

DISABILITY, LEAVE, AND CAREGIVING

This is a verbatim transcript of the March 29, 2019 symposium panel. The video of the panel is available at: http://bit.ly/Leave_Caregiving.

Speaker names are in bold, followed by the minute and second marks in parenthesis to indicate the location at which the remarks begin on the corresponding video.

Robin Runge¹ (moderator) (00:00)

I'm thrilled to have everybody with us today and I know hopefully some more folks will join us. My name is Robin Runge and I teach part time at George Washington University Law School and I also work at the Solidarity Center, which is a global worker's rights organization where I focus on equality and inclusion issues. So, it's a privilege and an honor to be here and be a part of this really momentous workshop and conference.

I just want to credit Marcy and the students here at the law school who I know have been working very hard for months. And I was just saying to our panelists, even though I went to law school a really long time ago, I remember that it was just enough for me to get to class and do my homework. And I don't think I could have ever planned right symposium like this--with the quality of speakers that we have on this panel, and that we had just in the plenary, and this whole day. So, to the students who were involved in this, I just--I hope we find them today and we stop and thank them. Because this is a conversation we need to be having. And I don't see it happening enough. And so, I can't wait to hear from our panelists.

So, we have four phenomenal women. Love it...With us today.

Women power. Nothing? You know. [*Laughter*] Gotta go with it.

So, I'm going to introduce them by their names and their titles; their bios, and the materials you have. I really commend you to read them; because they do have exceptional experience. And I'm sure if you have more interest in what they've been working on in their careers after today, please feel free to come up with--come up to them after the panel. You will have time for questions. But we really are fortunate.

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We're structuring our time to make sure there is time for questions. So, each of the presenters will speak for 10 minutes. I'm going to do timekeeping, which is always fun. And then we'll open it up to questions. So importantly, use the microphones. This is a fabulous smart room. So, there are microphones at the desks. There may be one literally right in front of you. If not, we can make sure to get it closer to you. Accessibility is really critical. I struggle to hear. So, I appreciate the use of the microphones. And I speak quickly, but I'm going to try to behave myself and I think if we can all slow down in our speech, that'll be helpful as well.

So, our first speaker today is going to be Jessica Mason. She's a Senior Policy Analyst and Engagement Manager at the National Partnership for Women & Families.

And our second speaker is Joanna Blotner. She is on the Paid Leave Family Campaign and she's the manager of that campaign, which has been very successful here in D.C., at Jews United for Justice.

Then we're going to hear from Vivian Nava-Schellinger. Did I say that right? You're like a good... [unintelligible] Generous really, you're going to give it to me? Thank you. I appreciate that. Make sure when you speak, say it correctly so everybody knows. Associate Director of Strategic Partnerships and External Affairs, National Council on Aging.

And then our fourth speaker is Tina Smith Nelson, who is a Managing Attorney, AARP Legal Counsel for the Elderly. So, as I said, we really do have a tremendous level of expertise here.

A few words just to contextualize what we're going to be hearing about. Is there's just been such--I was just listening to the plenary, and this reflection about our journey in the last ten years, since the Americans with Disabilities Act Amendments Act was passed. And I was thinking in that context that a lot of what we're going to be talking about here has so tremendously grown and developed in those last ten years. The whole paid leave movement, the concept, that you could actually have paid leave from work in the United States of America. Sorry, did I say that out loud? But it's true. Really it is new. Right? And so it's really exciting: I mean--to hear about that and to hear about the usages of that; the thoughtfulness about accessing that; the thoughtfulness of that; about the people who are involved in doing that work; both here in D.C. and nationally. And even the evolution of caregiver responsibilities.

I'll speak for myself. My father passed about 2 1/2 years ago, and I was literally not in the office for-for two months. I was working for the federal government at the time, and he suffered a massive stroke right before the election. I'm just going to put that out there. Mourned my father and then the country. So, I really, firsthand, recently experienced--I had power of attorney for all medical and financial decisions--then had to fly home. And I had every privilege on the planet. Let me just say that. You know the federal government gave me a lot of time off. But I was running out of time, and I could not afford to care for my mother really. To be honest. It was my *mother* I was caring for. Does that make sense? Because of the trauma of losing her husband of over 50 years.

My father was not competent anymore. Right, and I was fighting Medicaid and fighting Medicare. Spending all my time on the Social Security Office. And this is where my background as a legal aid lawyer was incredibly helpful. My mother was like, “How do you know all of this?” Well.

But seriously *that* has evolved. Our understanding of the caregiver responsibilities as individuals has shifted. What a family is has shifted; so much in the last ten years. So again, it is a privilege for me to be here with all of you.

And I'm going to sit myself with the audience and do time keeping. So, I'm going to pass the microphone off to Jessica. And you are welcome to come here or stay there, we're a flexible crew. Thank you.

Jessica Mason² (05:50)

Sure. I'd like to stand because I got a little bit nervous when I'm talking so it gives me something you can like move a little bit. So, my name is Jessica Mason, I'm a senior policy analyst and engagement manager, which is a long title, with the National Partnership for Women and Families, which is also a long title. So, our Partnership has been around for--I think forty-seven? Forty-six, forty-seven years--long before I was there. And has fought for every major change in civil rights law, for women's rights, and has tried to fight really hard for rights across the board.

Right now, we do a lot of work across the organization on healthcare policy, on reproductive health care policy, and on workplace policies, which is where my focus is. And so today I'm going to talk a little bit about the work that we're focused on right now around getting more people, and hopefully everybody, access to paid time away from work so that they can take care of themselves and their families. So, I'll run through some kind of background, about the existing law in this country, which is—spoiler--pretty limited. Briefly, I'll go over the sort impact that has on people. And then talk about some of the policies that are moving at the federal level. And then I think Joanna will take over and tell us, give some specifics about what's happening in D.C. or what's been happening.

So, right now, the only national law we have providing for leave for working people in general is the Family Medical Leave Act that was passed in 1993. And that provides unpaid, but job protected, leave for people who have a serious medical condition, are caring for a family member (that's a limited definition of family) that has a serious health condition, or to bond with a newborn or newly adopted child. Now, it's been a cornerstone law. It's been very important; it is extremely valuable to the people who have been able to use it. But the FMLA has a pretty limited coverage level; it only covers people who work at employers with 50 or more employees; who have been at their jobs for more than a year; and who have worked 1,250 hours in the previous year. So, as you can imagine that starts to cut out quite a lot of people.

² Senior Policy Analyst and Engagement Manager, National Partnership for Women & Families.

So, it covers about 60 percent of the workforce. And then once you get beyond that, imagine how much time you could afford to take off from your job if you were not getting paid. For many of us that's very little. And particularly for the people who are most likely to need this, and least likely to have benefits from their employers, it's really, really quite close to impossible. So, the FMLA is kind of this cornerstone that has a lot of really severe limitations. And then as-as was mentioned in the plenary, the Americans with Disabilities Act provides leave potentially as a reasonable accommodation from employers. That also is unpaid. So, some people have rights to some amount of time. Not everybody has that right, and nobody has a guarantee that--that is going to be paid time. And if you don't have money to pay your rent or your medical bills, your kind of stuck.

So, the other thing I'll say about the FMLA is in the work that I do when you say, "paid leave" people sort of immediately jump to an image of a mom holding a baby. Leave covers a lot more than that. As I mentioned that is particularly important for this crowd that covers family caregiving for--for a spouse, for an elder, potentially for other family members, depending on how that's defined, and also covers people's own health conditions. Actually, we know from FMLA statistics that more than half of FMLA claims are filed for personal medical leave. That is by far the biggest use of FMLA. And so, as we're thinking about what a national paid leave policy would look like, we're thinking sort of that is the center: people's leave for their own health conditions. The second biggest bucket of leave is about 20 percent who take it for family care leave. And another about 20 percent take it for parental bonding leave. So, it's really medical leave plus family caregiving plus that baby bonding time, and in adoption and foster care.

And so that's about 20 million uses a year, which is pretty remarkable for a law that guarantees no money huh. Which I think indicates something about the importance of having that right. And critical of the FMLA, you have a right to be reinstated at your job or a similar position, and your health coverage from your employer is continued. So if you get--if you get health coverage through your employer, you will maintain that coverage through your FMLA leave, which is vital.

So. So we have this sort of ground rule, not much above that. Just about 17 percent of people have access to paid family leave through their employers. Fewer than 40 percent have access to personal medical leave through an employer's temporary disability program. And we now have six states that have passed paid family medical leave programs and D.C.--depending on, we'll say seven states. Yeah? But anybody outside of those states is, again, a little bit S.O.L. So this is particularly a problem for people with disabilities who are especially likely to be working at part time jobs, to be self-employed, to be working in low wage jobs; all of which are jobs that are much less likely to provide basic benefits like health insurance, basic benefits like paid sick days, much less a longer term paid family medical leave.

And so, kind of thinking about what a national policy looks like, we're paying--we're trying to pay really, really close attention to policy design; to make sure that as we're trying to put something in place it doesn't replicate some of the problems that the FMLA has had by disproportionately leaving out certain parts of the workforce; that are

more likely to be women, more likely to be people with disabilities, more likely to be people of color, more likely to be immigrants. Right? So, we want to aim for something that's going to be much more inclusive, much more universal.

And so, I will say for this audience, I often don't think of my work as about disability policy, because we're sort of pushing for more universal coverage of workplace policies. And so one of the things that I've been thinking about, as we've been for reasons I'll get to in a second, working more closely with people on the disability rights community, is what does it mean to try to create a universal coverage program that works for people with disabilities and that works for people who are caregivers for people with disabilities? You know, what is the specific policy parameters that we have to be paying really close attention to? And what are some of the things we need to think about ahead of time about how that policy is going to interact with other existing policies and laws? And so, we can maybe get into some of that in the discussion.

So, I'll brush over some of the statistics that basically show how people don't have enough money. Most people don't have enough money. Many people don't have enough money, that's a problem. So, I have a lot of stats about that. If you look at the resources I passed around on the handout, you can get some good talking points et cetera et cetera. But I'll brush past that since we're in a limited time schedule.

So, the two kind of buckets a policy area that we focus on are expanding access to paid sick days and expanding access to paid family medical leave. So, I'll kind of brush on both those and how we expect them to work together.

Paid sick days are a shorter period of leave. Often the law is guaranteeing these might be ensuring that workers can earn five or seven paid sick days a year. They can typically be used hourly. And typically, there's sort of a guaranteed right to take them without having to have a manager's approval. And for the shorter periods of leave, you don't necessarily--depending on how the law is written--you don't even have to tell your employer specifically what it's for or get a doctor's note or anything like that. And so, with the paid sick days laws, right now we have about a third of the workforce not covered by paid sick days; they can't earn paid sick days at all. It's much higher for lower wage workers et. cetera as you'd expect.

And so, a number of states, cities, and counties have been putting in place laws that require employers to allow their employees to earn paid sick days based on the amount of time they work. So, for every 30 hours you work you can earn an hour of paid sick days up to five days a year or something like that. And for those policies, they generally cover a pretty wide range of health care needs: whether that's recovering from an illness, taking a family member to a doctor's appointment, taking yourself to an appointment. Many of them cover needs related to dealing with the effects of domestic violence or sexual assault. Sometimes public health emergencies are folded in, yikes, school appointments, that kind of thing.

And the core of the paid sick days is having the money and also having the affirmative right to take it. And that's the thing that we have been getting into some fights about with opponents of these laws; about sort of how do you establish that? The business backlash sometimes is sort of about if they're going to be burdensome to the employer, which I'm sure is familiar to many folks in this room. So that's paid sick days.

The second bucket is the longer term paid family medical leave. That's a longer period--at the federal, level we're pushing for at least 12 weeks of leave, and that is for more serious health conditions, ongoing health conditions, chronic health conditions. The current proposal that we're working on federally is called The FAMILY Act: Family and Medical Insurance Leave Act. That's from Senator Gillibrand and Representative DeLauro. And that sort of sets on top of the existing FMLA, but would add a social insurance trust fund that all employees and employers would pay into. That would essentially pay out a paid leave benefit for just about everybody. Right now, it's tied to the Social Security eligibility. And so basically the gist of that is for the same purposes as FMLA, but not limited to FMLA coverage, anybody who needs that leave could apply for the paid leave benefit. The payment would come out of the trust fund, and then they'll be able to take the leave, which also helps spread out the cost, not overburden employers, and so on. And this is how the state programs have been working, which Joanna can talk a little bit about the details of D.C.

So, we envision that to be is adding a new universal benefit, adding that basically a benefit that's kind of a baseline standard for everybody in this country that hopefully-- hopefully--could start putting some pay into the pockets of people doing caregiving. I'd be happy to talk more details in Q and A.

Robin Runge (16:34)

Hi, yeah. Our plan is to have all four speakers speak and then open it up to questions, if that's all right?

The fear is that if we don't, we will get through all four speakers. Sorry that wasn't clear. Thank you.

Joanna Blotner³ (16:54)

Hi, good morning. My name's Joanna Blotner. I'm the Paid Family Leave campaign manager for the D.C. Paid Leave campaign here in D.C. I work for a small group called Jews United for Justice. We're one of the lead organizations on that campaign. And for those of you who either live in D.C., work in D.C., pay attention to D.C. politics, you may know that D.C. passed a paid family leave insurance program back in 2016, and we are now working on implementing that law. And the first part of that implementation happens this July; with the beginning of tax collection for the program.

³ Paid Family Leave Campaign Manager, Jews United for Justice.

Sort of what Jessica touched on; this is an insurance program that means that all people are paying into it. I'll go into that in a second. But that way everybody here in the District who works from the private sector is going to have access to paid family and medical leave. Basically, the only folks who are not covered by the D.C. law are people who work for the federal government, because we are not able to create laws that affect federal employees in D.C. We can talk about that later.

So, at the time that we passed our D.C. paid leave law, we were widely touted as the most generous paid leave program in the country. And I will say we were also widely criticized, not just by the business community and the media, but also by our local Democratic leaders that this program was too generous. It is a program that offers eight weeks of paid parental leave, six weeks of family caregiving, and only two weeks of personal medical leave. In large part, because of what Jessica talked about, that the personal medical leave is the most widely used and the most expensive component of most paid family leave programs. So, it started out with two weeks and we had to fight to keep that in there. The D.C. Council tried to take out personal medical leave *entirely*, so it would only be a family caregiving program. We fought really hard to make sure that we had at least some access to personal medical leave that folks could take and that we would seek to expand that first and foremost when the program was financially stable.

The other really great thing about the D.C. paid leave program is that it was the first program in the country to create what's called a progressive wage replacement level. That means the lower your income, the more money that you're gonna be paid when you take leave. So, you could either do, you know, everybody across the board gets 50 percent of their wages or 60 percent wages. I think it's 65 in FAMILY Act. 66. Sorry. So yes. Across the board, 66 percent of wages in the FAMILY Act. Here in D.C., by comparison our program starts at 90 percent of your wages paid out, if you earn up to 1.5 times the minimum wage in D.C. So, if you earn lower incomes, you're going to have more of your wages replaced, and that amount goes down the more you earn. Because we wanted to really create an equitable system that would allow people to really take the leave. You know if you're earning minimum wage in D.C., you can barely pay your bills or afford to stay in D.C. to begin with. Getting half of those wages is just not realistic and it means people won't be able to actually take paid leave. And so that was really important to us.

Now in other states you're seeing Washington state pass the paid leave law next. They also had 90 percent wage replacement. Then Massachusetts also had 90 percent wage replacement. Yes? Something like that, it was close. But this is the new normal that we're setting for state paid leave policies that we have these progressive wage replacement rates.

One other thing to mention about D.C. law, for those of you who this may be applicable to, D.C. has a higher threshold for FMLA law than the federal. So, if you work for a company of 20 or more employees, you are protected by FMLA, that is your job protected but no pay, job protected leave to take. It also applies to folks who are

working at 1,000 hours or a year. So, it's a little bit lower of a threshold for folks who are working hourly jobs to offer more protection.

And what we're really paying attention to now in D.C. is again this implementation piece, and how--and how the law really gets off the ground. So, like I said tax collection is going to start on July 1, and in order to do tax collection what we need to make sure is in place are regulations. And the regulations of any law kind of help to spell out exactly how this law is going to function in the real world. And for--for folks with disabilities or folks who are caregivers to folks with disabilities or to aging parents, you know the practical application of this law is what really matters. It's nice to say you get six weeks of caregiving leave on paper. But how do I actually apply for this? How is this actually impact me in my life?

So, one of the things that's really worth noting in any paid leave law; you really want to make sure that there's access to what's called "intermittent leave." And intermittent leaves allow you to take leave on a day-by-day or week-by-week basis, so you don't have to take your leave all at once, all in one chunk.

You know, long term chunks of leave make a lot of sense for folks who are doing parental leave, for example. Or if you, you know, have a planned surgery and you need all that recovery time. But for someone who has, you know a chronic condition that needs to go in for--for maintenance health appointments or physical therapy on a regular basis that's where intermittent leave really comes into play, and it's super important to have those in any paid leave policy.

Here in D.C., we do have intermittent leave. You can take leave on a one day-by-one day basis to--to be a caregiver for your own personal medical leave, et cetera. But really interestingly, the first set of regulations that came out from D.O.E.S, which is sorry, the Department of Employment Services, which was effectively our Labor Department here in D.C. The first set of regulations they put out had zero information about how to apply for intermittent leave. Zero. So that's a huge problem. We want to make sure there's really clear policies for how you apply, because you have to specify you know in your--in the notes that you're providing or the documentation you provide to the--to the agency: here's what they leave us for; here's what we're gonna be doing; here is what my schedule will be, et cetera.

How do we coordinate the schedule and the payment with D.O.E.S.? How do we coordinate that schedule with your employer and making sure that you're still going to have access to your FMLA leave to hold onto your job and get paid? And have all of those things work together really seamlessly. And again, there was nothing in the regulations there. That was one of the big things we want to flag for--for the agency that this really needs to happen, so that people can use this leave in a practical way.

One of the other things that we're paying really close attention to is how you have to notify your employer or how your employer has to notify you about your access to leave. Most people, when they think about paid leave or unpaid leave, they assume that the U.S. actually has paid leave. Every other country in the world has it. Of course, we

do. Obviously, that is totally wrong. We do not. We are like, one of three. So there's an assumption that we have access to leave or we have the assumption that our employer is going to hold onto our jobs and it's not until you get into a situation that you realize, "what are my rights?" What? How do I apply? Do I actually have access to pay? Do I have access to my job being held for me?

My, one of my best friend's, her father had a stroke two weeks ago. She works on the Hill. She is you know, one of those like very smart competent D.C. people, who had no idea what the rules were in terms of like holding on to her job. Her dad is a professor up in Pennsylvania. Like what are his rights and everything? Had no idea. You know, so again, like we think of people who are smart and competent and know all the things, and then you get into these situations and you have no idea what your rights are.

The--the most recent version of regulations that we have from D.O.E.S, again, this is on the tax, tax collection side of regulations. They have language in there that was a little bit confusing to us. That said you can--the employer only has to notify the employee in a situation of needing leave, when the employee tells you that they need to take leave from work. So that puts the entire onus on the employee to know their rights in the beginning and to know them and to be able to advocate for them when a situation arises. That is not very practical for people's real-life experiences.

Again, most people do not know their rights. It's on the employer to be able to say, you know, here's how we're complying with the law. Here's what we're supposed to be able to provide for you or here's what the government the D.C. government's going to provide for you. And so, we really want to flag that for them that that's not going to be a practical thing. It also doesn't comport with FMLA, which says when an employer is aware of need for leave you know, they email their employee or their employer or their boss and say, "My dad had a stroke. I have to go to the hospital." That is a--a trigger for the employer to say, "Did you know D.C. government provides you with access to paid leave? Here's the steps for applying." So, it's another one of the flags we have for them.

The last thing to note for folks is a lot of paid leave programs, D.C. included, state paid leave programs, have what's called a "waiting period." That means that when a need for leave arises that you would apply for that leave; you submit your paperwork, and there's is a waiting period before you're able to be paid out. Usually that's about a week. A lot of it is for administrative purposes; for the government to like go through your paperwork, make sure everything's in order, make sure you really qualify, but that can be a really big burden and barrier for folks who need access to money immediately, and for situations where like we know this is a chronic condition. We know we have a disability, and we're going to need to have leave ongoing. Advocating for waiting periods to be waived in those situations is really important. And that's one of the things that we are going to continue to advocate for with the D.C. paid leave program. So those are just some highlights of things that pay really close attention to as you're doing paid leave implementation on a practical level. Thanks.

Vivian Nava-Schellinger⁴ (27:05)

And I'm going to try to--I tend to use my hands when I speak so if I'm holding a mic, I feel like I can't talk.

Yeah ok. Can everyone hear me? No. So so? OK. All right. That's OK. We try to be flexible.

Thank you very much for having me here today and to talk about a very important--well a whole host of issues inherent in caregiving. My name is Vivian Nava-Schellinger. My father only had daughters and so I felt like even though my husband has a really long last name it was imperative for me to keep my own. So again, hashtag, women are great.

But I'm the Associate Director for Strategic Partnerships and External Affairs at the National Council on the Aging. I think what I'd like to do is, of course, like my fellow panelists gave a very in-depth, inclusive, and universal explanation of what paid leave policies and some of the policies and laws impacting the disability community, older adults, and caregivers from federal, state, and local level. But I'd like to actually take a step back, and think about caregiving in general, and really what the narrative looks like for those who are caring for persons with disabilities, or those themselves that, you know, maybe one day will become a caregiver. So really thinking about how we shape the narrative of what that looks like today.

At the National Council on Aging we focus, of course, on older adults, and what it takes to recognize that there is really no one size fits all to aging in this country. And if we aren't talking about every single community, then we've left out someone. And so imperative in that narrative of caregiving is to focus on the fact that ultimately caregiving is an everyone issue and inherent in that issue are issues on aging. If we're lucky enough, we get to age. And so, restructuring and shaping that narrative in this country is imperative to the work that we do.

I'd like to talk about really two things. One is, again, what is caregiving look like. The odds are pretty good that all of us in this room will be a caregiver. Some of us *are* caregivers currently or will be a care recipient. Or both at some point or another in our lives. I'd like to focus on that, and also think about who are caregivers in this country?

We know at the National Council on Aging that close to 75 percent of caregivers are women, and because of that we've really shaped our focus--for at least 2019 to focus--on women. And how really whether it's caregiving or aging in general and issues that really are inherent in that, how women really are driving the narrative, and shaping the narrative, and really taking control of what it means to age in this country. We are actually having a national conference this year July--July 17 through, sorry, June 17th through 21st, here in D.C. It's the Aging Action Conference, and we are focusing

⁴ Associate Director of Strategic Partnerships and External Affairs, National Council on Aging.

primarily on women. We know that women are disproportionately impacted by aging, and black and brown women are disproportionately impacted at even higher rate.

Because of that, there are a lot of stressors when it comes to caregiving. We know that half of African American and Hispanic Latino caregivers find themselves sandwiched between caring for an older adult and a younger person or persons under the age of 18. And oftentimes, those that are receiving care are persons with a disability. I know that I'm personally, I saw my mother care for my grandmother while she was trying to raise two--two adolescent kids. And I know that ultimately, I will be a caregiver myself as an eldest daughter to my sister who also suffers from a chronic condition. And I know that inherent within, kind of again, that cultural lens of caregiving, that we see in black and brown communities and other communities. You know it's something that really is a family issue. I think my colleague here said that you know, when talking about paid leave or these policies that are very important to not only persons with disabilities, but caregiving in general, that we do need an aim for something more inclusive and more universal.

At the National Council on Aging, we are recognizing that those policies and programs that we hold near and dear: Medicare. [*Sneeze*] Medicaid. Bless you. Medicare. Medicaid. SNAP also known as food stamps. And ensuring that seniors have what they need to age well, and age with dignity, and economic security, is inherent in the caregiving narrative.

We at the National Council on Aging, we have programs and resources that elevate--that alleviate the stressors of caregiving for caregivers, while also preserving the autonomy and dignity of the care recipient. We try to forge partnerships with providers and doctors and communities across the country because I think that's also an issue that needs to be really talked about and advocated for. Caregivers and care recipients are-- regardless of whether they're an older adult, or younger person with a disability, or somebody suffering from chronic condition--caregivers are part of a health care team, really. Not only are caregivers thinking about the best way to communicate the needs of the care recipient, but they're also at times trying to manage both the relationship with the provider, the care needs, medical needs, and then maybe even communication and relationships with other specific specialty providers as well. And that can get really, really complex.

So, the coordination of care is a huge daily lift. And again, that goes to the narrative of who as a national organization we are really reaching out to and forging partnerships to make sure that caregiving is at the heart of family issues. We have programs and resources from our Center for Healthy Aging; our Center for Benefits Access, that alleviate again the burden and the stressor on caregivers by, at the end of the day, putting more money in the pockets of those that are caring for older adults or persons with disabilities. We do that in a couple of ways.

Primarily one of the tools and I actually left these cards, these really little cards, and actually had to hand out to lift an Uber driver, I carry in my wallet. And it tells you a little bit of information about our benefits checkup tool. The benefits checkup tool was a

tool that we created close to 12 years ago. It's a free online resource where you can actually check if you or the person you're caring for, your older adult, your person with disabilities, qualifies for additional federal, state, and local programs. Everything from Medicare, Medicaid, down to vouchers for farmers markets, that are given through the SNAP program. And so Benefits Checkup, again prescription drugs, medical costs, food, housing, rent, in-home services, and more and so you--you log into the tool you put in just very, very basic demographic information; really what triggers it is your zip code and your income level or the income level of the person that you're checking for.

I've used it with so many family members and friends and what the tool does is then it generates a whole host of benefits. Again, federal, state, local, level that are specific to your search. So, if you'd like to just look at health care benefits, great. If you're a veteran and say the person you're caring for is a veteran as well, then that's something that you can check in your query. And then the applications to these benefits are actually directly linked to pop up as a PDF. It's mobile friendly so you can do it while you're in line at the grocery store.

But the benefits checkup tool really is are--thank you--really is one of the tools that we hold near and dear to help families that are experiencing, and you know I don't like to say burden, because I think back on taking care of, really as a family effort, taking care of my grandmother, and it never felt like a burden. It just felt like how we express love. And so, I think it's more about stressor. The stressors that the caregiver experiences. And it really more at the end of the day, more money in your pocket. You know increasing your income every month. It does help to alleviate the stressors.

Another way that we are continuously thinking about how to shape the narrative of caregiving are our advocacy and policy efforts. We are at the cusp of the reauthorization of the Older Americans Act. And inherent in that is preserving those gains that we've made in Medicare, Medicaid, and SNAP, especially with this administration. It's been an uphill battle, but we've really gone to bat and I'm proud to say that.

And why is it important for us to continue to shape this narrative in regard to caregiving? It's important to recognize again that there is no one size fits all to caregiving. Or to how we age well. This means something different to everyone. And I think over 65 years that our organization has been in existence, we have really done our due diligence in the last couple of years to say, we need to put out resources, materials, services and connect with those in the community that really actually have a voice that need to be heard.

And then lastly, I'll say that caregiving must be highlighted through an intersectional lens, really. Again inherent in that narrative that there's no one size fits all to aging, we need to understand that caregiving looks different based on geography; based on transportation needs; based on whether you're living in the rural frontier; you're living on the border; or you're living in an urban center. It's going to look different. And so, because we have advocates working at the federal level to ensure that there are federal policies that take into consideration that there is no one size fits all. We do,

you know stand with you, in your best efforts to ensure that we're becoming more inclusive and more universal in what we do. So, thank you. [*Applause*]

Tina Smith-Nelson⁵ (38:00)

Good morning everyone. I'm Tina Nelson. I'm with Legal Counsel for the Elderly. We're an affiliate of AARP. Legal Counsel for the Elderly: We provide free civil legal services to low income seniors here in the District of Columbia. We have a Housing Unit. We have a Consumer Unit. We have a Public Benefits Unit, which I supervise, and we also have the D.C. Long Term Care--Long Term Care Ombudsman as a part of the Office of Legal Counsel for the Elderly. So, again, I supervise our Public Benefits Unit.

And today, I'm going to talk to you all on a local level about a crisis that we are seeing here now in the District of Columbia that's affecting individuals who are receiving benefits through the D.C. Medicaid program. So, within our Public Benefits Unit we represent individuals with disabilities who are seeking public benefits such as Social Security, Medicare, and Medicaid. And in the District of Columbia, and actually every city, in every state, there is a program under which individuals who need nursing home level care can receive those services in-home. So, in D.C. that program is actually run through the Department of Health Care Finance. So, what it allows is, again, allows beneficiaries to receive a nursing home level of care in their home and in their community. Because we know that seniors and anyone with a disability tend to thrive longer and live longer and have better health outcomes if they're aging in place in their homes, as opposed to a nursing home or some other type of long-term care facility.

And under the D.C. Medicaid program, it allows an individual, a beneficiary, to receive a number of personal care aid service hours that allows them to, again, maintain their residence in their home while they're aging. So, in D.C. there are two types of D.C. Medicaid programs for which beneficiaries can be eligible for: and that's a state plan program, which would allow beneficiaries to receive up to eight hours per security services in their home; and then there's a program called the EPD waiver, which is the elderly persons with physical disabilities waiver program. And it actually allows up to, in theory, 24 hours of care in your home.

So, whether you're receiving services under the state plan or under the EPD waiver, basically the beneficiary is allowed to have a home health care aide. That provides personal care services to help the beneficiaries with what we call ADL's. And ADL's are activities of daily living: so eating, bathing, toileting, dressing, and transferring; as well as some IADLs, which are instrumental activities of daily living. And they include things such as preparing meals, money, management, housekeeping, and shopping. So, under this program, again beneficiaries are allowed to receive these services in home as opposed to being in place in a long-term care facility.

⁵ Managing Attorney, AARP Legal Counsel for the Elderly.

Well, in 2018 in September, the perfect storm hit the District of Columbia. The Department of Health Care Finance rolled out three new portions of this Medicaid plan. They hired a new medical director. They hired a new assessor called Liberty Health Care. They implemented a new assessment tool; the tool determines how many P.C.A. hours you're allowed to receive in your home. And they implemented a new case management system. And we had meetings with the Department of Health Care Finance prior to September to tell them, "Why don't you have some type of pilot program? Because we can see out rolling all of these three new things at one time will create some problems with regard to the services that are being provided to beneficiaries in the District." And, unfortunately, our greatest fears were actually realized.

Since September, my office--we have had at least 200 calls for assistance for clients who either have had their personal care aide services hours terminated or reduced. So, they no longer meet the level of care to receive D.C. Medicaid services. So, there's these new assessments that are conducted by the company that I told you is called Liberty Healthcare. Right now, they are reassessing all beneficiaries in the District of Columbia to see whether or not they are eligible to continue receiving PCA services under the D.C. Medicaid program.

So, they're--they're reassessing individuals who are up for recertification; because every year you have to go through a recertification process to make sure you're still eligible for the program. And they're also assessing all the beneficiaries generally just so that they will have a baseline going forward on the next recertification period. And they are using this new tool called "Into Ride" that will determine and kick out a score as to how many PCA hours a beneficiary is entitled to. So, we have a nurse that's coming to the beneficiary's home and doing an assessment.

The information is put into this new interactive tool, which uses some kind of algorithm to determine how many hours you have received. So, since this program was out rolled in September, we have seen numbers, and numbers, and numbers of individuals within the District of Columbia having either their PCA hours reduced, or their level of care terminated. So, we brought this to the attention of the Department of Health Care Finance, and these are some of the things that we have pointed out to them. One that there wasn't--there has been huge number of inappropriate reductions in PCA hours with no improvement has occurred, including in some cases where medically need has actually increased. We know--we know in a perfect world we want people to improve, but we know that that really does not always happen, especially as people age. So, to say that someone is improving, and they need less hours, really is beyond our imagination. How this can actually happen? Because most of our clients either stay the same or their health actually decreases.

There's also, we would point out to health care finance, a failure to incorporate evidence of medical conditions into the program. There was a prior assessor, called Delmarva, the new Liberty Assessors are not looking at the past history of the beneficiaries. So, they're not looking to see--receive how many hours did you receive in the past, what were your medical diagnoses and proceeds in the past? And they're just

starting from scratch. And we're saying that they need this historical data to make a better assessment as to whether or not an individual should keep the same number of hours, should have an increase in hours or a decrease in hours.

But the most startling thing for us, especially as advocates, is there's been either no notice provided to the beneficiary or inadequate notice provided to the beneficiary. So, we have been--had--under this new case management system called "D.C. Care Connects." Right now, whenever an assessment is done by Liberty, the information is put into the new system, and the home health care agencies and case managers see it immediately. And so, when this assessment has been completed and they say, "Someone's hours were reduced from 16 hours to 3 hours," they would automatically reduce those individual's service hours without any notice going out to the beneficiary, which is against the law.

So far, we've been filing hearing requests. We have case management agencies calling in and filing these new hearing requests as well, because you have to have a notice if you want to take someone's benefit away. We also have found out that the assessments results incorporated into the process of a care plan without proper notice of the beneficiary. And there's failure to include Powers of Attorney, agents, and guardians in the assessment meetings with the beneficiaries. And the assessment tools were improperly limiting beneficiaries to receiving 19 hours PCA hours; when actually in D.C., you are allowed 24 hours. But the new tool was capping it at 19.

Then we also found, astonishingly, that cognitive impairments were not being taken into consideration when determining the number of P.C.A. hours that a person was entitled to. So, we have extreme examples of clients that have been reduced greatly. And how does that impact the beneficiary as well as the caregiver? We have individuals and beneficiaries who are losing benefits and services that they are entitled to receive. We understand that 36.5 percent of the reassessments done by Liberty have, have led to a reduction of at least two hours. And 14 percent of those have lost level of care completely. So that means that people are being moved from aging in place in their community to going into nursing care, to nursing homes. And in D.C., there are not enough nursing home beds. And so, we have individuals actually going to Maryland and Virginia. And so, they're creating family dynamics issues as well.

And then there's also the how it impacts caregivers. Because someone has to make up those hours. And if I'm reduced from 16 hours to 2 hours, then what happens to the other hours I was that I was given? Oftentimes, the caregivers have to come in and step in at that point to make up those decreased hours. And so, it's impacting beneficiaries. It's impacting caregivers. It is impacting advocates. It's impacting the courts. And so, we're working right now to--with all of our stakeholders, too--to come up with a solution to these--to this issue, this crisis that now exists in D.C. Thank you. [*Applause*]

Robin Runge (48:50)

Thank you, Tina. Thank you to our panelists. I think this has been a great--I've learned a lot--and a great overview. And as I sit here, I'm thinking about you know this intersectionality. And as several of you said, you know, we are each individual, we're going to be placed in our lifetimes likely—right?--as a caregiver, or as an individual with a disability, legally defined or otherwise. And some of us may experience those things at the same time. Right? And so, what we heard from this, which was so wonderful, right, is a [unintelligible] analysis as a big picture level right from that perspective. Through becoming an individual with a disability through the process of aging, but then also as an individual who wants to care for an individual with a disability who may be through an aging process. Right?

And then also this really critical piece about what all of this highlights is what are the systems in place in this country? And what are the legal protections in place in this country for individuals with disabilities and caregivers for those individuals to maintain employment if they want to? Right? Stay in their home? Right? This is a costly endeavor. And I think we've heard some highlights, some--some bright notes, bright notes being that finally the United States *is* starting to move in the direction of recognizing the need for paid family leave and paid sick days and we heard that those are two different things that are intended to work together. And I really appreciated the point that Jessica made, which is when people think of the Family Medical Leave Act, or they think of paid family medical leave or paid sick days, they think about this in the context of maternity leave; *because we don't have that either.*

But in fact, as someone with a non-visible disability, I have allowed myself FMLA--Family Medical Leave Act--time to care for my own serious health condition, and I have absolutely availed myself of that to care for my aging parent, who has a disability. So, I really appreciated bringing that piece into this. And Tina, I just want to say the closest that you described here in the District of Columbia about what we recognize about the need, and the viability, and the importance of individuals to age and live where they want. And that we know that there is a direct health consequence to that. That people live longer healthier lives in their homes. And yet, we have systems that are not, not making that possible--financially or otherwise. And the ripple effects that has, as you describe and it's a microcosm. I happen to know this is happening in Illinois, which is where my family is. Right? In states all around the country. So, I appreciate the level of detail you gave us. Because it's a real opportunity to hear about how these systems, which are intended to work for us, are failing and for us to think about how to do that.

So, with that, I want to open it up to questions; and remind everyone that--Ooh, we've got hands. This is fabulous. I want to try to keep a queue. Reminding you, you have a microphone in front of you and I'm going to ask you to utilize that. When you—[*Sneeze*] bless you-- ask a question, please introduce yourself. And why don't we take a couple of—three? We have three hands here, is that alright? And then go to the next group. OK. Bob? OK I think you've got to push that button there. There's a green light situation and you have to hold it, I think. Push and hold.

Audience Member #1 (52:30)

Alright, I'm not pushing hard enough. Hi, thank you. I was wondering, I've heard about QMB and I was wondering how that works with Medicare and Medicaid. Where that fits into the picture?

Audience Member #2 (52:49)

It would be great if someone would define QMB.

Robin Runge (52:51)

Yes, I think one of our panelists will. And I saw two more? Is that right? And I think you have a hand? Yep. And then you. If you can use the mic, that's great.

Margaret Worthy (53:00)

My name is Margaret Worthy. Is it working?

Robin Runge (53:02)

Yes.

Margaret Worthy (53:04)

Actually, I have two questions, but I'll just ask one for right now.

Robin Runge (53:06)

OK. Thank you, Margaret.

Margaret Worthy (53:07)

I was curious when you were talking about the FMLA, and whether or not if you've had people who found themselves running into the intersection of being declared "not fit for duty," because their leave had extended some--some specified--maybe non-specified point, but as you know it had gone on for a moment.

Robin Runge (53:32)

Yeah. Margaret, what you highlight is--there's two great law review articles have been written on this--it's called the Bermuda Triangle. That's not uplifting, but it's the truth. It's the Bermuda Triangle for individuals who need to take extended leave. And the travels. What are the protections under the Family Medical Leave Act, the Americans with Disabilities Act, and then worker's compensation system? Right, because not infrequently, the illness or condition from which the individual is seeking time off may actually be exacerbated or caused by a workplace-related injury. So that's a great question for our panelists and then, Paula, you want to try that mic in front of you first? You got to hold it down. It's a little tricky. Let me know if you prefer this OK.

Paula Madison (54:22)

Hello, my name is Paula Madison. And I was just asking about the paid family leave. Is that only for people who are working full time, and not for people who are part time employed or people who work for temp agencies who, you know, go from assignment to assignment and are working under 40 hours a week? Thank you.

Robin Runge (54:45)

That's a great question. That goes to the inclusivity and recognizing the shift in the workforce, right? That is increasingly kind of Uber-esque, for lack of a better description. So, we've got three great questions. One with an alphabet thing that I don't understand. Tina, you said you wanted to take that.

Tina Smith-Nelson (55:02)

Great I'll take that one. QMB is Qualified Medicare Beneficiary. Well, basically when you have Medicare, there are four parts of Medicare: A, B, C, and D. Some of your Medicare premiums are paid from your Social Security benefits. So, if you, let's say, are on SSI or you, or you meet whatever the level is, yes. Yes. Then, the District of Columbia will pay your premium. Your part, is it part A or part B? Part B premium under the QMB program. So that's an application that you would complete, and you would submit it to the Economic Security Administration. And once this process--then, then, the District, then government pays for that portion of your Medicare premiums. [Inaudible] No, it does not.

Robin Runge (56:11)

So, going to just—we're moving into legal advice now, which makes me nervous. So, I think Tina and her colleague would be happy to follow up with you with additional resources. I'm sorry to cut that off, but I don't want to put anybody in an unfortunate condition. OK. So, the second question was from Margaret. You folks remember what the question was? Who wants to take that?

Margaret Worthy (56:33)

Oh no. I didn't ask it.

Robin Runge (56:36)

Yeah you did. You asked a really good question, which is, what if the effort relieve--yeah, your question. You asked about what happens, right? If people need to take that leave longer?

Jessica Mason (56:48)

I can, I can give a short answer, which is that I don't know the answer to that question. But I can get your contact afterwards and check back with my colleagues. Yeah.

And speaking to, I think, part-time, full-time coverage. That is a critical question and one that I think I've personally, until I had my current job in D.C., I was never covered by FMLA, because I always had short-term contracts that were often part-time. So well, anything at the federal level and would cover all workers who are covered by Social Security. So, part-time, self-employed, short-term, multiple jobs would all pay and be accounted for, if it's--when it's passed. I'm going to say, yes. It's something we're paying a lot of attention to because it's been left out of other things.

That's the goal. Yeah.

Joanne Blotner (57:41)

And just a follow up on that from a D.C. law. Our law does cover you if you are a part-time, self-employed, full-time. Doesn't matter. Your benefits are paid relative to the amount you are working and relative to the wages that you were earning. For self-employed folks, you can opt into the program; you don't have to take part in it, but you can choose to take part in our--in our paid leave program.

And just a really quick point to Margaret's question. One of things that makes me very nervous about paid leave programs from like a bad actor employer perspective is the assumption of well now if we have to pay for paid leave, I'm not going to hire people who have disabilities, or chronic conditions, or are likely to have a child, or other reasons that they may be become more costly. And I think that's actually one of the really important things to keep in mind is we're how we're designing paid leave laws.

There are two real ways to make paid leave a reality: one is by asking employers to pay for benefits out of pocket and have their own internal policy; the other [is a] social insurance program that either the employers pay for or employees pay for. When employers pay for things in insurance land, it really means employees pay, because it gets factored into your total wage compensation. And that's one of things to be really mindful about in advocacy. That's why Jessica and I both work on things that are insurance minded. Because they, they reduce the likelihood of incentivizing discrimination. You know the cost for me is the same as a cost for, for anyone else. Even though I don't have a disability that is, you know, visible or invisible. You know, I am not a higher cost to an employer than, than someone who you know says they're planning to have kids the next two years or planning to be a caregiver for an aging parent. So, neutralizing that cost and making sure that everybody, whether it's you know men, women, no matter the age, are all looked at the same by the employer.

Vivian Nava-Schellinger (59:42)

I just wanted to touch on that. That the NCOA, National Council on Aging, is what we're also talking about is really with 10,000 older adults turning 60 every day. That means that they are using, across the country, bad actors are, using age as a proxy for discrimination. And to be able to say, "We don't really want to hire you because you just have such a wealth of experience." That's actually legal language in appellate court decision recently.

And so really using "experience" in that way to-to-to say, "We don't want to hire you." What we're seeing, is again, just a detrimental impact to all older adults who are trying to seek re-employment. You know, they may have had careers of 20, 30, 40, 50 years; but ultimately, whether it's a caregiving issue, whether it's just really a daily income issue, I mean they have to go back to work. And when they are applying for these positions, which they are absolutely qualified for, they're being told that they're too experienced. So whether that's inherent in some of these protections that are really at the table, and saying well we really just don't want to have to pay for that as an employer or it's really just making sure that we're highlighting that those things are happening in this country. And so again it really shapes the narrative on how we look at work. And Robin, you said something, you said, "How we're defining need and viability in this society," and that really struck me.

Robin Runge (1:00:21)

Thank you. I would just add that you know for those of you who were able to go to the fabulous plenary this morning, we heard a lot about implicit and explicit bias. And that's really prevalent in what we're talking about here. And as you know as a woman I can guarantee you, that I had a phase in my life when I was still of childbearing age, ha ha ha, when they would ask me...in interviews, this is in the 1980s and 90s, "So are you planning to have a family?" You know. So, this has been present forever. Since the dawn of time. I see a lot of sisters in the room nodding. And the women on stage right now are in full employment.

This is a very interesting moment for these implicit and explicit biases. We see these present in a way that you might not otherwise. And so, there's just a flag. There is a law, federal law that prohibits discrimination based on your age, if you're over the age of 40. Right? So, there is a law that acknowledges exactly what Vivian was just talking about. And there was we heard Jessica and Joanna talk about that we have paid and unpaid family leave, often with anti-discrimination and anti-retaliation provisions. So that in theory, you should not be retaliated against for utilizing or accessing those things. And then the Americans with Disabilities Act that we've been talking about and heard about this morning, also has a very robust anti-discrimination and anti-retaliation provision. And then, I'll just add onto that the Title VII of the Civil Rights Act, in every state in the District of Columbia has an equivalent, also prohibits discrimination in terms of conditions of employment based on race, sex, national origin, color, and religion.

So, getting to the intersectionality point that you all have just highlighted in your comments is that we may see people struggling to utilize these limited resources to paid and unpaid leave not just because they're a woman. But perhaps because they're women of color who is a caregiver. Or a man who is Spanish speaking who has a disability.

And we need to think intersectionally as lawyers. That is a different claim. That is a different injury, and it requires a different benefit.

And Tina, when I think about the work that you are doing with the AARP Legal Counsel, and that's where you see this every day. I'm certain of it. In the provision and the denial of benefits. Right. I know and I've seen the statistics. That women of color are denied at higher rates than men, than white men. And that's—we need to understand that when we're analyzing and understanding, and I appreciate so much, Joanna, what you said. How do we write these? Things we can't prevent. And respond to all forms of violence. But we have to recognize that, and integrate that, into how we implement, draft, and think about that. So, I really, I mean.

Your question, Paula, about recognizing what percentage of the workforce is people who are in a full-time job now. But you know, with that full-time job comes benefits. Right? It's decreasing every day. Either some would argue by choice, and some would say, "Not." OK.

We've got time for another set of questions. I've got four more. So, I think we're going to squeeze them all in. Martha, I'm going to come to you. There are two women behind you. Can you try to use the microphones by pressing the button and introduce yourself please? And if not, I'll come around.

Stacey Cloyd (1:05:00)

Hi. My name is Stacey Cloyd and I was wondering about how the process for disability determination works in the states that have paid leave. I spend a lot of time thinking about disability determination and Social Security disability, where it is a slow process and often requires many stages of appeals. In short term disability, you don't have that same timeframe. And so, what resources do you need to make the decisions quickly and accurately? And within the context of the FAMILY Act, how do you make sure that Social Security would have the administrative funding that it needs to make those additional?

Robin Runge (1:05:41)

Great question. I saw your hand.

Adrian Gottshall (1:05:44)

Hi, I'm Adrian Gottshall, I'm at the D.C. Bar Pro Bono Center. I have a question about returning to work following parental leave. I've had two friends ask me, and I did not have the answers. Maybe one of you do. They both work in D.C. they're brand new

parents. They're returning to work. One has requested an eight to four schedule instead of a nine to five schedule. One has requested to have Fridays off by working 4/10s as opposed your typical 9 to 5, and they're getting a little pushback. And they're asking me, "Isn't there a legal protection for this?" And absent a reasonable accommodation for disability, I wasn't sure that there is. So, I'm wondering if there are any accommodations, for maybe new parents returning to work following parental leave?

Robin Runge (1:06:27)

So, I'm just going to ask a clarifying question before we go to the panel. There's no such thing as a parental leave. Well, there's Family Medical Leave Act that can be used. So, I just want to clarify, if the leave they were taking. And they both took it as parents, which was related to the birth of the child and care for the child. OK. Just when I thought that might be helpful to all of you. And then I saw two more hands. OK. So, you have your second question. I see that woman over here. You want to try the mic or do you want me to give you the mic.

Martha Worthy (1:06:58)

All right. Actually, this is more of a comment for the last speaker. I just wanted to say that I've been around a lot. And I remember when a lot of these protections came about. And I was just gonna say a lot of it was based on cost effectiveness. And so I'm just thinking that health care finance may need to be reminded of the cost effectiveness of having a personal care aide in the home versus the back end of having to pay more Medicaid for more services, or having to pay for someone being in a nursing home—and how, my goodness, just an inadequate assessment tool caused all of that.

Robin Runge (1:07:48)

Great comment. Sarah?

Sarah Harper (1:07:50)

Sarah Harper with the National Women's Law Center. And I do a lot of work on the Child and Dependent Care Tax Credit. And we work on pairing that with advocacy for direct childcare assistance. And so, we're thinking about expanding more work on the dependent care side. And what are some gaps in public benefits for dependent care that we can compare that with? Because like, this little tax credit is in solving the childcare crisis, and that's why we need to work on that front, but also, it's not going to solve the dependent care access issues that we have.

Robin Runge (1:08:28)

We've got four good questions. We've got a question about determinants of disability, right. And then we've got a question that's leading into legal advice. But I think we can give some general information. Then Margaret's fabulous statement, and Sarah's question about the dependent care. Who wants to go first? Everybody's got something. I'll start with you, Tina. We just, you know.

Tina Smith-Nelson (1:08:46)

You brought up a really good point about the costs. Because our theory is--even though health care finance is denied it--is that these reductions and terminations are really determined by cost. Because CMS is sort of a Medicaid and Medicare Services has basically advised the District of Columbia that they have to meet cost-neutrality; which means the cost of providing care in a nursing home has to be at least equal to or less than the cost of providing care in the community. And so, we--we had a meeting with Health Care Finance a couple of years ago and they told us they were getting to the point where they were not meeting cost-neutrality. Because the cost of providing the care services in the community is bound to outweigh the costs of providing nursing home care. And so, this new assessor comes in, Liberty, and all of a sudden everyone's getting reduced and terminated. So, guess what? The cost-neutrality is going down. So, we believe that is definitely a factor.

Joanne Blotner (1:09:51)

Go down the line. All right. So, Adrian responding to your question: in D.C. there's, in addition to FMLA, there's a pregnant--Protecting Pregnant Workers Fairness Act, and this only applies to birth mothers. So, dads and adoptive parents are not going to qualify. But there is universal access to job protection, to anti-retaliation provisions, and to reasonable accommodations. So--and most employers do have--do not know about this. It is not well advertised. It's administered by the D.C. Human Rights Office. They should absolutely exercise those rights. They should remind their employer that this law exists. Those are very reasonable accommodations that they should be able to access.

Yes. Yes. But it also relates to caregiving after the fact, including breastfeeding, including you know personal medical, you know healing recovery. So definitely look into that and have that happen. And I will also say that 99.9 percent of the stories I heard around paid leave in D.C. were around bad actor employers. And these are, you know, like your fancy law firms, and you're a very social justice-y law nonprofits. Who, when their employees have babies, do not like the burden that it puts on them. And who make it very difficult and do all sorts of weird random things, including like moving someone's desk to a weird corner in the office or right in front of the bathroom.

And one woman who actually works for the D.C. government who was going through chemo, and they moved her office right in front of the bathroom, and it's like her immune system is compromised. And he moved her--her desk and workstation right there in ways that are gonna be completely detrimental to her health and recovery. But it's a desk spot no one wanted. You know, it's just this is an unfortunate reality. They are not alone in this. But we do have decent laws in D.C. that can help them advocate. And if they need legal counsel, First Shift Justice Project is by far I think the best program in D.C. that advocates for working moms and Laura Brown would be a fabulous resource for them. Yeah. [*Laughter*]

And just very quickly on the disability termination for paid leave states: I don't think that we have a super clear definition, Stacey, and how that's going to work in D.C. The idea in D.C. and that has happened in many other states that have paid leave is that, really it is based on doctor note and--and medical providers certifying whatever information they need, and submitting that to the administering agency in the state to review and make sure that it qualifies. You know in D.C., the disability personal medical leave is two weeks; in California it's 52 weeks. So, you know you've got a huge range between there of the kind of leave someone would need, but a lot of it would be dependent really on-on doctor notes and--and then the independent jurisdiction of the agency. They try to match that best they can with them with codes in the medical space; of like this--this type of leave, this type of disability, the type of illness is going to require this much care, and this type of like treatment, and maintenance. But it is a lot of discretion, for better or worse.

Jessica Mason (1:13:27)

I can speak a little bit to the timing because that is something that we've said in the advocacy community, as well as academic researchers, have been looking into a lot in the existing state programs, especially in California, New Jersey, and Rhode Island that have been in existence for the longest time, about how long does it take to process a claim? Like when do people actually get their money? Because that is sometimes a particular barrier for lower income people.

And so, it's been a little bit hit and miss in different states. A lot depends on exactly who was in charge of the program once it was rolled out. For example, if the program passed under one administration, and someone else got elected right afterwards. So, these kinds of things that have to some extent, made the programs less effective than they could have been. And so from state to state it sort of depends on who's been in charge, whether that turnaround time is a week or two or less, or whether you know we've heard some horror stories, particularly from New Jersey, where people don't get their check until they're already back at work.

And so that's something that the state now is really doing a lot of work on. To speed up their I.T. processes, and speed up their application processes, and try to streamline as much as possible, like how much data you actually have to go out and collect from people, you know compared to what you might already have on file somewhere. And so those are also things that we're looking at really closely ahead of, fingers crossed, passing a federal program. So that we have kind of taking those lessons into account when we're thinking about rolling out something nationwide.

The Social Security Agency funding is an absolutely critical question and something that I hinted at in my comments earlier, but didn't get into, is this is both about proactive policy design and about other things that are being proposed. So, the FAMILY Act does include specific funding to start up a new office and program in the Social Security Administration, which is absolutely essential. If you're going to stand up a new program you have to have staff, you have to have I.T., you have to have actual funds to pay for things, and so that--that bill does include funding for Social Security.

Some of the alternative proposals that we've been seeing, most recently from Senator Rubio, from Senator Ernst and Lee, Senator Romney, I guess, have been---not only not proposing--they've been proposing essentially to create a new parents only, baby bonding "leave program."

Leave program in quotes because they haven't so far contained any job protection whatsoever. So, you have no particular right to take leave. And what these programs are proposing to do is pull money out of the Social Security old age trust fund to give to new parents. Unclear how it gets paid back. And then at retirement people are supposed to delay their retirement, which as we know a lot of people don't get to choose when they leave their job at the end of their careers. So, it poses problems at both ends of the spectrum. And so far, they have not, and they have not contemplated providing any new funding for Social Security to do any of this. So, it just...it raises a lot of sirens across the board. And it's something that we're thinking about really a lot and pushing back hard both on the lack of comprehensive coverage, as we've been talking about, and also these just disastrous funding mechanisms that would be really bad for Social Security, and also really bad for the people using them. Nobody should be penalized for taking time that they need.

Robin Runge (1:16:47)

And I would just say as a follow up: there's no such thing as a right to a reduced work schedule after coming back from paternity leave. Period. Just because you're struggling with day care getting it. That's what I see my friends dealing with all the time. The first few months after you get back like--whoa.

You know like, I have one of my friends just come back as a single mom and literally three days before she says to come back her childcare arrangement fell through. This happens all the time. Right? And so, you know, but for the fact that she was in a union at my organization, she was risking losing her job. She had...It was you know; she didn't have--it wasn't just about pay. So, I think it's a really real is that similar with every caregiving responsibilities. I know when, I know I was struggling, and I need to get back to work. It wasn't just about pay. It was about keeping my *job*. You know nobody cares about the fact that there--some--some booklet wrote up that, "Oh that illness was supposed to last this long." Right? Or that disability after this period of time is supposed to have figured out Medicaid and Medicare and gotten a personal assistant. Never mind the fact that you have a parent who doesn't want a total stranger in their house. I can just go on and on. Right? Like, there's no structural accountability for any of that.

So, I want to thank our fabulous panelists and all of you.

[*Applause*]

And again recognize UDC Law, and Professor Karin, and all the students who have worked so hard to make this possible. So, thank you.