom with you today. Maria Town is the president and CEO of the American Association of People with Disabilities, an organization we are honored to support at the CARE Fund. Rahnee Patrick is the director of the Division of Rehabilitation Services at the Illinois Department of Human Services and a longtime disability rights leader. We will put details of each of their impressive bios in the chat. So let's start by asking each of you to introduce yourselves with your name, pronoun and visual description, and just one sentence that you would like the audience to know about yourself. Maria, let's start with you followed by Rahnee.

MARIA TOWN:

Thank you so much, Anna. I'm really delighted to be here with all of you this afternoon. My name is Maria Town. My pronouns are she, her and hers. I am a white woman with long brown hair. I'm wearing a fuzzy tweed jacket and a pink dress, and I've got on bold red lipstick and I'm coming to you all from my apartment in Washington DC on unceded Piscataway and Anacostan land. And a sentence about me, I'm someone who receives care on a daily basis. I'm a family caregiver myself, and I support other caregivers as well, both in person and remotely. Rahnee, I'll pass it to you.

RANHEE PATRICK:

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Hi. Thank you so much, Maria. I'm Rahnee Patrick and I use she, they, her pronouns. I am the daughter of Ubonwan and Daniel Patrick. So I am Thai and white. The best expression of my skin tone is the stone at a Clinique line of foundation. And I have short gray, brown, curly hair and wearing an orange blazer with a white dress shirt underneath it and some gold hoop earrings and some kind of grayish rim rectangle glasses. I am in Normal, Illinois, which is the unceded ancestral homeland of many Native tribes, including the Kickapoo of the Algonquin language group who are forced to move west of the Mississippi. Also, the Peoria, Kaskaskia, Oglala, Sioux and Miami Nations land. And I look forward to our conversation. Thank you very much.

ANNA SHIREEN WADIA:

Thank you so much. So hearing for each other is fundamentally what makes us human. And we all have deep personal experiences providing and receiving care. So I'd love to hear from each of you starting with you, Maria, how has your personal story shaped how you navigate the care movement?

MARIA TOWN:

What a fantastic question. So I have been disabled my whole life. I have cerebral palsy, and I, like everyone else, have received care my whole life. But I as a child received home and community-based services via a Medicaid waiver. And this waiver allowed for me to receive physical therapy, occupational therapy in my home. It allowed for my mother to receive respite services as she raised three disabled children and went to school. And when I was about 10, the state of Louisiana went through some significant reforms of its state Medicaid program and I lost my waiver services. Did my cerebral palsy go away? No. Did I still need all of those services? Yes. Could my family afford them? No. And so there was a significant period of time that I went without services and my mother and my family and I challenged the decision in court and we lost.

And this was one of my first very explicit advocacy moments as a child where I had to go tell my story in front of a judge. And it was one of the moments where I realized that systems that are meant to care and to provide care and support for people like me sometimes don't and sometimes can make things more difficult because of decisions that are out of our control. And so that is really my origin story and my approach to this movement. And since then, I've had a lot of different experiences with care and experiences in community that have given me a lot of hope that families will not be faced with what my family was faced with so many years ago. But we've got a lot of work to do.

ANNA SHIREEN WADIA:

Thank you so much. Rahnee, would you like to share your story?

RANHEE PATRICK:

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Yeah, Maria, I am very moved by your experience and just feel your fierceness. And I also feel like I understand myself in terms of my own ferocity because I did not get home and community-based services, and what that did, it put a lot of pressure on my family and a lot of shame around... As my physical needs increased, I acquired arthritis at 10 years old, which is two years after being diagnosed with head-to-toe psoriasis. And so as it became clear, I tried to go for cure and healing and that was not happening. And I didn't know as I became a teenager that there wasn't going to be a cure experience for me. And my disability just became more and more, the arthritis recruited more and more joints in my body, so I now use a wheelchair. The turning point for me was a woman who had arthritis too in college invited me to have pizza at her in her apartment, and she introduced me to a shower chair, which I didn't know about.

And I was taking a shower in a standing shower stall and sitting on the floor of the shower stall and letting the water come down on me, didn't know that there was equipment out there that you can use to shower with, and I didn't know that you could also have strangers, essentially, workers that could come into your home through a home health agency and have Medicaid pay for it to help clean me, my own body, until this woman told me about her own experience over Starlite Pizza in South Bend, Indiana. And so I have had a direction around making sure that I never again have to crawl around on the floor or go to public places smelling unclean and contribute in the world as my own just ferociousness demands. So that's what's going on for me. And I also care for my husband too, who also has muscular dystrophy. You may know Mike Ervin. He has a blog called Smart Ass Cripple, so check that out too if you want to know about disability rights.

ANNA SHIREEN WADIA:

Thank you so much, Rahnee and Maria, for sharing your stories of fierceness. It's so moving and so important people to hear. So Maria, we've touched on this a bit, but some people on this call may be very well versed in what the care economy and the care movement is, and for others, they may be new to it. So let's turn to you to explain what we mean when we talk about care and the care movement.

MARIA TOWN:

So when we say care and the care movement and care economy and care infrastructure, what we are talking about is a segment of the economy in our society that makes all of our other work possible to quote the great Ai-jen Poo. The care economy and care infrastructure is inclusive of both paid and unpaid care work and includes things like care for older adults or elder care, childcare, paid family and medical leave and disability care or what Rahnee and I have both referred to as home and community-based services. The movement, the care movement is fighting for things like increased wages and better job quality for direct support workers and childcare workers, more flexible policies that allow family members to work and care at the same time.

And I think it's really important to acknowledge that when we're talking about who comprises the care movement, again, as Anna's already mentioned, and we've already demonstrated disabled

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people are both recipients of care and our care workers ourselves. Children and young people are often care workers as well as adults and older adults. And care work is often disabling. So one of the things I'm hoping we can talk about today is how this kind of binary of a care worker and a disabled person has been really disruptive because both care and disability are natural parts of the human condition.

ANNA SHIREEN WADIA:

Thank you, Maria. And that's a perfect lead-in into my next question, which is why is public policy and more specifically public investment, public dollars, so essential to ensuring that people with disabilities have the care they need to live independently with safety and dignity, can care for others in the way that they need to, and at the same time that the professionals providing care have decent living wage jobs and stay in this profession and can advance in it? So Rahnee, let me start with you.

RANHEE PATRICK:

Yeah. The reason that that's so important is that we won't be able to reach long-term social solutions without the talent of people with disabilities, our support workers, the folks that assist in terms of childcare. Without those kind of interdependent supports, we won't be able to resolve long-time problems that our communities face because people are having to use their minds, their talents, their energy to solve issues of just simply being able to make sure someone has a diaper change or making sure that someone has hair that's washed or being able to transport through out there to basic sort of functions that you want in your life. Currently, there is no other way besides public dollars for people to get access to services.

So you may be able through private employer-provided insurance to get short-term home health services or a nursing home stay. But that's very short-term and it is only through the work of disability rights folks, parents, other folks that are looking out for workers that we've been able to get the amount of public investment. Yet, there is not an equity around those services and there's many, many people still suffering, still probably crawling through their own homes, unconnected to the types of supports and services that give them basic human dignity. So that's really what my insight is on that need.

ANNA SHIREEN WADIA:

Thank you, Rahnee. Maria, can you elaborate on that and talk a little bit about how the politics of austerity have gotten us to this place of pitting all of the care constituencies against each other and what's being done to fight against that?

MARIA TOWN:

Yes. So historically, again, we haven't looked at these different pillars of the care economy together and policymakers, decision-makers, folks who are preparing budgets have basically said, we have forced us into choices that say we can either provide funding for childcare or we

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can provide funding for elder care. We can provide funding to increase direct support worker minimum wage, which means, and this is a real example, that disabled people and others who rely on direct support workers will have to have a reduction in hours. And we see this fight over and over again where because of things like reductions in hours, you have the disability community kind of opposing changes to work or pay because our care needs aren't going anywhere.

And then you're forcing folks to basically find unpaid care workers and the politics of austerity instead of saving us money, what they do is put strain on other aspects of our lives that ultimately cost us time, agency, independence and dignity as Rahnee said. And I will take us back to the Build Back Better fight, which was very recent, policymakers were coming to coalitions of organizations that AAPD was involved in and saying, "Okay, we can have this money for paid leave or we can include more money for home and community-based services." And thankfully, this was a really important moment for this movement. All of us said, "No, we need both, and you all have to figure it out. We are doing the work on the ground to provide you ways to pay for these solutions."

And ultimately, we did not get paid leave in the bill that became Build Back Better. But what we did get out of that moment was relationships, greater trust and more of the foundation that we needed to try again in the future. And so these are just a couple of examples. In my case, austerity politics literally meant that the state of Louisiana determined who was and was not disabled enough to receive services. And I had a judge told me I was too smart regardless of what my actual needs were. And that is consistently where we are at over and over again. But austerity politics doesn't save us anything as I mentioned previously.

ANNA SHIREEN WADIA:

Right. Right. I mean, it just costs our society and our families and our economy more in the long run. For example, if a family member needs to leave their job or can't move up in their career, it costs more in the long run, which is why so many care groups are actually organizing to be prepared for fights about taxes and fiscal policy next year. So Maria, you talked about Build Back Better and coalition building and the trust that had been built. And we all know that that didn't happen overnight. That took time. It took time, and it took the creation of safe spaces to understand each other, have difficult dialogue, and really bring movements together to support each other and each other's policies.

And I want to say that one thing that I've learned over the many years that I've been in philanthropy is what an important role philanthropy can play to create those spaces and that time for trust, that patient capital is such an important role for philanthropy to play. So I was wondering, Rahnee, let's turn back to you. If you could share your experiences with needing that time and space and how funders have been and could be, could continue to be helpful in creating processes to build trust between the siloed parts of the disability and care movements.

RANHEE PATRICK:

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This is Rahnee. I have a couple of examples. One was in Chicago, there is a philanthropy group that really wanted to get dig deeper about resolving long-term social problems around folks with intellectual and developmental disabilities. So they convened state government, which I'm a part of, family members and their board to ask for an educational series. So first, understanding what Maria and I are talking about, giving some basics about all of the acronyms, all of the policies and things like that in a very high level way. And then you give space for a dialogue or question and answer. And then after that, they then created strategy around, well, here's where we are going to work on like transportation is a gap, say for successful employment for people with disabilities when you want to be paid, have wage protections, minimum wage protections, as well as working amongst people without disabilities.

And so they started to address transportation in that space. So it was very intentional too. So that kind of quality of this is what we intend, these are our values, and those are some of the... that was an experience that I had. Another one I had had to do with a women's funder, like a women's foundation around working for women's equity. And there was sort of a firestorm on the board where the fact that accessibility and basic legal protections for people with disabilities to be included in the funding caused people to resign. And it was really stressful for people. But then I came in as the good cop afterwards, which I really regret because I wanted to be more united like Maria said. But I think the burn that people felt after that resignation allowed some reflection and people to be more open about fixing the wrongs and doing something about it. And they did a much better job and continue to include people with disabilities in their work and how they fund. So those are a couple of examples.

ANNA SHIREEN WADIA:

That's great. Thank you. Maria, I know that over the years you've been very involved in various coalitions and spaces for people with disabilities, workers' rights groups, care advocates to come together. I'd love to hear some more about those experiences and how you feel you've built, brought different perspectives to the care movements and the workers' rights movements and also what you have in turn learned from that.

MARIA TOWN:

So speaking specifically to the role of philanthropy and all of this, I have to say that the CARE Fund itself has been a very important space for AAPD in the fact that the CARE Fund and the leadership of Anna and others help facilitate connections and relationships across the care space that AAPD would not have been able to create on our own. And that is both a reflection of our capacity as an organization. And also, childcare being a great example, childcare is not an issue that we have worked on historically, and we wouldn't have known really where to start in building those relationships. But because of the CARE Fund and other funders, they actually said, "Here's who we're funding in this space, we think they would be open for a conversation." And it really has resulted in some incredible work across our organizations and informed some other policy pieces.

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We began working with a group of parents with intellectual disabilities in New England who are focused on increasing the accessibility of child protective services in their home states so that parents with disabilities understand what's happening when they get a welfare check because they were being asked to sign documents they didn't understand. And because we were building relationships in the child care space, we could have better informed conversations with our advocates so that they could also know what was happening in broader child care advocacy. And ultimately together we contributed to a report by the Government Accountability Office on the accessibility of child care for disabled parents and caregivers. Another example that just happened recently was we came together with organizations like the National Women's Law Center, a group called Little Lobbyists, as well as Caring Across Generations to put on a community integration summit. In my experience in working in the care movement, because there has been the siloing and sometimes some real tension and because of historic ableism generally in our society, disability has been on the periphery.

And what we and our partners decided to do was to create a space where everyone could be educated on concepts like community integration, like the Olmstead decision together, where we're not assuming that anyone has more knowledge than one another, and really taking the time to educate all of our partners, whether it's groups like MomsRising, or I mean, any number of other groups on why the care movement is important for disabled people. And I think one of the things that I've learned from worker rights organizations for example, is how they understand disability. And that sounds kind of basic, but prior to getting connected to the CARE Fund, becoming engaged in these coalitions, I hadn't spent much time with direct support workers as a whole beyond the workers who I'd worked with directly and who had worked with my friends. So hearing from them about their experiences, about their experiences caring for someone like myself or Rahnee during the day and then going home and caring for their families and just how depleted they felt was really important for me.

And the last thing I'll say is historically, and this is thanks to the Disability & Philanthropy Forum, we know that only one penny of every 10 foundation dollars goes to disability rights related work that's focused on systemic change. So one of the other reasons that this kind of coalition and collaboration work has been tricky is that there have been power dynamics related to funding. And so labor organizations or women's organizations or child care organizations historically have had access to a lot more funding than organizations like AAPD. And because of groups like the CARE Fund providing funding to do this work, it actually allows us to get over the power dynamics that have historically been at play and say we all have something to bring to this conversation and to this table on more equal footing instead of it being dominated by one perspective or another.

RANHEE PATRICK:

This is Rahnee. I did want to add something to what Maria said, which is this idea, you said so well Maria about this idea of agency for people with disabilities and our workers. So I brought my worker to tears because she sacrifices her time to help me to eat and get ready for the next day and misses time with her own children. She's getting paid for it, but still that's an energy and experience that actually is a lot of experiences for domestic workers, right? And people with

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disabilities, we in this whole care economy are often like the threshold or the way that dollars are accessed to be used to pay wages or pay for overhead, that's our eligibility as disabled people, then opens up the different units of cost to then be distributed, which I think creates some strange relationships. And I don't think it gives a lot of people with disabilities power. So that also came up for me when you were talking.

ANNA SHIREEN WADIA:

Yeah, thank you both, and thank you, Maria, for sharing about the impacts of the CARE Fund. We're so glad to have been able to support you and other organizations that are advocating for people with disabilities and family members of people with disabilities. So this is a perfect segue into how we want to close our panel before we open it up to questions, which is really what are the different ways that philanthropy can be supportive of all of the types of work you all have been talking about. So we have talked about coalition and movement building and power building. We've talked about organizing and advocacy. We've talked about creating safe spaces for trust building between different communities and constituencies. Those are all things that philanthropy can support. There's a lot of other things that philanthropy can support as well. Philanthropy can support narrative change and communications. Philanthropy can support research, and philanthropy can also support the extremely important outreach and implementation.

Rahnee, your story just illustrated this so clearly how you didn't know about the programs that you actually were eligible for. And that is so common. So there's going to be some foundations listening today that are very comfortable supporting organizing and supporting advocacy and that's fantastic. And there's others that are more focused on programs and services and you can actually play an extremely important role in educating people about their rights and making sure that the barriers to accessing those rights are removed. So I'm going to put one thing in the chat, which is an example of some collaborative communications research that the CARE Fund supported and that we would encourage all of you to use and share with your grantees. But I'd just like to wrap before we go to questions and answers to ask first Rahnee and then Maria to just share any other thoughts you have about how funders can get more involved with this work.

RANHEE PATRICK:

Yeah, so this is Rahnee. I encourage research. I encourage funds to be available to talk about business transformation that actually allows people with disabilities to have equal influence on the direction of the organizations and policymaking, an idea very similar to Maria's organization like leadership development for people with disabilities or how to get the voices of people with disabilities who are impacted by policies, and identify, like we've talked about already, those gaps so that then we can push together and create the change that we all want in terms of care for all.

ANNA SHIREEN WADIA:

Thank you. Maria?

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MARIA TOWN:

I'll add that building trust, sustaining relationships and getting big wins in advocacy takes a lot of time. And so in addition to everything that Rahnee and Anna have shared about getting involved, I would say if and when you get involved, no matter which partners you're working with, whether it's folks from the paid leave space or the gender justice space or the disability rights and justice space, please have patience and give us time to really take on thoughtful approaches to these issues. The other thing that has contributed to austerity politics is not only an austerity of funding but an austerity of time. And we need time and space to really make that shift in our nation's policies, infrastructure, and society.

ANNA SHIREEN WADIA:

Thank you so much. So we are now going to turn to your questions. And before I do that, I'm just putting my email address in the chat. Feel free to reach out if you want to talk about any of these issues further or brainstorm about how you can be supportive of the disability rights and care movements. So we have a lot of great questions coming in, but I'm going to start with one that is a clarifying factual question for you, Maria, which is, what is the Olmstead Decision?

MARIA TOWN:

What a great question. And Rahnee, you should answer this too. The Olmstead Decision is a Supreme Court decision that was issued in 1999 that ruled that it was illegal to institutionalize people with disabilities when there were community supporting community care options available to them. The plaintiffs in this decision were two women with intellectual and mental health disabilities, Lois Curtis and Elaine Wilson. And it is their advocacy that really catalyzed the home and community-based services system that we have today, which allows people with disabilities and older adults to continue living in their homes and communities rather than being institutionalized in a nursing home or other institutional setting. Rahnee, do you want to add to that?

RANHEE PATRICK:

Not at all. You did perfectly. It's beautiful. Well said.

ANNA SHIREEN WADIA:

Great. I think that connects really well into another question we have, which the questioner asked, "Our nonprofit is at the intersection of the need for accessible housing for people with disabilities and the need to provide financial support for direct support workers. We are developing caring communities with financial incentives for direct support professionals in mixed income settings. Does this resonate with the panelists?" And they put the website of the organization in here, so I'll put that in the chat. Rahnee, would you like to start or Maria on answering that one?

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RANHEE PATRICK:

Yeah, I did a thumbs up on that. This is Rahnee, because yeah, it totally resonates with me and one thing, it's not even off the ground and I'm already thinking, "Well, what about this?" So please forgive me for this, but I would just want to make sure that when you're setting up the intentionality of the values of the community, that power dynamics are established where people that are receiving care like the person with a disability has power and autonomy and respect just as well as the person that is the worker or the giving the care. And I think that why we've come so much to as disabled people to press for in-home services is that you have much more control over laundry soap or what food is given to you and the meal for the day.

And that's really about control. And when you have more of a congregate setting, it becomes more using manufacturing techniques to deliver services to people. And we know where you only get this kind of food and we're going to economically buy bulk food to then serve everybody. Like those sort of approaches to how we work together so that people are clean, fed and involved in the community that we need to change it, whether there's equity between folks that are working to support folks with disabilities.

ANNA SHIREEN WADIA:

Maria, anything to add there?

MARIA TOWN:

I have two things. I'm actually glad you brought this up. We could have a whole nother webinar on how physical infrastructure issues feed into care infrastructure related issues. And I think housing is a great example. The shortage of affordable accessible housing in dense, walkable communities directly impacts disabled people and care workers and families alike. And as an example, the fact that many direct support workers cannot afford to live in areas where their clients are located, forcing them to drive hours and hours to get to work causes greater strain in our workforce contributing to this massive workforce shortage that we have. And the fact that there's, again, a huge lack of supply of affordable accessible housing often means that disabled people wind up having no other choice but to live in an institutional setting. We don't often talk about building homes or mixed use housing or multifamily housing in terms of care infrastructure, but it is, we often have this binary around our economy.

So I'm glad you brought that up. And to Rahnee's point, I wanted to ask the group if people were familiar with the burrito test and I'm seeing Rahnee smile, but she might not be familiar with it. The burrito test is a quick way of figuring out if something is an institutional setting. So if you're living in a place, you ask yourself, can I get up at 3:00 AM and go heat up a burrito? And if the answer to that question is no, because you're not allowed out of bed after a certain amount of time or you're not allowed to use the microwave by yourself or you're not allowed to choose what food you eat, if the answer is to any of those questions are no, then you're likely in an institution or in an institutional setting. So, again, related to what Rahnee said, I would just ask you to think about how you're setting up these housing projects and consider how much agency

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everyone living in this space will have over their own decisions, including whether or not they can eat burritos at three o'clock in the morning.

ANNA SHIREEN WADIA:

That's great. I think that's the kind of thing that people will really remember and I appreciate you giving us that image of the burrito test. So now, I'd like to move to a question that is broader and the question is, what is the hesitation with lawmakers and policymakers to make policies that supports caregivers and care recipients to make this policy happen? And I'm going to just broaden that a little bit and say, "And what are you all doing about it?" Because I know you are very actively working to change the mindset of policymakers and to work with champions in policy who are actually supporting this agenda. So, Rahnee, let me start with you, maybe talk nationally, I mean, to talk at state level and then Maria to talk nationally.

RANHEE PATRICK:

Yeah, so I'm going to start with what I'm doing, which is we do, Department of Human Services has moved forward in working with the General Assembly, we hope in the veto session to increase how much a person with a disability can earn in their job and still qualify for Medicaid as well as allow a pilot project for our in-home care program that I administer that's paid through Medicaid so that people can have retirement accounts, which they won't be able to access without penalty until they're 59 and a half years of age, which we don't allow, it's ineligible. It makes you ineligible for our program right now. And to work toward getting that language introduced in the spring session of this year.

People were concerned just about right back to the scarcity component. What an old term that also has tanked changes to Title XIX of the Social Security Act that sets states to have to have nursing home beds paid by Medicaid, but not setting them to have in-home care paid for through Medicaid. They call it a woodwork effect. So if we set this in place, oh, so we just don't have any measure of knowing how much is the financial impact in the end in terms of who's going to come out and qualify now for the program. So we had to work through it, and hopefully in veto session, we'll get through. And that's some of that was my experience.

ANNA SHIREEN WADIA:

Great, thank you. So Maria, we're seeing attention to these issues by policymakers, by candidates, by politicians like we've never seen before, and that is due to the work that you and others in this movement have been doing. So can you share a little bit about what you are doing to get the attention of policymakers and what folks on this call can do to help?

MARIA TOWN:

We are really trying to push these issues on all fronts. Everyone knows that we are approaching a major election. So AAPD has a voting initiative called REV UP, and through that initiative we have sent memos to major networks covering the debate, both pushing for greater accessibility

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of the debate broadcast, but also pushing for moderators to ask questions related to disability and related to care. Similarly, we have created voter issue guides that connect everything that we've talked about today in the hopes that candidates running for every election from city council to president will understand how important disability and care related issues are at the polls. We have also been doing a lot of advocacy in the executive branch in the Biden administration as well as in the legislative branch on Capitol Hill.

Just last week, we brought in advocates from 21 different states who traveled something like 65,000 miles across the country to go on Capitol Hill and advocate for the home and community-based services Access Act, which provides funding to states to basically decrease their waiting list for home and community-based services. In states like Texas where I used to live, the waiting list is 10 years long, and all of those waiting lists reflect the individuals that have been able to get signed up for these programs. They do not reflect the full scope of everyone who needs them because like Rahnee mentioned, many people don't even know what they may be eligible for. We are also advocating to end the use of subminimum wage for people with disabilities.

And this is a sort of historic, an outdated option for employers that was originally intended to encourage the hiring of people with disabilities and is now a tool for oppression. But one of the arguments to continue keeping this oppressive practice in place is the fact that people with disabilities need these special employment arrangements because we need care. And I think one of the things that we are really trying to do in all of our advocacy in this space is to not allow care to be co-opted by others who want to keep people with disabilities in specific spaces or keep us out of our communities. And also, we're not going to allow care to be co-opted by policymakers who think that the family should just be able to figure it out because that is simply not true.

ANNA SHIREEN WADIA:

Very well said, thank you. And I also want to let folks know that AAPD is part of a broader coalition called Care Can't Wait, and they just did a bus tour around the country to share these messages and I'm putting that in the chat as well. So I think we have time for one last question. So I'm going to choose this one to wrap us up, which is what makes you feel hopeful for the future of the care movement and what is an event that you felt supported in? Who would like to start?

RANHEE PATRICK:

Well, I want to give Maria, I want Maria to be the closer. So it's my own little control factor. I am very hopeful when we have over a hundred people joining a call about philanthropy related to care and the care economy. And that's exciting. I'm so excited. So that's my answer on that. And where I was included in an event was at the Women's March sometime ago where they had a ramp up to the stage. I was integrated into the lineup, they had a dance at the end, and I was just part of it, it wasn't any special thing or I was just a human being amongst other folks

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that were there and it was so wonderful. So that was my... And I got to meet my favorite author, Sara Paretsky. Okay, that's it.

MARIA TOWN:

So something that gives me hope, this is very recent news, but one of the programs that historically has supported the use of subminimum wage is called the AbilityOne Program. And it's actually a contracting program by the federal government. So huge contracts, as of September of this year, they are now paying all of their employees at least minimum wage if not higher. And as of last week, AbilityOne employees who are all people with disabilities have collective bargaining rights. And I'm so excited about this, I don't even quite have words right now, but we got that together working with SEIU and it's just we haven't seen these moments of collaboration and progress in the past. And this issue is a little bit more straightforward than some of the other issues that we work on together, but it gives me a ton of hope for what's possible.

And then an event where I felt supported, probably CareFest, which was almost a year ago, Carefest was an event put on by Caring Across Generations. And I was invited to participate in the opening plenary, which doesn't typically happen at events like this. Usually, there's a breakout session on disability. Very rarely is disability in a care conversation that's on the main stage for everyone. And so, one of my current care needs is that I cannot put on my own shoes. And it's very frustrating. And when I travel, if I have to travel by myself, I have a pair of shoes that I bring with me that I can kind of slip onto my feet and wheel out of a hotel room and make it work. On the morning of CareFest, didn't matter how hard I tried, I could not put my shoes on my feet.

And I rolled into this conference barefoot with shoes in my scooter basket and went to my green room and was honestly really nervous and anxious about asking for support to put my shoes on. And I looked at this woman named Ashley and said, "I'm so sorry to ask this, you just met me, but could you help me put on my shoes?" And she was like, "Of course, thank you for asking me. We're here to support you with anything." And even for someone like myself who has had to navigate interactions like this my entire life, it can still be really hard to ask for help and to ask for support. And it was just a really good reminder that I am a valuable expert and advocate on these issues and I can show up as I am and people will support me.

ANNA SHIREEN WADIA:

Wow. Well, thank you both so, so much. And thank you to the Disability & Philanthropy Forum. This has been an incredible discussion. I wish we were in person and we could give you a huge round of applause. I wish I could give both of you big hug at this point, but this has been just such a rich discussion and I'm so grateful that I've been able to get to know both of you and just please everyone join me in thanking our incredible panelists. Thank you so much. Olivia, I'll turn it back to you.

OLIVIA WILLIAMS:

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Yes, thank you so much everyone. We will end it there. There is a survey link in the chat that you'll also receive following the webinar, and we hope you'll join us on October 10th for Disability-Inclusive Hiring. Thank you so much. This was a wonderful conversation. Have a great rest of your day.