



NCAPPS Webinar Transcript: “Love and Disability - Exploring Person-Centered Supports and Marriage Penalty”

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SPEAKERS:

David Goldfarb, Lydia X.Z. Brown, Shain Neumeier, Al Lewis, Renita Bundrage, Kile Pelletier, Stephanie Pelletier, Ayesha Elaine Lewis, Alixe Bonardi, Bevin Croft

Alixé Bonardi 0:00

We are going to get started now and welcome to today's webinar. Let's move to the next slide please

Alixé Bonardi 0:16

My name is Alixe Bonardi, and to provide a brief visual description I am a white middle-aged woman wearing dark framed glasses. I'm wearing a burgundy sweater and I'm in my office with an abstract print behind me and a festive poinsettia on the desk beside me. Welcome today to today's webinar. I am one of the co-directors of the National Center on Advancing Person-Centered Practices and Systems and along with my other co-director, Bevin Croft, and our team here at HSRI, we're delighted to welcome you. Thank you for joining us to learn about the marriage penalty for people with disabilities and what that means in the context of person-centered supports. We would like to thank the Administration for Community Living and Centers for Medicare and Medicaid Services for funding this webinar and our center and for making these webinars free and open to the public. Next slide please. The National Center on Advancing Person-Centered Practices and Systems is essentially designed and to promote systems change that make person centered principles not just an aspiration, but a reality in the lives of people across the lifespan. We have many, many different aspects of the work we do to focus in on making sure that supports for people particularly people with disabilities are person centered. And today's conversation will bring additional richness to the con the whole construct of person centeredness. Next slide please.

Alixé Bonardi 2:16

A few webinar logistics before we get into today's webinar. As you will note participants are muted during this webinar. However, we have the chat feature open, and we encourage all participants to use this chat feature liberally. This is a place to ask questions for people to share their excitement about the conversation that is happening, share ideas and resources as well. Toward the end of the webinar, our speakers will



have an opportunity to respond to questions aloud as time allows. Please do go ahead and enter your questions into chat. Because even if we do not get to every question, we do make sure that the speakers have a chance to review questions and we can make those responses available afterwards. This webinar will be live captioned in English, and live interpreted in Spanish. And there are instructions being entered into chat for accessing the captions and for Spanish interpretation as well there are on your screen. There are also descriptions of how you can access live captions by clicking the CC button at the bottom of your zoom screen and live Spanish interpretation by clicking the interpretation button as well at the zoom at the bottom of the Zoom screen where it looks like there's a little world icon. This live webinar, we are going to have one poll and end evaluation questions at the end. So, we appreciate you being prepared to interact with polling at those times. Next slide please. And after the webinar, you can send follow up questions and feedback to about this webinar or any questions you might have to our web address, ncapps@hsri.org. Please note this email address is not being monitored during the webinar so you can reach out through chat if you are having issues or questions. An important thing to note is that the recorded webinar this entire webinar, along with a version of slides and a plain language summary will also be available within a few weeks on our website ncapps.acl.gov. And at that time, as I mentioned, we'll also include questions and responses to in those materials as we post them. Next slide, please. And here's the important part as we get into our conversation with our panelists today. It's, it's all of you joining us that makes this a very engaged conversation. And our panelists are really interested in hearing who is here with us today. So, there is a poll that is open, and I see that a number of people have started responding to the poll, please know, there is a little gray bar to the side of the poll. If you're looking at it, it's a little hard to see visually, which allows you to scroll down, and there are a few other response options if you don't see the whole long list there. So, as we are seeing responses coming in, we have about half of our participants who have responded, but with the number of participants here, we are going to give a few more people a few more seconds for people to go ahead and respond in.

Alixé Bonardi 6:19

And I do see responses still coming in. So, we're giving people just a little bit more time to make sure that those who are working to get their responses entered are getting those entered in. I also see some folks are putting how they identify also into chat, which is wonderful to this really gives us a great sense of who all is here. So okay, so let's see who so we can share who is here. It looks like we have the majority of folks who are joining in this webinar today. Well, just about, it's pretty evenly split between people who identify as being a social worker or counselor or care manager, and government employees, federal, state, tribal or municipal employees. Now, of course, that could be some people who are fit into both those categories, noting people you can



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choose more than one. You can also we also are joined by about 15% of people joining here identify as a person with a disability and another 16% As a family member or loved one. And over 24% about 1/5 people here identify as self-advocates, we also have peer mentors, researchers and people who represent community or faith-based provider organizations. So, a good range of people and I do see that we've got some really excellent detail that people are adding in here into chat as well. Thank you and now next slide please.

Alixé Bonardi 8:32

Let's move to let's move to meeting our speakers of the day today. We are delighted to have such a rich group of panelists and I'm going to briefly introduce each of the speakers. But before turning over to our first our first speaker, we have Lydia X.Z. Brown, who is an advocate, activist, scholar, attorney, and organizer. They are director of Policy, Advocacy and External Affairs at the Autistic Women and Non-Binary Network and founding executive director of the Autistic People of Color Fund. Lydia teaches courses in disability studies, women's and gender studies and American studies at Georgetown University and American University. They are co-president of the disability rights Bar Association and Disability Justice Committee representative on the National Lawyers Guild Board. We also have Shane Neumeier joining us who is a lawyer, activist, and community organizer, as well as an out and proud member of the disabled, trans queer and asexual communities. They are a trial attorney in the commitment defense unit of the committee for Public Counsel services mental health litigation division. Previously, Shain worked with the intersex and gender queer recognition project, autistic women and non-binary network Community Alliance for the Ethical Treatment of youth, Connecticut legal rights project and Disability Rights in New York as well as a solo practice. We're glad you're both here. Next, Al Lewis and renewed urban bridge are elementary school sweethearts who have not been able to marry due to the marriage penalty for people with disabilities. Together, Al and Renita share their love story in support of marriage equality and with the hope of ending the marriage penalty so that others do not have to experience the pain they have felt as two people who love each other and should be able to marry. Al has been a board member of People First of Georgia since 2016. Anita was one of several founders of long road home. She was president of People First of Atlanta for eight years. Anita was also founder of a president of People First of Georgia for a year after being vice president for four years. We're glad you're both here to Kile and Stephanie Pelletier are married disabled couple. Once they were married Stephanie's benefits went down to \$8. And some sense, getting rid of the marriage penalty has become a priority in their lives. As they know that other people with disabilities would love to get married and keep all their benefits. However, they must often settle for relationship ceremony instead of being able to get married and maintain their quality of life. Kile currently works for Speaking Up for Us in Maine, where



he teaches and supports other self-advocates to create change in their community. Next, we have Ayesha Elaine Lewis, who is a staff attorney and member of the leadership team at Disability Rights Education and Defense Fund. She is a graduate of New York University School of Law where she earned her JD and 2013 an LLM in taxation in 2015. Ayesha uses her experience from various aspects of civil rights advocacy to inform her work to advance the civil and human rights of people with disabilities at the Disability Rights Education and Defense Fund. Her work spans a variety of areas including marriage equality. And finally, in this panel, we are joined by David Goldfarb, who is the Director of Financial Security Policy at the arc of the United States. Previously, he spent nearly eight years at the National Academy of Elder Law Attorneys, where he oversaw that organization's advocacy initiatives. He currently co-chairs the disability and aging collaborative and the Consortium for constituent constituents with disabilities, social security, and financial security task forces. He was inducted into the National Academy of Social Insurance in 2017. We have a tremendous group of people here and we're excited to hear from them. To get us started, I would like to turn this conversation over to David Goldfarb, to help set up the background and context for the rest of our discussion. And over to you, David.

David Goldfarb 13:40

Thank you, Alixe. Well, I'm David Goldfarb, a white male with a short brown hair and pink shirt on sitting in a background of bricks with an arc logo in the corner. If we can get started with the slides, I'm going to give an overview of what are these marriage penalties? And how why do they affect so many people with disabilities. These marriage penalties are within two sections. One is supplemental security income. And the second is part of the Social Security system with a benefit called the disabled adult child benefit, or DAC for short. Sometimes it's called the childhood disability benefit. Both of them are important benefits. Supplemental Security Income is a means tested benefit. That DAC benefit is earned based on a parent's work record. And if you're someone with a disability that had developed disability before the age of 22, you may qualify for this benefit based on your parent if your parent retires, develops a disability themselves or dies and there's different benefit amounts. So those are the two systems and programs that have this marriage penalty, SSI, and DAC. Next slide please.

David Goldfarb 15:02

And the reason that this is so important is not just for these cash benefits. SSI is benefit is extremely low the maximum of \$841 a month this year, but it provides what's called categorical eligibility in most states to Medicaid and Medicaid is what I think is the people on this webinar no provides the long term services supports in the community that people need to survive. Importantly, that death benefit can also get you Medicare



after a 24 month waiting period. And what we see a lot of at the arc for people with intellectual and developmental disabilities. Yes, disabled adult child benefit is what that stands for. And all I can keep the longer term is that people start off on SSI. And then as they age, parent may retire, they get a benefit the DAC or disabled adult child benefit based on their parents work record. But because they were on SSI, first, they can still maintain their Medicaid benefits, so long as they maintain the eligibility rules within SSI. So, there's some complication there. But it allows them to get this bigger benefit. And OASDI stands for old age survivors and disability insurance. Thank you for answering that the chat. Next slide, please. So, what are these marriage penalties, there's multiple marriage penalties within those benefits. And we're gonna, we're gonna dive into all of them here. The first is that if there are two couples that are both on SSI, so they're both on SSI, you can see a 25% cut in their benefits and a 25% Lower asset limit. The second is what happens when a SSI beneficiary marries a non SSI spouse. And what happens is something called spousal deeming or the program seeing the income and savings of that of that non SSI spouse is available to the SSI beneficiary. And then finally, for the disabled adult child benefit. As we'll talk a little bit more about that benefit, if they're, if they marry someone else, with some exceptions, they lose their death benefit. And of course, with all of these, when you lose this benefit, you also lose Medicaid, or you also lose Medicare. And so, it's not just the cash benefit. That's so important. It's the health and long term service supports benefits that are tied to it. Next slide, please. So, the first one is to dive in a little bit deeper, the married when two people are on SSI, and would like to get married. And so, what you can see here is that they face both a stricter asset test, as well as a lower benefit amount. So right now, if you're unmarried, you can have \$2,000 in the bank. And so, two individuals separate that are SSI beneficiaries could have 4000 total. But if they weren't married, they could only have \$3,000 in the bank, lower benefit a low excuse me lower asset limit. And obviously, these asset limits are already painfully low. And that's something we've been working on this year. The second is the benefit itself, the maximum is \$841 a month. That's 75% of the federal about 75% of the federal poverty level, these are extremely low benefits. Those benefits get reduced when they marry to a total of \$1,261 for 2022 versus a potential if they're separate \$1,682. So, this is a major. This is one of the marriage penalties and major one that prevents to SSI beneficiaries from getting married. Next slide, please.

David Goldfarb [19:33](#)

Next, is what happens if an SSI beneficiary wants to marry someone who's not on SSI? As we talked about, there's a concept of deeming where a portion of the non SSI spouse's income as well as assets are allocated, as part of that means testing. And so that impacts the benefits and eligibility like countable assets get brought together. And if that value exceeds \$3,000, they're no longer eligible. The income that the non SSI



spouse can keep. And if they have children, there's a whole calculation, but it's extremely low, and really not feasible for most people. So next slide, please, I believe might have some extra dollars there. Yeah, so it's a very small income is allowed for the non SSI spouse below the poverty level. And a modest amount of income will basically reduce you to zero. And again, what happens when your SSI gets reduced to zero, it can make you ultimately ineligible for Medicaid, which provides the service and supports. So those are two of the penalties and next slide, please.

David Goldfarb 20:56

But it's even more than that, just when you thought it couldn't get worse, because the SSI statute isn't just looking at whether you're married, they're also looking at whether people are holding themselves out as married. And so, we see a lot of people who want to live together, as we'll talk about, and I'm sure we'll hear the stories about, but they can't, because if they have a commitment ceremony, if they use the same last name, for instance, they're living together, they're sharing bills, there's a risk that Social Security Administration will find them or to be as if they are married. And so therefore, the 25% lower benefit, the 25% lower asset limit, or the spousal deeming can actually apply to them as well. And so, navigating what you even do before you get married, and how far you can go in terms of, say a commitment ceremony, and then the ability to live together is a very thorny issue that's laid out in the statute, unfortunately. Next slide.

David Goldfarb 22:07

So those are the SSI marriage penalties. There's another marriage penalty within that disabled adult child or DAC benefit for short. Again, DAC benefits, a lot of people on SSI, transition to this DAC benefit as they age, you had to have developed your disability before the age of 22, and the child is insured by the parents Social Security. So, it's, it can be a survivor's benefit, it could be if you're if your parent developer needs SSDI, or if they retire, you get a certain payment level. And that's often higher than SSI, which is why it's ideal. But if you get married, you could lose, you can lose your benefit. And if you lose your benefit, you're going to lose your Medicare. There are some exceptions. If someone is on old age, social security benefits, or they're receiving another secondary benefit called title to benefits like SSDI or a survivor's benefit, then they don't lose their benefit. But importantly, if someone is on that DAC benefit, and they want to marry someone with an SSI, that's on SSI, that's not an exception. So that means that if they marry someone on SSI, they could lose their DAC benefit and their Medicare. And so that's the DAC marriage penalty that we're working on. Next slide, please.



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David Goldfarb [23:52](#)

So, there is some proposed legislation to try to address a number of this. Not going to pass this Congress. This is a long term fight. But right now, it's piecemeal. And I know Ayesha is going to talk more about what you can do. So, I'll just be brief here. There's legislation called the SSI Restoration Act, which addresses the SSI issues. There's a number of There's another one called the marriage equality for disabled adults Act, which eliminates that DAC marriage penalty. One other item I'll mention right now we're pushing as part of the art to raise the SSI asset limits under the bipartisan SSI Savings Penalty Elimination Act. Importantly, that asset raise would address at least the marriage penalty there. So, it would move it from \$2,000 for individuals and \$3,000 for a couples to \$10,000 for individuals and \$20,000 for a couples so we so there were there was a nod to try and address this marriage penalty, but it wouldn't fix the benefit issue. So that's the Marriage penalties that we're dealing with it in a nutshell, and I will turn it over to my colleagues to share their stories. Thank you.

Alixé Bonardi [25:13](#)

Thank you. Thank you, David. This is Alixé, and in a short while David has shown quite a number of the complexities as it relates to the marriage penalty. Absolutely. And of course, this is just scratching the surface of how this is and people's actual lives, we want to do is we want to turn to some of our other panelists who are going to speak from their experience, about their own relationships and experience there, and how this has played out in their own lives. And with that, I would like to invite Lydia and Shain to join into this panel group and come off mute if you can and join us by video. Hi, Shain. Hi, Lydia. And we'd like to hear from you about your story of how you met your reflections on what the marriage penalty means for you. We'll start there.

Shain Neumeier [26:24](#)

My name is Shain Neumeier. I use they/them pronouns. I am a white person with short blonde hair and glasses and a T shirt, sitting in front of a blank white beige wall. Lydia?

Lydia X.Z. Brown [26:41](#)

Hello, this is Lydia X.Z. Brown. I am a youngish East Asian person with short black hair and glasses. I'm wearing a dark polo shirt, a jade necklace. And behind me is a fake background that shows some autumnal trees. It's a picture that I took when I was out on the campaign trail this year.

**Alixé Bonardi** 27:08

Glad you're both with us. So, to get started, can I ask both of you to reflect a bit on how you met and what the marriage penalty means for you.

Shain Neumeier 27:21

So, we actually met through a college friend of mine. And as somebody who went to a writing program with Lydia during previous school years, like an extracurricular program, she put us in contact. And we actually didn't meet for about a couple of years after that funny story. We met in person the day that I broke things off with my abusive quasi-ex, like I was literally getting on the bus sending this guy an email, not to contact me if he wasn't going to shape up. And then I showed up at a meeting for ASAN, Autistic Self Advocacy Network with Lydia. And we met for the first time that day. Um, we've been in a relationship since 2013. And we got married in 2019. So, we're coming up on four years now as of June technically and anything to add there? Where are you from your perspective.

Lydia X.Z. Brown 28:25

I always tell people that the two of us are both openly autistic, queer, non-binary lawyers who've worked on issues of deinstitutionalization and abuse within disabled communities. And that none of that is how we met each other. Because I think it's hilarious that that's we've ended up having some very, we've had we work on many of the same issues. We've worked in parallel, sometimes our lives have had many parallels. But that's not how we met we met because we're geeks that's how we met. And I love that about our relationship. But you know, I think like the other couples who will be speaking today, you know, we had the privilege to be married, although why we got married was also a very disabled situation. Do you want to share about how that happened?

Shain Neumeier 29:17

So in 2019, while I was running my own law practice, the American Health Care System happened and I went from having MassHealth which is the Massachusetts equivalent of Medicaid and being able to run what was effectively a small business to losing my MassHealth because I made to watch the first year of my practice and having to suddenly ration my seizure medication was and stop my stopped my ADHD medications all together, which sent me into a mental and to some extent, physical health, tailspin. I'm all sorts of terrible things happened as a result of that. But the non-terrible thing is that Lydia and I got married on the 50th anniversary of Stonewall in 2019, in a small ceremony with some of our closest people, and fortunately, the circumstances that



necessitated a quick way more than I needed health insurance very quickly. But I am very glad that we did finally get married rather than kind of one day we'll think about doing it, suddenly, there was a fire under our butts, and we went ahead and did it. And it was great, despite the hat, the last minute nature of it.

Alixé Bonardi 30:51

And you're describing an experience, Shain and Lydia, that as we know many 1000s of people have in terms of choose being pushed in or sort of choosing the time in which they're going to be married as well. What I wanted to ask you, though, is how can case managers or people who were supporting you or guiding you in any way, best support you when it comes to personal relationships, or marriage, what's some information that you would like to have like to have had into terms of collecting up information and just knowing about what the marriage penalty means or might have been meant to you as you were, as you're coming together in your relationship and thinking about what it what it means you.

Shain Neumeier 31:46

To be honest and fair here, neither of us have been on SSI benefits, I was on Medicaid, for low income reasons, but did not qualify for services. What would be useful, from my vantage point is, to the extent that there are community mentors or other resources for people in the community who don't qualify to help connect people with resources, coupled to, for instance, work on setting up in formal support. So if one spouse, for instance in this situation, me, has more serious disabilities in terms of affecting ADLs, it doesn't mean they shouldn't vote for the other person to be the caregiver draft because they're the fast unfortunately, given our system, which, you know, treats us all as individual little family units, disconnected from the larger social network such as it isn't just kind of three, it will usually be the responsibility of some other family member to act completely unpaid as a support person, if somebody doesn't qualify for a any kind of services. So, helping people figure it out. And Vance whether there as was more or less the case with Lydia and I agreed to do that for each other to the extent that it is mutual recognized like that, I believe, and being the bulk of the care taking meeting side of things, to see if people agree to do that. Or if they're saying eight people, they're looking at each other saying we're going to need more how to find that and helping people to arrange that if you are a mentor or a counselor or service provider of any kind. And also, to talk through just identify points of conflicting access needs that may or may not be able to be addressed by service providers of any kind to plan in advance, like when you and I unfortunately, can't live together because of the nature of our disabilities. And thankfully, we didn't try to before figuring that out. We just figured it out without doing that. But that can cause problems to have any support people form or otherwise help



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people identify, Okay, this is where your disabilities are going to cause problems in the relationships and how we mediate that before and during an account accounts for that in services budgeted for otherwise, that can be helpful for the relationship.

Lydia X.Z. Brown 34:43

This is Lydia, I would add to this conversation, and I apologize for the sake of our interpreters. I actually do have a sign name is L Brown. Yes, thank you. I would add to our, to this conversation, right, that we know both as disabled people, ourselves and as advocates in the disability community that so many disabled people are caught in a trap, where there is no middle ground, there is no intermediary period, the way that our current political system and economic policies are set up, where you were either trapped in poverty, ABLE account access notwithstanding, because many of the people that are meant to benefit from ABLE accounts, I saw some questions coming in through the chat about that topic, are not actually able to open them, you know, they're supposed to be right, you're either trapped in poverty, because of income and asset limits, in order to receive Social Security funded benefits, which is the topic of today's conversation, or to be able to access other benefits like to be able to access Medicaid funded long term supports and services, for example, or you make too much money to qualify, but not enough money, to be able to private pay for necessary support or services or to maintain a decent standard of living, decent being defined by whoever that person is, and what counts as a decent standard of living.

Lydia X.Z. Brown 36:14

And the reason why our economic policies have created this trap is in in my view, largely because we have tied employment and the ability to maintain what is considered a normal amount of employment 32 or more hours a week on regular employment, to the ability to have reliable access to health care, and the ability to have reliable access to housing, and food. If that were not the case, then disabled people who struggle to find or keep work, or who are not capable of working 32 hours a week at all, or consistently, would not have to be reliant on an archaic benefit system that is designed with the idea that somebody is only receiving benefits for a very short period of time before presumably returning, quote, unquote, to full time work of benefit system that in other words, is very much rooted in very regressive social policies about socio economic class, and the maintenance of wealth and resource hoarding, as well as trapping people in a cycle of poverty and being blamed for their own impoverishment. When it's not an accident. It's not a passive experience. It's something that society causes. And then if you are a person who is not poor, but you're also not wealthy, then you're really screwed if you are a disabled person, because you make enough money, perhaps to afford your rent, perhaps enough to afford food. But you are not necessarily



making enough money. Unless you are extraordinarily wealthy, or you're only paying somebody at minimum wage or under the table for a couple of hours of support a week, you are not making enough money to be able to afford to live say, in a housing situation that is fully accessible.

Lydia X.Z. Brown 38:05

So, I have friends who have different disabilities who live in Washington, DC, who are forced to decide either to live somewhere where they could save a little bit of money, but the building will not be accessible. And it will not have access to transportation to get to work, or to expend more than 50% of their take home pay on rent so that they can live in a building that is actually accessible for their disabilities. And that's not really a real choice. Are those people poor or destitute? No, but they're also not able to fully exercise self-determination, or to have the fully available range of choices that non-disabled people do. And if you do need support or services of literally any kind of personal care attendant, you need somebody to assist you with homemaking services, you need someone to serve as a home health aide. And if it's not funded through Medicaid, because you do not qualify for Medicaid, almost no private insurer, which underwrite nearly all employer sponsored health plans will cover long term supports and services. At best, you might qualify for temporary coverage of Rehabilitation Services. If you've experienced a discrete injury, and you have been discharged from an intermediate or skilled nursing facility back home, you might get a few weeks or a few months of payment and kind of coverage from your plan for those services. But if you need those services as a basic function of daily life, your plan will not pay for it unless it is Medicaid. So, you either have to be trapped in poverty forever, even if you could work and wanted to work. Or even if you want to work but you can't work 32 hours a week, or you can't work reliably in a job that offers access to an employer sponsored health plan. Then you are also screwed because you work too much. Much to have access to Medicaid. And then if you are privileged enough, and like we're both privileged in that we have access to employer sponsored health care, right? That doesn't mean that your plan is going to fund any disability related services, it might fund therapy, which is great. And I love therapy, and more people should be able to access it. And it's not affordable to a lot of people. But if you need regular support work in your daily life, you can't get it. And Shain, I'm sorry. I think you've been trying to say something.

Shain Neumeier 40:29

Yeah, I have. There was a question about what the solution to these problems is. Universal housing that is accessible, and universal health care, and I'm not talking about affordable, I'm talking about zero cost to anybody, you get what you need, all of what



you need, because you are a person living into society. And no questions asked. That's the policies we need. And universal basic income, I would say as well.

Alixé Bonardi 41:01

Terrific. Thank you, Shain, for starting to answer that question. Because I was just about, I was just about to ask that as well. So, you know, with that, actually, I think this might be a great time to say really, thank you, Lydia, and Shain, for sharing this experience of your lives with us, as long as your great wisdom as well as your great wisdom here. And I want us to turn to another couple panelists who we are going to hear from and as I see a lot of action going on in chat. And as people are starting to come up with suggestions about how to how to start solving some of these challenges. So that people can truly live in a way that they are living the lives of their choosing. These are some of the solutions we need to get to. So, with that, I want to turn the conversation to Al and Renita. And I'm going to start with the same questions. I started with Lydia and Shain. We were asked, I started by asking Lydia and Shain, the story of how you met and what the marriage penalty means for you.

Al Lewis and Renita Bundrage 42:20

Yes, my name is Al Lewis, I'm an African American male wearing a blue and white collared shirt. She stated that her name is Renita Bundrage and she's an African American woman with a black and gray striped shirt on.

Al Lewis and Renita Bundrage 43:04

And our story is that we met all the way back in 1988 where I was registering to be in elementary school, our Ridge Elementary. Renita was she was 13 at the time, I was 11 at the time. And we met through the class, and we used to always, from the beginning, we both used to it was something about you know, we both were used to like looking at each other and we were basically interested in each other, but we're from way back then. But we you know, just looked at each other and just constantly what, you know, I always like, you know, like give each other and like try to you know, find time to be with each other we would like you know make time see each other spend time with each other and it started from there and you know, back then I thought it you know, it was popular. We was young and everything and, but it went from starting that way all the way through elementary up until we went to high school, the same high school together and we were you know, still together and a couple.

**Al Lewis and Renita Bundrage 44:56**

Well, what is an interesting story is that, you know, it started that way. But as we got older, when Renita, she showed me, she was interested in, you know, by looking and how we stared at each other. But as we got older, she finally sent her cousin over to just officially approached me and let me know that she was, more than just interested in everything and because of it so she sent her cousin over and she told me that she did that because she didn't know, like my reaction or what I would say was, you know, I really interested in everything. So, it from there it grew into a relationship, we would come to school see each other and things like that. And it was more of a school type of relationship where we would see each other at school, and we, you know, eat lunch together and things like that. And it went from there to finally, in high school, I graduated, and I was going off to college, and I got like a sports, we used to play wheelchair sports, also in school. And that's basically I got like a scholarship to attend a college in Wisconsin, for playing on wheelchair basketball, and I left to go off to college, and we talked over the phone a lot, and we kept in contact and, you know, we stay in contact with the children too. I was just so you know from being away and being my first time being away from home and being in an area where I didn't know anyone I do so good, I ended up just not focusing enough on the opportunity that was given to me, and I ended up back here at Georgia, back with coming back home. And soon as I got back, we basically started out where we left off, we were still seeing each other, I was living at home with my mom, she was living at home with her mom. And we would just make time to you know, visit each other see each other and up until finally a few years after that. When she says she received a waiver she received a section eight way to get her own place. And she moved and got her own place. And we started living together. And from then on, it's been us together. And, you know, prior to us being together we're living together, I, myself didn't, I had no knowledge of the marriage penalty in itself, I had no idea what that meant. Or I was under the impression that people still could marry anyone you want. And I had no idea that until she informed me of that. And you know, ever since she has informed me of it, it's been a passion of ours to try to do whatever we can to try and get that situation to where it's no longer because it doesn't make sense to me that you or anyone should be not able to be well marry the person that they love and want to be with. It just doesn't make sense to me. Because I always prior to me knowing that I always felt and knew or thought that anyone if you meet a person, you love them, you can marry them. And that was the case, you know, but I didn't I didn't know that there was this thing called a marriage parenting but ever since of me being informed, but it has been a passion of ours, you know, just to make sure that no one has to you know, if possible, go to a situation like that where you love each other. You should be able to marry I mean, it's just not enough to some people say, "Well, you're sleeping, you're living together, you have in that life." But it's not enough to just have that, in my opinion, I think that I should be able to legally marry her and, you know, have a ceremony and legally be able to America without having any issues. And I think that's



something that should not be an issue. And we shouldn't be able to do that anyone should be able to do that.

Alixé Bonardi 50:34

Al and Renita, really thank you for, for sharing your story so much, and your passion, and actually speaking the truth about Yeah, everybody should be able to do that, of course, you said that you're really interested in, in advocating being advocates to, you know, work and make sure that, that anybody who wants to get married, can, could you talk a little bit about how others will your experience, what you have been doing to advocate for this, and some suggestions for how people can advocate so that people with disabilities just have the right to get married without worrying about losing their benefits?

Al Lewis and Renita Bundrage 51:41

Before the pandemic, she was stating that, you know, prior to the pandemic happening, we were very much active in going to see legislators and going to the Capitol and trying to make this issue known. And, you know, just keep the issue itself out there and spread and spread it as far and wide as we could, you know, to keep people and the legislators on the topics, believe it or not, it's a lot of that whole issue of the marriage penalty, a lot of people who are not affected by us don't know about it, they think that doesn't even know that it exists. They don't even know. So, it's like, an issue of educating and letting people know, you know, that it's a real thing. And it's something that really needs to be dealt with and done with and that's the way how we go out and keep that it out there and people talking about it. And another thing that we were doing were, we're going out and just speaking like how we're doing now speaking to, you know, certain people who would allow us and would invite us to speak on behalf of marriage penalty and let people know that exist. And, you know, let them know that, you know, basically, our advice would be, you know, to go to your state legislators that are in your state and to just try to keep the keep it out there and keep it you know, to where it's known, and people go if you don't talk about certain things that people, they won't think about it. So, it's just basically keeping it out there and I'm trying to, to get them to get it out there as much as possible.

Alixé Bonardi 54:20

It sounds like you've been busy getting the word out. Absolutely. And honestly, just starting with the awareness that marrying someone you love is one of the basic human rights that people have, and I think people maybe have an assumption that that is a right that everybody has available to them. In terms of all you said that you weren't just



you just weren't aware about the minute marriage penalty even you know, when you were coming into your relationship and living with her Nina what advice could you give to You case managers or service coordinators are people to help give services to just help raise the awareness and help people navigate this and make change?

Al Lewis and Renita Bundrage 55:25

Well, you mean, well, she said that, basically people who, like you said work in a field that deal with disabled people, she was stating that, you know, in her opinion, she feels that they should, the best way that they could, or one way that they could help us, as you say, is to talk to them. And when I asked them, like, basically what's, you know, their caregivers in general could talk to them and try to ask that same question that your saying, see what they could do best to help them for the poor, you know, the, in their way of what they're going through it for us, that's concerning them and everything like that. And I also think that a good thing is, I always say like, you know, awareness, awareness, I big on test, you know, I don't think things are getting a word get changed, when we change, the awareness wasn't brought out, and just to constantly aware, you know, to make the congressman, your, your state officials aware of the situation, and to like, you know, just keep it out there. And, and, and I don't think, I think that that would be the spark that would actually get something done. If they were to just be constantly made aware of that situation. And, you know, keep it on their minds and keep them thinking of it. And that's the only way I believe that change will even be made, you know.

Alixé Bonardi 57:22

Al and Renita, I so appreciate both of you bringing your voices into this conversation, because you're right, that awareness, part of it is critical, as a foundation for the work. And thank you for all the work that you're doing to continue to talk to people and keep it going. Please, go ahead.

Al Lewis and Renita Bundrage 57:48

No, I was just, absolutely. I was just basically saying thank you and absolutely.

Alixé Bonardi 57:57

Great. So, I think we're we've been seeing a lot of conversation going on in in chat as well. Al and Renita and I, I think there's a lot of appreciation also for the work you are doing with that, I would like to actually say we'd like to bring another perspective into this conversation. And I invite Kile and Steph to join us to share their reflections and their story as well. So, thank you, to Al and Renita, and Kile and Steph, welcome to the



stage, as it were, and I'm starting with the same question here. If you could start in and say hello and tell the story of how you met and what the mental marriage penalty means for you.

Kile Pelletier 58:55

Well, I'll thank you for having us. Well, my name is Kile Pelletier. I'm a white man with black hair, and a black beard with a gray button up shirt and we're in our background is the back wall of a kitchen.

Stephanie Pelletier 59:16

My name is Stephanie Pelletier. I'm a white female. I have dirty blonde and red highlights in my hair. Oh, yeah and I have a blue shirt on.

Kile Pelletier 59:39

So yeah, I mean Steph we met at our local day program. And we kind of it's actually a nice story because it was me and her. It's like it was actually her first or second time going to the day program. And she kind of when she came, and she saw me. And she kind of say, Wow, this handsome, handsome guy. So, she was kind of like playing with her hair and all that kind of stuff. And then I kind of looked at it, how she was looking at me. And I was kind of thinking back in my head that this person likes me. So, I just let it go a little bit. Then it came to ally, our break. And she came to sit next to me. And it's like, okay, why is this person sitting next to me, I think she back in, thinks she likes me. So, then we kind of just started talking, and I won our programs. And at first, she didn't have my Facebook. So, I kind of like, found her Facebook before her add her then she kind of added me after then she kind of wanted me to go, like, hang out with her for birthday. But I kind of said, well, I want I want to meet your parents before I do that. So just give her respect wise. And she said, Okay, so I met her I met her parents, and then we kind of cannon started dating and kind of happen like that.

Stephanie Pelletier 1:01:25

So, okay, before we got married, I, my Social Security was 700 something, and 75 cents. And when we got married, in went down to \$6.75. And then close to live in one app. So, I got \$14.75. Then I was supposed to get \$23.75, the beginning of January. But then I got a letter from Social Security a couple of days ago, said that I'm gonna lose that. \$23.75. So, then I felt I felt lower than low because I was getting \$0. So, I felt like I was not independent anymore.

**Kile Pelletier 1:02:37**

So, and I have my mother in law that wants to say a few things that for a mother and a children caseworkers experience of dealing with a child that has security and losing it by nothing. So, I'll kind of turn it to her.

Cindy Tardif 1:03:00

Hello, my name is Cindy Tardif. I'm Stephanie's mother. I've been her biggest advocate since she was a child. I'm white, I have dark hair and maroon shirt. I'm in the same kitchen is different. Kile, he described it a while ago. Steph and Kile had been together for a long time for about 10 years before they got married. And Stephanie's a devout Catholic. And she was getting her full benefits living with us. Our income did not matter. She had her full benefits. And so, she was independent buying her clothes, you know, food, vacations, and she had money to if she needed her. Her personal items, clothes, so she was pretty independent. So, when we go on vacation, she had her mining, whatever. So, she met Kyle she fell in love, and they chose to not live together. Like I said, Stephanie is a devout Catholic and she wanted to be right in God's eyes. And she thought well, before I get married, we got to find out from Social Security, how much benefit she would lose. So, Stephanie's case manager, I, and Kile's case manager we call social security and they determined to be about maybe \$200 that she'd end up getting. I thought that was bad at the time. But the end result ended up being \$6.75 I almost fell on my butt when he told me that it's like that doesn't even pay for her personal items, you know her monthly things. So how does that even make sense? So, I said so now what's happening is that she went from being dependent on herself to now being back to dependent to our parent her parents, because cars on a fixed income. He's on Social Security benefits, and he's on disability. as well. So, they're saying that because he has SSDI and SSI, which he was only getting \$23 SSI based on because of Stephanie, and she was getting now \$23. And because his income went up a little bit, be working 20 hours a week, now, cost of living went up, Social Security income went up. So, she lost her so scary. I'm thinking like, so she went from poverty to below poverty. And my husband is on Social Security because he's retired. I'm retiring in four years. So right now, um, you know, we made an order of flows through Venus, Okay, guess who's going to be paying it, it's going to be me, she has no more money. They're paying their fuel, they're paying their rent, they have a little bit of help, not with the ramp and a little bit of help a tool. And right now, it's been about 600 gallons or \$600 a year, but their oil is to over 2000. It'll even be more than that now, because of how things went up. So, I so called Social Security. And they said it was based on Kyle's income, that it went up a little bit and plus, Social Security went up on the income making her losers. So, when cow went to Washington, DC to advocate for the marriage penalty, and against that they were focused on quality of equality of marriage, which I saw the



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President sign. But for marriage penalty, they told me how we wouldn't know where to get the money for to fund that. And I said to call what my response would have been to that she had the money; you took it away. Right? already happy. Right? So, this is poverty.

Alixé Bonardi 1:07:03

This, that you bring is really such a clear, clear picture of, you know, a problem that is, you know, brought into people's own experiences. And it really is, it's a painful story, honestly, to hear and to also, hopefully, this is something that we can use to fire people up to understand what this all means in people's lives.

Cindy Tardif 1:07:38

So, we have spoken to the legislators, we have, and we feel like we're talking to deaf ears. And 50 years ago, they started with the Social Security back then you couldn't have more than \$2,000 in your bank account if you one person. But then if you're a married couple, you can have more than 3000 Why can't it be four, but anyway, 3000. But that was 50 years ago, 50 years ago, that was a lot of money. Okay, today, it's not a lot of money. And we're having the same guidelines. I can't even count. It's not comprehensible.

Alixé Bonardi 1:08:17

Absolutely. And even starting from the earlier remarks that David Goldfarb shared, the I think that that the collective group of us here are recognizing that there are so many things that need to be addressed. And actually, the asset limit that you just mentioned, is absolutely one of them. We have just a couple more minutes before we turn to our next panelist, I want to ask you, Kile, and Stephanie, when you have been advocating have you been what is the one message the one thing that you are really looking for legislators to change when you go and have a conversation in Washington, and as you're traveling around advocating against the what's happened with the marriage penalty?

Kile Pelletier 1:09:07

One, one question I want them to, to answer that. We want like, I want them to bend backwards to help us out to make sure that we get our voice like our voices heard that the marriage penalty needs to be eliminated because it's not right. Because people with disabilities should be able to have equal what rates to get married, be happy, start a family and actually have both incomes and make sure that you're above property, so



you can actually have a half decent life and I want them to hear that and say, I know how you feel. And I want to work harder to get the This eliminated.

Cindy Tardif 1:10:10

Can I say one thing? This is Cindy, again. The advice when we did seek out to like Pine Tree Legal and when this first happened when they got married and they lost even more, she lost even more than what we were expecting the advice, the advice that they are getting, get a divorce.

Alix Bonardi 1:10:33

That's not for lawyers and case managers to make a decision about when people marry and when people divorce. I mean that that is something that you're really, you're really pointing to something that we have also heard that folks have heard. Thank you so much for the story, Cindy and Kyle and Stephanie, for bringing this forward. I know it, it's a difficult situation that you're in. And I think I am really hearing a lot from our we're seeing a lot in chat.

Kile Pelletier 1:11:10

Yeah, it just frustrates me that I'm telling my story as hard as I can I, I keep going to DC and I keep going to this and it's like, if doesn't seem to be going anywhere, it's going moves. And they said keep trying to tell your story keep pressing the stories, keep doing this keep doing that keep doing it's like, how it's like how many? How much times do I have to do it? Do I have to do until I'm blue in my face, or like six feet under? It's sad. It's like everything else gets like, I had this. And people with disabilities are still under property. And there's continuing struggles. And there's always that wall that needs to be broken down. And it's like we go to talk to the people that we need to talk to. And we had to wait for all these co-sponsors to actually sponsor these bills. And to get into their communities to hear from us, then go back to the Capitol Hill for them to vote on it.

Cindy Tardif 1:12:27

It's like, Stephanie and Kile are at risk of having, you know, displacement, because they're places like falling apart. And they need to have a new place. And we have a piece of land next door that we would have like a well into or put in for them and everything. But we want to build them a tiny little home. But they can't even afford for us to help them. And we will be giving them lunch, but we they can't do it. Yeah.



Stephanie Pelletier [1:12:55](#)

And we want to be able to have kids.

Alixé Bonardi [1:13:01](#)

Right? All the all of the pieces have a true and loving relationship that everybody has a right to. Right. It's happening.

Kile Pelletier [1:13:12](#)

The other group Sorry, just like the other couple. And it's like they're working like pushing things. It's like, what more can we do? I can't cry enough. What more can we do?

Alixé Bonardi [1:13:26](#)

Yeah, Kile, and that's where I want to try and take this conversation too. And this is going to be maybe difficult to invite you into the room. But Ayesha Elaine Lewis is somebody who want to make sure that we hear from you. And I also want to say thank you, Kile and Stephanie, because I think Ayesha Elaine, you can provide some have some have some more context and discussion about what's coming next and what can happen in some of this fight for people's rights. So, with that, I wanted to turn it to you for some of your comments. Thanks for joining us.

Ayesha Elaine Lewis [1:14:12](#)

Thank you. My name is Ayesha Elaine Lewis. I am an African American woman with brown and blonde dreadlocks and white sweater against the beige background. And I would also I also look like I have a annoyed expression on my face because I always get annoyed when I go over these archaic rules that harm so many people with disabilities. I'm also a person with disabilities and so it feels personal. And, you know, we all deserve our rights to have marriage family love, make our own life choices.

Ayesha Elaine Lewis [1:14:55](#)

Okay, so, to your question about what can we do to support efforts to end marriage penalties? Well, the first thing we could do is learn more. David's overview of the SSI and DAC marriage penalties gave you all a sense of how complex these rules are. If you're interested in learning more, feel free to check out DREDF's marriage equality page, and I'll drop that link into the chat. And this will also be provided for folks afterwards as well. You can find fact sheets and annotated bibliography, a link to a more



detailed workshop that David and I gave on this topic, and another and other resources as well. David might have additional links from the arc to share as well. Another thing that folks can do is support legislative reform. As David mentioned, there have been about five bills introduced in the current Congress, which would address different aspects of the marriage penalties. One powerful way to support passage of those bills is to contact your congress members to express support for these issues. Members of Congress take notice when their constituents care enough about an issue, to write a letter or call. It doesn't have to be you know, anything complicated or fancy. It's better if it's not a forum, but just simply taking the time and effort to show that you care means a lot and they do notice. The more voices that are reaching out to members of Congress, the more powerful the impact will be. The recent passage of the Respect for Marriage Act shows that support for marriage and family are issues that can be potentially bipartisan, even in divided government. And we're hopeful that, you know, folks across the aisle will Ansari on both sides of the aisle will be amenable to hearing about real life impacts of these penalties on folks and how much you know, people across society want to see them. And another thing that we can do is sharing our story. As he saw today, the real life stories of people facing these marriage penalties make the issue more real than a fact sheet or a journal article ever could. Both DREDF and the ARC are collecting stories from folks who are directly impacted by these penalties. If you are interested in sharing your story, I'll drop the DREDF link to share your story in the chat. There's also okay, it's been shared already. Okay, great. There's also a link that the ARC has as well.

Ayesha Elaine Lewis 1:17:36

Another thing folks can do is help build awareness. Too many people still aren't aware that these marriage penalties exist. And some only find out about these penalties after they're married and are hit by them. If you want to share your own story directly on social media platforms, you can use some of the hashtags that we've been using hashtag marriage equality, hashtag marriage penalties, love tax and the love tax. You can also share social media posts to amplify the work shared by groups like the ARC and DREDF. So, if you see the arc posting something about these marriage penalty issues, you could retweet it, you could share it with your networks to help get more people seeing these issues and knowing about them. Sorry, hold on. In addition, people can file complaints directly with the Social Security Administration. Last month, DREDF filed an administrative complaint on behalf of Laurie Long, requesting a waiver of the DAC marriage penalty on the basis of religious freedom. The Religious Freedom and Restoration Act, otherwise known as RFRA, requires the federal government to provide exceptions when federal law or policy substantially burdens someone's religious freedom. So as a devout Christian and a Sunday school teacher, Laurie has strong religious beliefs about marriage. And therefore, what the complaint asks is that the



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Social Security Administration which is part of the federal government, waive the rules about marriage and benefits so that she can engage in the religious sacrament of holy matrimony, aka marriage.

Ayesha Elaine Lewis 1:19:28

So, one high profile example of RFRA being used recently is the Hobby Lobby case where the privately held corporation argued that it had religious freedom interests and not having to provide certain kinds of health care to employees. And so, refers out there refers being used and, you know, you think dread is that it's a potential tool for folks to use to advocate to get an individual kind of relief. Now, we haven't actually gotten the administrative complaints resolved yet. So, folks might want to wait a little bit to see what happens with lorries. But if you want to do it on your own, that's something you can explore with, you know, with counsel with your advisors, to see if that's an avenue you're interested in. You can read our complaint and press release, and I'll drop the links for those as well. And our recent op ed Mansi, Altman, from Social Security works called on the Biden administration to provide waivers to people who seek to marry for religious reasons. Or if they don't want to do an individual waiver for millions of benefit recipients, they could simply announce a waiver for everyone receiving SSI and DAC under the authority of RFRA. And so, again, I'll share the links that were listed, that I discussed, and it'll also be provided after the training. Are there does anyone have any questions?

Alixé Bonardi 1:21:13

While, well, that, I think probably there are many questions probably, but the richness of some of the resources and some of the actions that are being taken, I really appreciate. And before I hand it over to my colleague, Bevin, I just wanted to say thank you, to Aisha, and to all of our panelists who have shared both their passion and their love stories, right. This afternoon, I don't know that we've had quite as many love stories packed into one end caps webinar ever before. So, so thank you for all of this, as well as bringing forward the really, really important issues that we still have to work on. And with that, I wanted to invite them in to bring us to two of possibly one or two questions we could have. And then wrap us up.

Bevin Croft 1:22:16

Hello, everyone. This is Bevin Croft; I am a white woman with blonde hair up in a bun I have things behind me is my home office that has many plants. We have just a couple of minutes. If anyone does have a question that they'd like to ask, please put it into chat. We received a lot of technical questions that I think may be better answered in writing.



But we did have someone wondering earlier on about how marriage rights play out for people with conservatorships. people under guardianship. And I expect we could do a webinar on that topic alone. But I wanted to raise this to our panelists and see if any of you have anything to add. And, David, I see you've gone on camera.

David Goldfarb 1:23:25

Yeah, I'll just add it's a complicated question. Because it depends on the state statute. I think generally speaking, there are limited powers for the ability to divorce. And I know attorneys are loath to do that. But there was actually a recent Supreme Court of Kentucky case that dealt with the issue of divorce when a young woman married someone with Alzheimer's was convicted of felony financial misappropriation of his funds, and was set to receive his funds as inheritance, although she would be in jail for about 10 years, as a result of her financial exploitation. They were under a guardianship and the guardian was able to get divorce. So that adds that does add an extra layer of complexity, as well as what are the rights to get married? If you are if you are under conservatorship or guardianship? The answer is probably you're not. So that's another way in which people's rights might be infringed. So, a big thing that the art works on, and I think a lot of others work on is something called supported decision making and other means to keep people as free as possible so they can choose who they want to live with. And that's, you know, probably someone referring to, for example, that Britney Spears case where she was not able to marry someone. So, it's both that's a, again, a complicated state question. And so I'll leave it at that but definitely issue.

Bevin Croft 1:25:03

This is Bevin. Thank you, David.

Bevin Croft 1:25:07

We've gotten a couple other questions in chat, really related to action. So, any tips for you know how to get representatives in person to speak to this issue. And also, are there any bills with bill numbers that folks can use to contract to have their contact. And I will sort of quickly say that there are bills listed in the PowerPoint. And if anyone wanted to drop them into chat, we could we could put, put those there, we will also be sure, at the end of this webinar, when we put the materials up on our website, we will include all of the resources that we've described today to cut it together in one place, call it your advocacy toolkit. And that'll be a resource for you.



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Bevin Croft 1:26:05

We have come to the end of our time together. I think I probably speak for many of you that my heart has been on a roller coaster in this afternoon, you know, fluttering and excited with, with how romantic and beautiful these stories are. And outraged and heartbroken for our panelists as well, knowing that our panelists are speaking, you know, stories that hundreds and hundreds of 1000s of, of people with disabilities across the country are experiencing. So, I hope that everyone channels, this experience, and these feelings into action as we as we were to support marriage equality for all. All right, so I have one final poll to invite you to take, we take continuous quality improvement very seriously, at the National Center on advancing Person Centered practices and systems. So please help us before you leave this afternoon. By taking the six question post webinar evaluation before you head out. We use your feedback. We look at it every time every webinar, and we use it to improve. I hope that we can continue discussion on this topic, and we will have webinars coming up this year that touch on some of the issues that came up in chat. So please do stay tuned. Please do join us again. It was wonderful to have you here. And huge, huge appreciation to our panelists. David, Lydia, Shane, Renita, and Al, Kile and Stephanie and Kile's mother-in-law, Stephanie's mother (Cindy). I apologize. I have your name escapes me. And I wish you for sharing your wisdom and your experiences. We are grateful to you. And I wish everyone good afternoon.