

Transcript

>> SHAWN ULLMAN: All right, let's get started. Good afternoon, everyone. And welcome to The Arc's Center for Future Planning webinar entitled The HCBS Access Act: A Law 70 Years in the Making. The Arc of the United States was founded over 70 years ago by families who wanted their family members with intellectual and developmental disabilities or IDD included in every aspect of life. Yet most people had to leave their families and go live in institutions to receive the daily supports they needed because of their disability. Our system of services and supports for people with IDD has come a long way since those days. But, many people with IDD in their families still struggle to plan for the services that their loved ones will need to live a quality life in the community in the future. Many people with IDD wait years to get off the waiting list for services only to find few direct support professionals available to provide the services they need in the community. And even more limited, affordable and accessible housing.

Even when they do find a home in the community and a trusted professional to meet their needs, they often have to start their search all over again in six months or a year because the turnover in the field is so high. Or worse, they move to another state to be near family after their parent dies, and end up on the waiting list for services all over again. Congress has finally proposed a bill The Home and Community-Based Services Access Act, to make changes to the system of support for people with disabilities, to ensure community-based services are there for all people with disabilities who want to live their lives in the community with their friends and family.

Our speaker today who's going to tell us more about that act and about the current barriers and changes to the system is Nicole Jorwic. Nicole is

senior director of public policy at The Arc of the U.S. Prior to joining The Arc, Nicole served as senior policy advisor and manager of the Employment First initiative in Illinois. Prior to that appointment, Nicole served as the CEO and president of The Institute on Public Policy for People with Disabilities. Nicole is also an accomplished special education attorney and an advocate for students with disabilities in their families. Nicole received her law degree and child and family law certificate from Loyola University and her bachelor's degree from the University of Illinois.

Most importantly, Nicole is also a sibling. Her brother Chris is 31, has autism, and drives all of the work that Nicole does. Nicole welcome, and please teach us about the new act.

>> NICOLE JORWIC: Thank you so much, Shawn. Really glad to be joining a webinar for The Arc's Center for Future Planning. Obviously, one of the most important programs that we have as an organization, and have the opportunity to share with you all about the HCBS Access Act discussion draft that was released in March and we expect to be fully introduced sometime in the fall. And also really to tie all of these issues together, not only for the history of the organization, but also some of the threats and advocacy that have gone on in the past four or five years, and kind of talk about how it all works together.

But as Shawn mentioned, I would be remiss not to start with my why and why I do the work that I do. Some folks on the webinar might be familiar with me, and a little bit about my story, and know about my brother Chris, who is an advocate in his own right, and a better advocate than me in his own right.

But actually, my relationship with disability started before my brother Chris was even born. The other gentlemen on this slide is my friend Sam. And Sam and I were in the first included classroom in our school district. So I've

been very lucky that people with disabilities being included in all aspects of life and being part of the fabric of communities and the fabric of schools has been a part of my story. And also because of that, it's never far from my mind how history could have been very different had my friend Sam or my brother Chris been born during a different time.

And I think always in order to get to where we're going, we have to remember where we've been. And for much of history, people with disabilities have not from a societal viewpoint been seen as deserving or equal when it comes to access to services. There were misconceptions about capacity, now we talk about presuming competence and presuming that everyone has the ability to communicate, even if behavior is a form of communication. But that is a very new thing. There was a lot of limitations placed on people with disabilities that weren't even accurate.

Some people with disabilities did receive services. But again, because of misconceptions, and oftentimes families were told that the best places for their family members to be were in large institutions and congregate settings. So if people and family members were keeping their family members at home, oftentimes they were doing that with taking on all the responsibilities there.

We saw that several Arc chapters in history have been involved in litigation around closing some of those large institutions. And something that's really important to note because I think a lot folks don't realize this, is that those institutions are still open in 36 states. And I'm going to talk a little bit about that later, but it really is important to remember that. I know I was talking to ... I'm from the state of Illinois, as Shawn mentioned in my introduction. And Illinois still has seven institutions open. And I was talking to a family friend of mine who themselves was a parent of a person with a disability and who

also herself was a direct support professional. So a worker in the field, and she didn't realize that.

So while I'm talking about this as a historical perspective, it is important to note that those places are still open. The same places that Geraldo Rivera did the expose on Willowbrook in the early '90s. And while that specific institution may be closed, and while generally there might be some improving conditions, there are still people with disabilities in those large settings. And just recently in Iowa, there's a case that the Department of Justice is involved in.

So that's just an important factor because that is still where a lot of funding is going and when it comes to supporting people with disabilities, when there are so many other people who are waiting for services that are based in their homes and in their communities. Obviously we know, and it was exposed and exacerbated during the COVID pandemic. But this is not just a disability issue. For aging adults, there has also been a historic over-reliance on large congregate settings and on unpaid family caregivers to fill in the gaps in services in our support system.

So what happened is was the birthplace of The Arc. The Arc formed I think about 71 years ago now by families like mine, who didn't want to put their family member far away or in a different city. And also, a lot of the families that started The Arcs all over the country were also really focused on education and wanting to ensure that there were inclusive education opportunities.

The vision ultimately is around people with disabilities having self-determination and having their rights recognized so that they can be supported to live as independently as possible, and be supported no matter the level of support needs live in the community.

We know that data makes really clear that people with disabilities want to live in the community. And when I'm talking about data in that regard, I'm talking about waiting lists. If people weren't willing to wait for home and community-based services, then they wouldn't be willing to wait sometimes depending on the state that you're in, over a decade for those services. And I'm going to talk more about how that correlates later.

We also know that aging adults, and that includes people who are aging who have disabilities, AARP has data that shows that over 90% of those individuals would prefer to age in place.

All of this to say that means that we need to make huge investments in the home and community-based services delivery system. If older adults who are part of the population needs and receives these services, and people with disabilities want home and community-based services, then we need to create more. So that was the driving force of The Arc. And that unfortunately, but fortunately, because we have good stuff going on, is still the fight that we have right now.

I'm going to talk a little bit about the groundwork. And when I'm talking about the groundwork, I'm not just talking about that 70 years of history. I'm really talking more about recent history and recent path. In the past four years, because of some of the threats to Medicaid, which is the program that has different names in different states. But that generally is the main or only funding stream when it comes to home and community-based services, has been at great risk. During 2017, folks I'm sure remember, and actually I have one of the signs right behind me, the save Medicaid sign from our 2017 advocacy. Because some of the bills to repeal the Affordable Care Act, also sometimes known as the ACA, also sometimes known as Obamacare. To appeal it, to pay for it, there were proposals for folks that might not have been part of The Arc's network back then. There were

proposals to cut Medicaid up to a trillion dollars, \$1 trillion over a 10-year period.

So when we saw those big cuts, we'd knew that we had to do a lot to educate because there was a lot of misunderstanding about the threats that were out there, and also about the services that people were receiving. I fielded a lot of phone calls in 2017 saying, "My family member doesn't receive services for Medicaid. They're on a waiver." Well, it's a Medicaid waiver. And I'm going to talk a little bit more about the specifics. Or, "I'm not on Medicaid, I'm on BadgerCare or TennCare." And because Medicaid is a program that is funded by the federal government and the state government, but really run by the states, that's part of why it can be called different things.

So we have to do a lot of education not only with the general public, but also within our network around these services, around Medicaid, around what those services do for people within our constituency. But also, so that those same folks were sharing their stories with members of Congress.

During 2017, so many families, so many people with disabilities most importantly showed up and told their stories and shared their stories. We knew that 2017 was not going to be the last threat to Medicaid. And we also know that we have to continue to remain vigilant, and that eventually, we would get to the point where I think we're finally starting to be now. Which is where we can actually start talking about building and fixing some of the inefficiencies in the program.

So in 2017, The Arc led a lot of coalition efforts. We worked with a lot of other disability organizations. But also broader than just disability organizations, we led a lot of grassroots advocacy. The picture on the top left of the slide is a letter writing campaign that we ran over two weekends

in July of 2017. And we had stories from every state and territory in the country to deliver to Congress about why these services matter.

It really fundamentally raised the profile of Medicaid. I've been with The Arc for almost six years. And I can't tell you in the last six years, but especially in the last four, how much different the level of understanding on the hill is about Medicaid. And specifically, about home and community-based services. And that is because of every person that was willing to share their stories. And because that legislator, that Senator, that representative then has a story, and an image, and a thought in their mind when they're thinking about different decisions around Medicaid funding and specifically around home and community-based services.

So we were able to do that constituency education. Not within the disability community, but also broadening it out a little bit. And also, we saw national media attention and education around Medicaid and around home and community-based services.

The Arc was at the table at many key points. One of the pictures there is with Senator Booker. And the reason I use this one, it's not a partisan photo or anything like that. It's because I was at that event with Sarah Bal, one of her former comms directors. And it was where I saw it click in the mind of Senator Booker of him understanding what Medicaid is. And so many people, and I'm going to go into this a little bit more around the mechanics of Medicaid, but so many people including legislators, first of all, sometimes they mix up Medicare and Medicaid. And Medicare is a very specific health program for older adults. There are some people with disabilities who qualify, but that's healthcare. When it comes to Medicaid though, a lot of people including legislators, including really smart legislators still don't think of it as anything other than a healthcare program.

So I was at that event where there were people with disabilities. There were also direct care workers, direct support professionals speaking. And I saw it click what was really at risk. So I think that's part of why I use it. And it's part of why I just really always encourage people to share their stories.

2017 was an intense year. There were people from the organization National ADAPT that literally laid their bodies on the line. That was really when we started seeing national media attention shift from just talking about Medicaid expansion, which is an important part of the Affordable Care Act, to traditional Medicaid and traditional Medicaid. When I say that, I'm meaning home and community-based services, as well as healthcare components.

So in 2017, there was a lot of kerfuffle, a lot of fights. And September 30th of 2017, we were able to take a deep breath because we knew that that attempt to make those huge cuts to Medicaid at least for the foreseeable future would move. And then we started to have other conversations.

I mentioned that The Arc was able to, along with the rest of the disability community, start talking outside of our disability silos. So we started talking with groups that were really working on healthcare reform more broadly, etc. and without taking any position on the bills, because I really want to make that really clear. The Arc does not have a position on Medicare for all or anything like that. But what we did say is you can't talk about a program that's for all or for anyone, if you're not also talking about long-term services and supports, specifically home and community-based services. So we use that momentum.

And then in early 2019, we were glad and frankly shocked to see that all of the big universal healthcare proposals from the Medicare for all to the more of the public option plans, Medicare for America now all include home and community-based services.

So why that's important is because there is still right now an outstanding Supreme Court decision around the Affordable Care Act that we expect some time this month. And once that comes out, depending on what happens, we might have to turn to healthcare reform really quickly. And the fact that we've already baked in and embedded the idea that any sort of healthcare reform needs to include long-term supports and services in HCBS, or home and community-based supports is incredibly important. So the other picture on that slide is actually from the first meeting that we ever had about what ultimately became the home and community-based services, HCBS Access Act.

And that was actually, a lot of people I think, think that this all stemmed out of COVID. Because of the timing, it obviously would make sense. But that picture is actually from the end of 2019. Once all of the universal health care proposals included home and community-based services, we started thinking about how we could pull some of those good ideas into a standalone bill specifically to address home and community-based services and Medicaid.

I talked a lot about Medicaid already. And I think you really can't put me in front of a camera or in front of a podium back when I was leaving my house without having me do a little bit of Medicaid 101, because it's complicated. I didn't even remember that my slide said that -- it is.

We moved from a protect Medicaid kind of mentality. That's what we've been really focused on in the last four years. But obviously, while in advance in that to how do we really take a look at how we can fix Medicaid and update Medicaid?

Medicaid as I said is a healthcare program, but it's so much more than that. One in five people rely on Medicaid for healthcare. As of June of 2020, that obviously the roles grew. The people who were relying on Medicaid grew

because so many people lost their employer sponsored insurance. But also, over 11 million people with disabilities rely on it for healthcare, but also for access to those home and community-based services or HCBS.

People with disabilities, and it shouldn't say senior citizens, we don't use that anymore. And older adults only account for about 20 to 25% of Medicaid beneficiaries. So people who qualify and receive Medicaid services, but they account for about 48% of the costs. And why that is, is because of the costs of long-term services and supports or LTSS.

LTSS is the umbrella term that includes both institutional services like nursing home care, like institutions. And also home and community-based services. So if you hear LTSS, that's the umbrella term. Home and community-based services specifically about services that are provided in the home and in the community. Not all our chapters, but some of our chapters do provide services. Those are going to be typically home and community-based services that can include anything from day program supports, job coaching. A lot of folks don't realize how many employment supports are funded by Medicaid. It includes community supports, community volunteering, support with cooking assistance with self-care, support with personal hygiene. Those are all services that technically qualify as Medicaid home and community-based services.

Medicaid is really the only game in town or the main game in town at the very least when it comes to funding these LTSS, but specifically home and community-based services. The rest is private pay. A lot of people think about long-term care insurance, but it's a really, really small 11%. And I actually think it's gone down percent of the market, and the majority of it is funded through Medicaid.

Medicare. So for older adults, Medicare does not cover any sort of LTSS or long-term services and supports needs outside of a short-term

rehabilitation stay. Why all of this matters generally is around what we call the institutional bias in the Medicaid program. I talked about the fact that that Medicaid covers long-term services and supports. But under the umbrella of longterm services and supports, the institutional services, institutions, nursing homes, etc., as well as the healthcare spending is mandatory under the federal law. Whereas home and community-based services that I mentioned are optional. Obviously, they're not optional to the people who need them, but they're optional under the federal Medicaid law.

How that shows up is waiting lists. If a service is mandatory, then it means that states can't cap or put a limit on how many of those services that they're covering. But because HCBS home and community-based services are optional, they can. And those caps are why there are waiting lists.

Medicaid is overseen by the federal Medicaid law, but it is the cost of Medicaid services shared between state and federal government. There's something called an FMAP or a federal matching assistance percentage. And you just think about -- it sounds complicated, but it's really just the share that's paid by the federal government, and the share that's paid by the state government.

On average, even if it's 50.1%, it's always more heavily weighted on the federal side. On average, federal government pays 63%. In more wealthy states like New York or California, it's very close to that 50%. But that is how funding goes.

So the state knows that if they invest a dollar into something, that if they're a state that gets a 50.1% match, they're going to get 50 cents recovered on that spending by the federal government. So the states make the investment, and the federal government matches it.

Nicole Jorwic:

So I kind of got ahead of myself. But as I mentioned, there some services that are mandatory under the law, the federal law, and some that are optional. So really, the way that we need to address the problem is to really take a look at the federal law, which is what the HCBS Access Act does. And I'm going to come up to that sooner. But really we know a lot of the problems that were exposed during the COVID pandemic are not new problems. We already had a huge over-reliance on unpaid family caregivers, providing supports to people with disabilities. Oftentimes in lieu of their own employment opportunities. So that's an over-reliance on family caregivers. And now, that's really turning into an over-reliance on aging family caregivers. It's a really big issue.

We have waiting lists all over the country. There's at least 850,000 people on waiting lists. Not every state has waiting lists. That doesn't mean that not every state might have people waiting for services, but some states don't even track.

We also know that there are plenty of people that might not know that there are waiting lists to be on. So we probably think that that number is closer to one and a half million at least. We also know that there was a huge workforce crisis that existed before COVID-19. The national average wage for direct support professionals and other direct care workers is less than \$11 per hour. So leading to, as Shawn said in the introductory comments, a really high rate of turnover. This is something that my family's facing literally last week. My brother's main DSP just quit, and the tumult that it puts the family in, but most importantly, the lack of stability that it provides to my brother's life is huge.

COVID-19, the pandemic resulted obviously in a recession. State budgets are stressed. And while there's some funding that's flowing in right now, we really are concerned not necessarily for this year, but for the coming years.

Because this is going to be something that the effects of which are felt for a really long time in state budgets. And we know historically, state budgets when there's any kind of crunch, human service budgets, which would obviously include Medicaid are some of the first to get cut.

And again, the same reason we had to activate in 2017 is the same reason we need to activate now. And that's because home and community-based services are in particular danger because they're considered optional under the federal Medicaid law. Why that is is because states do not have a choice as to where to cut if the federal government doesn't change anything about what's optional versus what is mandatory. So that's why home and community services were particularly at risk of a trillion dollar cut. Because at that time, we heard states saying that they might have to cut their whole support and employment program, or their whole home and community based service system altogether, because they had to keep providing those mandatory services with a huge slash in budget. So that's what we have to make sure that we fundamentally address. And that's what all of us in DC have been thinking about since 2017.

This is just a little bit more about the waiting list. We know that the majority of people on the waiting list are people with intellectual or developmental disabilities. According to Kaiser, it's about 67%. And so again, that's why The Arc is so invested in really figuring out a solution to this problem.

We also know that COVID exposed things like in my home state of Illinois, like I said has seven institutions still open. The National Guard was actually called in, because in two of the centers, half of the residents and staff had been infected with COVID. We also know that a lot of the data, particularly from Dr. Scott Landes at Syracuse University has shown the death and infection rates are disproportionately high among people with IDD. And there's another study also from Dr. Landes out of California that correlates

the larger the residential setting, the higher the death and infection rate. So it's just another focus on why we really need to move away from these larger congregate settings, like institutions. And also, I'd be remiss not to note that there are also plenty of people with disabilities who are unnecessarily living in nursing homes as well.

So where we are, I've kind of outlined the history. I've outlined some of the problems with the structure of the Medicaid program. And we're building on some of that attention in some big proposals. The last of which I will talk about is the biggest and long-term goal, which is the passage of the HCBS Access Act, which would deal with some of the fundamental problems that I've talked about. But we've gotten some really good funding streams falling in before we get to our ultimate goal.

The first of which is really funding that I compare to plugging in holes in the sinking ship. Because this is money that passed on March 11th of this year that really should have passed on March 11th of last year. It's a 10% federal matching assistance percentage or FMAP bump. So a 10% shot in the arm of federal dollars to states to support Medicaid home and community-based services. It totals \$12.7 billion for one year of funding to strengthen and expand access to Medicaid HCBS.

The one year of funding is really important because while it is a shot in the arm, because it's only one year of funding, we already know from states that they're not likely to do something that requires a longer-term investment because they're worried that there's a cliff.

But, the positive thing is that we have more money in the pipeline. On March 31st, March was a big month. The 11th was the ARP or American Rescue Plan funding. The 16th was when the HCBS access actually came out. And then on March 31st, President Biden in his infrastructure package, which is The American Jobs Plan included ... actually the biggest part of

the infrastructure package was a proposal for a \$400 billion investment in Medicaid home and community-based services. This \$400 billion investment was meant to address access to services, but also to create more and better direct care jobs. And when I say direct care jobs, that includes direct support professionals. It includes home health workers, home care workers, personal care attendants. We're trying to use the direct care worker term to make sure that we're being inclusive, because sometimes you'll see that there's only a focus on home health, etc. So we're being inclusive so that we don't leave any job category out.

So I said the \$12.7 Billion for one year of funding was really kind of holes to fill a sinking ship. The \$400 billion I'm comparing to a bridge pun intended to what our ultimate goal is, which is around getting us to the point of the HCBS Access Act. But all of this is around continuing the momentum and the focus on home and community-based services.

There's a lot of polling actually. An organization called Data for Progress did polling in 10 key states that showed that the HCBS funding, the \$400 billion was polling better than any other part of the infrastructure plan. And that was bipartisan. Republicans and Democrats were rating it really high. So we need to continue to push.

It's time to advocate, it's time to keep going. It's a much different experience to advocate to make something better and to build towards something versus being in defense mode where we really have been. So ultimately like I said, our goal is around the HCBS Access Act. This bill would address long-standing issues of limited access to HCBS. And fundamentally, what the bill does is make home and community-based services mandatory service under the federal Medicaid law. But it does a lot more than that. It also is really sure to be inclusive of HCBS, because there are right now a lot of different statutes, a lot of different state plans.

I mentioned that there are waivers in Medicaid. The way that the HCBS Access Act is drafted, I'm going to start saying HAA because that's what I call it. The way that the HAA is drafted would eliminate all those different waiver systems. There wouldn't be an I, and a K, and a J, and a C. And I'm not exaggerating. That's actually what there are. There would be one set of services. There would be a federal floor for services. So states could always go above that. But what that ultimately what do would mean in a family like mine, if my brother was going to move to live closer to me for example, and he gets one service in Illinois that's on the federal list of services that that would be available.

Also making HCBS services mandatory would eliminate waiting lists. If you're making a service mandatory, you cannot have a waiting list for it. It would also increase funding for direct support professional wages. But I do want to say that the workforce component, I mentioned that this was introduced as a discussion draft, which is a term I know working in DC, but probably not a term that many folks know. The reason that they introduce it, it's just like it sounds. It's a draft piece of legislation. Doesn't mean that they're thinking about not putting it out there. What it means is that they wanted to get feedback. And one of the biggest pieces that they wanted to get feedback on is around the workforce components. So there'll definitely be huge pieces around increasing wages, and increasing training, and career development for the workforce. But we're still --between discussion draft and full introduction, we see a lot of that change.

The drafters of the legislation, I should have mentioned from the very beginning, are Senators Hassan from New Hampshire, Brown from Ohio. And of course, our always champions, Senator Casey from Pennsylvania. And then Representative Dingell from Michigan. We are working on--the other nice thing about going from discussion draft to introduction is it allows us to continue to work on building bipartisan support around this bill.

And ultimately, what it's about is that it would ensure that anybody who wants to live in their home and community can get services no matter their level of support needs, and also make sure that we have a robust infrastructure and direct care workforce.

So we have been on the forefront of all of this on the policy perspective. As I mentioned, these are conversations that have been going on for a couple of years, but even for longer than that. Home and community-based services were created in the early 1980s, so 40 years ago. And making home and community-based services mandatory under the program has been part of The Arc's legislative agenda for 40 years. But again, because we have this momentum, because we have this unique moment in time where there's an understanding for the need of these services, we have to keep it going. You have to make sure that the history of this issue is understood. But also, that the way the problems of the service system, it currently exists. Waiting lists. Overall and some large settings.

We've been providing and will continue to provide resources for grassroots around waiting lists, around portability, which is the ability to move across state lines. But ultimately, what we need, and what's the most valuable, and what I've seen in the last six years is stories. You don't need to be an expert on anything other than your own needs, your family members' own needs, in order to be able to talk about this.

I can tell you during 2017, I did hundreds of hill meetings. I do probably more than that now, because it's a little easier on the phone. And oftentimes, the thing that gets the most attention isn't data I'm presenting or a really good policy idea that I have. Oftentimes, it's a story that I heard or even sharing information about my own family member, my brother Chris.

So I always want to share that because I don't want people to feel intimidated. This can seem like a lot of information. But really, all you need

to know is your own family. And I also want people to think about sharing your story outside of just with legislators. I think it's really important. As I said, I am a family member. And I think so many times, we take it on and we just handle it. And we don't even talk about maybe with our extended family or our friendship network, about the reality of what it's like ... not to turn it into a pity party, but to talk about the services that people with disabilities need. How those services are funded. Not trying to change anybody's mind or do anything, but just making sure that people are informed when they're having conversations about the services and supports that people with disabilities and older adults need. I wanted to leave plenty of time for questions, so I will stop. I've seen the chat going a bunch. So I'm assuming Shawn has some questions for me.

>> SHAWN ULLMAN: I do. And now that I'm going to ask them, I'm going to start having a harder time tracking them. So someone asked about the reciprocity among states. And you touched on that a little bit. But if you could just sort of emphasize what the new act does for folks who might move from one state to another. And the person specifically asked about for example college students who might go to college in another state, but be eligible for home and community-based services where they are. How will this affect their ability to keep their home and community-based services?

>> NICOLE JORWIC: I'm sure. So there is not reciprocity between the states. That's part of why we need the HCBS Access Act or HAA passed. And it is a big problem when people with disabilities are going to college or when people with disabilities get a job offer in another state. We have that internally if we want to hire a fellow, because in Virginia there's a waiting list as an example. So it's a problem. There are some programs for military families where there is some not jumping of the line, but making sure that military families if they're stationed in another state do receive access to

services if they're moving to a state with a high waiting list. But generally, that's the biggest issue. If you're living in a state that doesn't have a waiting list but you want to move to a state like my home state of Illinois that has 20,000 people on there, you have to go to the end of the waiting list. So that's fundamentally one of the biggest reasons aside from waiting lists why we really need to get HAA passed.

>> SHAWN ULLMAN: Thanks, Nicole. So someone asked, you mentioned, sharing your stories. Someone asked how people can speak up in support of the bill. Where can they share their stories? Who should they be talking to? Can you share a little more about that?

>> NICOLE JORWIC: Sorry. You cut out for a second. Who should they be sharing their stories with?

>> SHAWN ULLMAN: Yeah. Who should they be talking to, to support the bill?

>> NICOLE JORWIC: Got it, thank you. So right now, it is a discussion draft. So actually, really what I would be suggesting to people. And I know it's confusing. This bill was supposed to come out last fall, and I wish it had, because the timing does make it a little bit confusing. But really, what I would be encouraging people to be talking about. And if you look at thearc.org/action, in our action alerts, it's really focused on that bridge funding, that \$400 billion funding. Because that investment will get us closer to a mandatory service, that HAA.

So what I would say is though, is that you should be reaching out to your legislators and saying that there needs to be a significant investment in home and community-based services to expand services, to address waiting lists, and address the direct care workforce crisis. It doesn't have to be a lot. You could share a story about what it's like on the waiting list if

you're in a state that has a waiting list. Share what it's been like if you haven't had the support, the workers that you need. That sort of thing. And people should be sharing that with district offices. Every Senator, every representative has district offices. You don't need to come to DC. You don't even need to necessarily call DC. It's just as important that those district offices are hearing about these issues, and why they matter, and how you'd like your representative or Senator to be voting.

>> SHAWN ULLMAN: This question is on a slightly different topic. But the person, I'm not sure if you want to direct them somewhere else. An individual wanted to ask about two people with disabilities who want to get married, and how that affects their SSI and Medicaid, and notes that it's not equal access if getting married affects their level of support. Is there somewhere you would suggest they look for more information on that topic?

>> NICOLE JORWIC: It's a really important topic. I know that it's one that we hear from our National Council of Self Advocates about all the time. And it's one that my colleague, Bethany Lilly, our senior director of income policy is working on a lot. When it comes to social security, whether it's SSI or SSDI, income asset limits, marriage penalties, those are all also things that are on our agenda. Right now organizationally, many of our public facing things are around home and community-based services. But it certainly does not mean that that's all that we're working on, and Bethany is definitely working on all those issues. So maybe that's something that the CFP can think about for a future webinar. But it's definitely something that we're talking about. And I agree that there shouldn't be a penalty for people getting married and they shouldn't be worried about their benefits, just like people who want to work more shouldn't be worried about losing their benefits. So we're definitely working on that. And we have some fact sheets

actually on our website that should be able, if you go to The Arc's policy homepage, you should be able to find.

>> SHAWN ULLMAN: I will look for those and try to send them out with the slides. Sorry, just making a note for myself to do that everyone. Someone wanted to know more about how you find out about the status of waivers in other states if you're thinking about moving. Where would you recommend they look for that kind of information?

>> NICOLE JORWIC: The problem is there's not really a clearing house because so many things can ... but obviously, I'm not just saying this because I work there, but if you're moving to a state, or if you're considering a state, I would strongly urge you to reach out to the state chapter of The Arc in that state. Also, there are some data points, so the University of Colorado Boulder has the state of the states on people with disabilities. So you can go there and see the size of waiting lists. And also, Kaiser does have some data on waiting lists by state. So I can send that stuff to Shawn to send out, but those are the two places that I usually go or send people to.

>> SHAWN ULLMAN: Thanks. Someone asked, "Does making the service mandatory mean that it becomes an entitlement?"

>> NICOLE JORWIC: Yes. Yes, just like right now. So any of the 20,000 people in Illinois who are on waiting lists for home and community-based services have an entitlement to a bed in one of those seven institutions, but would rather wait on the waiting list. So that's part of why we are trying to turn. And something that I do want to mention, because there's been a lot of misinformation around this. HCBS Access Act doesn't do anything other than putting home and community-based services on equal footing. It's not doing anything to take anything away from other funding streams. It's just

adding additional funding and creating that entitlement to home and community-based services.

Right now, the Olmstead Supreme Court decision, which is a Supreme Court decision from 1999 that says that all people with disabilities who choose should have the right to live in the community really can't come to fruition if you have people on waiting lists. So we really see in the drafters of the legislation, really see the HAA as getting to the entitlement that really should exist for HCBS. So yes, that is.

And it would mean that when school services end, that families don't have to worry about the education entitlement that ends at anywhere from 22 to 26 going away. So hopefully that will help people that really dread the day when the school stopped.

>> SHAWN ULLMAN: An individual asks whether the legislation bans waiting lists. And I think that's not quite the right word, but it does make them go away. Right?

>> NICOLE JORWIC: Right. So it doesn't ban them per se. No, it doesn't ban them per se. What it does is it includes a planning period. So we know that we can't just put a million more people or a million and a half more people into the current system without harming the people that are currently in the system. There's just not the infrastructure and capacity for it. So there is some time to plan. So I do want to clarify that it's not like on the day this bill passes, there will be a ban on waiting lists. But ultimately what it does is it provides an additional 100%. So an additional 100% federal match of dollars. And in order to access that additional 100% of money, which why would a state not want to access that? They can't have a waiting list. And it's not like it says on paragraph one you may not. But it does you may not if you want this extra money. And that's typically how federal legislation is written.

>> SHAWN ULLMAN: Thank you. Someone asked a question. I'm curious if this is too complicated to answer, how this legislation affects Medicaid buy-in.

>> NICOLE JORWIC: Right now unfortunately, because addressing the income and asset limitations on Medicaid would be, this HAA is already going to be a huge and costly bill. We're not addressing that in this particular bill. But what I will say for folks that are not familiar, Medicaid buy-in is for individuals who have needs for LTSS or long-term services and supports, but make more money than is the threshold for being eligible for Medicaid. So some states have opportunities for those individuals to buy into the program. But there are still very strict limitations on that. So ultimately, that would kind of be our step after HAA has passed is making sure that we're also addressing buy-in programs and making sure that people who are working can also receive these services without losing the services that they need by working more and making more money. So it wouldn't specifically address it, but that is the long-term plan.

>> SHAWN ULLMAN: Someone wanted to know do you know if there are other organizations who are supporting the legislation?

>> NICOLE JORWIC: Oh yeah. There's hundreds of organizations that have sent letters of support. There's 2,000 comments submitted. Some of them of course might not have been positive, but the majority of them were just giving feedback on the legislation, but supportive in theory. There's a lot of other disability organizations, a lot of other aging organizations that are supportive. We even had the National Association of Medicaid Directors sent a letter that supported the concept of a mandatory benefit. So there's like huge coalition within, but also outside of the disability community that support this.

And I also do want to clarify obviously, I work for The Arc and we were there, but there were also other organizations that worked with the hill offices on this legislation as well. So the Autistic Self Advocacy Network has been really involved, the National Health Law Program, the Epilepsy Foundation. And before Bethany joined us when she was at Bazelon, we were working on this as well. So that was just the initial drafting group, but there's a much larger group that's very supportive, groups a little obvious, etc.

>> SHAWN ULLMAN: An attendee wanted to know where they can find the numbers for the cost efficiency of providing services in the community versus an institution. Do we have that available?

>> NICOLE JORWIC: Sure. Yes. I mean that data is available actually. State of the states has that data, the data that I usually cite that people might've seen me quoted around is that the average cost on average to serve somebody in the community is about 45,000, where to serve a person in an institution is more like 300,000. But I do just want to put a real kind of caution around the idea of using the cost argument. While it is true, there are plenty of people including people who might need to move out of those larger settings that might cost more to provide the services that they actually need in the community. And also, while one-to-one, it obviously costs less. If we're also investing in a million, more people getting into the service system, it can be a tricky talking point. So I just want to kind of caution everyone with that. But state of the states is where I have gotten that information from with the data on the cost.

Another really good place though that we have strong data is around the Money Follows the Person program. I haven't been able to look at the chat at all, but they did see Money Follows the Person mentioned once. And if there's something I talk about second as much as HCBS, it's Money

Follows the Person. And Money Follows the Person program is a program that has been around since 2005 that provides 100% of federal money. So 100% FMAP for one year to states for moving people out of large congregate settings like institutions and nursing homes and into the HCBS.

And that program has obviously longitudinal because it's been 16 years, but really strong data around cost savings that it shows 22% per beneficiary per month savings to the Medicaid program. But most importantly, it also provides better outcomes to the people being served. So those are the two sources. State of the states, and then Mathematica, but also actually CMS or the Centers for Medicare & Medicaid Services submitted a data on MFP that also has that data.

>> SHAWN ULLMAN: Thank you. I think a really good point is that not everyone who gets services in the community is going to be less expensive than those in institutions. So people need a lot of significant supports, but that doesn't mean they shouldn't be able to get them in the community. Someone asked where they can see a copy of the discussion draft. Is that something that's available?

>> NICOLE JORWIC: Yeah. Yeah it's public. It was publicly released. So even though it hasn't been officially introduced, it's fully public, so I can make sure that we send it around. And it's not a long bill, and it's actually not a complicated bill to read through. It's 25 or 30 pages. And the findings are really strong, and I'm not just saying that because we helped draft them. But it really outlines the history and the problems within access to HCBS. Also some of the equity issues, because obviously there's a lot of equity issues when it comes to home and community-based services. And also in the workforce component, we know that the direct care workforce is primarily made up of women of color. So I would strongly encourage anyone to take a look. And also always happy to hear any feedback that

folks might have about any of this, and anything that we can be doing better in HCBS.

>> SHAWN ULLMAN: Yeah. Everyone I'll make sure to connect with Nicole after the webinar. And any links that we can provide to some of the things we're talking about, we'll try to put together between the two of us. Someone wanted to know if this means additional funding overall for Medicaid, how is that being received by our legislators?

>> NICOLE JORWIC: A complicated question. What I will say is that there is bipartisan support for home and community-based services. Even when it comes to the \$400 billion investment that's being proposed in unfortunately what's turning into a very partisan process. And even during 2017, there was strong support of these services. And I do think that because of some of the issues that COVID unearthed, I think that there's more understanding of the fact that Medicaid is the only game in town. Because Medicaid definitely has some connotations. But once you expand people's view of what Medicaid is and the fact that it is providing these supports to low income seniors and to aging adults and people with disabilities, it really is not that difficult to get support around. It is a huge investment. So obviously when it comes to finances, there are some offices that aren't as apt to making such a large investment. But when you really lay out the historical lack of investment, we haven't seen the pushback frankly that I was expecting.

So I'm really hopeful that we can move a lot of this forward in a bipartisan way. And it's even possible that that could happen with the \$400 billion that was included in The American Jobs Plan. As much as there's been a lot of things in the media, so far, no one has completely taken that out of the conversation as part of being part of a bipartisan infrastructure package. So I think there is a growing understanding that care, and people that provide

care are actually a part of infrastructure. And we're trying to make sure that the disability community and The Arc are our main part of that conversation as well.

>> SHAWN ULLMAN: Thanks, Nicole. We only have a couple of minutes left for a couple more questions, and there are lots that I didn't get to. I want to let everyone know that we certainly will be going through all of the questions that you're putting in the chat. And any that we're able to answer afterwards, Nicole and I can touch base and figure out what makes sense to try to share that information out with everyone.

I did think someone asked a good question about the difference between services and eligibility when saying that home and community-based services will become mandatory. Does that allow states to then restrict eligibility so fewer people will be able to get the services?

>> NICOLE JORWIC: We're going to be really careful that it didn't. What the question may be referring to is around something called Maintenance of Effort. So far, we've been really careful and the legislators have been really careful that for example, that 10% FMAP bump that was included in the American Rescue Plan has really clear language to ensure that that doesn't happen. So states can't change their rates or in states can't change eligibility in order to access the additional funding. So something like that would be done to ensure, because the last thing we'd want to be doing is adding people in, but then somehow shrinking it. So that already is part of the thinking and will be included for sure.

>> SHAWN ULLMAN: And I think maybe this is our last question is can you talk a little bit more about what the possible steps and timeline are from where we are now to when we might actually see some movement and even possible passing of the legislation?

>> NICOLE JORWIC: Sure. So I would be remiss not to say everything in Washington DC moves at the pace of a glacier. As I mentioned, this has been part of The Arc's legislative agenda for 40 years. I am in no way implying that I think it will take 40 years, but I just want to set expectations.

I think that we're really likely to see some sort of second large investment in home and community-based services. I'm hopeful and will be pushing my hardest to make sure that it's the full 400 billion. But something that is a large investment that will come together at some point. We're hearing now that it likely won't happen until the end of the year. That whenever grand, big package comes together.

And as far as the HCBS Access Act, I think that next year is an election year. So while obviously it will be introduced and there'll be a lot of conversations around it, I think a realistic timeframe to think about when things could really move could be early 2023. And then I would hope it's quicker.

But, there are a couple of ways that it could happen a lot faster than that. So two or three years sounds like a long time, although in some ways it doesn't. But if for example the Affordable Care Act, something happens with the Supreme Court decision where they take a look at that, there's no reason why the HCBS Access Act could not become part of the Affordable Care Act. Folks might not remember that the Affordable Care Act originally actually did have an LTSS component that was later repealed.

So I guess all that to say it's likely to be three years let's say in my best case scenario, before we get to the ultimate goal of HAA. We should have a short-term investment before the end of the year. But theoretically if healthcare reform goes through, we could see [inaudible 00:58:12] a lot sooner. And we'll be trying our darnedest to get it in as soon as we can, because we know how many people are waiting desperately.

>> SHAWN ULLMAN: Great. Thanks so much, Nicole. We really appreciate all the wonderful information. Again everyone, we will be sending a copy of the slides and the recording to everyone who registered. And I will be going through the chat box and all of the questions that we didn't get to and seeing with Nicole, how we might be able to get you all some answers to the questions. Thanks so much for joining us everyone today, and enjoy the rest of your afternoon.

>> NICOLE JORWIC: Thank you.