

Transcript

>> KRISTIN WRIGHT: And I will get to that in just a moment. But first, I really did want to share one really interesting thing that I learned about Fred just last week. And it really speaks to the impact of The Arc and it speaks to really the impact of people with disabilities.

When Fred was a teenager, he worked as a summer camp counselor at The Arc. So, clearly, that was his first involvement with the organization. Clearly something there definitely struck a chord early on. Because then, Fred went on to join the National Board of The Arc in 2012. He also served as chair of the policies and positions committee.

Fred has also served on the legal advocacy subcommittee and on the ad hoc committee on planned communities and other residential alternatives for people with I/DD. And Fred, as you may know, also previously served as the president of The Arc of Massachusetts. And on top of all that, in addition to Fred's work at The Arc, Fred is a trust and estate lawyer with over 30 years of experience representing families.

Hi, Fred.

>> FRED MISILO: Thank you, Kristin.

It has been a long time since I was a teenager. Thank you for that generous introduction.

It is my honor and privilege to welcome all of you to this virtual town hall meeting for self advocates, for family caregivers and service providers.

Thank you for taking the initiative to attend this meeting, to learn about The Arc's response to the pandemic and the challenges that remain, as well as to receive a briefing on the new Strategic Framework for the future of The Arc.

Now, we come together at a time in the midst of a deadly global pandemic and an uneven economic downturn impacting millions of American families and domestic unrest over policing practices impacting communities of color.

This triad of troubles has exposed weaknesses in our healthcare systems, demonstrated great disparities in our income and wealth and widespread polarization throughout our nation.

Unfortunately, these circumstances have these challenging circumstances have had a disproportionate impact on people with intellectual and development disabilities and their families.

Throughout this period of unprecedented challenges, I'm so proud of the heroic and lifesaving work at all levels of The Arc, national, state and local that has made such a huge positive difference in the lives of individuals with I/DD and their families.

In a few minutes, you will hear from Julie Ward, Shira Wakschlag and Claire Manning of the ongoing work of The Arc's national office, and our chapters across the country in meeting these current challenges. For those of you who have been around The Arc community, our organization's response really doesn't come as a surprise.

It's what we do.

Since our founding, our mission has been to promote and protect the human rights of persons with intellectual and development disabilities and actively support their full inclusion and participation in their communities throughout their lifetimes.

We have changed lives for over 70 years. Yet, despite all of our gains, we have many, many challenges. Long waiting lists for services and supports, the lack of employment opportunities for persons with I/DD, the inadequate wage base of direct support workers, continued efforts to end the Affordable Care Act, to just mention a few.

Such is the nature, however, of an organization committed to social change as is The Arc.

There will always be challenges and it is our responsibility to continue to gain power, as an organization, to meet the challenges of today and of tomorrow.

I believe Reverend Martin Luther King captured the notion perfectly when he wrote "power properly understood is nothing but the ability to achieve purpose that is the strength required to bring about social, political and economic change". A key objective of The Arc's new strategic framework is to organize and mobilize a powerful movement to bring about needed change on behalf of individuals with I/DD, their family members and their supporters.

Given the current challenges we are facing, The Arc's new Strategic Framework for the future is incredibly relevant and important. The new Strategic Framework for the future of The Arc invites us, no really demands of us to begin to reimagine what our nation and what we'll look like can and will look like when we achieve our mission of full inclusion and

participation of people with intellectual and development disabilities in their community.

It is a future where people with I/DD are valued members of their community with opportunities to achieve their potential. It is a future where we as a nation value the humanity of the individual. And is a future where we act both individually and collectively in the public and private sector in accordance with those values.

There's much work to be done. And we look forward to your active and strong contributions to this effort. So, thank you and again for participating in this town hall and I will turn it back to Kristin.

>> KRISTIN WRIGHT: Thank you, Fred.

So, now we want to move on to our panelists and I work very closely with these three very determined and dedicated advocates nearly every day. They are really key in The Arc's response to COVID 19, in addition to the rest of our team.

So, Claire Manning is the director of Advocacy & Motivation.

Shira Wakschlag is senior director of legal advocacy and general counsel at The Arc, and Julie Ward is senior executive officer of public policies.

We will start with Julie.

>> JULIE WARD: Thank you very much, Kristin. Good afternoon.

As Kristin mentioned, I serve as the senior executive officer for public policy and I lead a five member team of extremely experienced, knowledgeable and passionate advocates for people with I/DD.

Our role at The Arc is to influence public policy by raising concerns and solutions to Congress and the administration. And to fight to protect the rights of people with disabilities and ensure that our needs are being addressed by policy makers.

I want to begin to just briefly acknowledge the lives lost due to the pandemic, the illness that is widespread and whose future impact we maintenance unknown.

The loss of services and supports that people with I/DD need to live in the community, the pressure and the very difficult choices that families are facing, the loss of jobs and economic security, the strain on the service delivery system and on the direct support professionals that provide urgently needed supports.

In the last six months, we have focused on raising these issues to Congress and demanding action. We have been supported by the incredible resiliency of The Arc network, people with disabilities and their families.

Our communications team has gained national media to these issues, which helps us make our case with Congress and the administration. Three COVID relief packages have passed Congress, but the last one passed on March 27th, that's over six months ago.

We have had some small victories in these packages, but we continue to really push. While current negotiations for future packages have started, and stopped, and started and stopped again, we have been encouraged that the House has included dedicated funding for Medicaid home and community based services, which is one of our top asks since March. Since it will stabilize the entire support system.

I just want to briefly mention our priority issues. They have been dedicated funding for HCBS and access to personal protective equipment for DSPs and other workforce issues. We want to see stimulus payments made to all without barriers.

And we have been advocating for paid leave for caregivers without limitations. These are just the top line issues that we have been working with our grassroots about.

We have also been working tirelessly on a wide range of related issues, including access to healthcare, housing, special education funding, social security payments and many, many other issues.

All the other important work we have been doing on an ongoing basis is working with the administration, working on implementing the provisions that have passed and on recommending improvement on addressing issues that have arisen.

We have been in constant contact with the Centers for Medicare and Medicaid services, which oversees the Medicaid program and with many other federal agencies which are crucial to the lives of people with intellectual and development disability. Our team will continue fighting for action on these urgent issues and will take every opportunity to raise the issues faced by our community and to demand action.

I know in a few minutes we will have time for questions and answers. Right now, I'm going to turn it back to Shira to talk about another important aspect of our advocacy.

>> SHIRA WAKSCHLAG: Thanks, Julie. Hi, everyone. And thanks so much for joining us today.

Back in March, we learned that the country may become overwhelmed by the pandemic and hospitals could reach capacity and begin having to ration medical care. This set off alarm bells in the disability community that people with disabilities would be denied access to care given a long history of experiencing discrimination.

Since late March, The Arc has worked with state and national partners to file 12 complaints with the U.S. Department of Health and Human Services, Office of Civil Rights (OCR), to challenge discriminatory crisis standard of care plans, hospital no visitor policies, and inaccessible COVID testing sites in states across the country.

There are several common issues in the crisis standard of care plans we have challenged.

Including categorical exclusion based on disability diagnosis, exclusions from treatment based on assumptions regarding greater time and resources required for recovery or projected life span, failure to modify triage assessment tools to avoid penalizing people with disabilities, allowing reallocation of personal ventilators to another patient deemed more likely to benefit from treatment and disproportionate impact on Black, Native and Latinx communities.

We've also challenged hospital no visitor policies enacted to prevent COVID spread that

discriminate against people with disabilities by denying them effective communication needed to make informed decisions and provide informed consent, leading to the denial of necessary medical care.

Finally, we have challenged the state's failure to accommodate people with disabilities in its COVID testing program by requiring the ability to access and use the internet to complete prescreening and the ability to drive to a testing site. Things that many with disabilities, particularly those living in congregate settings or with vision disabilities don't have access to.

Within a week of filing our first complaint in March, OCR issued a bulletin strongly reinforcing the prohibition against medical discrimination during COVID and has since reached favorable resolutions in four states with additional investigations ongoing.

Highlights from these resolutions include Alabama withdrawing its plan excluding those with profound intellectual disability from treatment. Connecticut revising its no visitor policy to allow family members or other supporters to accompany patients with disabilities to the hospital and provide them with necessary PPE.

And Tennessee and Utah removing all categorical exclusions based on disability of resource intensity, eliminating long-term survivability considerations, requiring reasonable modifications for triage assessment tools and no visitor policies. And prohibiting the reallocation of personal ventilators.

There's much left to be done and we are optimistic that we will continue to make progress in the coming months. So, please stay tuned for future developments. And now on to Claire.

>> CLAIRE MANNING: Thank you so much, Shira.

Hi, everyone. I'm Claire Manning, the director of Advocacy & Mobilization at The Arc of the United States. I am very excited to be with you all this afternoon and very grateful to all of you.

I know everyone is very busy. There's a lot going on. So, very thankful for the time you are taking to be with us.

In my role at The Arc, I work with chapters, people with disabilities and families all across the country to make their voices heard on issues that are critical to our community. Often what we call, Grassroots Advocacy. Working to make sure that the people who are most impacted or are going to be most impacted by a policy or an issue are at the forefront and are able to connect with policy makers, share their stories and really have an impact.

So, back in March when the pandemic was just beginning, we knew that people with disabilities were going to be disproportionately impacted and we knew we were going to need to fight hard and advocate for key legislation, all of the priorities that Julie just mentioned. And we needed everybody on board.

So, we created a campaign called hash tag we are essential. Hopefully you have seen it and it is aimed to focus on the needs of people with disabilities, their families and direct support professional workforce that is so critical. This campaign is ongoing. As Julie mentioned, several bills have passed, but not for a long time. And it has many different components.

From the efforts on Capitol Hill, the work of our communications team, social media, days of action that we have organized closely with coalition partners and all of you. And much, much more.

We focused in the "We Are Essential" campaign a great deal on stories. Work with individuals with disabilities and families to make sure that the

stories of how real people's lives are being impacted every single day by this pandemic are getting in front of lawmakers, legislators, the media. We know that personal stories are one of the most powerful advocacy tools that we have.

Another big component of the campaign has been the hard work of all of you. Using our action alerts, we have encouraged and asked advocates to call, text, email their members of Congress and urge them to pass legislation that includes the key priorities for our communities. Your members of Congress work for you. They need to hear from you.

And I'm very happy to share that so far, we have over 122,000, that is an incredible number,

tracked contacts, tracked calls, emails and texts to members of Congress from The Arc community. That is incredibly powerful. I know it will have a big impact. So, a huge thank you to all of you for your advocacy during this very scary and very difficult time. Kristin, I will turn it back over to you now.

>> KRISTIN WRIGHT: Thanks to all of you and all of the hard work that you do. So, as I mentioned earlier, I'm senior communications manager in the national office. And I wanted to share with you that during the pandemic, journalists have been very interested in covering how COVID 19 has impacted the lives of people with disabilities, how it has affected families and also the direct support workforce.

And so, in addition to offering perspectives from within our national office, we have worked really hard to try to connect reporters and producers and writers straight to the source for their stories. So, that meaning people who are directly impacted by the isolation, by the fears about the virus and by the important needs of service providers and the experiences of people, you know, who are being treated in hospitals for COVID 19.

So, from the Washington Post, New York Times, NBC, NPR, and that's just to name a few. The very serious impacts of the pandemic on the disability community have been really compelling to the media. And that we think has raised public awareness about the issues that are really important to us. And it has also supported our advocacy efforts.

I want to get to questions now. I see that we have a few in the Q&A. And we welcome you to continue to submit those. These can be questions for any of us here, for Julie, Shira, Claire and myself. I will do my best to get to them. And there will also be an opportunity to ask questions later.

The first question is for Julie. We know that state budgets are in trouble right now after all of this. So, we're wondering if possible tax revenue losses, et cetera, how does that impact services for people with I/DD?

>> JULIE WARD: Thank you, Kristin. We are extremely concerned about this issue because we know there will be a major impact on state and local governments due to the decrease tax revenue and the many competing spending needs that states and localities are facing. We have to prepare ourselves for major challenges in the state and in the Federal Government.

But our strong advocacy will be needed more than ever as these legislatures face a shortage of funds and will be looking to cut wherever they can.

That is why we have been fighting on the federal level to ensure the Federal Government provide more state relief and also more federal matching for the Medicaid program. We have you are urgently advocated for that in all of the bills that have passed and in pending negotiations.

And we are talking about more money for Medicaid in addition to dedicated funding for HCBS. States will need that extra help to meet their challenges. And frankly, we will just need more people to get involved and to speak up about the challenges.

It will take all of us working on the federal level, our state and local chapters and all of the advocates and supporters that we can rally to make sure our voices are heard and keep our programs from being cut very deeply.

>> KRISTIN WRIGHT: Yeah. Okay. I know it is a lot. It is a team effort. It is a lot of work.

Thanks, Julie.

Shira, I wanted to also ask you about legal advocacy. You know The Arc has really, fortunately, seen a lot of victories in its work fighting medical discrimination, in particularly during COVID 19, through resolutions with specific states. So do these resolutions have a broader impact beyond the states that we are talking about and beyond the states that are directly involved?

>> SHIRA WAKSCHLAG: Yeah. That is a good question. Absolutely. OCR quickly put out a bulletin that applied nationwide stating that disability rights laws continue to apply during the pandemic. And outlining obligations of states to comply with these laws.

Following the states specific resolutions I mentioned that were with ORC and also the extensive media coverage in these resolutions, we have seen some states being more willing to engage with disability advocates on these issues and be more proactive about changing their policies. And we

have also seen a greater awareness of people with disabilities and their supporters about how to enforce their rights.

Having examples of policies that comply with disability rights laws helps states and hospitals understand concretely what their obligations are and how to modify their policies without having to reinvent the wheel. So, we have definitely seen a larger national impact beyond the specific states that have reached resolutions with OCR.

>> KRISTIN WRIGHT: Okay. That is good to know. Thank you, Shira.
Question about advocacy, Claire.

So, as an advocate, I think it can be frustrating, you know, to really not know you're advocating for something and writing to members. And you're not sure is anyone getting this. You get an automated reply and you don't know what happens next. So, I think that can be frustrating for people to not always see the direct, immediate impact of reaching out to members of Congress and expressing your point of view. So, what do you say to that?

>> CLAIRE MANNING: I say I get it. It can be frustrating. It can be difficult to see. Especially in these very hyper partisan times that we're living in. But it is really important to understand that it is not just your outreach alone. That it is not just your phone call or your email. But that it gets combined with the hundreds of people on this call right now that took time out of the middle of their day to be part of this.

The thousands of people back home who weren't able to. And it is our entire movement.

A long time ago I used to work as a legislative aid for a state representative in New Jersey. And we would get calls and emails all day long from

constituents about different issues and we kind of had a ticker, and the minute we got to 15, we would basically stop what we were doing on a particular issue. We would stop what we were doing and we would write a memo. We would research – what is this issue, whose supporting it? What's going on? And give it to the state rep that we were working for.

So, I think it is really important—it can feel like members of Congress or your state reps don't care or aren't interested, but they absolutely do. They care a lot about what their constituents think. They need to hear from you. They work for you. And so, I think when you're feeling frustrated, to remind yourself that your outreach you're not alone. We are all in this together. We are part of this movement together. And think about your phone calls and outreach as one little piece of moving that ball forward.

>> KRISTIN WRIGHT: Yes, and sometimes it is hard to remember that. But coming from you, from someone who is in it, you realize okay, at 15, this is what happens. So, it matters. It really matters.

Claire, another question for you coming from someone who is here with us this afternoon. How is The Arc helping to promote voting among people with disabilities and their families? We know that it's critical. It is like-- this is the time.

>> CLAIRE MANNING: Absolutely. That is a great question. You know, people with disabilities face a lot of challenges in voting. There's a lot of accessibility issues around voting. Of course, there's issues with guardianship and a lot of the systemic issues that already exist are going to be magnified by the pandemic this year. Voting is going to be difficult for everyone and it is so important that we plan and we vote early.

The Arc has a lot of useful resources. You can I will type this into the chat in a moment, but you can find them at the thearc.org/vote. We have plain

language materials that are available in English and Spanish, in designed and word documents that are accessible to screen readers.

They have information about what voting is, how to do it, and we also have the ability for individuals to register to vote, look up their registration, find their polling location. Information about their specific voting situation and their state at thearc.org/register tovote.

>> KRISTIN WRIGHT: Okay. That is all really important. This question is, I think for Julie.

Will The Arc be spending time advocating for marriage equality with the disabled community in the near future? Please and thank you, team.

>> JULIE WARD: Thank you. This is a really critical issue. And I think I would like to just spend a minute about it because even though we have been completely focused on COVID and trying to get Congress to respond to that, there are also other behind the scenes advocacy that's going on, on a lot of different issues. And so many of things that we have been working on and making progress on at the beginning of the year, just came to a halt because of COVID response.

The marriage penalty issue is something that we hear about at every forum we do. We know how heartbreaking it is to have these barriers to people living a full and whole life built into many of the laws that we depend on. There has been some progress in terms of legislation being introduced. There's been heightened interest by members of Congress. So, there's some behind the scenes working going on trying to pull together a piece of legislation that addresses all of the laws and is comprehensive. But doesn't result in people losing access to healthcare or other benefits. It is a very complicated issue because of the way the laws have developed over the years. But we are working on it.

It has not been a front and center issue for us because we have wanted to be really, really focused on getting our top issues considered. But it is like many other issues that we were working on and we continue to work on. And we're trying to capitalize on the interest that we're seeing from members of Congress in both parties about disability issues and bringing these issues to the surface. So, of course I can't say we have made the type of progress that I wish we had made. But I do want to assure people that we do continue to work on these other issues.

>> KRISTIN WRIGHT: And those other issues are always important to us. Julie, following up on that in terms of our advocacy related to COVID 19. Where do you see that we have made progress over the past several months?

>> JULIE WARD: I think that we have actually made tremendous progress in really creating a better understanding of what home and community-based services means to policy makers.

We have really built on the advocacy that we had done in 2017, fighting against the Medicaid block grants. We knew at that point that Congress needed a lot of educating. So, we have spent a lot of time doing that. We have had this tremendous response from the grassroots, thanks to Claire's hard work. People telling their stories. It has helped us gain bipartisan support, particularly in the senate.

We haven't had the victory that we wanted in the Senate. But we have been assured that people are listening. We have really been caught in the politics of an election year where Congress just can't decide on what their strategy should be or how broad their response should be. So, I want to assure people that we're really making progress in helping Congress to

understand these issues and move them forward. Relief was provided in the House bills that passed. The last two bills that have passed. We just haven't gotten it over the finish line.

>> KRISTIN WRIGHT: Sometimes it takes our persistence.

>> JULIE WARD: Yes, it does.

>> KRISTIN WRIGHT: Which we have.

So, to sort of shift a little bit, Shira, I wanted to ask you about our legal advocacy because it has been extremely important over the past several months as we are living through a pandemic. So, I'm curious about some of the other ways that maybe The Arc's legal advocacy team has fought against disability discrimination during COVID 19, aside from the OCR complaints, which are very important. But can you talk about some of the other ways that we have had an impact?

>> SHIRA WAKSCHLAG: Yeah. Definitely. The complaints have definitely been a big focus.

But we have also pursued some other advocacy avenues for COVID advocacy over the last several months. So, one big thing that we did back in April along with 30 other state and national groups, The Arc filed an amicus brief before the Wisconsin supreme court in a case challenging the state's extension of the stay at home order.

And that brief explained that if the stay at home order was lifted prematurely, this would disproportionately harm people with disabilities, older adults and people of color, who face higher risk of contracting the virus in a life threatening capacity. Unfortunately, in that case, the court allowed the order to be lifted with no alternative plan in place to contain the

spread of the virus. But we tried everything we could to help put the disability view and perspective there before the court.

In addition to that brief, we have also provided technical assistance to the many individuals who have reached out to us regarding instances of medical discrimination on an individual basis and developed resources for stakeholders and evaluating crisis standard of care plans to determine whether they comply with federal law.

And we are regularly updating these resources and putting new ones out. I did put in the chat that you could sign up for our newsletter to get updates on those when we put new materials out. And they are also available on our website.

>> KRISTIN WRIGHT: Thank you. There's a question from Frank and I think it is a question that a lot of people have. It's, how do they get involved? How do they do something? So, Claire, I think this is a perfect question for you. What should grass root advocates be doing right now? What kinds of actions should people be taking?

>> CLAIRE MANNING: That is my favorite question. There's really there's a lot going on this year, right? But there's three big things we are asking everyone to do right now. One is even if you already have, go to the thearc.org/action. I will type this into the chat again. And contact your members of Congress in any way that you feel comfortable. Whether it is a phone call, an email, a tweet. You could use our system. We have sample talking points. To ask them to pass COVID legislation that supports people with disabilities, their families and direct support professionals. That is number one.

Number two is complete the Census. The Census, we have until October 31st, directs billions of dollars in federal funding that supports people – key

programs for people with disabilities. It just takes a couple of minutes to answer a few questions about everybody living in your household. Please take a few minutes and do that. That impacts the disability community for ten years.

And then three, we have already touched on this, but vote, vote, vote. Whether it is local, state or federal government. Every single day government, elected officials, make decisions about people's lives that impact our community. It's really important that everybody has their voice heard and that you are choosing the people who represent you. So, again, we have that website --thearc.org/vote and thearc.org/register tovote.

>> KRISTIN WRIGHT: Thank you. And thank you to all of our panelists. So, I'm going to move on for now, but again we will have a second round of Q&A coming up in just a little bit.

First, I wanted to introduce Peter Berns. He is the CEO of The Arc's national office and over the past 18 months, Peter has really facilitated the development of the new Strategic Framework for the future of The Arc, which I referred to earlier. And he's worked closely with our long-range strategic planning committee and board of directors.

Peter has led The Arc since July 2008 and under his leadership, The Arc has charted an ambitious course of progress, innovation and change to advance the human rights of people with I/DD. Before joining The Arc, Peter was executive director of the Maryland Association of Non profits-- non profit organizations.

He also served as CEO of the Standards for Excellence Institute. And interestingly, as a public interest attorney earlier in his career, he won a major victory in a class action suit that reformed state and federal Medicaid

regulations, which we know is critical for our population, for us. And those reforms were really critical in improving life for persons with disabilities and their families. Peter and Fred –Fred's going to come back now, they are going to lay out the new Strategic Framework.

>> FRED MISILO: Thank you, Kristin. Nice to be back. You have just heard about The Arc's efforts on multiple fronts to support folks with I/DD and their families, support providers and others to weather the storm that we have all been in. And obviously, the fight is far from over.

And at the same time, as all of this has been going on, we recognize a need to plan for the future. Our ten year long range plan was sunsetting this year.

So, coincidentally, as the pandemic hit, we were in the midst of doing some long-range planning for the future of the organization and the work that we do for people with intellectual and development disabilities. And we are really excited to share with you this afternoon on our new strategic plan. We call it Strategic Framework for the future of The Arc.

As you will hear, this plan lays out our vision for the future of people with intellectual and development disabilities and how we are going to work with and for them, their family members and supporters to make that vision a reality.

>> PETER BERNS: So, before we jump into the details of the plan, we want to emphasize that developing this plan was really a true participatory process in the classic way we do things in The Arc. There are literally thousands of stakeholders just like you from both within and outside The Arc network. Led by a 24 member long range strategic planning committee.

More than 4,000 people participated in a national stakeholder survey. We interviewed about 60 leaders from the disability community, the business community, the non profit sector, other civil rights organizations. There were more than 18 large and small meetings held both online and in person at our various events. We really want to thank all the volunteers and staff leaders that were involved in this process. Really thanks to everybody that participated.

>> FRED MISILO: The plan was adopted against the backdrop of The Arc's mission.

The mission hasn't changed. The Arc's mission is to promote and protect the human rights of people with intellectual and development disabilities and actively support their full inclusion and participation in the community throughout their lifetime. What is new is the vision. The vision is how we imagine, how we think about what the world will look like when we achieve our mission.

We have stated that simply in a way that we think everyone can embrace. The Arc's vision is for people with intellectual and development disabilities to be valued members of their communities with the opportunity to realize their potential and a future that is secure. That's worth repeating. Let me repeat that.

The Arc's vision is for people with intellectual and development disabilities to be valued members of their communities with the opportunity to realize their full potential and a future that is secure.

>> PETER BERNS: So, Fred, we are seeing notes in the chat that your audio is garbled, fading in and out. I don't know if you want to try to sign off and sign back in again.

>> FRED MISILO: All right. I will try that.

>> PETER BERNS: People are having difficulty. And I will just keep us moving forward while you do that. If that's okay. Fred was just talking about the vision. And we think-- one of the things we feel really good about is, we think that the vision as Fred just stated, is simple.

It's understandable. That it can be easily embraced by self advocates, by parents, by siblings, by professionals and by supporters.

And that it really communicates a lot in one short sentence. It makes me think of our colleague at the national office, William Washington. Some of you may have met him over the years at Convention for those involved in The Arc. I'm reminded about the way William has really managed within the District of Columbia community to build a full life that is meaningful to him. He is our receptionist at the national office. He is a resident of the District of Columbia, fully involved in his community, living the life he wants and he has plans for the future.

>> FRED MISILO: Hopefully everyone can hear me now.

>> PETER BERNS: Much better.

>> FRED MISILO: So, everyone was excited about the vision, but that really leaves the hard question of, how are we going to get there? After reviewing all the input we received, we came up with four goals that we think express and represent the collective wisdom of our stakeholders.

The idea of goals is that we work constantly to achieve them and if we are successful, then the vision becomes a reality. So, let me share them with you. The Arc's first goal is for every member of society to recognize and respect the human dignity of people with intellectual and development

disabilities. Second goal is for people with intellectual and development disabilities is to be masters of their own lives and destinies with help from family, friends and other supporters if needed.

The third goal is for people with intellectual and development disabilities and their families to have timely access to the quality supports and services they need and want to achieve a life of personal significance.

And finally, the fourth goal is for The Arc to be even stronger, more diverse force for change, capable of wielding power with and on behalf of individuals with intellectual and development disabilities and their families at the local, state and national level.

>> PETER BERNS: We were really excited when we put these goals out for comment. They were really fully embraced by our constituents, our stakeholders. When we asked, do you agree these are good goals for The Arc and that working on these goals will move us towards achieving the vision, nearly everyone from 86% to 96%, depending on the specific goal we were asking about, nearly everyone agreed or strongly agreed with the goals.

I have to tell you, frankly, we weren't surprised because the idea for these goals really surfaced strongly in our national stakeholder survey and other information gathering that we did. Take goal one, for example. That every member of society recognize and respect that the human dignity of people with intellectual and development disabilities.

We heard repeatedly in our interviews and meetings that among the general public there's a lack of respect for the humanity of people who are an intellectual or developmental disability. And that is one of the big barriers we face as a community.

Our national stakeholder survey really bore that out as you could see from the slide here. More than 87% of our survey responders agreed or strongly agreed with the statement that the human dignity of people with intellectual and development disabilities is often not respected in our society.

>> FRED MISILO: And a summary of our stakeholder survey is available on our website. That is a very important piece of information to go through. We don't have time to go into detail this afternoon about all we have learned. But the summary and the results are available on our website.

Of course the Strategic Framework itself is also on our website. We would like to tell you a little bit more about the strategies that we developed that we're going to use to pursue these goals.

The Strategic Framework has five strategies. Let's review them now.

Strategy one. Build the movement. The Arc will organize and mobilize a more powerful movement of people with intellectual and development disabilities and their families and supporters to be activists for change.

>> PETER BERNS: And this strategy, too, is really driven by our stakeholders. In our national stakeholder survey, 85% of the survey respondents stated that it was highly important to them to be part of a nationwide movement dedicated to people with intellectual and development disabilities.

Strategy two is, speak truth to anyone who will listen, and those who will not. The Arc will work with people with intellectual and development disabilities and their families to amplify their stories, call for recognition of their human dignity and the day to day challenges they face. Affirm their abilities and contributions and demand change.

The Traversa family provides a great example here. We work with our one of the chapters from The Arc New York, the chapter in Nassau County, New York, to get 80 year old Harriet Traversa and her 49 year old son, Sal, on the Today Show. And they told their story about the hard choices that families had to face as a result of suspension of services during the pandemic. The isolation, the challenges in understanding and protecting yourself from the virus.

>> FRED MISILO: Strategy three. Advocate.

The Arc will aggressively advance the interest of people with intellectual and development disabilities and their families before the executive and legislative branches of government and in the courts and influence the practices of other private and public sector organizations.

Now, a young man named Eli Latson comes to mind here. Latson, who has autism and has experienced continuing injustices. Horrifying mistreatment in the criminal justice system in Virginia. He became entangled in the system because of behavior directly related to his disability. And frankly, the fact that he was a young lack man, didn't help his situation.

The Arc's legal advocacy team, along with others, are working hard to persuade the governor of Virginia to grant Latson a full pardon. And we this continue to do so.

>> PETER BERNS: Strategy four. Extend our reach.

The Arc will expand and sustain our presence as a critical part of the fabric of every community where people with intellectual and development disabilities live.

Strategy five. Innovate.

The Arc will capitalize on the collective knowledge and creativity of our federation of Chapters to envision, pilot, and implement new and improved programs, supports and services, and to create new opportunities for people with intellectual and development disabilities and their families that they need and want.

So, the idea here is that if we implement these strategies, we pursue these strategies to the fullest of our ability as a federation, that that will help us achieve our goals and draw us closer to making our vision a reality.

>> FRED MISILO: So, we start with goals. We go to strategies and the next step are tactics.

We frankly don't have time to go into the next level of detail with respect to tactics. These 43 tactics we have identified in total, which explain more specifically some of the things we're going to do with respect to each strategy.

However, there are some themes that you'll see in the tactics that I would like to mention. First, you will see a lot of references to reaching out to and engaging diverse communities and bringing intersectionality into our work. By that I mean we need to learn about disability and how it is experienced by those who are also part of other marginalized communities such as racial, ethnic, religious minorities, LGBTQ+ individuals and to factor that knowledge into our work.

Second, you will see an emphasis on expanding our relationships with business in industry and professional associations, civil rights and human rights and social justice organizations with social services and religious groups and more. And finally, certainly not least, you will see an emphasis on the chapter network and the central role it plays in everything. Everything that The Arc does. So, in closing we want to invite all of you to

join the movement and work with us to achieve the future we seek for people with intellectual and developmental disabilities. For now, let me turn the floor back to Kristin for questions and comments from all of you.

>> KRISTIN WRIGHT: Okay. Thank you, Peter and Fred. We do know how much effort and care and collaboration went into the Strategic Framework. And we think it really is an important moment for The Arc and for people with disabilities and families. So, thank you. Keep in mind that the Strategic Framework and the summary of the stakeholder survey are both on our website, which is the thearc.org.

Right now, we want to hear from you. So, we have been getting a lot of questions coming in and we definitely want to hear what is on your mind. We invite you again as a reminder to enter questions in the Q&A box for the entire panel. You can also share thoughts through the chat function and then we will try to get to as many questions as possible.

I wanted to start with Shira and Julie. We have a few questions coming in about education. And we know this is a big issue right now because of the pandemic. And so, there were a few questions that alluded to the question of, what are we doing? What is The Arc doing to address the what is The Arc doing address the challenges school systems are facing right now when it comes to virtual learning versus at home learning? I don't know if Julie or Shira, who wants to chime in first. But that is a very serious thing right now. Because we all want the best for our kids when it comes to education. But it is really a challenge right now.

>> SHIRA WAKSCHLAG: Absolutely. And this is definitely one of the most common questions that we get. It is one of the biggest concerns. There's been, I think a lot of media coverage on the needs of students with disabilities and the disadvantages they are facing in this process with online learning. So, it's really a big thing. And there's a lot of angles to it.

And it's just been an incredibly challenging time to ensure that kids can meaningfully access the remote learning opportunities. I think one thing more broadly is most important thing to keep in mind when you are thinking about education is that the concept of the Free Appropriate Public Education, or FAPE still applies, no matter what. And just like we discussed with the medical discrimination, it might be an emergency situation right now. A lot of things may have changed and be in flux that does not change the obligation of school districts under the law. So, that is one thing to always be keeping in mind when you are advocating.

Of course, it's hard to say anything universal about the situation, other than that--in the sense that every school district has different resources, is handling things differently based on a variety of factors that allows for the safety of students and teachers. Also, it could be dependent on the infection rate in the community.

So, each student and family is really going to have to work with the school individually to reach a workable solution for their IEP and make sure they are getting the accommodations they need to receive a FAPE during this time.

Some examples of things that could be advocated for during times like these are, let's say, extended school year services were not delivered over the summer because of COVID.

Schools could factor whether the offerings could be provided during the school year or during breaks or vacations.

Some schools are prioritizing in person learning for students with disabilities that need it, versus having more online instruction for others.

But it really turns to turns on an individualized assessment of the student's needs.

There's not really a blanket solution for all students in schools. But I think the most important thing to always be keeping in mind is that the law still applies. People's civil rights still are just as worthy being protected no matter what the situation. And we're doing everything we can to advocate for that.

And another resource that we offer this is not from legal advocacy. But we have resources for parent advocates through our Arc at school website and resources., which I am happy to put in the chat so people can see how to access that website. And hopefully that can be helpful as well.

>> JULIE WARD: Hi. This is Julie. I just want to chime in too that we have been fighting for dedicated funding for special education services throughout our response to the pandemic.

We have not been successful. Congress has allocated additional education funding. But it has kind of been an open pot. So, it has really been difficult for local chapters and state chapters to get in there and fight for some of the money to be used to meet the needs of kids who require services and supports.

It's a very difficult situation that Shira acknowledged. We know not everyone can benefit from virtual learning. We know not everyone can benefit from virtual telehealth and virtual supports. But yet, we know some people do benefit, and finding the right balance and the right accommodations for people-- we're in a period of transition in a lot of areas where temporarily we have relied on a virtual world. So, there's going to be a lot of policy and advocacy as we move forward to keep what works for

people, improve what doesn't work for people and return to some of the things that we know are successful for people. So, it's really a multi pronged advocacy, individual advocacy and systems advocacy approach that we need.

>> KRISTIN WRIGHT: Okay. Thank you. Question for Claire. This kind of goes back to what we were talking about earlier. It is so important that people be involved and really use their voice or if they don't speak with their voice, use their whatever they feel. It is important they communicate that. Can you explain kind of the best ways for people to do that?

>> CLAIRE MANNING: Sure. So, there's a couple of ideas that come to mind kind of how to get involved with advocacy with The Arc Through he Arc on the state and local level. Connect with your local and state chapters. You can find them at the thearc.org/findachapter.

Many of them likely have self advocacy groups where you can get even more information about what is going on, locally or on the state level, and how to get involved.

The Arc of the United States also has a National Council of Self advocates and a National Sibling Council, which are involved in advocacy, and we are actually going to be looking for members of both of those very soon.

Other ideas. Each Wednesday we have a little campaign that we call hash tag We Act Wednesday, where we post on Facebook and Twitter, different ways to get involved in advocacy each week. For example, this week we posted some materials that we are asking people to read through. So, new plain language voting materials from our partner ASAM.

You can always find our action alerts-- if you're kind of like—what's the latest, what's going on, where do I find this? You can always find the latest action alerts at thearc.org/action. And an action alert has talking points, a little bit of information about what the issue is. Julie mentioned earlier the four COVID priorities. So, our COVID advocacy alert, for example, has all of those listed out. And it will have a sample email that you could send to your legislators. A sample tweet. You could always edit things. But we always have those samples available for you.

And the last thing I wanted to mention is we have a training coming up. At the end of the month as part of The Arc's National Convention, we have what we're calling an advocacy power hour. It is going to be fun. Anyone is welcome to join. It's free. It will be October 27th at 5:00 p.m. eastern and you can find more information about that in our National Convention website and our National Convention planning doc.

>> KRISTIN WRIGHT: Okay. Perfect. Sorry. I'm trying to fix sun is doing funny things and I look like I'm in a horror movie right now. Sorry about that.

So, I want to ask a question about direct support professionals because they really are the backbone, in a lot of ways, of our advocacy work. Julie, I wonder if you could shed some light on what's going on in terms of our advocacy to make sure we are keeping in mind direct support professionals and their needs and their heroic actions a lot of times during this pandemic. Because they really have been between a rock and a hard place trying to do their jobs, protect their families. What can you tell us about that?

>> JULIE WARD: Well, I just want to reinforce, I briefly mentioned that addressing the concerns and supporting direct support professionals was

one of our top priorities. As part of the HCBS money that we are advocating for, it does include money to help address the turnover, the wage issues. We know people need to earn a living wage in order to do this work. So, we have been advocating for any of our approach to HCBS to include workforce issues.

We have also aligned ourselves with other advocates in the aging community, in the family support community, across multiple generations to build we know that our voice is strengthened when we work together in coalition. So, we do coalition work on almost every issue we work on. We have been very involved in the last year and half, two years, in really trying to bring more attention to the workforce issues impacting children, people who are aging, people with disabilities.

Because we know it is a critical issue in nearly every state. And we need to provide whatever critical federal support that we can to address the multitude of issues. It is included in the framework of what we're advocating for, but I did want to call it out because I know how critical it is to families, to individuals and chapters.

>> KRISTIN WRIGHT: It is. Thank you, Julie. Shira, what is The Arc doing to address social isolation, which is a huge problem, of people with disabilities that has resulted, for example, from no visitor policies?

>> SHIRA WAKSCHLAG: I would say this and education are really like some of the top issues that we have been hearing concerns about during COVID. So, I discussed a little bit in the main presentation about the work that we have done to make sure that hospital no visitor policies are allowing for accommodations for people with disabilities and ensuring that supporters can come with their family members or those they are

supporting to help ensure effective communication or other supports that are needed.

But another question that we often get is around other settings where visitation has been limited. For example, ICS, long term care facilities, nursing homes, et cetera. So, those are definitely in a somewhat different category, because in general, the staff there is trained to support and accommodate people with disabilities. And they actually know the people with disabilities on a longer-term basis. And can theoretically support them as needed.

That being said, there's been a lot of restriction to the outside world as you can imagine with the no visitors policies because of outbreaks in these facilities and things like that. And people are really concerned about family members and others that are not able to see them during this time because of those limitations.

So, there's been some advocacy around, beyond the hospital setting on advocating to get more guidance on those issues. And to make sure that accommodations are being provided when needed but also taking health and safety into account given the outbreaks in these settings. Towards that end, CMS recently issued a guidance document about visitation to nursing homes which expands compassionate care visitation, addresses visitation rights for [inaudible] and protection advocacy organizations to make sure they can still do the monitoring that is needed and discussions when modifications to visitor restrictions are required under the ADA and 504.

So, it is not as straightforward necessarily as the accommodations that are needed for supporters to visit hospital settings. But we are doing everything we can on that front as well to try to reduce the social isolation, keep everybody healthy, but also make sure people are able to access the

community and their family members and other supporters as much as they possibly can.

>> KRISTIN WRIGHT: And Shira, do you happen to know when OCR has issued these resolution, do you know if states are doing what they are supposed to be doing? If they are following up and taking the corrective actions, doing what they are supposed to be doing?

>> SHIRA WAKSCHLAG: Yea. [laughs] That is always a good question. That is what we are here for to try to help push that process along. I would say that with a lot of the work that we have done and all of the publicity that has come out especially through OCR, and national agencies taking ownership their and kind of taking a leadership role and saying what is prohibited and disability discrimination is still prohibited during the pandemic and there aren't exceptions to that, I think that has really sent a strong message.

That doesn't mean that advocacy is not still needed. There's a lot of specifics, of course, to work out beyond just follow the law. And of course, some states have been more willing than others to change these plans more proactively. We still have a lot of work left to do on that front, but we have seen a lot of progress as well. And I think partnership with OCR and all of the leadership that they have taken has been really helpful in pushing states to do the right thing.

>> KRISTIN WRIGHT: That is really important. I don't know if Peter, Fred, you want to jump in with anything related to the Strategic Framework. And just maybe how situations like this pandemic, which hopefully we will never experience again --but crises situations and how, you know, you hope the Strategic Framework will be kind of a guide in terms of getting through those situations.

>> PETER BERNS: Sure. It was really interesting, Fred mentioned earlier, we were just coming off of a ten year Strategic Framework. The Strategic Framework for the Future of The Arc 2010 to 2019 that we developed right after I arrived as the CEO in 2008.

And our committee this time around actually spent a fair amount of time discussing what is the right time frame for this Strategic Framework. Is it ten years, five years. When you look at it, there's no specific time specified. The idea is that this is intended to be a living document in that every year we have got to take a look at it in the course of our planning. But the board and staff—every year we have to take a look at it and ask ourselves is it still relevant and do we need to change it and retool our approach.

I think we think that most likely the tactics are going the change more often. The strategy is probably second. And the goals maybe have a little bit longer shelf life. But particularly in the wake of COVID and in the wake of all the unrest we're seeing around police brutality and racial injustices, we have to be ready to pivot and be responsive to the circumstances that we are living in at any particular time.

>> FRED MISILO: I would add that when we were going through the Strategic Framework planning process and seeing the murder of George Floyd and seeing the civil unrest and the action of so many citizens who otherwise would be in their living rooms, that people were moved to action, to take to the streets.

We began to reflect on the great intersectionality between the experiences that our community has with respect to families being the backbone along with the direct support professionals, inequality of healthcare, really harsh treatment of people with intellectual and development disabilities in

correctional facilities and in custody. The real thin margins people are facing with income and wealth, that our interests there's a great mutuality of interest between the disability world and other communities.

I think one of the things that really strengthened the Strategic Framework planning process, a recognition that we have to kind of think about getting out of the silo that is the disability world into a greater broader movement of shared values and shared interests within our country. And if you look at the millions of people we serve every single day, that is a huge network.

But if you buttress that with other communities who have very similar shared experiences as our community, I think it really spoke to the Strategic Framework planning process. That's why you see some of the things that is in the Strategic Framework.

>> KRISTIN WRIGHT: Thank you both. One last question before we move on to our closing remarks. And I think this is a good one for Claire.

In a world where pre COVID, I guess interest in how things are publicly, how things are impacting the disability community in a world pre COVID, that was all very limited. How can we break through in terms of education, in terms of reform, in terms of informing people of what is going on and making sure that people are engaged and feeling a sense of the importance of their participation, where do you see that going next? How do we really keep that going?

>> CLAIRE MANNING: I think that is a really big and really critical question. It is something that we spend a lot of time thinking about at The Arc. It is something I know our chapters spend a lot of time thinking about. I think the strategic plan really gets to a lot of that. The bottom line is we have to bring more people into our movement. More people have to be engaged,

have to be involved, have to understand the lives of people with disabilities and what it takes, and the supports needed to live independently in the community.

And I believe there are so many people that support disability rights. Maybe they don't know about The Arc. They don't know how to engage or get started. It is our job to help them do that, to bring them in. I think we have had a lot success here. I think a great example, as Kristin shared, we have a ton of really, really, really big media successes with sharing stories.

And that matters because that is out of our echo chamber. That is out of the disability community and into the broader community. As more people are educated and here different perspectives, they're like, "Oh, what is The Arc? How do I get involved? Or I didn't know about this." And that is so critical.

We have also done a lot of work in the last couple of years on paid social media campaigns. We have worked on Facebook and Twitter to get our messages and our messaging and our action alerts in front of a broader community. And we have had a lot of success there as well. But there's a lot more to do on this. Thank you for the question. And as I said, I really think-- I'm excited about the strategic plan. And I think it starts to get at a lot of this.

>> FRED MISILO: Peter, were you going add something?

>> PETER BERNS: I was just going to tell you to mute.

>> FRED MISILO: Thank you. I take direction well. I was looking at my name and I didn't understand why I didn't unmute.

Over the last hour and 15 minutes, we have been providing you with a glimpse of the ongoing work of The Arc, as well as a look at The Arc's Strategic Framework.

On behalf of the board of directors and our members, thanks to Peter for his leadership.

To Julie and Shira and Claire for participating in this, as well as to Kristin Wright for organizing and moderating this event.

Now the question is, and it has been asked during this session, how can you become more actively engaged with The Arc? And how can you work with our chapters to advance our vision? I encourage you to get involved with your state and local chapters. Also, please stay current on all of the communication that comes through from the national office on a regular basis and also the strong social media presence that we have. There's no getting away from The Arc if you really are looking for it. There's tons of ways of being involved.

To achieve our mission, it is going to take the efforts of you, everybody here, friends and colleagues who weren't able to attend the webinar and many, many people to achieve our mission. And each of us has a role to play at all levels of our organization and in our communities.

Frankly a very important part of this effort to is to vote in the upcoming election. Claire spoke of it. That is probably the most important thing that we should be doing. Up and down the ticket.

Up and down the ticket from President, Senate, House of Representatives, governors, state legislators, local officials, mayor, city and town, council, school committee people. Learn about their platforms and their views.

While we are a non partisan organization, our core values are crystal clear. And I encourage you to support candidates and work for candidates who support our values as a priority.

Stay safe. Thank you all for attending this and have a great rest of the day. Thank you.