NCIL

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>> JENNY: Thank you to our captioner who just hopped on at the last second and hello everyone, my name is Jenny Sichel with the national Council on Independent living in the operations director there I welcome you all to NCIL preconference webinar the policy briefing I use she/her, am a white female, with dark haired ponytail.

Some accessibility tips today, we will have CART captioning and ASL available you can access captioning in the menu bar; if you do not see that you can look under more options it should be on the right-hand side under More were the three ellipses. And captions are also running at AI media. This website allows you to enlarge the font and color and contrast of the captioning is also a chat feature to submit questions, and the URL is too long to read, but we have posted in the chat and it is posted on our conference website.

Our ASL interpreters should be appearing in the video screen. We are screen sharing so please ensure you are in side-by-side mode and I forcing this presentation in gallery but if you are not already you can go to the top of your screen where it says Jenny is sharing her screen and in the drop-down menu be sure you are in the side-by-side, you can optimize for dual monitors and that side-by-side mode will allow you to adjust the video and PowerPoint to the size you prefer.

We do not recommend joining sessions by mobile or tablet if you want to see the interpreters and PowerPoint at the same time but if you do join via mobile, you can swat swipe left and most to change your view public chat is turned off but you will still be able to send chat messages to the host and panelists, we ask you reserve chat requests for technical support

And please do not use the panelists chat to submit questions for the presenters. You can do this under the Q&A tab that is in the Zoom toolbar or, this will be allowed during the Q&A portion in the chat box. I will go over that a little bit further once we get to the Q&A portion.

Now that we have our housekeeping out of the way I will turn the mic over to the current vice president Lou Ann Kibbee.

>> LOU ANN: Welcome to this afternoon's policy briefing, my name is Lou Ann Kibbee vice president of the NCIL board; I am a white female, navy blue shirt and long straight hair with a lot of gray in it. And I am wearing glasses. We will be reviewing NCIL legislative advocacy agenda in advance of the NCIL conference, we hope you are able to attend the conference, or participate in the conference whether you go to DC or not Congress needs to hear your voice – the goal of today's policy briefing is to present information on the current NCIL legislative advocacy priorities set by the mentorship and approved by the board. Followed by a short presentation on preparing for Hill visits and time for Q&A – before we get to that, we have L&A committee, the legislative and advocacy committee is comprised of all legislative and advocacy subcommittee chairs, word to Steve Higgins, myself as vice president, NCIL interim Director Jones and Director of policy Jessica and when she starts in her position on July 18th which we are excited about.

I would like to take this time, the subcommittee chair has put a lot of work into keeping the subcommittees going and getting ready for the conference, always a lot of work to keep up on, so I do want to thank the L& A committee and chairs and all members for the work they do, the subcommittee chairs, I want to recognize, with the rehab funding subcommittee Ann McDaniel and Jeff, housing, ADA civil rights is Steve Higgins, Marty, long-term service support and healthcare is Lisa Hayes and Jeff Hughes, Employment and Social Security Christine Fitzgerald, transportation Peter Johnke, Technology subcommittee is Susan Tachau, Education subcommittee is Maureen Hollowell, Mental health subcommittee is Yvonne Smith, the Voting rights subcommittee Meg Coffin and Sha’ Anderson, Cronic Pain and Opioids task force is Kristi McGarity and Liz Steckler.

NCIL surveys membership to determine community needs to set legislative policy priorities every two years, L&A committee reviews the results and makes recommendations or priorities to the board based on those results. The NCIL board reviews the recommendations and formally adopts NCIL legislative agenda. The survey will be done again in the fall with the new agenda adopted by the board in February 2023. NCIL adopted the following priorities as a form of legislative issues to work on. Authorization of the rehab act and funding, long-term services support in healthcare, housing, four, ADA civil rights, and five, transportation. NCIL does advocacy and other issues covered by the other subcommittees and sometimes issues not covered by our subcommittees, but these are the current top priorities that were mentioned. At this time several subcommittee members or chairs will make their presentations on some of the most pressing issues that you need to know about and as a reminder following the presentation, we will have the Q&A session so if for some reason we don't get your question please send your question to Jenny@NCIL.org and someone will get in touch with you.

You should have received a link to the advocacy priority booklet before participating in the conference and I recommend thoroughly reviewing this booklet to be prepared for your meetings with your congressional members.

>> JENNY: I know Lou Ann mentioned if you have questions throughout the presentation or in the Q&A portion you can email myself, Jenny@NCIL.org or you can also type them into the Q&A box that is on Zoom – if you are dialing in you can hit star nine and we will unmute you and you can ask your question and that will only be used in the Q&A session.

Let's move on – Lisa are you ready to go on LTSS and healthcare?

>> LISA: Sure, I can go.

Great to be with you all and thank you, I am Lisa Hayes, I'm a white female auburn colored hair I wear glasses I am a chair user and today I am wearing a green white and black beautiful summer dress. It is great to be with you and share some of our legislative priorities and long-term support and services and healthcare. I will dive right in, we have seen investment in home and community-based investments and Medicaid home and community-based continues to be needed now more than ever, home care worker shortages are putting the lives of people with disabilities at risk of entering nursing facilities. Many of you know this. It is a big deal we need to let our legislators know this needs to be self. We need permanent authorization of Money Follows the Person. We need investments in Centers for Independent Living to fulfill our core mandate, transitions. Something we were asked to do years ago yet no funding followed it. Better care, better jobs, we would like to see this go through built on the ARP infrastructure funding, expand access to home and community services and seniors, supports home care providers of which 63% are people of color and women. More than 800 state and national organizations representing older Americans, people with disabilities, labor unions, home care providers, health insurers, and more have voiced support for better care, better investments and home and communicates infrastructure is, some talking points addressing the workforce issues, in your Hill visits is critical to supporting the system that keeps disabled people in their homes and communities. Second talking point, home and community-based services are the future of long-term care, unprecedented investments were made in HCBS with the American Rescue plan, we need funding to sustain these investments. That's why better care better jobs are so important, the average cost of care through home-based care is approximately $26,000 a year compared to 90,000 for institutional care, so talk money to conservative just letters, it makes sense, it will cost less and we want to be in a community, not in a nursing home.

The institutional bias – take a look at the LaTonya Reeves Freedom Act, it requires government entities and insurance providers to offer community-based services to people with disabilities prior to institutionalization, people of color are institutionalized at higher rates and in the community we see fewer services and have higher death and infection rates. Your talking points, money, cost of care, rehabilitation facility is significantly more than services in the home.

How many people do you know what to raise their hand to vote to live in a nursing home? Ask them, what would they prefer? Nursing facilities, rehab facilities should never be the first option for our consumers or us at all.

Let's talk about healthcare, continue advocacy against disability discrimination. As more state health departments require more managed healthcare organizations, they are need, we insist they contract to be alongside after those and do the services that we do, we know what we do we are here modeled, it works, we need to make sure legislators know that should be a mandate. Nondiscrimination and equity must be core features of any program, use of discriminatory standards to authorized services, treatment, or equipment cannot be allowed, accessibility must be a requirement for all providers. I don't know about you but I can tell you, being a doctor can be a challenge, if you cannot get on a table independently, we need to have our physician offices need to be more accessible. We need to have interpreters; we need a lot of things and still after 32 years of ADA are fighting for access.

Electronic visit verification, we need to continue advocating to remove Geo tracking and biometrics from electronic visit verification.

We need to continue opposition to physician assisted suicide. And chronic pain opioids, we must through advocacy maintain the right of people with disabilities to manage chronic pain through opioid therapy. We need policy changes accessible to people with disabilities

Congress needs to support efforts to restrict and repeal requirements like geo-tracking requirements, having – if this is having an adverse effect on caregiving providers, we already are challenged with keeping a caregiver work for us. This is critical. Much of the response to COVID-19 has demonstrated that disabled and aging lives are not valued. We were always last to the table. Efforts to limit care or use discriminatory standards to determine priority of care are unnecessary, immoral, and illegal. And people with will live with chronic pain and other disabilities should have access to treatments necessary to support their health, safety, and well-being. And that's all I have for you!

And we are going to Gloria!

>> GLORIA: Good afternoon, everyone, my name is Gloria Garton chair of the housing subcommittee and have a wonderful group of advocates that joined me each month, I a white female with shoulder length blonde hair, my pronouns are she/her, I am wearing glasses today. For advocacy, when it comes to housing, there is a lot we all can talk about. Obviously affordable accessible, safe, and integrated housing for people with disabilities has been a problem for many communities for quite some time. The pandemic and the increase rise in rent, and while wages remain stagnant, most recent statistics say there are now zero counties in the United States where full-time workers earning minimum wage can even afford a two-bedroom apartment. Considering a lot of individuals that we work with come from, especially low income, we know how bad the housing problem is or many of our consumers.

One of the most important topics that you all can talk to your legislators about, that hopefully will have the most immediate impact is the upcoming appropriations bill for the next fiscal year, the good news is, the draft was passed on June 30th that calls for a nice increase in housing. It is a 17% increase in housing from the previous fiscal year. However, like we have seen with the build back better, we need bipartisan support in order to get that past. Most likely, we will see a bill that is not as robust as we would all like to see. Considering, after Congress reconvenes following the July recess, you have an opportunity now to talk to your legislators and really share with them important stories and examples happening within your community and why maximum funding for housing is so important this year.

Some of the things in the housing bill for next year's appropriations that are important to people with disabilities, includes tenant-based rental assistance, if they would approve the full bill, it would renew all existing contracts and expand housing vouchers to an additional 200,000 households, that is huge. Also, to help preserve public housing, it would include $5.6 billion for public housing operating fund. Homelessness continues to be a problem although our communities, the appropriations bill also includes additional funds for homeless assistance grant programs, that would address the needs of people experiencing homelessness. The other component of the bill is legal assistant, to preventive actions, as well as an additional $300 million for competitive tribal housing programs targeted to tribes with greatest needs.

We are talking with your legislators, doing visits, stress the importance of maximum funding for section 202 housing for the elderly or section 811 housing for people with disabilities, the house bill does include a significant increase in funds for both section 202 and section 811, the increase for housing for the elderly is $167 million increase from fiscal year 22 while increase or section 811 is a $48 million increase and 112 million above what the president's original funding request was.

One of the other key challenges we are having when it comes to vouchers is, as it is a such a hot seller's market right now, many communities are seeing the loss of landlords accepting section 8 vouchers, so we need to find ways to incentivize landlords and restore and renew as many of those vouchers as possible.

The last bullet point, in addition, the house bill does provide additional funds for the construction of an estimated 5600 new units of affordable accessible housing for older adults and people with disabilities. To me that seems like such a really low number still, considering the magnitude of the problem, but we want to emphasize we need maximum funding and support for housing for all people. Without housing supports, how do we fulfill our obligations to help people remain independent in their homes or provide transitions out of institutions?

The housing subcommittee, other issues that we are addressing include the problems of homelessness, and again, sharing stories of consumers that you have worked with or that conveys the need or why homelessness continues to be a problem. We still are hoping to see some movement with the Eleanor Smith inclusive home design act, we have a workgroup working on those issues, in chemical, electrical, and environmental sensitivities, this past year we actually had a special meeting and spoke with some experts in the field and we realized with the 5G rollout and other things happening in the world today, climate change and technology in general, chemical electrical and environmental sensitivities need to be on the radar.

I covered everything about the housing appropriations bill for the coming appropriations year, so that is the end of my presentation – thanks everybody, and go out and advocate for better housing for people with disabilities!

>> Steve would be next –

>> Steve: Good afternoon, everyone it is good to see you once again I Steve Higgins, the cochair of the ADA civil rights committee, I will be joined during my presentation by Marty Musser, my pronouns are he/him, a white man with graying hair and glasses and today I wearing a long-sleeved checkered shirt because turn up the air conditioning in my office. That is not a bad thing.

2022 is the 32nd anniversary of the Americans with disability act, but there's so many things and threats that are happening in regards to our rights. During the current session, ADA notification is once again emerged and something, there is several bills followed by the committee cross over into the work of other committees especially in areas around care and civil rights. I would also like to acknowledge on our slide, Kimberly Tissot who was our cochair for many years, and has done a lot of work and she passed that cochair and to Marty earlier so Marty will be making her debut this year, so Marty, I will pass it to you to talk about introducing yourself and talk about HR 77

>> MARTY: Hi everyone I am Marty Musser a white woman in my 30s, I have a blue sleeveless blouse and coming to you from my home office so there are bookcases behind me, and thank you for those kind words, Steve, I have big shoes to fill. I will talk about HR 77 it is called the ACCESS act although that is quite a misnomer, it does not increase access, to be clear, and NCIL are opposed to HR 77. The ADA compliance or customer entry to stores and services – basically what this does is this weekend the protections that we have under the ADA. Specifically, under title III with businesses, it creates more hoops with people with disabilities to jump through in order to hold business accountable to the ADA. Foods a lot timeline that you have two put the business on notice and wait a certain amount of time and then they get to respond and you have to wait another length of time but basically the ADA has been defined law for 30 years and personally I do not believe businesses need more time to receive notice that they are supposed to comply with the ADA. We don't like that.

They have been on notice.

I will leave it at that – Steve if you want to take it

>> STEVE: The next two pieces of legislation we are following, you notice they both have containing bills in both the House and Senate which is very exciting, Senate 6558 and on the house side, HR 4938 and the Ready for Disaster Act. For assisting individuals with disabilities and older adults, age 50 or older, with disaster preparedness. One of the exciting things about this is the bill is bipartisan over on the house side which is important because when we see pieces of bipartisan legislation in today's day and age is a much better tendency or that bill to move forward. Under REAADI is a requirement of an advisory committee that it includes disabled individuals and older adults to oversee the use of funds rate available by the bill. It allows states to contract with Centers for Independent Living to provide services and support for disabled individuals in preparing for hazards. It requires the department of Health and Human Services to carry out projects of national significance to create opportunities for disabled individuals in older adults directly contributed to disaster preparedness recovery and mitigation and it modifies and expands the membership of the national advisory committee on individuals with disabilities and disasters to ensure that it represents the diversity of the disabled and older adult communities. Finally, it establishes the disability and disaster preparedness \divisor recommissioned to review settlement agreements involving potential violations of the rehab act and the Americans with disabilities act of 1990.

As we move down, we have what has been referred to as DRMA, Disaster Relief Medicaid Act, Senate 2646, in the how we have a companion bill HR 4937, that bill is to provide Medicaid assistance to individuals and families affected by a disaster or emergency and for other purposes. What is important, over on the house side the bill is bipartisan and establishes a series of programs and requirements relating to Medicaid coverage of individuals affected by federally declared disaster. This is important as we look at this, in particular, the bill provides for specific disaster relief coverage under Medicaid or individuals who meet specific income eligibility standards and during the seven-day period preceding the disaster where either resident of the impacted area were employed in the impacted area and subsequently lost employment. Coverage of this is effective for two years after the date and state Medicaid programs must provide disaster relief coverage that is at least as comprehensive as the state's Medicaid coverage. Medicaid coverage of the individual's home state is applicable. This bill applies 100% federal medical assistance percentage, the federal matching rate, to such coverage and related administrative expenses and once again in both cases NCIL supports these bills so as you do your Hill visit share with your registered letters please share that. I will pass it back to Marty who was going to take the last couple bills that our committee has been following and after that she will pass it on to Peter

>> MARTY: And I use she/her, I forgot to share.

These last two we will talk about have to deal with guardianship, as many of you have noticed, Britney Spears has put guardianship in the news in the country so can you use that as your segue to talk about that with legislators, and use that. It is a great thing for people to pay more attention to guardianship issues. Also called conservatorship, those are the same thing, different ways to talk about this concept.

The first one is HR 4545, the Freedom and Right to Emancipation from Exploitation Act. Like the last few, this has bipartisan support which is a great thing, the two big things that happen under HR 4545, first, it allows for the individual to petition the court to replace their designated Guardian. In most states that is very difficult once a guardianship is in place. And secondly, it allows for the individual to communicate their own desires and goals for their lives in themselves, and they get to speak for themselves more without interference or objection from the Guardian regardless of who that person is so that is a very good thing. And we support this bill. Similarly, Senate 2881, guardianship accountability act of 2021. Has bipartisan support which is great, and one of the big things here is it will create a national resource center on guardianship, which will publish reports and share data on guardianship which is great because this is not something where we see consistent data collection in many states related to their laws and guardianship so that is good, the resource Center will provide technical assistance, and the second big thing that this does is it will create more accountability at the state level for court-appointed guardians. We need more oversight so we hope they will pass this bill

>> PETER: Thanks everybody I am Peter Johnke, white male, light brown hair, and sitting close to my screen so you can't see what I'm wearing.

For transportation, it is a crucial part of everything that happens because you have all kinds of great services but if people have no way to get there, then it does little good, and air transportation has become really hot topic now. Were people who use wheelchairs and other mobility devices, it should not be dangerous for them or even life-threatening, this is actual happening, when we are talking to people on the Hill, we need to advocate for improved training for airline personnel, using technology improvements, so ultimately wheelchair users can use their chair during flight. It has become critical in many areas. The paralyzed veterans of America, whenever they have a conference, because they know this is such a problem, they automatically set up a wheelchair repair shop on site because people are always coming in and need repairs and that is just unacceptable.

We also need to advocate for more accessibility and equity in all modes of transportation, we talk a lot about public transit with buses, and light rail, and even longer rail services, Amtrak, but there is more and more emphasis now and bicycling, for exercise, including ebikes and even for boats, and these are areas often forgot about, there is advocacy work that needs to be done, rental bikes, they should also have accessible bikes for rental as well. We also need to advocate for a strong Bill of Rights and I will get to this also in more detail because strong Bill of Rights was just released by the department of transportation, it was originally included as part of the Air Carriers Access Amendments Act which was HR 1696 on the Senate side it was 642. There are other provisions of that bill which are also still important and which NCIL supports but the department came out with the Bill of Rights which I will share after I get through this slide – we did not have the opportunity, since it just came out the first of July, to get it in the slide before this presentation. And also, advocacy for equity, equivalent service or ride hailing services and transportation network companies, and when I say equivalent services, when the percentage of vehicles that are wheelchair accessible is so low, it just becomes – it does not become an equivalent service, the company, whether Uber or Lyft, they may have, they may need to have 10 or 12, in terms of making sure they have an equivalent service. There has been a lot of work done with Amtrak, advocates, and part of that was precipitated by Department of Justice lawsuit, advocates are continuing to push Amtrak to improve services and continue to do that, the latest from Amtrak was they were going to use newer railcars that had reduced with aisle, which would limit accessibility to parts of the train for people in wheelchairs and that is just not acceptable. And as always, we need to really make sure we can have a sustainable transportation funding mechanism, as most of you know, but most of the federal highway systems are supported by gasoline tax which has been steadily decreasing over the years because of the push or using electric vehicles. So, there really needs to be a bipartisan effort in the legislature to come up with a methodology that creates a sustainable long-term funding source for transit for all facets.

Since we could not put this on the slide, Jenny, is it possible for you to share my screen?

>> GO ahead and you can share your on-screen –

>> PETER: How do I do that? Can you see what I have put on the screen? The Bill of Rights?

>> No, we cannot – if you want to send it to me, I can post it –

>> I can send you a link

>> Or we can put a link in the chat as well

>> PETER: Let me do that – I will go through it as well.

I just put a link in the chat what I will go through this, so people get a sense of it.

>> Peter, I can share my screen with the link now – I will just describe it for people that are visually impaired.

Because we did not send this out ahead of time.

>> PETER: There is not much descriptive material here, it is a drawing of airport facility with boarding gates and in the background through the windows you see an airplane in the back. They show a person in a wheelchair, a person of color, making an effort to be inclusive. If you can scroll – this is the airline Bill of Rights and it is important to say, this does not give, this is not anything that is a new law, if you look into each of these links in more detail, you see specific references to federal code. Their 10 Bill of Rights, the first being the right to be treated with dignity and respect; number two is the right to receive information about services and aircraft give abilities and limitations; number three is the right to receive information in an accessible format; number four, the right to accessible airport facilities; number five is the right to assistance at airports; number six, the right to assistance on the aircraft; number seven, the right to travel with an assistive device or service animal; number eight, the right to receive seating accommodations; number nine, the right to accessible aircraft features; and number 10, the right to resolution of a disability related issue.

If you go to this page, each of those is a link which goes a little more into depth in each one of these, so just as an example, in number three where it says, the right to receive information in an accessible format, it talks about the need to have a website to be accessible. In terms of receiving information, you have to have an accessible website so that is away in terms of how they expand and explain a little more in detail, each of these rights. We are really excited about the fact that this has just come out and was just released in July 2, so it is brand-new. A lot of advocates did a lot of work over a period of time to see this happen. The Department of Transportation says this is a living document, and there is a link at the top of the page where you can see the " current version" and they will be updating it as you are able and I can already see some things that I would advocate for, where things like assistance at airports and assistance on aircraft, the right to have safe assistance on aircraft – because, the assistance people are getting now or not safe. I will now turn it over to Ann

>> ANN: Jenny if you could start my video –

And move back to my slides over my side.

My name is Ann McDaniel executive director of the and cochair of the Rehab act/IL funding of NCIL along with Jeff Hughes was in the process of trying to join us. I have been around a while, some of you know me, you may not know that I worked at the Center for Independent living for 11 years before I went to my job, so I am familiar with the set spectrum. I want to go over a few things, that the rehab act/IL funding subcommittee are working on, and you need to be aware and aware of.

We are rolling out a new Drive 5 for 5, asking for 500 million budget for Independent Living for our five core services, the fifth one is really three – so that we, the Centers for Independent Living can fully implement the core services. There are pieces to that of what that would include. In addition to increasing the funding for independent living program itself, to 500 million, it is currently at 118 million and change, we have asked for the 2023 fiscal year budget total funding of 250 million, and that would be an increase of 131.8 million, as a step to move in the direction of reaching 500 million. We will be having national push on this drive; we will have state coordinators to help get information in a timely manner so you will be hearing a lot more about that.

The current request that NICL submitted, for the 2023 budget was 249 million. And there is an increase in the House appropriations bill – not enough. For a total of 140 million, which is an increase over the 118 million, but we need to keep pushing for more. There are people in this country who do not have access to a center for indefinite living, no access to IL services and many centers are operating on shoestring budgets. We need to keep pushing for funding.

Looking specifically at transition services, core transition services, we will look at funding for transitional institutions that there be requirement for Centers for Independent Living to receive 5% of the money all as the person funding at the federal level. As a direct based funding from ACL. That money be carved out and funneled to Centers for Independent Living for institutional transition.

We are asking for funding for diversion from institutional placement as well, and for the youth transition requirement, the title I program has to set aside 15% of their funding for preemployment transition for youth, we are suggesting that one third of that, 5% of the total title I fund be directed to Centers for Independent Living as they go through the administration for community living.

Is telling Jeff he cannot get on – as anything other than attendee.

I will find him and boost him into a panelist

>> ANN: Thank you

Designated funding for statewide Independent Living councils, not carving it out of part C or part B but new designated funding specifically defined the operations of SILC we included not request for the FY 2023 budget we are also looking at that in language for amendments to the rehab act so there be designated funding for SILC 250,000 minimum per SILC in states and territories to be smaller, and we realize some get more than that now, many get less, but we are trying to get them designated funding, not taking away other funding that they are getting, until we get sufficient funding for SILCs to fulfill their duties. There are some in this country that barely have enough funding to have regular meetings four times a year. There is a huge gap between the high and SILC and minimum funded SILC and we need to work on that.

>> I believe Jeff is on, via phone

>> JEFF: Thank you so much!

>> ANN: We are also looking for $5 million from NCIL for the development of the first national hotline directed and operated by people with disabilities to assess the needs of disability communities in crisis with priorities given to BIPOC communities. Black indigenous and other people of color.

And the last thing on this slide is the ongoing challenges of people with disabilities receiving postemployment services and support. We realize there is some intention in the rehab act for that to happen, we are not satisfied with the degree it is going to happen, so Nicole is requesting 5% of the title I postemployment funding be provided to Centers for Independent Living to provide postemployment support.

This is slide six, Jeff –

>> JEFF: Which one is that

>> Slide six, starts with independent living network is committed to providing all the core services –

>> JEFF: I want to apologize for everyone, my wife is having surgery – wonderful medical system we have. And I appreciate Ann for picking this up and covering as she does so well, the Rehab act and all the work.

Obviously with the things she has been talking about with all the issues is that the centers provide we have stretched our budgets to the maximum, there is no other spot, nothing left, so stretch. Trying to provide the support and services that people need in our community, and have historically just not received the support that we need. Our drive for five to continue to expand, not services but support for centers and funding. If we can reach that 500 million that also have funding for, like we have for COVID, so we can support our communities by assisting in emergency situations such as when personal care assistance with air or assisting with supplies or medical equipment, technology, emergency situations, needless to say it is something that will be tremendously useful for our community. I know that in our experience here in Oklahoma, because of our leadership in our state, money that came in was not utilized in a way that supported people with disabilities, it was incredibly difficult to get masks and other PPE to the disability community, in essence there was absolutely nothing and it was left to the centers to pick up their role and fortunately we had continued to have a little bit of support, but it is nowhere enough.

As we move towards his conference and our march on the Hill and meeting with our members of Congress, mention any of these issues that we have discussed, expanding the title, utilizing title I funding for postemployment services, increasing funding just for getting us where we need to be please mention all of this so we can continue to find really good support.

>> ANN: One of the things that we wanted to point out with the CARES Act funding gave the centers an opportunity to help people get out of congregate settings during the pandemic and we know the settings are very dangerous, we know a lot of people contracted COVID in institutional settings and many did not survive. With permanent funding, centers can keep people out and, so they are not in a target setting when something like this occurs. Centers for anybody living believe all people with disabilities are valuable, and they help people facing all sorts of discrimination. We have got to make sure that the centers have the resources they need to help people with disabilities fully participate in their communities, live in their community's and have access to the support they need.

>> JEFF: I will just go ahead and say, one of the challenges that we had here, instead of – a tight year in our state – instead of really providing support and services to help people in our communities, our governor gave a lot of money to nursing homes. And we all know, that is the worst place that people could be. We have a lot of work to do, but that gives a really good indication of how much work we have to do. Again, as we meet with legislators let's make sure to point out that everybody examples that everybody has,

>> I think we are passing back to Lou Ann

>> LOU ANN: thank you all, we do have a few questions but before we get to that, I wanted to talk about preparing for the hill, the March rally and Hill visits are being held on July 27th, for the March it will be a virtual march again this year so send your pictures to eleanor@ncil.org is more information on the conference website for that. And the rally will be a hybrid model this year with the rally held at the conference with some recorded messages and some in person. To register you go to the conference website and under event information to get more information about these events. As I said earlier whether you are participating in the conference or not, it is important that conscripts hear from everyone. Meeting with our senators and representatives has always been one of the most important pieces of the NCIL conference, as with everything the last couple of years Hill visits are different this year. Some senators and representatives are doing in person meetings while others are still only doing virtual. If you have not scheduled your Hill visit yet, please try to get those done soon and when you schedule a Hill visit, be sure to be clear with the scheduler that you are wanting to schedule a meeting as part of NCIL Hill day to advocate for people, if you are attending in DC in person, ask if the representative or senator is doing in person meetings and if you prefer virtual, be clear of that request with the scheduler.

If you or someone in your group needs and accommodation whether in person or virtual be sure to request that of the congressperson staff immediately. NCIL is not provide accommodations for the Hill visits is the responsibility of the congressional offices to do so. Try to schedule your visits on July 27 if possible to make a larger impact for NCIL. Review the L&A policy booklet and mentioned earlier and in advance to be prepared for the meeting. Make sure you send them. For those attending the conference you should get extra copies in your regional caucus, regional caucus will be held July 26 in this caucus help you organize with others in your region and state. If you are attending the conference in person know that you need to be prepared for the temperatures, it is very cold inside the hotel especially in the meeting rooms. Be prepared especially if you get cold easy, like the.

If you are going to outside the hotel at all be prepared for hot temperatures, make sure you have cold water, sunblock it about 1 mile walk from the hotel to the Capitol. stay hydrated. You can take the Metro but there is still walking and wheeling so be prepared and be prepared, too, so you know how to get back. Stay with your group and watch out for each other. If you are doing in person meetings beyond time and be respectful.

Maybe we can go to the Q&A, I know there have been questions in the chat and also in the Q&A.

>> JENNY: If anybody has questions, as a reminder we have about 12 minutes left in the session and if you have questions, you can put them in the chat at this point and you can put them into the Q&A section and Zoom, dial star nine if you are connecting via phone or email me, jenny@ncil.org.

We have one question now, this is for Ann I believe, and Jeff, this question, one advocating for 5% of MFP funds will that apply to states that opted out of the newer round of MFP?

>> I don't have a definitive answer but if your state is not receiving MFP funds I would assume you would not be carved into that 5% – that might be a good hook to try to get your state to go back in to that pool.

>> JENNY: Thank you. Our next question, comes in the form of a chat, asking, how can we advocate to Congressman when we cannot lobby using part B money? I am the chair for my inability counsel and we always run into this – I will throw that out to anybody who wants to

>> YOU just have to know where the line is. Lobbying means, you cannot say, vote for this, support this, or oppose this, vote against this, but you can absolutely explain how proposed legislation affects the people you serve for the people you represent as a SILC so they understand what the impact of legislation is. You can explain what you do, you can explain the needs of people with disabilities that you were present or serve. You just cannot say, vote for this bill, support this bill, vote against the bill. You cannot ask them to take a specific position but you can certainly help educate them so they understand what they are taking a position on, if anybody wants to add to that, go for it.

>> JEFF: I will jump in – back to the MFP thing – the MFP issue, we are hoping that we might be able to get it through a different approach, we are working two or three different angles to get people funding for the nursing home transition. Do not look at it, as just limited to MFP, we will be getting out more information pretty quick. Just stay tuned for that.

Related to the lobbying, in addition if you are a nonprofit, you can lobby, you just cannot use federal dollars to lobby you can just use unrestricted fund, or if you are just going up there. If you are taking annual leave just do not recorded, those are strategies you can use as long as you are not using federal dollars in influencing it. But that's exactly right if you educate, that is totally different.

>> JENNY: Thank you. I think you guys put that well, and if anybody has any follow-up questions, feel free to put them in the Q&A.

We have another question, this asks, is the proposed increase in Rehab reauthorization a flat 250 K floor for the centers or based on a formula?

>> JEFF: That's a good question. We don't have reauthorization we cannot really change the funding yet, however, we are trying to maximize by increasing it by 250 total – we know that the ceiling, if we reach that, the larger states are going to have a lot more money than what those smaller states like mine, we will not see much of an increase, but we will go ahead and move forward with this approach of reaching that 500. So that maybe next year we might be able to move something around the formula at the same time, we need to have discussions about how we can amend our existing formula and maybe grandfather in some of the larger or centers that have been around longer. I don't really have a good strategy with that and I look forward to having this dialogue with centers throughout the country because it is something that we are going to just try to change, the funding formula just does not work for us – for anybody really – if you have been there a long time, maybe it works for you but smaller centers and especially the newer ones, just does not work. Especially with the challenges that we have with part B funding, not getting into the issues of the centers that also receive part B dollars but those that are solely part B. In trying to bring them in will take forever. This time that we have right now is critical, and if we don't work together, we continue doing the same crap of letting these entities divide us between SILCs and centers and part B and part C, – we will never get anywhere. It is time to start making some of these changes and that's why we have, we are taking these approaches right now

>> I am looking at your question, it looks like you are talking about a flat $250,000, as a minimum, that was for statewide Independent living councils, not centers. We are trying to establish some designated funding for the SILCs apart from the other funding streams that are available and that is something that would be worked on more in reauthorization as well to include a formula.

I hope that helps.

>> JENNY: Thank you! We have one last question. And we only have three minutes left, our last question, and whoever can to this, feel free, can you comment on where NCIL is doing to support the able age adjustment act?

This is to raise two able account age eligibility from current age of up to 26 to 46 is there anybody able to speak to that and if not, we can answer your question later on via email.

>> LOU ANN: I probably can't speak to a lot of detail what we do support the increase in age, what we will do is we will have – I did copy down the question – we can have the employment Social Security subcommittee chair get back with an answer and that. Since they are not on this briefing right now.

>> JENNY: Thank you.

We have one more minute and I cannot answer this question – do we know which senators and representatives will be speaking during Hill day during the rally? We have about 11 recorded videos from senators and representatives that we will be showing during the rally and we also will have members from our community speaking during it. There will be the opportunity, we will get signed making materials if you are at the conference or you can make your own sign at home and send it to eleanor@ncil.org, or make a sign outside and I think that is about it for today's policy briefing!

Thank everyone for joining us thank you to our panelists for speaking about the policy briefing, and remind everyone that weeks a week and halfway conference is going to be a fragrance-free conference make sure you note that, and looking forward to seeing everybody either in DC or virtual! Have a great day and thank you again!