## JEANETTE CÓRDOVA:

Welcome everyone, we are letting folks come in. Welcome to the 2023 disability policy-- I forgot I'm the only person. That can do this. Welcome to the 2023 disability policy seminar orientation Policy Education 101, preparing to educate policymakers in D.C. and at home.

We were given a few minutes for participants to enter. ASL is available and captioning. You can select captioning by hitting the CC button. Please feel free to introduce yourselves in the chat. We would love to know your name, your program, center name, and what your role is.

A little resume logistics, again, ASL and life captioning is available, use the chat box to introduce yourself, name, program, Center and role, enter your name is displayed correctly in the participant list you may also include your program name, state and preferred nouns. An example is Jeanette Córdova, AUCD and I go by she and her. You can hover over your name in the participants box to select more and then rename. Please remain muted and last speaking during Q&A opportunities, and also when you do speak state your name prior to speaking, you are also welcome to use the chat.

So, I am Jeanette Córdova, Program Manager at AUCD and I work on the iTAC team with Jackie Czyzia, who is our senior program manager and will say a few words.

#### JACKIE CZYZIA:

Hi, Jeanette, thank you so much. As Jeanette mentioned my name is Jackie Czyzia, I'm a white female with brunette hair, wearing a black shirt and just wanted to welcome you all to our annual policy education workshop, as Jeanette mentioned, iTAC is the interdisciplinary agency disabilities every year we haven't policy delivered by our AUCD policy team, we want to thank you for preparing this workshop, and for their expertise. So I will turn it over back to Jeanette.

#### JEANETTE CÓRDOVA:

Thank you. So now I would like to introduce Liz Weintraub, the senior advocacy specialist, and she will introduce the rest of her team.

## LIZ WEINTRAUB:

Thanks, Jeanette. My team is Kevin Riley, and he is our policy fellow for this year, every year we've had a policy fellow that works in our office, and Kevin is that person.

We also have Denise Rozell, Director of public policy innovation and she works on policy and other things. I will turn it back to Jeanette.

## **DENISE ROZELL:**

I think it goes to Kevin next, Liz, do you want to tell us a minute about how you got into the field or why you are in the disability field or who you are for an introduction?

### LIZ WEINTRAUB:



I'm Liz Weintraub, Senior advocacy specialist and a person with a disability I'm a and I've been advocating for over 20 years. First as a volunteer in people first, and for the last few years and more of a professional role and I do a lot of plain language work as well as trying to help my friends and others with disabilities to have good lives.

So, Kevin or Denise?

#### **KEVIN RYLE:**

I can go next, as Denise said my name is Kevin Ryle, and the policy fellow, I have a lot less experience than Liz, and I'm really excited to be able to talk to you guys today and I will pass it to Denise.

### **DENISE ROZELL:**

I'm Denise Rozell, as Liz said I'm the Director of policy and innovation at AUCD, I've been in the disability world, until people in the policy agree, that's what I love, my training is in law but I love teaching people to make a difference in what they do.

And so, I'm an ally, I relatives with disabilities as well, but primarily I'm here as an ally. So Jeanette might think it's back to you, or Kevin. Kevin are you doing the agenda?

## JEANETTE CÓRDOVA:

Yes, Kevin is doing the agenda.

### **DENISE ROZELL:**

Excellent.

### **KEVIN RYLE:**

So we can go to the next slide. So this is just a little overview of what we are going to be doing today we can start briefly in the beginning with what you can do as trainees in the AUCD network, we can tell the difference between lobby and and educating and what you are able to do as trainees underworking under federal funds.

We will do a overview of plain language, then we will discuss the three branches of government, how the government works, how a bill becomes a law, we will do an overview of the 118 Congress, which is the current congressional session, then we will go over the budget timeline.

Then we were going some important issues we want you guys to know going into DPS and things we want you to know as trainees within the network and then we will discuss a little bit of an overview about how the disability policy seminar will work and then at the end we will wrap up with some examples of what you can do at home and when you are attending the virtual DPS session or the fly in day.

And so, we will jump right in and start off with leadership roles you can do as trainees and I will pass it off to Liz.

Page 2 of 21 Downloaded on: 04 May 2023 11:05 AM



#### LIZ WEINTRAUB:

Thanks, Kevin. First of all I wanted to say that I was LEND trainee, so I was in your shoes probably four years ago, and it was one of the best experiences in my life. You are part of a national network that helps to create change, as trainees and leaders we all have a responsibility to help improve services and supports for people with disabilities. And doing practice, research and policy work together, so they all work together, that's when the balls are juggling, I think.

When we better understand how policy works, then we can teach policymakers how policy impact practice, so sometimes a policy that sounds good on paper doesn't work in real life, so we have the right. We can tell people how we can help people with disabilities, we are family members. Go to the next slide.

Why your voice matters. My voice matters, as I said I'm a person with a disability and you have importance, and you also have important knowledge from your lived experience, whether you are a family member or Self-Advocate, policies affect your work in life.

You can work to make changes to ensure policy protect your civil rights and your access to services, and if you don't speak up, someone else will speak for you and how true is it if you don't speak up, and you are shy, someone else will speak up for you. Next slide.

#### DENISE ROZELL:

This one is mine, Liz. Before I started want to say one thing and that's that we will be joined by a couple of hill staffers and we will see when they come in, which should be any time now, I think. When they come and we will just pause, those of us who are speaking, and let you hear from them. There are folks who work, one Michael McCormick who works for the Senate aging community and Sarah Mueller who works for the labor pension committee and they're going to talk about tips and tricks and was going on on the hill.

So if you see is just kind of literally stop and introduce somebody new, that's why and we will come back to the slides. OK, so lobbying versus educating policymakers, there are – this is important for you all as LEND trainees, there are different rules for how you can communicate with policymakers as a LEND or ECEDD training as opposed to a private citizen, when you're a private citizen working with policymakers, as a LEND training you are being paid, basically, your time is being paid and supported with federal grant funds, meaning federal money, and there are limits to what you can do when you are doing that kind of lobbying versus educating, with policymakers and you are on federal funds, so this is an important one to know. You need to know the difference between lobbying and educating, OK?

So first, lobbying is when you try to change the mind of a policymaker or government official and/or the public, but a government official on a specific piece of legislation, like a bill. You're asking them to take action "please vote yes on this bill, please vote no on this bill" that's lobbying.

Educating is talking to policymakers about data and evidence and lived experience, and stories can help them make decisions, their own informed decisions about a bill. So when you go in and talk



about, I am a person with a disability and this is my story, that is educating.

If you go in and say I'm a researcher and I've looked at all this data about disability, and this is what I've learned. That's educating. They then can use that to impact bills they are looking at. OK, I have an example. Next slide. The example, one second. So, an example, and this is directly related to what you guys are doing.

Congress is going to be discussing how to reauthorize the Autism CARES act. Reauthorize means to do it again, basically. It expires at a certain time, you have to pass a bill and continue it, and that's with LEND programs live, in Autism CARES.

As a private citizen, from your personal emailer, your phone when you're not working, you can call, leave messages, talk to members and ask them to sponsor or vote in favor of the Autism CARES bill, that is a private citizen. As a trainee, from your officially male or official phone, you can share and discuss how your LEND program impacts you, impacts the community, you could talk about people you serve if you are somebody who serves people with disabilities you can talk about your story, if you're a person with a disability, your lived experience, you can also share how the Autism CARES act affects the lives of people with the scum there are some University rules and I would be remiss if I didn't say that, we also have to be clear and your supervisor will be able to tell you if they are our university rules about how you can talk in terms of being a LEND training, you can educate policymakers.

You may also have research, that's another you can share, and how things really work on the ground. That's what policymakers don't necessarily hear from other places. How this really looks on the ground.

Next slide: I see that there is in the room. Are there any questions around lobbying and educating? If there are, please type them into the chat and -- yes ma'am?

## SPEAKER:

When you said "working on the ground", can you give us an example?

## **DENISE ROZELL:**

... If you are a development old pediatrician, you know what it really means to have somebody visit you and what accessibility features they may need, or what questions they might ask, or how certain things actually work in real life. You (indiscernible) families, you know about how things really work from the ground, that is what I mean.

Sometimes laws me well and don't quite (indiscernible) when they get to the ground. I see both Sarah and Michael are in the room, so I am going to stop talking. We will be more than happy to take questions later, around lobbying and educating. I can answer some questions, one that is just in their about how we vote, you avoid that question and tell them this is what you want to talk to about today!

I am going to ask Jeanette to please turn off the recording. Thank you, for Sarah and Michael. I told



you earlier that we will be joined to people who are great friends of ACT, the land program -- LEND, Michael works for the Senate (indiscernible) committee, Sarah works for the Senate health committee, they are both staffers. Sarah was a fellow for ACD in the past, Michael was my boss when it I first started working at ACD six works ago. I am going to turn it over to them and they are going to talk about what is going on in health and tips and tricks for doing Hill visits and what this is all about. Thank you to both of you and I'm going to toss it to you guys!

#### SARAH MUELLER:

It is great to be with everybody. Always great to be with trainees. I wasn't a LEND trainee, but I was a (unknown term) training at the Institute of disabilities so it is great to be with all of you today will stop as Denise said, I am the policy director on the Senate Health Committee. Michael?

#### MICHAEL McCORMICK:

Hi everybody, I am Michael McCormick and I the disability director for the (indiscernible). We work through the special committee on aging that word aging sometimes trips people out. We really work from prenatal to death. We are not age limited here, as my former staff director used to say, the second you are born you are aging.

Sarah mentioned that health education (indiscernible) jurisdiction for her committee, our committee does not have jurisdiction. Which means that, in many ways, we have -- we get to play in the playground of every policy.

### **SARAH MUELLER:**

Great, I think what Denise texted us to share is: what creates a great Hill meeting. Is that right Denise?

### **DENISE ROZELL:**

That would be great.

## **SARAH MUELLER:**

I can start, Michael, please time and because you have had more Hill meetings than I have. I hopped on a minute before hand and heard Denise give the explain around the difference between education and lobbying and sharing your expertise.

Michael and I are probably somewhat of an anomaly on the hill, in terms of staffer, and our understanding of disability issues. you will likely be meeting with all kinds of staffers with different understanding and orientation around disability. In the work that you do in your varying capacities with LEND. Always make sure that you are expanding things and making sure that you ask them what they know, before just diving in the worst meeting I have taken is when people assume I know nothing. (Laughs)

It ends up in a very unproductive meeting. So, that would be one piece of advice that I would get.

MICHAEL McCORMICK:



Yes, and I would say another piece that is associated with that is asked little bit about what the person you are meeting with does. Sarah mentions the fact that she and I - our responsibilities are (indiscernible) disability policy, but you are going to be meeting with people who helped with employment, education, sometimes veterans, disability might be a small section of their portfolio.

You want to moderate what you are saying to them, in terms of what their background is. You also may have a really seasoned staffer and you may have a brand-new staffer. All are worthwhile, and these are the people who collect information and then talk to their bosses and, ultimately, the Member about these issues.

So get a little bit of a sense to whom you are speaking as well.

#### SARAH MUELLER:

I would add to that: do not be discouraged if you have a meeting with your Representatives office and it is not with the member, directly. You know, oftentimes the Members are very busy and have packed schedules. Really, at the end of the day, it is the staff who are driving a lot of the policy. Building that relationship with the staffer is just as important, if not more important, then building the relationship directly with the Member.

#### MICHAEL McCORMICK:

And I often talk about the fact that you will be doing, in association, many of you with the disability policy seminar, you have time to touch base with some offices, but that shouldn't be the end of your relationship. As Sarah says, it needs to actually be a relationship.

I often say to people, "touch base to three times a year, so that the staff member remembers you and where you're coming from." Once -- want your pool of knowledge is, there are people now that, when something comes up, I go to the I actually go to them in Pennsylvania, and I used to do the same in lowa, and I asked them, "What is this going to be like?" And how important is it? Or, when we are developing pieces of legislation or letters, we will go back to trusted people in the state as well, and ask them their opinion as well. And they introduce a piece of legislation on guardianship, both national and state, which meant a lot of time asking people like you what the problems were and what to do about those problems.

#### **DENISE ROZELL:**

Michael, Senator Casey has introduced a lot of bills lately. Would there be anything folks on this call should hear about? Or things going on on the hill? Either one of you?

## MICHAEL McCORMICK:

I would actually say, that in many ways Sarah's office and our office work in tandem. So, it is not quite like riding a bicycle built for two, but close (Laughs). Sarah, do you want to talk about what HELP (?) is doing?

#### SARAH MUELLER:

I think you pedal sometimes faster than me, Michael.

Page 6 of 21

So, the committee under Chair Sanders, is focused on several bipartisan efforts with the ranking Member, Senator Cassidy from Louisiana. So they are working together to address the healthcare workforce shortage and my boss things about that from multiple different lenses, including physicians, nurses, behavioral health workers, dentists, and Michael's and others classes (indiscernible) distress care workers, and so many workers providing home care services. That will be a big priority moving forward with the health committee.

We also are looking at reauthorizing what is called the PAPA the pandemic preparedness act. This is an important piece of legislation that authorizes programs in the federal government to respond to pandemics and other disasters. So, given all of the things we have learned from COVID 19, it will be a unique opportunity to make sure we are addressing the needs that we have learned, from the community, for lack of services and barriers that folks with disabilities faced during the pandemic.

The other one that we recently announced a reauthorization of the education sciences Reform Act, which is focused on education research, including special education research. So there is definitely a lot of work ahead for our committee. And Michael can add other priorities and things, given the lack of jurisdiction (Laughs).

#### MICHAEL McCORMICK:

The thing Sarah talked about are critical because those items are items we have hope will actually move through the legislative process and hopefully pass the Senate! Things like PAPA are important, not just from a pandemic or disaster point of view, but also how is disability policy woven into that type of piece of legislation? It has lots and lots of applications.

Same with education research. Or workforce development. I think the thing that Sarah and I are lucky enough to be able to do is think about the broader legislation that is moving from Congress and how this sort of policy can be embedded into that.

I will talk about just three other things that Senator Casey has been working on. Denise mentions that she has -- he has introduced a fair amount of legislation in the last three months. One of those was a reintroduction of the transformation competitive and integrated employment act, that was state health minimum wage payments and the ability for employers to pay minimum wage. (?) This will be (indiscernible) Congress and that is not unusual, each Congress is 2 years, so this will be the seventh year that this bill has been active. We do have a Republican cosponsor. Senator Daines (?) from Montana. They are working hard to make sure we can get some other Republicans on the piece of legislation as well.

I mentioned the guardianship bill that was introduced on 30 March. Senator Casey help hearing on the issue and then introduced that piece of legislation. It is a challenging piece of legislation, because there isn't a clear-cut way for the central government to address guardianship. We have to do it often like we do it with education, through a funding source. Guardianship under our federalist system, the country, the Constitution, is something that is primarily controlled by states. So we had to figure out a way to actually hook it to specific federal funding, which we think we have done and we are trying to



actually do a good job of analyzing the legislation. And making sure that it is addressing concerns that are out there, regarding guardianship as well.

And then third piece, I would just think of would be that with community health centers looking at reauthorization, we are trying to make sure the existing community health centers are prepared to serve people with disabilities within those health centers.

So, there are health centers that serve underserved populations, or underserved areas of the country, and we want to make sure that the healthcare workers in those settings are actually able to serve people with disabilities, and also that they are actually truly accessible as well.

### **KEVIN RYLE:**

So we have a question in the chat, this is Kevin by the way, hi Sarah and Michael, thanks for joining. I know we only have about four minutes left in the time. So some of the asked, what kinds of questions are good to ask policymakers about how to best inform the community on disability policies?

So I guess, are there any kind of questions that our trainees should be asking to give them more affirmation that they can share with networks back at home once they leave their meetings?

#### SARAH MUELLER:

I guess it would kind of modify our response for the question to making sure you know the member and what their priorities are, and tailor your questions around that. You know, it's best to go in with the targeted question of, you know, I saw the Senator was a cosponsor of this bill but not this bill, could you tell us more about, you know, what the Senators priorities are on disability and how he can provide more information around why this other bill is important for the Senators to support?

So it's really getting to know your member, understanding what their priorities are and filling in the gaps based on all of your expertise from the field.

## MICHAEL GAMEL-McCORMICK:

And in addition to what Sarah just said, you can bring forward state-level information or district level information about an issue that a Senator might be interested in. For instance, if guardianship is a concern, particularly for those with intellectual and develop mental disabilities, you might think forward what's been happening in that area in your state or your congressional district.

Is extraordinarily valuable to a staff member to have state-level or district level information, which can get passed on to the member. My boss loves to have data from the 67 counties in Pennsylvania because he wants to be able to talk about Marisa County or elk County or Pike County when he's in those areas.

#### **DENISE ROZELL:**

I just saw Liz put the question in the tank, I put in the chat Liz, why don't you just ask your question. Go for it. There you go.

Page 8 of 21 Downloaded on: 04 May 2023 11:05 AM



#### LIZ WEINTRAUB:

Hi, Michael, Sarah. What happens if you don't understand the policy, and you're kind of shy about policy? Can you still advocate to your member? And you are on mute.

#### SARAH MUELLER:

Absolutely, it's all about sharing your experience. Some of the best ways for us to know how policy is impacting people is based off their-- how they are living their life and what problems they are having in their everyday life. And those stories help us draft policy and make policy decisions.

#### MICHAEL GAMEL-McCORMICK:

Yeah, and Liz, I think you do this with a lot of people, if somebody shy, it's great to go with somebody who has done a visit before and watch and listen to them, and hear how they present information and to Sarah's point, each of you as individuals have contact either from your personal experience or people you know, and can share those experiences and those stories, which again most members of Congress want to know what's happening to their constituents and they really care about the individual stories.

Also, always question that you get permission to share a story if it's not from you. But, you don't have to know the policy. What is important is sharing the experiences that people are having, particularly where they are having challenges and experiencing barriers.

#### **KEVIN RYLE:**

Liz, you have something to say, sorry?

## LIZ WEINTRAUB:

No, I just wanted to say sorry.

#### **KEVIN RYLE:**

I had trouble in the beginning, but I'm getting used to it now. I know we have time, it it's been 20 minutes and we have more training to get back to. So want to say thank you on behalf of AUCD and our trainees for Sarah and Michael regarding today and sharing some updates on what's going on on the Hill.

We appreciate your partnership, as always and it's always great to hear from you guys.

#### SPEAKER:

Thank you guys.

## **KEVIN RYLE:**

Now we can take more questions on educating and lobbying, since this is important for everyone to understand, then we will move on to some more updates. A slide maybe on educating and lobbying before we move on, I know we got cut off, sorry about that.

So I will give it a second to see if any questions come in.



#### DENISE ROZELL:

Is a great example actually of how things work. When Hill staff are available, they are available because they have really busy jobs and their time is short and very scheduled when they are available, they are available and make sure you meet their schedule. Is actually really good lesson on how to do visits because that's important.

Alright, what we go on, Liz. What you want to plain language and we will keep asking questions as we go along. If there are more questions on lobbying or educating or whatever, we can take them later.

#### LIZ WEINTRAUB:

Thanks, Denise. And this is my favorite language. Plain language. And we have links to our plain language guide here and we also have a glossary, or dictionary of policy terms that I know that Michael and Sarah use some of those words today, and they are in the dictionary as well.

And they are also here as well as on our website as well. What is plain language, you would ask? A language that everyone can understand. Some people call it clear language. And it's just language that anyone can understand, no jargon, no abbreviation. That's not a plain language word, but no AUCD, try to spell that out in the beginning.

And why this is important, it helps people participate in the conversation. It helps me and my friends to be part of the conversation. There are tons of meetings that I go to that I'm coming back and I'm like, what are they talking about? Denise or Kevin, can you help me understand what's going on?

Because I would like part of the conversation, and that's why we use plain language in the disability policy news. We hope you have a sign up for that, and if you can benefit, I would say anyone can benefit, it can help, I can see that it helps people, staffers as well as people with disabilities as well as trainees because it is short and can get to the point about what the word means. So, the next slide.

And this is how the three branches of government work, and I'm assuming you all know from your high school days about the three branches of government, but just to review, the President and the administration is the executive branch, Congress and the legislative branch and the judiciary are the courts.

And, just a story about how it all works, during the Cavanaugh case last year the President nominated someone to be on the Supreme Court. Congress, the Senate, approved them. I'm losing my words. And then he eventually got approved-- got appointed to be on the Court. So, that's how, and that's what we call checks and balances.

The next slide. The President and the executive branch, and I think Kevin will go over the next two branches, the presidency and the vice-- the President is President Biden and Vice President is Vice President Harris. And they propose new ideas for new laws, they appoint agency heads like the Department of Education or the administration in community living, they appoint federal judges, they write regulation or rules that make the laws work, they enforce, or make sure laws are being followed,

Page 10 of 21 Downloaded on: 04 May 2023 11:05 AM



and they sign veto saying no to a bill, there's no line you can veto in most states. So next, slide. And I think that's you, Kevin.

#### **KEVIN RYLE:**

Yes, thanks Liz. Next's judicial branch, so this is all the courts, the federal courts in the United States make up the judicial branch and it is made up of the district Court, the Court of Appeals and United States Supreme Court, this is the one most people are familiar with, there's nine justices, they are reported by the President and confirmed by the Senate as Liz mentioned earlier. And they serve lifetime appoints.

So they sit on the bench for life, that if a member decides to retire or passes away, whoever is President is able to appoint a new justice and the Senate confirms whoever the President decides to nominate.

The Supreme Court is the highest court in the land. It is the only court mentioned in the Constitution, it is the only court establishing private Constitution. The other court the District Court and the Court of Appeals were set up later we can go to the next slide.

The Supreme Court makes the final decisions on how to interpret federal law. You may have heard around Supreme Court cases that dealt with (indiscernible), and the legality of it, the summer -- Supreme Court some cases around (indiscernible) overreach of the government.

A lot of times bills will go before them and -- based on sort of cases that are filed and a lot of times they decide how it is interpreted and if it is constitutional for it to remain in effect.

The District Court and the Court of Appeals must follow the decisions of the Supreme Court. This is going -- called following president. The Supreme Court is the highest court in the land, so the District Court, since it is below the Supreme Court, must follow any rulings the Supreme Court decides on.

For example, the court entered the meeting of the Americans with disabilities act or any ADA that goes before the court, the District Courts and Courts of Appeals have to follow the same rules of the court -- Supreme Court follows.

And, the AUCD's Plain Language Glossary on Policy Terms Helps Everyone that Liz just pointed out, when it comes to these different branches of government, it can get confusing and a lot of the words I just used are explained in plain language on that AUCD's Plain Language Glossary on Policy Terms Helps Everyone.

We can move on to the next slide and talk about the legislative branch, or Congress as it is commonly known. The first chamber of Congress is the United States Senate. There are 100 members, 2 per state, they serve six-year terms and 1/3 of those members are up for election every year. -- Every even year. In 2020, only one third of the senators were up for reelection, 2022 and other third and in 2024, it will be a different selection and then it starts again once we reached 2026.

Page 11 of 21 Downloaded on: 04 May 2023 11:05 AM

Everyone here has 2 senators. Regardless of what state you live in.

The United States House of Representatives has 435 members and there is at least 1 per state. The number of representatives per state depends how big the population of your state is. I live in Pennsylvania, there are 18 presented this year, whereas estate like Delaware only has 1. It just depends how many people live in the state.

They serve 2 year terms, and all members are up for reelection every even year. Yes, that is a good note except for folks in territories like DC and Puerto Rico. So the US territories as well as the District of Columbia, they have nonvoting delegates so they also have the election every two years to vote in a nonvoting delegate that will represent them in the House of Representatives, and they do not count toward those 535 members -- 435 members.... They do not vote on those bills. That is the makeup of Congress.

Please go to the next light. So, we are in the 118th Congress at the moment. It started on January 3 of this year. The House of Representatives is controlled by the Republican. There hurt 222 Republicans in the house and 213 Democrats. The Republicans have the majority and they also have the leadership, so I am sure back in January you may remember speaker Kevin McCarthy going through the process to be voted speaker of the house. It was a longer process than normal, so, you might have heard about it or seen it on the news.

There are a couple of controls... And it is the opposite in the Senate. The Senate is controlled by the Democrats, there are 48 Democrats and 49 Republicans in the Senate. There are three independents, to who caucus with the Democrats and one who caucuses alone. In this case, "caucus" means when you work with people that smaller -- similar ideas of the lease as you. So Senator Sanders is the boss of Sarah Mueller, he is independent. So is Senator King from Maine. They sure beliefs with the Democratic Party. So... That gives the Democrats a majority of 50 and that is how they control the Senate.

Then there is one senator from Arizona, (Unknown name), who is newly independent. She used to be a Democrat and has now changed to registration. She does not caucus with any party. She doesn't add to either of the numbers. For number say, it is 48 Democrats, 49 Republicans and three independents...

That is a little overview of the 118th Congress. Let's go to the next slide and see if there are any questions. I will check the chat. Again, you can raise your hand or placer question in the chat and I will read it out and answer it.

## **DENISE ROZELL:**

, There was a question earlier that I think I entered def answered in passing. That was about educating and lobbying. What do you do if you are in a member -- meeting, and the member says how should I vote for this bill? You need to be careful. That is the answer. The answer is: you cannot tell them vote yes or no.

Page 12 of 21



If you are there as a LEND trainee, and you want to talk about how the activities under that would benefit or hurt, will you see, you can talk about impact, you can talk about a lot of things. The yes or no, you kind of have to fudge it -- I would probably say something like well, that is up to you. I have shared some of my thoughts. But, you have to be careful.

If, as a private citizen, you can say, "I support the bill. I wish you would support the bill. I like the bill. The bill will benefit the people I serve." But not in terms of can you actually tell them how to vote for the bill. No, not as a LEND trainee because you are there and funded by federal money. That is one of the rules that exists with the feds. Go ahead Kevin.

### **KEVIN RYLE:**

Another question: is it OK if I support this bill? Technically that would not be lobbying, as you are not trying to change the opinion. It does get very murky.

#### **DENISE ROZELL:**

It is clear as mud. Be cautious and, particularly as a LEND trainee, talk to your folks and see how they interpret that. Jackie will text me if I am wrong. But I think that's --

#### **KEVIN RYLE:**

Different programs have different rules around universities you might be affiliated with might have different rules when you speak with policymakers. So, you want to make sure you are not putting your university or the work you are connected to, you do not want to break any of their rules, either.

Another question: (Reads) So, as a LEND trainee, you can't lobby so do not say no do not bow this bill.

#### **DENISE ROZELL:**

That is absolutely right. The best advice we can give you is to chat with your LEND at your university and your LEND director. They have been further this -- they have been through this and they know how to respond... That is what Michael said earlier about getting to know your members. There are things that if you know about the member, you can answer certain questions.

Talk to your LEND supervisor about it. Any of these more funky or murky questions, and it is confusing. It is confusing. The way it is written is confusing, the law is confusing, etc. If you are a pastor previous LEND member, if you are doing the work you are about to be doing as a private citizen, if so, that is fine. And in the likelihood of you being up past LEND trainee,... If you are with other people from LEND and you are there as part of the training, I would stay away from it and treat yourself as a LEND trainee.

#### LIZ WEINTRAUB:

There is a question in the chat about (indiscernible) a bill? If I understand correctly -- always, always thank them.

Page 13 of 21 Downloaded on: 04 May 2023 11:05 AM



#### **KEVIN RYLE:**

Will cover this later, we talk about structuring. It is always great to do a little research on your member before you go into a meeting and see if there is anything they have recently cosponsored or introduced for voting on. I just give them the thanks for supporting the bill.

I think we will move on, to keep with time, if that works for everyone, and I will do a quick thing on how a bill becomes a law. You might remember from school, elementary, middle or high school, the (indiscernible) song (Sings) I don't want that to get stuck in your head too easily!

I will walk through this: a bill comes along, first step and it is introduced by a member of Congress. It is sent to the committee or subcommittee. This is what Sarah and Michael were talking about earlier with jurisdiction. Sarah works on the Health education and labor and pensions committee, so the jurisdiction there is a lot of things related to health, education, labor and pensions. If the bill is relevant to either of those four sections, it will be sent to the health committee in the Senate, and that there are different committees. Then there are hearings and markets held, so for hearings a lot of times experts will come and ensure that expertise. Then members will make some changes and the Full House and Senate debate on the bill. If both chambers decide to pass it, it gets sent to the president where the president either signed into law or the bill is vetoed, and the process starts from the beginning of

This process gets confusing, and sometimes there are missteps. So this does not always -- is not always what actually happens. I will pass it to Denise. She will talk about the types of bills in Congress.

### **DENISE ROZELL:**

Thank you Kevin.

There are two major types of bills in Congress: authorization and rations. I will also say, these are in the vocabulary and guide as well. Authorization, I was saying early, continues the program like Autism CARES Act it means it comes back and Congress continues (indiscernible). Appropriations is the money. This is how you fund authorized programs. Theoretically, commerce could pass a bill that creates a program and then not put any money to it. So if if there and doesn't get active, because they also have to bow to get money. That's what appropriations are.

Right now, Congress is middle of deciding how much money programs like LEND will get in fiscal year 2024. So we're talking about starting October 1, 2023 through September

Then there are two types of funding you also need to know about and this is been in the news lately because there's been talking about whether or not to touch what's called entitlement programs, so their discretionary programs and discretionary spending which is only one third of the budget, and those are things that have to be voted on every year, funded every year and new budget numbers or new numbers, amounts of money, going every year. So that's like IDEA, special education law, the DDE act, Autism CARES act, vocational real, everything has to be on a specific amount of money for each of those programs has to be voted on once every year and it comes out of the one third of the budget. The two thirds budget, the other two thirds is what's called entitlement or mandatory spending.

Page 14 of 21

That is programs that guarantee things like Medicaid and Social Security that don't have to be voted on every year, they continue because they are mandatory. People are guaranteed the right to certain benefits in those programs. And there's a line here to a fabulous, Tuesdays with Liz episode with incorporations with Liz, we didn't talk about Tuesdays yet, we gave links to, but that's Liz Weintraub's YouTube channel where there are over 200 short videos, 3 to 5 minutes, particular issues about policy that Liz has done, and she can talk more about that later.

But this was really good, what is appropriations and how does it work. OK, next slide. We can add the link for you. So how is it supposed to happen? This is, like I said in the middle of it right now, this is what's supposed to happen. Let's say it doesn't always happen.

The President submits a budget to Congress, usually every February, this was early March, this is how much you want to spend on all these programs. Then Congress passes what's called a concurrent resolution, which-- a concurrent budget resolution which means the both the house and Senate make a conclusion this is how much we are going to spend by April 15, they come to an agreement. They reconcile, so if they passed everyone's they come together with the budget reconciliation, so it all agrees.

Then they get specific numbers that are divided up into different appropriations bills, there's the labor health, human services, education related agencies, that's when the covers most of the things we're talking about, the committees, Sarah's committee actually in some of the others, yes, in plain language, Liz says Tuesdays with Liz is in plain language, absolutely that's the point of it to explain policy in plain language, so they get a number, top-level number of how much they can put into each of the appropriations bills, the neck it's divided out among the programs.

The house and the Senate voting there appropriations bills and the new federal budget starts October 1. This is the way it's kinda supposed to happen, next slide, it really hasn't happened this way in quite some time.

The reality is, this year the White House released its budget on March 9, there still is no budget agreement, they can't agree on the numbers per each appropriations bill, everything is tied up in conversations about raising the debt ceiling, which you probably heard about on the news, which is the limit that the federal government's-- the limit on the federal government's credit card.

The federal government spent a certain amount of money, the debt ceiling says you can only go out to this amount and we are at that amount so in order to spend anymore we have to raise it, and so far that has not happened. I don't see how they are going to solve that problem at the moment.

House Republicans want to cut discretionary spending in order to raise the debt limit, Democrats don't want to cut discretionary spending to raise the debt limit, there's questions about mandatory spending, Social Security and Medicaid, Medicare, there's certainly questions about Medicaid cuts, so it's kind of a mess right now is the answer, and we're not quite sure what's can happen yet. Go to the next slide,

Page 15 of 21



Kevin, is that? Yeah, go to the next slide.

We've been doing a lot of work, we, that would really be Kevin and Sidney Smith was not here today, who is our Director of public policy, and Liz, all three of you guys have done meetings, have spent the last two months meeting with congressional offices and asking for funding for programs that are particularly affecting people with disabilities including LEND. As LEND training you can help educate offices on the importance of LEND and the other important programs, you can't lobby up you can go in and say this is what the LEND program is, this is what I'm learning, this is what it's about, this is why is important to what I do. And to the people I serve.

Next slide. The priority funding that AUCD has been looking at, this is the list of our priority programs having from the LEND, you see the LEND programs out there, you see ICEDD which is the ICCDR people, those of you with Inclusive Postsecondary Education in your states, assistive technology, national Institute on disability, independent living and rehab research, all of these are funding priorities that we have been talking to members about, basically. OK, next one, Kevin, is that back to you? Somebody, I think?

So, questions? Happy to answer questions. I know the appropriations stuff is a little confusing, but the most important thing to note is you are going in and talking about, again, your story, what's important to you, why LEND is important to you, why UCEDDs are important to you, why people you serve the programming, that kinda stuff.

You don't even have to know all the nitty-gritty about appropriations, particularly about appropriations. You need to talk about what you know and what I said earlier about, how this all works on the ground and why this is important. OK.

You can say I'm a LEND trainee, and it's important because it's important, absolutely, Liz. Trying to see if there's any other questions, I don't think so. OK.

To you.

## **KEVIN RYLE:**

This some of the important issues aside from funding for disability programs we think are important for US trainees to talk to policymakers about at DPS or at home if you're able to meet with a policymaker in their district office were virtually. So, we recommend these three issues, the first one which we just talked about, important funding for helping people with disabilities and then the Autism CARES act, and the better care better jobs act, and as a reminder, when you meet with policymakers, you can reference these last two bills, but you cannot ask them to take any specific action on either of them.

So just a little reminder on the lobbying educating piece again. And then I will introduce the Autism CARES act. The Autism CARES act is a bill that supports research, services, education and monitoring related to autism and other Neuro develop mental disabilities. It was originally enacted in 2006 and has been expanded and reauthorized, which Denise explained before, just sort of passed again with some changes, several times since 2006.

Page 16 of 21 Downloaded on: 04 May 2023 11:05 AM

The most recent one was 2019, currently the Autism CARES act is set to expire at the end of fiscal year 24. So next October 1 is what we call the sunset date on Autism CARES, so we need to work on a reauthorization before then.

Yes some CARES Act funds many programs in the CDC, the National Institute on health and the health resources and services administration the LEND programs and also the developmental behavioral pediatric programs are funded under the Autism CARES act, so this is something you can check out for the LEND fiscal year 24 fact sheet if you are a LEND training and want more information on how your programs archly funded, but this bill is how the LEND programs get their federal money. So we can move to the next slide.

So, as the sun set date approaches, not super soon, but October 1, 2024, next October 1, it will creep up on us very fast, so AUCD is working with other disability organizations, and also the champions for just sort of autism related policy in the House and Senate on the reauthorization.

So, we are working with representative Chris Smith from New Jersey and also Senator Menendez, also from New Jersey if anyone else is on the call from New Jersey, they are from different parties, Representative Smith is a Republican in Senator Menendez is a Democrat. And we are working with their offices and discussing what we want to see in a reauthorization, specifically around language to require culturally competent care and also increased funding for programs.

And so, it's really important, we need your help to educate policymakers about what the Autism CARES act does and the difference that LEND programs make in the lives of people with disabilities and the professionals that work with them.

So moving forward, and as we get closer to that date, October 1, 2024, we will be working with LEND trainees and LEND Directors to collect stories and have you sit in on meetings to educate specific policymakers on the importance of these programs, and even if you are not a LEND trainee, if you're with UCEDD or IDDIE, this bill still funds low programs you do that provide a lot of research and services for people with autism, and related disabilities across the whole country.

So that's the Autism CARES act, and the second piece of legislation that we want to highlight before the disability policy seminar is the better care, better jobs act so we can move to the next slide. Sorry, before I do that, list you want to talk about Tuesdays with Liz episode and then I will move on?

#### LIZ WEINTRAUB:

This is an episode I did probably before the last time we needed to get reauthorized with representative Chris Smith because he's a big champion, he still is, and this is in plain language so there's two episodes just to fill the interview, there's two episodes because the interview was long.

So, enjoy that, if you are interested. Kevin?

**KEVIN RYLE:** 



Thanks Liz. Next I will talk about the better care better jobs act, these links which were also sent in the chat, thank you Jackie and Rachel, have the bill text, this bill would increase funding and then make some changes to improve Medicaid's Home and Community Based Services, this is when someone receives healthcare in their home as opposed to going to an institution or a nursing home, or a congregate care setting, this allows people to receive any sort of care in the comfort of their own home. So, states would be eligible for a permanent 10% point increase to the federal Medicaid match for delivering home and can switch is often abbreviated as HCBS.

If you hear someone say that while talking about health policy, they are probably referencing Home and Community Based Services, and that would also provide enhanced funding for administrative activities, so basically states would be eligible to receive more funding from the federal government to carry out, or to provide home and commuted base services.

The bill also makes changes and expands access around the country, by strengthening the workforce, and it will address payment rates and retention for home health aides, retention also asserted the amount of people that decide to stay home health aides over the years.

So as I believe Sara mentioned, it's a priority for her boss, Senator Sanders, it's a priority for many Senators and Representatives to address the workforce shortage and the sort of lack of home health aides and direct support professionals, and so this would be addressed by increasing the payment rate for these people to provide lifesaving care to people within the comfort of their own homes. So we can go onto the next slide.

This bill was introduced by Senator Casey, who was Michael's boss, who spoke earlier. And then worked in the Senate, and it was introduced by Representative Dingell in the house. And then the bill numbers attached up of the top will link you to more information on the bill, Congress.gov, and there's also some more information on Senator Casey's website and this is also where we love to get help from our network members to educate policymakers on why HCBS is so important so that we can provide increased funding for caregivers and make sure it's a steady career for people to have. And that they make living wages because that's always a very important.

And the links also I will send in the chat again, thank you. Thanks Jackie Rachel for sending out.

We will move on now talk about the 2023 Disability Policy Seminar I will pass it to Denise to cover some intro on what the seminar will be like.

### **DENISE ROZELL:**

In the interest of time, I am going to do this one pretty quickly, because I want to make sure you hear how to do a meeting, which Liz is going to do after me.

Basically, the 2023 Disability Policy Seminar is next week, it is virtual on the 24th and there are people flying in on the 27th. Even if you are not flying in, it doesn't mean you cannot do visits from home. It does not have to be on the 27th. Setting up visits with her Members at any time is a good idea.

Page 18 of 21 Downloaded on: 04 May 2023 11:05 AM



There is all kinds of information on where you can find info, what you can do. Each program is deciding and you will be hearing this, again, your supervisors however, each program is deciding if you want to do your own visits or folks from The Arc,... If you decide you do want to do it with your state, and you want to be connected with the state captain, please reimage -- reach out to Kevin and schedule roles.

Why 2023 Disability Policy Seminar? It is a good opportunity to hear a lot of what is going on on federal issues from Xers for -- experts from the Hill and Hill staff. I am sure both Sarah and Michael will be speaking at 2023 Disability Policy Seminar. You will hear from people who understand these issues and from hell staff. You have an opportunity to educate members, and sharing all the things you know. Next slide.

Liz, over to you.

#### LIZ WEINTRAUB:

I would also add, if you have meetings please let us at AUCD know, we might be helpful for background research or whatever. We like to be helpful. That's -- what you can do, you yourself, is write emails, make phone calls or personal visits starting today. I have the Congress number in my phone. You can submit testimony, which is a story or your story from hearings. Someone from Kansas just spoke of the guardianship hearing, so I know that Michael and Sarah, their bosses are always looking for people to testify and they might ask you to testify.

And it's quite easy. It's easier for me to say that, but in just telling your story, contact media, letters to the editor or send a letter to your newspaper. Organize and participate in nonpartisan coalitions. Old nonpartisan candidate forums to educate voters. And we always try to encourage you to invite members of Congress from your state and their staff to visit your program in your state. I know when I used to work for Senator Casey, one of my favorite things was when we were invited to see a program. Next slide?

Sarah and Michael went over this, but just quickly, do some background research on the members website to see what might be their interest. Always look at their website before you go.

And Kevin early day said this, but thank the members when you start the meeting. Thank your bosses, the senator or your representative for supporting something. It is just a really nice thing to do. Make it clear that you see the Member as a partner in ensuring people with disabilities can work and live in the community. That you have something to offer! And not just saying that, you really do have something to offer either life experience or -- take timing cues from the Member of their staff. Denise said this, but I remember once I was doing Tuesdays with Liz. With Senator Casey and his staff, came in the door and said, "Hurry up! Hurry up!" They were peeking in and telling me to hurry up.

Also, if the Member or the staff says, and usually meet with the Member -- I mean the staff, I'm sorry! The staff. And sometimes the staff will say can you walk with me I need to get to a meeting in three minutes? So you might have to walk and talk at the same time. Just do it! It's their time, you are on their time. Next slide?

Page 19 of 21

Be early, do not take it personally if you have to wait for the meeting to start. Be prepared to meet anywhere. I just went over that. Be prepared to meet anywhere! And be early! That is so important.

If multiple people or many people are attending the meeting, prepare in advance so you don't say, "You are going here, you are going first or second." Be prepared.

Go into your meeting with no more than 2 to 3 topics of discussion. In the topic, I know you might have 5 topics but try to limit to 2 or three. Actually, a colleague of Cindy's would always say "data makes incredible, stories make you memorable" meaning use the data, but stories, the personal stories are what people remember you by. And that is so, so true.

This is also really important: after the meeting, send a thank you email and any information. So don't fudge and say this is the correct information, we will get back to you about this. And then, when you say thank you, when you write your thank you letter at home, say this is the information you asked for and I would be glad to help you in any way I can. Next slide?

## **KEVIN RYLE:**

Next we just have some quick resources linked in the slide. There are two slides of resources. We can skip through those. And just remember, all of the work is always hard and confusing. If you have any questions, the policy team at AUCD is ready and willing to answer any questions. Prevention is just as good at getting something passed. You have to celebrate your wins! Sometimes it is an uphill battle. If you are successful in getting something passed, it is always important to celebrate and keep your head up!

The next slide is our contact information with our email addresses. Please reach out with any questions at any time, whether it is about 2023 Disability Policy Seminar or something in the future, we are always willing to help. I will pass it off to Jeanette with a quick survey.

## JEANETTE CORDOVA:

Thank you so much Denise, Kevin, and Liz. We really appreciate all the information and we really appreciate the guests. Thank you all for being with us today.

If you could please provide feedback on the webinar, you can scan the QR code with your camera on your phone or it is on the page. And, I think it should be in the chat box, by now. While you're doing that, we can open it up if there are any questions, we have 3 minutes! So, feel free to unmute or ask a question in the chat.

## **DENISE ROZELL:**

You guys ask great questions!

#### JEANETTE CORDOVA:

They sure do. Those are great questions. The link to the evaluation is in the chat. It was posted the same time as your message, Dean -- Tina. Alright, again thank you all so much Denise, Canada, Liz

Page 20 of 21



and it was great to have the hill staffers there. This will be archived as soon as it is ready, I will send out an email and you will be able to find it on the event page that was shared throughout the presentation and will be shared at the end, as well. Alright, thank you all so much for being here! And have fun at 2023 Disability Policy Seminar if you are going! Thank you so much.

DENISE ROZELL: Thanks everybody.
KEVIN RYLE: Γhank you.
SPEAKER: Recording stopped.
LIZ WEINTRAUB: Γhank you.
JEANETTE CORDOVA:  Thank you, Lisa, we really try to make it in plain language!
Thank you all. Thank you to our Captioner's and our ASL!
DENISE ROZELL: You guys were awesome!
Meeting ends)

Live captioning provided by Ai-Media