THE ARC

PAID FAMILY & MEDICAL LEAVE: THE DISABILITY ANGLE

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>> T.J. Sutcliffe: Good afternoon and welcome to today's Webinar on "Paid Family & Medical Leave: The Disability Angle." I'm T.J. Sutcliffe. I'm with The Arc of the United States, and I'm so glad to see that so many of you are on our Webinar today. Thank you so much for joining us.

I'm going to start by going over a few accessibility features for anyone who needs to access these features. First, to view the American Sign Language interpreter, click on the "participants" tab and you should see a window pop up with the interpreter on the right‑hand side of your screen. If you need to access CART captioning, click on the multimedia viewer and you should see captioning appear in the lower right‑hand corner of your screen. You can adjust the font size in the header, and then you can maximize these windows on the right‑hand side of your screen in a couple of ways. You can use the show/hide header and show/hide chat buttons at the bottom to hide the header. You can also close the chat box and you can get the chat box back at any time by clicking on the chat button which is in the upper right‑hand corner of your screen.

You can also make that right-hand panel wider and dragging the left border of the panel to the left. So you can adjust the size by dragging that border back and forth.

So, again, thank you so much to everybody for joining today's Webinar. I'm so excited that we very three amazing presenters who are joining us for today's conversation. First, we're going to hear from Erika Hagensen. Erika is a disability and advocacy ‑‑ disability policy and advocacy consultant. She is currently working with The Arc of North Carolina and the North Carolina Council on Developmental Disabilities.

Second we're going to hear from Kali Grant. Kali is a senior policy associate with the Economic Security and Opportunity Initiative for the Georgetown Center on Poverty and Inequality.

I'm T.J. Sutcliffe, and I'm the director of income and housing policy at The Arc of the United States. Finally, we will hear from Lauren Agoratus. Lauren is a parent and she's also the state coordinator for Family Voices New Jersey.

If you want to join the conversation on Twitter we are encouraging people to use the #Paidleave. And on this slide I have also provided Twitter handles for three of our organizations. The first is for The Arc of the United States. That is @thearcUS. The second is for the Georgetown Center on Poverty and Inequality which is @GCPIEconSec. And the last one is for the Family Voices knowledge and that's @SPANadvocacy.

I wanted to start off today's discussion by framing our discussion and talking about what is paid family and medical leave. What are we talking about? Generally paid family and medical leave is understood to be paid time away from work to address one of three situations. The first is to address your own serious medical condition. The second is to care for a family member who's experiencing a serious medical condition. And the third is to care or welcome a new baby or newly adopted child into your family.

There was a couple of features of paid family and medical leave that make it a little different from some of the other kinds of leave that we often think about, paid sick days or vacation days or paid time off.

One is that, in general, paid family and medical leave is leave that is there for you if you are experiencing one of these three situations. So unlike, for example, paid sick days, paid family and medical leave is typically not leave that you have to accrue. You do generally have to show some basic documentation to show that you are going through one of these three situations. But, again, that principle is that this kind of leave is there for you if you need it. Paid family and medical leave is also generally measured in weeks or months, unlike paid sick days which we often think about as being measured in hours or days.

Another important feature of paid family and medical leave is that it generally is associated with job protections. Generally, that's the idea that your job will be there for you when you return from leave as well as the idea that important employer‑sponsored benefits will continue while you are on leave. And for people with disabilities, one of the benefits that we most often think about is health insurance and making sure that that's there for people while they're on leave and when they return from leave.

And then the other main thing to think about is paid family and medical leave is that while ‑‑ for some workers and in some cases, it can be at your regular pay rate, in many cases what we're talking about is leave where you get a percentage of your regular pay. So maybe that's 75% or 60% but maybe not your full regular wages.

Now, in the United States, we have no national paid leave program. As Kali will discuss later, the U.S. really stands alone among industrialized nations in not offering any form of comprehensive paid family or medical leave program. Instead, in the United States what we do have is the Family Medical Leave Act which since the early 1990s has provided ‑‑ covered workers with up to 12 weeks of unpaid job‑protected leave if they need to take leave for one of those three situations that I discussed earlier.

The Family Medical Leave Act is really important. It provides workers with ‑‑ workers in the U.S. are not covered, roughly 40% are not covered. And in the absence of coverage, in many cases what we know is that workers end up cobbling together other forms of leave so that they can continue to get some pay while taking Family Medical Leave Act leave. So maybe a worker would use accrued vacation days or accrued sick days if they are lucky enough to have them to ensure that they can continue to see some money coming in while taking leave.

In the absence of a federal program, there are some states that are moving forward to put in place statewide programs. There are three states that currently have programs in place: California, New Jersey, and Rhode Island. And you're going to hear a little later from Lauren who's going to talk about New Jersey's program.

And then the District of Columbia as well as New York and Washington State have recently passed laws to implement statewide programs and those programs are due to roll out over the next several years.

In the absence of a national program, we know that many workers really struggle when they need to take leave for family or medical reasons but either have to cobble together existing accrued leave or in all too many cases are not able to access pay while they're taking that leave. Roughly two in five workers report they have no access to paid leave and only one in seven workers report that they have access to paid family leave if they need it.

Roughly half of lower income workers did not receive pay at all during the most recent time that they needed to take leave.

So on today's Webinar we're going to talk about paid family and medical leave in the United States. We're going to talk about why it is so relevant and so important to workers with disabilities and to people with disabilities and their families. And we're going to talk about why it's so vital that people with disabilities be at the table and be part of conversations about a national comprehensive paid leave program.

We're going to start off by hearing from Erika Hagensen and she's going to share a worker's perspective on this issue. Kali Grant is going to present new research findings by Georgetown and The Arc and I'm also going to hop in a little bit there and talk about some of our recommendations.

Lauren is going to close us out by sharing her family's perspective and talking about her involvement in advocacy to create a paid leave program in New Jersey.

We're going to close out with roughly ten minutes of questions and answers. And you can go ahead and enter questions at any point using the chat feature, and then we'll also take any questions that you may have during the Q&A at the end.

So with that, thank you so much again for joining today's Webinar. And I'm going to hand it over to Erika.

>> Erika Hagensen: Thank you, T.J. Can you hear me?

>> T.J. Sutcliffe: Yep.

>> Erika Hagensen: Okay, good. I'm so pleased to join this really phenomenal panel and truly this really critical discussion. For me, paid leave was a part of my story from the beginning and my mother experienced a really complicated pregnancy. She began bedrest in her second trimester. And despite every intervention, I was born three months early and weighed just over 3 pounds with an extended stay in the neonatal ICU. So for me and for my family, that was a critical time. My father really needed to take time from work to be there, and then that was the beginning of the journey because then once I received a diagnosis, I had ongoing therapy appointments, specialists, physicians. There's a picture of me on this slide sitting with my mother in my orthopedic shoes that required a special fitting in a different state several times a year. So this was a really tough time for my family.

And interestingly, I think that for the disability community we understand that this story is not in any way unique. And we also know that we not only need programs and supports and expertise to provide for our family and individuals with disabilities but we need to ‑‑ we need the ability to access those programs, supports and expertise. And that access is often during work hours. Because of paid leave and I think some work‑pay flexibility, my parents really maximized every opportunity that they could to help give me the tools that I needed to gain skills and abilities and opportunities as an individual with a disability.

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But I think as often happens, the unexpected doesn't just happen once. And for my family, it happened a number of times. But I'd like in this case to speak about when my mother was diagnosed with metastatic melanoma. My mom had been battling cancer in the picture on the left. She had numerous surgeries and interventions. She was on countless medications and was losing her hair. This was a picture at my sister's wedding and she had to leave the wedding early because she was scheduled for major surgery.

Two years later, so four years into my mother's cancer diagnosis, is the picture on the right. And that's my mom and I on Christmas day. It was the last day that she got out of bed, and it was the beginning of our experience with hospice in our home for end‑of‑life care.

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So I was in this really kind of unusual situation in my 20s. I was a caregiver. My father was the primary caregiver, and I was providing him support through these four years of really invasive, intrusive treatments that had difficult follow‑up and healing afterwards. A number of surgeries. And she was experiencing declining capacity in any number of ways and it was often unpredictable. So yesterday she could do this activity of daily living, and today she could not. And tomorrow it might be something different. So it required a lot of support. It required a lot of communication between family members. And it required a lot of time.

And in the end, as I mentioned, we were providing hospice care in the home. So as many of you who may currently engage or have engaged in care giving know, my life was a series of lists. One of them is to the right. And those lists helped me meet the needs of my family primarily but truly my mother and giving her the best possible ending to her life that we could.

But at the same time, I wanted to meet these family obligations, I still had bills to pay. I had professional responsibilities. And that was a lot to juggle when at the time all I really wanted to do was to support my family.

So I was lucky enough to have some paid leave in my job and I was a lower‑level employee. My benefits by any means were not deluxe. But I had this leave, and luckily for me I had a really engaged human resource professional at that company who helped me understand what those benefits were, how to use them, and how to achieve the most flexibility that I could with what I had. And because I was able to create flexibility in my job, it not only helped me help my family, but it also helped me to maintain my obligations at my work with my colleagues and with the individuals who reported to me, a truly important thing.

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So, you know, personally, I can easily say that paid leave was in many ways the unsung hero for our family on any number of occasions. And, in fact, I wouldn't have known to phrase it that way until I truly began to understand that opportunity from a policy perspective.

But professionally, I would say I vehemently believe in the value of the disability community at the table. This issue impacts truly every person and every family that we know. And what differs from person to person and family to family isn't the need ‑‑ isn't the need and the issue. It's the resources available and unfortunately often the outcomes that families and individuals experience. So this is an every‑person issue.

I also think that we have a responsibility to debunk some false narratives. I was praised entirely too much and told, again, and, again, that I was a, quote‑unquote, good daughter. And that rang so hollow for me because I wasn't any more loving or any more dedicated or any more willing to sacrifice than anyone else that I knew. I was just lucky to have benefits. And in situations like these, we don't need luck and praise, right? We need reliable, defined benefits that you can understand and utilize.

I also think that oftentimes when we talk about paid leave from the disability perspective, we're often talking about parents and their children with disabilities. Certainly that was my early experience with paid leave and important to my family.

But people with disabilities are some of the most unemployed and underemployed populations in the nation. And when we are ‑‑ when we are employed, I think we still often lack some of the critical benefits that others rely on and may not even know that they have. So as the roles for and expectations of people with disabilities continue to evolve, we need to make sure that we're at the table to inform the policies from our community's perspective and expertise.

Also, that as we talk about, also, I think debunking false narratives, oftentimes when we think about individuals with disabilities, we think of people with disabilities as receivers of care and not caregivers. And it's important that as we look at these nuanced employment policies and opportunities that we imagine an enhanced role for people with disabilities sort of beyond some of these previously held expectations.

And, finally, as we think about sort of these broad cross‑stakeholder collaborations, I think it's really important to remember that a broad lens informed by diverse experience always creates better policy than what I call an appendix approach, right? So if you have everyone at the table and you build a policy, chances are you're going to build a really robust policy that works in a number of scenarios.

If you only have a typical population at the table and realize later that you haven't included other populations, they often have a one‑page addendum at the end of that policy. It's not nearly as effective, and we can do better.

We've also seen, I think, a real increase in collaboration across diverse communities as we respond to critical and persistent policy challenges at the federal level, and we need to build on that so that collaboration sort of extends beyond a crisis response and really more toward a sustained, informed effort in policy development. And I think this is one much those issues.

When I look back at some of the policy pieces I've been a part of, I just want to say that I can't overestimate or over ‑‑ overestimate the importance of an individual voice, right? That your voice is important and it's not just important but needed. And it's not just needed but it's necessary for systems and government and policies to work well. And I think you're going to see a really vivid example of that when Lauren speaks later in the presentation.

Thank you.

>> T.J. Sutcliffe: Thank you so much, Erika.

I'm going to turn it over to Kali.

>> Kali Grant: Hi, everyone. This is Kali. And, yes, thank you so much, Erika, for sharing your story and your great insights. And thanks to everyone tuning in today for the opportunity for us to share some of the findings from our new report.

So today I'll be giving a brief overview of the state of disability and work in the U.S., and then we'll also go over some key findings. And then I'll turn it over to T.J. who will discuss some important policy recommendations for paid leave policy.

Next slide, please.

So, first, I'll get into a brief overview of disability and work. Next slide. And then you can go to the next slide again, please. Thank you.

So, first, nearly one in five people in the U.S. has a disability. And over one in four families include a child, adult, or a senior with a disability. Even though seniors make up the group ‑‑ seniors make up the largest share of people who experience disability as is shown on the previous chart, and this trend is expected to continue and increase as the population continues to age.

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So for the purposes of timing, I am going to skip through some of these slides ‑‑ or skip over a few of these slides. But we've included them for ‑‑ in case you're interested in learning more about the breakdown by race and by gender.

So now on to disability and work in the U.S. economic incomes. Disability and financial insecurity or intertwined. Disability or illness can lead to job loss and reduced earnings, barriers to education and skills development, significant additional expenses and many other challenges that can lead to further economic hardship. And on the flip side, economic insecurity can exacerbate existing challenges. What this means is that workers with disabilities and their families on average have lower incomes and savings as well as increased out‑of‑pocket medical and disability‑related costs. So as a result, this means that many more households with at least one member with a disability face poverty ‑‑ face higher poverty rates than households without a member with a disability.

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And, again, I'm going to actual ‑‑ sorry, T.J. I'm going to skip over a few of these slides until we get to slide 26. We've again included that information for your convenience.

So now let's move on to some key findings. The first key finding is that we have a real need for more comprehensive and modern policies. And what this means is that because of the prevalence of disabilities across the life span and the demographic changes like we discussed above, we really need policies that can address ‑‑ that can meet the realities of modern work family balance needs.

Next slide, please. Next slide, again. Thank you.

So what this means is ‑‑ so we found that ‑‑ next slide, T.J. Sorry.

We found that as she mentioned before, the U.S. has no national paid leave program. In fact, we are the only OECD country without one and many of our other peer countries have programs that are much more generous in terms of both benefit duration and amount. And even though we do lack far behind peer nations, at home we do have wide support for paid leave policies. For example, three in four voters and seven in ten small businesses support creating a national paid leave program.

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Our next finding is that paid leave helps workers care for both themselves and their family members. Erika's story is a really good example of how paid leave really does make a difference, whether it's caring for one's own illness or a family member's. And we found that 73% of employees' reasons for taking leave was for their own or for a family member's illness. Another 21% of leave was related to having a new child and 6% was for other reasons. All of this shows that access to paid leave can help provide support to a family member. It can help workers navigate their family's needs and maintain work hours, stay in the workforce, keep careers on track, and address their own health needs. This is a good segue into our other findings which is that paid family and medical leave have opportunity security.

If you can go back one slide, that would be awesome. Thank you so much.

So what we found is that having job‑protected paid leave can actually reduce poverty and mitigate potential workforce discrimination. It can also have positive effects on wages, labor force attachment, family well‑being, and overall health. One study of parents with paid family and medical leave felt experiencing positive effects on both their own emotional health as well as the physical and emotional health of their child, for example. Even though we know paid leave is extremely important for economic security and opportunity, only ‑‑ many workers and particularly workers with disabilities are not likely to have it. So, for example, over two in three part‑time workers don't even have one sick day. And workers with disabilities are twice as likely with workers without disabilities to be part‑time. It's a problem because even though they need it, they are not able to access it. Other jobs that are likely to be ‑‑ to be without access to paid leave include jobs that are low wage or lack flexible schedules. Of course, having those types of jobs also mean you are less likely to have enough money saved up or access to the type of income that would allow you to take unpaid time off or to pay for additional expenses that may come up.

These gaps persist even in states with their own paid family and medical leave programs. And all of this, particularly, affects people who are low income, women, young, LGBTQ and/or people of color.

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So now I will turn things over to T.J. who will discuss some of the policy recommendations we developed for the report.

>> T.J. Sutcliffe: Wonderful. Thank you so much, Kali.

So based on our research and findings, we put forward a number of recommendations for things that we think will help to craft a comprehensive paid leave program that is inclusive of and meets the needs of people with disabilities and their families, right? So as Erika said, looking at that broad lens, not just that appendix approach.

The first recommendation that we developed was that a comprehensive paid leave program should be accessible broadly to all working people. And that includes workers at large, medium and small companies, so no matter the size of the business. It includes part‑time workers, as Kali noted, that all too often includes workers with disabilities as well as many family members of people with disabilities.

We also think that it's really important that paid leave policy provide for an expanded and modern definition of family. So family should be clearly defined to include members including siblings, grandparents and families of choice which include many LGBTQ families. At The Arc just to give one example, we often hear from siblings who are involved in the lives of their siblings who have disability, and it's not always clear sometimes whether or not they can access paid leave or even sometimes unpaid leave to provide support to their sibling when a need occurs.

We think it's really important from the start of any policy to be very clear that we view families inclusively and that policies should recognize these existing relationships that so many families experience.

A second major recommendation is that we think a national comprehensive paid leave policy definitely needs to cover all of the major reasons that people need to take paid leave, including parental leave, medical leave, and family leave. And reasons for taking leave should be defined inclusively. Another example that we often hear at The Arc are from parents who are raising kids with disabilities who want to know if they can use their leave to attend school IEP meetings or related meetings to arrange for supports and services for their child with a disability. We think that policy should just clearly include and incorporate those kinds of uses of paid leave.

And a related recommendation was to allow for intermittent use of leave. That we recognize that sometimes serious medical conditions are going to last not just for weeks but sometimes for months or even years and that it may be beneficial and promote positive outcomes to be able to take leave intermittently rather than having to take the leave all at one time.

Another important recommendation is that paid leave should be adequate. You should get paid enough while you're on leave to promote economic security, to ensure that workers can pay for their basic needs, keep the lights on, keep food on the table, and ensure that families can get by while a worker is taking leave.

In addition, we think that paid leave should last for long enough to promote positive outcomes, right? Sometimes a week or two is just not going to be enough. Another key recommendation is job protection, ensuring that people can keep their jobs and not face negative job consequences and ensuring that important employer‑sponsored benefits like health insurance will be available to people both while they're on leave and when they return to work from leave.

In addition, we believe that a national program must incorporate broad education and outreach to the public so that workers and employers are aware of the program and know how to access it and that that education and outreach should be fully accessible to people with disabilities.

And then, finally, we believe that a comprehensive national program should be cost efficient for both workers and employers. One of the questions that we sometimes get from people is, you know: So are you talking about an employer mandate? And just mandating that employers provide paid leave for all of those up to 12 weeks that workers can take under the Family Medical Leave Act? And the short answer to that is no. Most policymakers, most policy experts who have looked at this issue believe that an employer mandate of that nature probably isn't going to either be politically feasible or the best way to administer and operate this kind of program.

The leading model ‑‑ and actually Kali and I were recently on a Webinar sponsored by the National Academy of Social Insurance on this topic. The leading model would be to operate a national paid family and medical leave program as an insurance program. The way to think about it is it would work like Social Security. Workers and their employers would each make contributions paid as a percentage of a worker's earnings out of each paycheck. Those contributions would go into a dedicated fund, and then if a worker experienced a qualifying situation and needed to take paid leave, the benefits would be paid out of that fund. Just an example of what those kind of costs look like, a bill that is currently moving through Congress to create such a social insurance model is called The Family Act. And the current cost estimates for that bill is that for a typical worker, the worker and their employer would each pay $1.50 per week to contribute to this kind of paid family and medical leave fund to support a comprehensive national program.

So as you can see, this would be a very cost efficient way to operate a federal program. And it's one that has gotten a significant amount of attention from policymakers and advocates across the country.

Some have also talked about creating a national program that might be funded and operated through the tax code. And then another way that you could look at operating this kind of program would be to fund it through general revenues, although we have not seen a lot of policy proposals in this area.

So with that, I'm going to take us back out of the world of policy just to thank everybody for the opportunity to share our research findings. We're going to provide a link at the end where you can access our report.

And with that, I'm going to turn it over to Lauren and she's going to talk a little bit about her family story as well as their advocacy in New Jersey. So, thank you, Lauren.

Lauren, are you there with us?

I'm going to keep talking because I suspect Lauren is encountering some technical difficulties. Again, really appreciate everybody joining us on this Webinar. I'm going to see if we can access ‑‑ while we're waiting for Lauren to hop back on ‑‑ our slides about how people can get more involved.

If you want to access ‑‑

>> Lauren Agoratus: I'm on. My phone got disconnected. I couldn't believe it.

>> T.J. Sutcliffe: Oh, no. It's inevitable. Excellent. Well, I'm just going to back up to your slide.

>> Lauren Agoratus: Okay, great.

>> T.J. Sutcliffe: Thank you so much.

>> Lauren Agoratus: So, hi, yes. I'm Lauren. And this is our paid family leave story. It started when my daughter was about a year old. I had the same situation where my daughter had some difficulty and she spent time in neonatal intensive care. And my employer had the primary insurance coverage, and our first ICU bill was $28,000. So not only did I not want to ‑‑ I wanted to keep working but I didn't want to lose my health care benefits. So my daughter was homebound medically fragile and a doctor okayed daycare with a few children, not in a large day‑care center. But she kept getting sick. And she weighed about 11 pounds at one year of age.

We needed to take family leave. And after that, we did end up with in‑home one‑on‑one support. But unpaid leave, and this was under the Family Medical Leave Act, resulted in lost wages and medical bills which was the perfect storm. Not having any previous debt, then going $20,000 in debt, putting our mortgage on a credit card and almost losing our home.

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So fast forward to age 19. My daughter needed a kidney transplant. The pictures you see here are her prom and her graduation, both of which occurred at children's hospital in Philadelphia. She had transplant complications which included four life additional diseases and she also had autism. We were fortunate that New Jersey had paid leave. We had two different ways to do this. I took ongoing leave for her transplant which took weeks instead of the usual couple of days because, of course, this is my kid. And her dad took intermittent leave for labs at Children's Hospital and also hospital visits. We had 14 admissions through the emergency room in three years.

Our medical bills were mostly covered by the catastrophic illness in Children Relief Fund and we were both paid 2/3 of our income for the time off. Not only were we able to take care of her which is huge in and of itself and know that we would still have our jobs but not having to worry about the financial piece took the stress off of us.

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So I decided I didn't want other families to go through the same thing we did; and I advocated for paid leave not knowing, of course, I would need it again myself in 2011. We had a statewide coalition called New Jersey Time to Care. And it included labor, religious, civic, civil rights, women's and disability groups as well as the Statewide Parent Advocacy Network, which is New Jersey's training center and Family Voices New Jersey. Family Voices is national. There is one coordinator in every state. And we seek to keep families at the center of children's health care. So we help families of children with special needs kids.

And so how did New Jersey Time to Care make this happen? National research on paid leave showed benefits to both employees and employers. So we had better retention. We had ‑‑ not having to pay hiring and training new employees, those kind of benefits. Our New Jersey poll showed almost 80% favored paid leave. So then we started thinking, well, how are we going to pay for this thing?

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It was financed through TDI which is a temporary disability insurance. And it was through a small paycheck deduction. And I'm talking pennies. And we named it Family Leave Insurance rather than just paid leave because that sat better with legislators and the public and it really is like an insurance program, like T.J. said before. You pay into it in case you need it some day. So Family Leave Insurance was introduced in New Jersey in 2005. And it didn't pass until 2008. And January of 2009 people started using the payroll deduction and then we had a pot of money. People could use it July 2009. And so you can see, it didn't happen overnight, and some states have passed some form of family leave. So there's a national movement besides New Jersey. You can see California, Rhode Island, Washington, New York, and D.C. have enacted paid leave.

I also testified at the hearing that that was one thing that our family was able to do to help the cause move along.

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So our next steps are a coalition is working on paid sick days and other family support issues. We are also trying to expand leave in terms of the number of hours, the amount of pay, and who's eligible for it. So for more information, you can look at the website and it will show you what we're working on, how we advocated in the past so perhaps you can replicate it in your state and what we're working on now. And this is also happening on a national level through the national partnership for women and families. And that's it.

>> T.J. Sutcliffe: Great. Thank you so much, Lauren. We really appreciate everybody joining in.

And I'm going to ‑‑ right before we go to the Q&A, I'm going to also make sure that folks have access to other links in addition to the New Jersey link that Lauren provided. If you want to access the report and additional information, you can go either to thearc.org/paidleave. Or on Georgetown's website, you can go to www.georgetownpoverty.org/issues/tax‑benefits/pfml. And if you want to visit the New Jersey Family Voices website, you can go to spanadvocacy.org. Those are some resources that we hope everyone will find helpful. And, then, again, the website that Lauren mentioned is njtimetocare.org where you can access more information about the amazing work they're doing in New Jersey.

I know folks have a lot of questions. I do want to start off with a couple of questions for our presenters. I wanted to start off with Erika. Going back to that point you made, Erika, about debunking some of the stereotypes and the myths here. One of the things that we sometimes hear as a potential concern ‑‑ and I'm going to set this up as a straw man ‑‑ is that, you know, some people say, well, employers may see a potential need for paid family leave as a disincentive to hiring a family caregiver like yourself or hiring a worker who identifies as having a disability. How would you respond to that?

>>  Erika Hagensen: I would say that a national comprehensive paid leave program is the answer, right? That it's available to all workers and employees ‑‑ and employers would help their employees hire and train all workers including workers with disabilities and family caregivers.

I think we see this as part of the solution because employers will know workers will have access to paid leave if they need it, right, through that national program that we talked about that promotes health and well‑being of workers and their families. I think it is actually the answer and not the disincentives that some people might fear.

>> T.J. Sutcliffe: We could not agree more and really think that this kind of policy is an important tool. As Lauren's experience in New Jersey has shown and in other states that have rolled out these program, it is an important tool for employers to recruit and retain workers. Often at The Arc we hear from family members who feel like they had no choice but to downshift their careers, sometimes to cut back on their hours' worked, sometimes to drop out of the workforce or retire early and we really think that if people have access to paid leave, at least in some circumstances it may help families and workers with disabilities to stay in the workforce and continue to have that employment there for them.

If you have questions, I'm going to keep going with a couple of moderator questions. But if you have questions please go ahead and enter those using the chat feature. I do want to get a question in for Lauren. You know, Lauren, if there are people on this Webinar who are thinking about how do I get involved and what should I do to get involved, do you have tips or thoughts for people who haven't been involved in this issue but want to hop in?

>> Lauren Agoratus: Sure. The first thing to realize is you are not alone. And by fighting the battle, so to speak, for your family you can help on a systemic level. So it could be something as simple as a letter to the editor to start out. It would be speaking at a hearing. Or if that's intimidating, sending written testimony to a hearing. Contacting legislators, those kinds of things.

Find like‑minded groups such as disability organizations. Our Time to Care coalition was spearheaded by New Jersey's Citizen Action as well as Rutgers University which gave us access to data and that's very important when you're trying to convince legislators that something is going to be cost effective.

>> So often the question that legislators have is: What's the cost and what's the bottom line, right?

>> Lauren Agoratus: Absolutely.

>> T.J. Sutcliffe: Yep. And, Kali, are there ‑‑ were there things when you were putting this paper together and looking at some of the amazing data that you all were able to compile at Georgetown, were there findings that particularly surprised or interested you that you think ‑‑ that you hope that people who participate in this Webinar look at the report will keep in mind?

>> Kali Grant: Sure, that's a great question. I think a lot of what we found had already been, of course, kind of backed up by anecdotal evidence because we all have ‑‑ as other presenters have noted, we all have seen out the intersection of disability and paid leave work out in our own lives and other people that we know.

But I will say that what I found to be not surprising but that was an important finding was just that really the types of jobs that workers with disabilities are more likely to have are also the types of jobs that are least likely to have access to any form of leave, let alone paid. And that's just crucial because when you are thinking about ‑‑ it's really going to people to the intersectionality of the topic when you are talking about part‑time workers, you are also talking about workers with disabilities and works that don't have flexible schedules and workers with low wage. It is all tied together. And I think that's one of the most important take‑aways.

>> T.J. Sutcliffe: Thank you so much.

We do have a question from Madeline who says: I was very intrigued by the point that Erika made about folks with disabilities not only being the recipient but also the providers of care and how that might change the discussion of how we might design an ideal family paid leave policy.

I'm wondering if any of the panelists have other ideas about how centering folks with disabilities might change the conversation among advocates about what kind of paid leave policies we'd want.

That thank you so much for your question. That's a really great question.

Lauren or Erika or Kali, do either of you want to hop in on this?

>> Lauren Agoratus: Sure. This is Lauren.

I think one of the things we need do is raise awareness that, first of all, people with disabilities want to work. It's that stigma thing again and also that they can be caregivers, not just care receivers. So they need to be part of the stakeholder group that's making the decisions on paid leave.

>> Erika Hagensen: Thanks, Lauren. I agree. This is Erika.

I think the more we can show varying role of people with disabilities, I'm a woman with a disability, I'm also a parent. Many of the policies related to parents don't necessarily consider disability as part of that equation as well. I think the more we can center the person with the disability and show the varying roles, I think we're going to have unique opportunities to build policy that helps further that effort. And I think that we have a number of policies that are really trying to push and accrue policies for folks with disabilities. I think these two scenarios are going to collide a little bit. And I think paid leave might be a really interesting opportunity to showcase that intersectionality.

>> T.J. Sutcliffe: Kali, do you have anything to add?

>> Kali Grant: I think they said it the best. (laughter).

>> T.J. Sutcliffe: Excellent.

I would just say The Arc has been involved in family and medical leave issues for many years. We feel fortunate to be involved in advocacy that helped put the Family Medical Leave Act in place. We have a long experience with this. But in the paid leave space, you know, we've been participating more actively over the last couple of years. And I've been really struck by how the broader community of paid leave advocates has really welcomed the disability perspective at the table.

I was a little surprised by the number of people who have come forward and sort of said to me, you know, so often the conversations focus on parental leave. There's sometimes a tendency in the news media or among policymakers to think first about parental leave because it is such a universal experience. But at the same time, we know that leave to address your own medical condition or to support a family member who's going to through a serious medical condition is an important part of the conversation that doesn't always get lifted up and that the disability perspective really speaks to all three of these perspectives, right? The parental leave as well as medical leave as well as family leave.

And so I've been really grateful for how welcoming the paid leave community has been and how interested they are in having disability be part of that conversation.

I don't see any other questions coming in through the chat function.

>> Lauren Agoratus: Can I ask something to what you just said?

>> T.J. Sutcliffe: Sure.

>> Lauren Agoratus: I just want to mention that people need to realize that paid leave is a life span issue. I hear a lot about elder care but truly it could be parents of children with special needs. It could be well‑spouse situations or elder care. It truly is a life span need.

>> T.J. Sutcliffe: That's absolutely right.

>> Erika Hagensen: That's a great point, Lauren.

>> T.J. Sutcliffe: We often hear at The Arc from families that include a worker with a disability, maybe it's a family that includes a child with a disability where the parents are also supporting their own parents who are going through some of those aging issues. So it's something that comes up for almost all of us over the course of our lives. We're all going to encounter this issue. And it's something that sometimes we often hear from people and from families who are dealing with different aspects of it, sometimes all at the same time. So it's a critical issue.

So thank you all so much. This has been an amazing discussion. Thank you, Erika. Thank you, Kali. Thank you, Lauren. And thank you so much to everybody who has joined our Webinar today.

I did not read everyone's bio, but I am going to make sure that when we provide an archived and recorded version of this Webinar that we do include information about everyone's background because this is a really experienced panel. This Webinar has been recorded and it will be archived so if you want to share the archive of this Webinar or if you have colleagues or friends or family who missed it and would like to get this information, we will send around a follow‑up link to the archive of the Webinar as well as the biographies and the presentations.

So thank you so much to everyone for participating in this Webinar on "Paid Family & Medical Leave: The Disability Angle." Thank you and we'll now close out the Webinar.