

Jennifer Koo: (silence)

Hello, everyone. Welcome. My name is Jennifer Koo and I am one of the hosts for today's discussion. It is wonderful to be here and to have the opportunity to talk with you all about the importance of inclusive and representative federal disability data. Before we get started, Marsha, who is producing the event today, is going to provide a quick note on some of the features for this Zoom and then we'll jump right in.

Marsha: Hi, everyone. Thanks for coming today. Just in case you're not familiar, you can access the captioning for today's webinar by clicking on the live transcript button at the bottom of your window screen. You can put up subtitles or a transcript pane. We also want to invite you to use the chat pane to post comments and questions throughout the webinar. Those will be monitored, and we'll try to get to as many questions as we can. So we'd love to hear your input.

And finally, if you would like to speak during the webinar and ask the question verbally, please go to the reactions menu and use the raise-hand button to indicate that you would like to be invited to unmute participants are not able to unmute until they are invited to do so. Go ahead, Jennifer.

Jennifer Koo: Thanks, Marsha. Hi, everyone. So again, my name is Jennifer Koo and my pronouns are she, her, hers. I joined the National Disability Rights Network as a research assistant in April, 2021, and have been working over these past few months with the census team to conduct a large scale analysis of disability, inclusion, and representation in federal data. So some of my contract objectives have included researching federal data sources such as the American Community Survey, and more recently, the decennial census, and conducting informational interviews with representatives from the U.S. Census Bureau and other stakeholders who are also involved in disability research.

So I'm here today with my colleague Erika Hudson, who has worked alongside me to advance our organization census involvement. And we're very excited to share more about the federal disability data report that we researched and wrote, which was published yesterday, and to have a great discussion with you all on how to access inclusive data and how access to inclusive data can help guide public policy going forward. So, Erika, would you like to introduce yourself and also talk a little bit more about your background with NDRN and our census work, specifically?

Erika Hudson: Yes, of course. Thank you so much, Jen. Hi, everyone. My name is Erika, you, she, her pronouns. And I'm so excited to be here with you all today. I see some familiar faces out there as in my previous role with Indira and I worked on all things 2020 census. Thanks to the work that you all did during last year's census, which now seems a world wind ago.

This will be my final project with NDRN and working with NDRN as I recently moved to Europe for grad school. So that is why I will be transitioning, but I'm super excited to be here with you all today and talk to you all about this important work and what the future holds for federal disability data. So thank you all for being here.

And just as a friendly reminder, this webinar will be recorded. So if folks need access to this webinar or want to share this exciting webinar with folks, as I'm sure you will, it will be available after today's session. So thanks again, Jen.

Jennifer Koo: Thank you, Erika, for that introduction. So I just want to give you all a bit of a presentation overview. And this is Jennifer speaking again. So today, Erika and I will provide you with a quick summary of the 2020 census. We'll also discuss the importance of federal disability data, talk about how to access and navigate disability data, and then share some recommendations for protection and advocacy agencies

And then after our discussion, we'll also have an interactive Q&A session. And we'll provide you with some resources that you can take a look at moving forward. So onto you, Erika.

Erika Hudson: Oh, there we go. I'd to get myself off you. Excellent. So we will kick this event off with what I will be calling Trivia Thursday, as I believe it's Trivia Thursday today, with a question for you all as we kind of talk about the 2020 census. And on this screen, I would love for you to participate in this question, which asks, which state lost a seat in the House of Representatives last year by 89 persons? In other words, if someone had 89 more people in their state, what would that have meant for the House of Representatives?

Your options are New York, Texas, California, and Indiana. And I see many people are participating, which I greatly appreciate. And it's somewhat unreal to think that it's 89 people that made a difference in this in terms of apportionment in the House of Representatives. And with that, it looks like most folks participated. And we will show the results as we had a really good number. No one thought Texas. That's interesting. I think a lot of people know they may be gained to see. And we will publish the results right now.

And the answer here is New York, which wanted to bring this app to kind of showcase why the work that you all did last year was so incredibly important because every single person makes a difference as evident by New York, because they lost the seat in the United States House of Representatives. It looks like a lot of you had that as an answer. California was a good guess, too. Makes total sense why people said that. Indiana. Grew up in Indiana. So that's why I probably suggested that answer here, too.

So with that, we'll remove the full and appreciate you all participating in this as now we know is New York and you can bring that as a fun party hack moving

forward or a party question if that's a thing. So we'll remove the poll and go to the beginning of our official presentation today.

So before we officially begin talking about the 2020 census and kind of what's happened and what is next, I really do want to take this opportunity to thank each and every one of you. If you lived in the United States last year, you had some involvement with the 2020 census, as you were counted. But I see a lot of familiar faces including West Virginia, New Jersey, California, Arkansas PNA, and so many more.

So please feel free to drop in your chat where you are from, because so many of the protection and advocacy agencies had a role to play in the 2020 census to make sure that everyone including the disability community were counted last year. And Jen and I both agreed that we couldn't really start this presentation to talk about the decennial sentences and the importance of federal data without taking a moment to thank each and every one of you.

So many things can be said about your incredible work. And I don't think we have time today, but I hope you all know that we greatly appreciate it. And on behalf of myself and NDRN, it was so incredible to see the work that the PNA's and disability rights organization and our civil rights partners and Census Bureau staff put into the 2020 census given that it endured a pandemic, it endured natural disasters, and so many things related to politics, perhaps, as well that it was probably a census like no other.

But I hope you all take a moment to recognize the impact that you had on it. And on behalf of myself, again, it was a distinct pleasure to work with all of you. And really excited for what the future has in store. And some of us were joking that we'll all see each other in 2030. So we'll see how that goes. But again, truly, thank you for your involvement in the 2020 census.

And with that in mind, let's recap a little bit about the 2020 census. A lot happened, began as early as January of 2020 in remote parts of Alaska and continued throughout September, which that timeline was extended, of course, because of the pandemic. And we had folks self-respond to the census. We had group quarters enumerations. And we had folks going door-to-door to make sure that people were counted.

And just this year we got results in April. We received those official apportionment results relating to the New York question that we just asked, right? And we know how many people live in each state in the United States and how many seats each state will receive in the House of Representatives. We now know that. So we'll see that change in the 2020 election cycle.

And just last month in September and in August, we received the decennial census redistricting data. That really gave us that closer look on where people lived in the United States and what their demographics were, i.e, age, race and

ethnicity, and what the household status was. So we now have all that information, which is really helpful, but there's a lot to unpack. And many folks are wondering, so what's next? What are we going to see moving forward, given that the count is done in the census?

And I think it's fair to say that all eyes will be on redistricting, in particular. Many folks on this call already participating in redistricting as a lot of states have deadlines fast approaching for what the next cycle will be done, given that this will impact the 2020 election cycle. Redistricting doesn't only impact congressional levels seeding, right? It also impacts school districts and the local and the state governments on how things are drawn.

So it's really vital that we continue this conversation. And we're happy to share additional resources with you all on what redistricting might look like for you and what the future holds for that. But also, of course, with the 2020 census will see these other surveys have an impact. Which are surveys that we're going to be talking to you all about today and overall federal disability data that is out there.

And I think the last thing I would like to leave you with, too, is that we might see continued conversations related to the 2020 census because of under-counts. People are rightfully so concerned about certain areas being under-counted, mostly related perhaps to the pandemic. And we want to make sure that no one was missed. So these conversations will continue to be happening over the next decade, I'm sure, until our next census in 2030, but this will have an impact as we move forward today and all the federal disability data that comes from the decennial census.

And with that, I'm excited to pass it on to Jen who will go into the meat of our conversation today to talk about overall federal disability data and the availability to us in this important work. So thanks, Jen.

Jennifer Koo:

Thank you for that beautiful summary, Erika. I'm just going to flip to the next slide. So Eric has shared a lot about the 2020 census and the importance of counting and including everyone in that survey. And as we all know, the decennial census is the largest and most comprehensive nationwide survey that tells us about our nation's people and determines what life will look like, politically, socio-cultural really, and economically, for everyone over the next decade.

And because of this, Erika and I initially began our research project with a sole focus on the decennial census. However, as we considered the diversity that exists within the disability community, we began to recognize that the large scope of the decennial census actually makes it quite difficult to find specific generalized information. So a little later on in this presentation, we'll talk a bit more about how we approached this need for representation beyond what is offered in the scope of the decennial census.

So as I'm going through this next section we'd love for you all to reflect on the following question. Why is inclusive and representative federal disability data so important? And you can think about this in terms of why it's important to you, or your community, on a personal level, or from your work with the disability community. But just feel free to think about that and share your responses to this question in the chat.

So again, while the decennial census is an important resource, there are many other surveys that also offer meaningful insights on federal disability data within the U.S. Census Bureau there are a variety of surveys that collect disability data, including the American Community Survey, the Survey of Income and Program Participation and the current population survey.

So these surveys also provide leadership with essential programming and planning information about our nation, but their varying scope and specifications provide us with different more specific insights that we might not necessarily get from the decennial census. So unlike the decennial census, the American Community Survey is conducted every year, whereas decennial census, as in the name, is conducted every 10 years.

The American Community Survey provides us with a snapshot of how we live and it gives us information about our education, housing, work experiences, and more. And it also provides insights on the social and economic needs of our communities every year. And while the American Community Survey does not require a total population count like the decennial census, a representative sample is selected. And it's really important, something that we want to highlight that the American Community Survey is a lot more thorough and asks about topics that aren't included in the decennial census, including access to internet, transportation, and disability.

Regarding disability, the American Community Survey asks about six different aspects of disability, including hearing, vision, cognitive ambulatory, self care, and independent living. And this information is especially helpful because it can measure overall disability numbers and be used to identify populations with specific aspects of disability, which is something that the decennial census can't necessarily do.

And similar to the American Community Survey, we also have the Survey of Income and program participation. Together, the American Community Survey and Survey of Income and program participation provide the most comprehensive federal disability data. And the Survey of Income and program participation is a household-based longitudinal survey that collects information on things such as economic wellbeing, family dynamics, education, assets, health insurance, childcare, food security.

And so this data from this survey is also used to evaluate the effectiveness of federal state and local government programs. And can you use to also evaluate

one's use of an eligibility for governmental programs? So it's definitely very... These two surveys are very important for disability research specifically.

And then lastly, we also have the current population survey which is an initiative that is sponsored jointly by the U.S. Census Bureau and the U.S. Bureau of Labor Statistics. And the current population survey is the leading source on labor force population data in the United States. So the survey also conducts an annual social and economic supplement, which asks additional questions relating to disability and workplace disability. And again, these surveys are not intended to measure disability or define disability in any way, but rather measure certain aspects relating to disability.

I'm just trying to move to the next slide. And because disability is a part of every community, we recognize that all federal data is important, not just the decennial census. So our report, which we'll link later on, highlights additional federal agencies such as the Department of Health and Human Services, the Centers for Disease Control and Prevention, the Department of Labor, the Department of Criminal Justice, the... Oh, just department of justice, and the Social Security Administration. They also has their own disability statistics and services. So, definitely keep a lookout for that in our report when we break down everything that they collect and how it connects to disability.

So one of the questions that we have thought about a lot in our research and that I'm sure you might also be curious about is where can I find federal disability data and how do I use it? And so with the protection and advocacy agencies and disability rights advocates in mind, we decided to put together a small guide in our report based off of what we've learned through conversations with the US. Census Bureau on how to get the information that we're looking for.

So your best resources for all things Census Bureau would probably be to check out your local regional office. So if you have any questions at all or want specific information on, let's say what your community needs in terms of accessible transportation, based on findings from the 2019 American Community Survey, then this is definitely a place where you can go to get the answers you need.

The field representatives at the U.S. Census Bureau regional offices are true issue experts, and they can provide consulting and analysis services about broader scope, national-level information, things from the census, and also, they can also provide you with more specific information that is specific to your state or region. And in addition to giving you information about the decennial census, these offices conduct continuous surveys all year long to supplement what we know about people, places, and the economy. So there are currently seven regional offices as indicated on this map over here and on the Census Bureau website, including the Atlanta, Chicago, Denver, Los Angeles, New York, and Philadelphia regions. And these regions support all 50 states and U.S. territories.

And regarding the 2020 census specifically, you can contact a new and temporary division within the regional offices called the regional census centers. These centers are a temporary branch that was established just in this past month with the release of the decennial census data. And these regional census centers are more than happy to walk you through your questions and concerns about information specific to your region directly relating to the 2020 census. So all of this information on how to reach out to them and how to get in contact with your regional office, how to find your regional office, is available in our report and also on the Census Bureau websites.

So again, the question that we've been reflecting on is where can I find disability data and how do I use it? And to answer the second part of that question, we spent a bit of time in our report and that it would be helpful to describe some of the limitations and considerations behind finding and using the data in our report.

So in a bit, Erika, will talk more about the specific applications and recommendations that we can use. And our report has a much more comprehensive overview of these considerations, but for now, it's important to note that the scope and specifications of federal data will really vary based upon which federal agency department and survey you explore and you choose to look at. So if you're approaching a field agent or representative from a federal agency, it's really important to consider what your specific advocacy and research needs are.

So for instance, if you are looking to learn about the statistics of people of a certain racial background with mobility disabilities, then it would be helpful to kind of bring that up to the representative and also look at what each of these federal agencies offer and identify that, the American Community Survey might be the best place for you to start and get that information of what you would need.

So again, our report outlines all of these various agencies and departments and surveys and what they offer in terms of disability data in detail. And unfortunately, as we were conducting our research, we also noticed that there are a lot of gaps in federal disability data, including healthcare inequities, racial disparities, and differences in how disability is characterized and defined based on the surveys. And because of this, because of all of these gaps and data, you, unfortunately, might not be able to find what you're looking for.

In addition to the gaps in federal disability data, there are also numerous factors to account for in terms of your research scope and regarding how you perceive and present the data that you find. So because of this, it's important to work with an expert to weigh in on their thoughts about the potential pros and cons of aggregating which is presenting the larger overarching story of what the data tells you versus dis-aggregating the data, which would be only sharing a smaller piece of the story, so you wouldn't share the whole thing.

So while aggregated data may be beneficial, it can unintentionally create some negative consequences by misrepresenting or over or under-representing a community, resulting in people not getting their needs met. And, Erika, I'm not sure if you have an example, but would you be able to speak more on just a specific example of like aggregated versus dis-aggregated data?

Erika Hudson: Yeah. Thanks, Jen. And this is something that came up a lot in our conversations with the Census Bureau. Because sometimes when we look at one piece of the picture, we're not getting the whole piece. And this has come about in numerous conversations with folks. So, for example, something that we discussed a lot was the question about whether someone has a disability. And this is specifically related to the American Community Survey, right?

The community survey doesn't say, explicitly, do you have a disability? Yes or no? So no one related to the Census Bureau is asking that question to the American public. Rather, they're asking those specific questions that Jen outlined in the beginning of today's presentation, that's related to a certain type of difficulty is what their wording is.

And the reason for this is related to the aggregated versus dis-aggregated data, because we're getting that specific answer to those questions rather than that broader question, right? And there's various factors for that. And whether that's the right approach or not, I think we don't know. I think some might argue that it is the best approach to ask those very specific questions, because some people don't identify as having a disability, right? Rather, someone would say, yeah, I do have difficulty with vision. So that's why we need to continue these conversations and look at that bigger picture of things.

Another example that comes from our partners within the civil rights community is the question related to gender. That's a conversation that comes up a lot, because in recent surveys, we had seen that statistic related to same-sex couples were doing very well financially through the different surveys that the Census Bureau was offering. And thus, folks were saying, well, it looks like members of the LGBTQ community are doing very well, but the reality is they were only getting a snapshot of those identifying and same-sex couples, right?

They weren't getting that specific data related to, perhaps, someone who's transgender. And we weren't looking at those pieces of the puzzle as we were getting this data. So I think that's a lot and very confusing even to me, still, after looking at this. But the moral of this, I think, for us, that we learned is that we need to look at those individual pieces of the puzzle, right/ And see how they fit. But we also need to look at the big puzzle, if you will.

Jen, was that helpful by chance? I don't know if I went there.

Jennifer Koo: That was wonderful.

Erika Hudson: Okay. Thanks, Jen.

Jennifer Koo: Thank you so much for sharing that example. We say all this not to discourage any of you, but to inform and support you. And we really want to emphasize that there are resources out there such as the regional offices. And on the other side of the coin, these federal agencies, they really want to improve the accuracy of their results.

So we strongly encourage that you set up these bi-directional relationships with these offices and encourage meetings with them and to just really ask your representatives specific questions about what you need. Tell them what you need and let them know what they can provide you with and just take notes. And they will be sure to take into account what you're saying to improve their data going forward.

And I guess bouncing up to level earlier in the presentation, I know we talked about what the 2020 census specifically. The Census Bureau, in case this is a topic of interest for anyone, the Census Bureau is currently conducting a variety of processes to evaluate the validity and accuracy of the 2020 census results. These include things such as the post-enumeration surveys and also comparing the results of the 2020 census with other surveys such as the American Community Survey or decennial censuses of the past.

So all of this will be released later this year. So if you're not finding what you're looking for, or if you are skeptical, in any way, of any of the results, or just want to know or better understand how your community is being represented in the data that is currently out there, the Census Bureau regional offices or research technicians from other federal agencies are great resources to start with.

And I'm going to pass things off to Erika. Would you like to talk a bit more about the specific applications and recommendations?

Erika Hudson: Yeah. Absolutely. Thanks, Jen. And here in the middle of the presentation, I'll also take a moment to kind of recap what we just talked about, because it's a lot. And we really gave you this high-level overview on all things and dove quite deep into this with expectation of, this is what the 2020 census was, and this is where we are today. And why we did this is basically because none of this existed prior to our understanding for the disability community.

And that's why we want it to be able to share these resources with you all today as Jen outlined, that it's not just the decennial census that gives you important data, even though that's what has been talked a lot about in the recent couple of years, arguably, as this really began at the last census in 2010, because that's when they started this process.

If you are interested in learning more about the 2020 census itself and all the twists and turns it took, definitely check out into your NDRN website. We have a

lot of great resources out there and also share the important work that you all conducted throughout the 2020 census. But also just really excited to emphasize that there are so many avenues out there that, admittedly, I did not know before getting into this work. And I think Jen and I have had conversations that she didn't know.

So that was really our goal with this report that we put together just to make things a little bit more clear of what's out there. But that doesn't mean the story ends here. And then we need to continue these conversations. And that's why I really appreciate Jen highlighting that we need to have these bilateral conversations. Because some of the data, we don't know yet. And we need to find out. And we need to have an actor role in these conversations, even when our partners are looking at data, because disability has a role to play. As Jen said, and as we all know, it's a part of every community. And we need to have that conversation on a continuous basis.

And that's why this next step we'll be talking about how this impacts our work. So the question we ask is how do we use this data on a regular basis? Right? And why is this important to our work? And I think a lot of us, perhaps, have different answers to this question, but I think, in particular, if we look at the 2020 census, right? The question that came up constantly was, well, how are we counting people in group quarters? I.e those living in certain settings, either college dorms or in skilled nursing facilities. And that, we need to know, we need to know what that looks like throughout the United States and whether it is looking at prisons, perhaps, and seeing how that impacts redistricting or just in general.

And one thing that I found really interesting as we were looking at the data of the 2020 census was that even though the overall population living in group quarters in the United States decreased in 2020 expenses, those living in nursing facilities and skilled nursing facilities did increase. And if you're interested in learning more about that, I highly recommend checking out the Census Bureau website. They have it laid out there as that can impact our work as we need to know where folks are living.

We also need to have a better understanding of the population demographics and the areas that we work in. Right? And we need to have that understanding. Not only disability-related, right? But across the board. We need to know the community that we're in. So that's why I definitely recommend folks looking, not only at the decennial census, but then looking at those other surveys that Jen highlighted, because that really gives us a better idea of what our community is and who we are. And the census has a role to play in that, because all these other surveys stem from the 2020 census with that overarching population that we learned in this once-a-decade count of the U.S. population.

But yeah, absolutely. Definitely keep an eye on the group quarters process. And I think with the pandemic, going back to what we said earlier related to

populations being under-counted or missed in the 2020 census, this is in particular importance because of the group quarters process. For example, in April, 2020, when the group quarters enumeration process began is, of course, while we were and still are going through the COVID-19 pandemic, right? And a lot of college students left. So that definitely has an impact on college towns and what their population looks like in the next 10 years. So that's why keeping an eye on the population changes and this continued conversation is really important as we move forward in these next couple of months and years, in particular with redistricting.

Obviously, for a federal resources, 2020 census, along with those population numbers, impact federal funding. So whether it's the protection advocacy system, that's formula-based based on state populations, to educational programs, to nutrition, it's so important that we know how many people or kids in the United States need accessibility resources in schools. Right? And we get that age statistic from the decennial census, right? We were asked, how old are you? And we know what the future will look like for our schools in 10 years based on how many people were five and 2020.

So it is really important that we have these conversations. And I say all of these things that are very broad, but we all know that disability has a role in that. And that's why it's really important that we have this continued conversation and keep an eye on this. And I know a lot of folks are, perhaps, saying in the chat too, the specific information, they need to evaluate what they're doing in certain issue areas. And that's also impacted with federal funding. If we only think 10 people live in a certain area, obviously, we're not going to receive a certain amount of funding. So that's why it's really important that we have these conversations and that we encourage those we work with and those in our community to make sure that they not only participate in these actions, but also have an active voice and how it goes about.

Also, reapportionment and redistricting. Again, reapportionment is related to the House of Representatives who are folks in public office are, and also to make sure that we have a voice in any action that is taken in an area, whether it's a referendum that happens related to a school, or if it's who will represent us in the House of Representatives.

So it seems really silly to still be talking about the 2020 census to some, but might be my only time that I get to say this ever again. It just makes senses, right? We need to have these conversations. And I know my fellow staff members are not so happy that I just said that, but I had to. It's maybe the last time I will. So, overall arching theme here is that we need to be active and everything that touches the census has some type of actor role on our end to do with.

So I'll leave that with you. And I'm sure you all have so many different possibilities of why this data is important and why we need to be aware of

what's going on. But if we don't have these conversations, people will be missed, people will be under-counted. And that will not be beneficial to anyone.

So with that in mind, you might be asking, well, then what can we do moving forward? How do we continue this conversation well beyond the 2020 census when the disability community stepped up and had an active role in this? It's not just on the disability community, right? It's on everyone. Federal agencies, all these federal agencies that Jen mentioned have a responsibility to ensure that they are including the disability community in their actions. And they need to have continued conversations, not only to ensure that any of the surveys they're putting out there are fully accessible to individuals with disabilities, right? Whether it's an online platform and then it needs Americans with disabilities act standards, or if they have paper resources that are accessible for folks, perhaps who are low-vision or blind.

We saw that in the 2020 census, but we see improvements to be made. And we outlined those in our report and encourage you all to take a look at that as well, to see what needs to be done from the federal agencies' perspective. But it also falls on us to have these conversations, because there are things we still need to note that we perhaps don't know the answers to, and we need federal agencies like the Census Bureau's assistance with. Whether it is asking the entire population, do you have a disability? Not to say that's the case, but we need to have these conversations.

And I think it's fair to say that the conversations have been somewhat limited over the past couple of years. And that's understandable because there's so much that's happening, but we need to have an actor role in these conversations. And if there a question that we need to know, and if we ask a regional office a specific questions related to how many people might need this transportation for accessibility, we can go to them and ask those questions. And if they don't have them, we can move forward and continue these conversations to ensure that change is being made.

And that's what I encourage you all to continue this conversation. Have an active role in redistricting if you have the opportunity. And also look at the Census Bureau on a regular basis. They have a national advisory committee and public comment periods where we as citizens or as people in the United States can give our input and make changes happen. And I recognize that's perhaps a really optimistic view of things, but it is possible. And things have happened as a result. So I definitely encourage you all to do that as well.

And also there's that participation and accountability. And that's why, one, we need to participate in these surveys. And if we see any problems, we need to talk about it and have these continued conversations moving forward? and if you're ever wondering, hey, what did Erika and Jen say during this conversation? Recommendations are outlined in our report that we definitely recommend you all checking out. And that basically sums up our entire

presentation and all these important resources as we continue this conversation after today's presentation as well.

So with that, we move on to what I believe is the Q&A session, which is really exciting. We wanted to take this opportunity to give plenty of time for you all to ask potential questions. Or if you just wanted to ask where you can find additional resources as we acknowledge we don't have all the answers, but we are wanting to share those who do.

So, happy to take this time to answer any questions that you all might have. And then just as a note, once we wrap up the Q&A a session, we also will have a resource page where Jen will be sharing, one, where you can find our awesome report that Jen worked so hard on. That is absolutely fantastic. And also some of these Census Bureau contacts that you can reach out to moving forward.

So if you have a question, feel free to put it in the chat and we will go from there. And, Jen, have I missed any questions in the chat? Or, again, if you want to raise your hand, as Marcia indicated in the beginning, feel free to do that through the reactions tab on Zoom and we will answer your question. Ooh, we do have a rather silent bunch. Right, Jen? if I haven't missed anything.

Jennifer Koo:

I think... Yeah, we do have... I know Lilly mentioned a few different resources that I think might be beneficial to highlight, especially for people who can't be here today, but really shared that, and I'm reading directly from the chat. She says, "I want to share a resource for folks to access disability data from the American Community Survey at the county level from the research and training center on disability in rural communities." So she provided the link in the chat there. And it looks amazing. And I think it can definitely be of benefit to P&A's who are looking for information from the American Community Survey specific to what they're looking for to their geographic location.

And then I believe... She also put another helpful comment, so thank you very much, Lilly, about a new collaborative group that has recently formed to address these issues of disability, data, and equity that emerged during the pandemic called Disability Data Advocates Taking Action. So Lilly you provided the contact information in the chat. So if you scroll up, you should be able to find it there. but again, the organization is called Disability Data Advocates Taking Action.

Erika Hudson:

Awesome. Thank you so much, Lilly, for sharing that and Jen going over. And I know it could be intimidating asking questions, and I imagine folks have a lot going on, but please do feel free to ask us anything that we talked about today or anything that's related to the report. And I will say, moving forward, definitely feel free to contact and NDRN if you have any specific questions related to this. Oh, I do see a hand up, Jen. Very exciting. And we will unmute you, [Erine 00:43:41]. I'm so sorry if I'm saying that incorrectly. Hello? I think you're unmuted

Erine: Hi, thanks. Yeah, that was a great presentation. I had a question about if you two know of any sort of movements or avenues for better representation for the U.S. territories with the ACS, or if you kind of know of, I don't know, know of any information on how to better access data for the territories or if there's anything happening with them? Because they seem pretty underrepresented.

Erika Hudson: Thank you so much. And did I say that correctly by chance, Erine? I just want to make sure I got your name right. We might've muted you already. I'm so sorry. But thank you so much for that question. That's a great point. And I think what's really important to note here is that with the 2020 sentences, right? We only specifically looked at the states as well as D.C. and Puerto Rico.

And when it comes to the territories, whether it's Guam, Northern Mariana Islands, Virgin Islands, I'm missing one more. Jen feel free to... I'm the worst. The four territories. We pivot to the American Community Survey. And related to the best places of outreach, it is probably on the local level and those folks that live there and the different organizations that are on the ground there.

I know that's not very helpful, but I think you bring up a really good point that we need to keep those in mind and that we need to have those continued conversations. Jen, anything in your resource that came up with the territories in particular that you would like to share?

Jennifer Koo: I think we were also kind of experiencing some, as we were doing our research, some frustration with the lack of representation there, but I think, again, the biggest recommendation I can give to anyone, and especially you, if you want to find information on the territories, definitely check out the regional offices. I know that they are including... I think the New York region, I might be wrong. I believe the New York region regional office has information on most of the U.S. territory.

So definitely that might be a helpful resource to start with. And the field agents there are more than happy to work with you and just kind of look at what specific gaps... You probably would have to bring the gaps to their attention, but at least you can start that conversation and they can start looking and improving the quality and the reach of the decennial census or American Community Survey going forward.

Erika Hudson: Right. Thanks, Jen. And this is Erika again. American Samoa came up with a fourth one. The only other contact who I would recommend is the delegate in the U.S. House of Representatives, too. They have a lot of good information on these things as well. So they also have good points of contact moving forward.

As a reminder D.C, Puerto Rico, and the four territories, of course, don't have voting representation in the U.S. House of Representatives, but they all have delegates who are there on behalf of the Derrick community and population. So if the Census Bureau doesn't have proper information and we can't find it on the

local level or in the territory itself, I also do defer to the delegates themselves who are in D.C. and of course in their community and they have, perhaps, some resources that they can share on that.

And of course, like Jen said, if gaps exists, that's why we need to have these conversations, right? And they will be a really good point of contact along with their staff on practices moving forward. So thanks for that question, too. I'm glad we got to talk a little bit about the territories today.

Excellent. I know we're at close group here. So if you do have any questions, feel free to raise your hand through the reactions tab. Or if you just want to share something you did in the 2020 census, that's also a great opportunity. We somewhat joked that this is our last Haraj because Jen and I are leaving to continue on with different things. But it's been really exciting to work with you all.

So if you have anything to add it, please do raise your hand through this Q&A session. But as we're waiting on more folks to ask questions, Jen, maybe you'll go ahead and talk about those resources. As I know, someone asks where they can find our important report.

Jennifer Koo:

Absolutely. Again, if you have any questions at all, just feel free to raise your hand or type it in the chat and we'll get back to that. But in the meantime, I just want to share a few resources. So before you go, we have a list of resources available for your reference, including a link to the NDRN's census website where you can follow all of them using work that Erika has started and that we've continued to add to.

So if you're interested in seeing what NDRN has been doing regarding census, you can feel free to visit our website over here. And Erika, would you be able to re-link the report in the chat again? So Erika will be sharing the link to our recently-published federal disability data report. We will also provide you with... On the slides here, you can access information on just upcoming data releases from the U.S. Census Bureau. So they have a calendar on their website. And they'll link press conferences like data releases, just any information you want to know about what's coming next. Because there's a lot to unpack from this past 2020 census.

So definitely check out that website. They also recently produced the, I believe, the 2020 American Community Survey as well. So you can also check out that data release on that link over there. And then lastly, we also have provided the direct link to the Census Bureau regional offices where you can see where your communities are represented and get in contact with a field agent who can help you answer any questions that you may have.

Erika Hudson:

That's very exciting. Thanks, Jen. And someone did ask in the chat, who can they contact given that you and I will be headed out? And fortunately, you can

connect our fearless leader who was on the census team with Jen and which is Eric Feldman, who is NDRN deputy executive director for public policy until transitions happen to fill the Census roles that Jen and I had. And we'll be sure to drop his contact information in the chat.

Of course, you can email me if you still have my contact as I recognize a lot of you here. You can email me and you can get Eric's contact information that way as I will have a handy-dandy out-of-office feedback for you all. So you can contact Eric. But for the time being, they will be our best point of contact in all things census, which you are definitely in good hands on that end.

Or of course just call NDRN and our awesome team will direct you to the best folks there. But as a reminder, NDRN has a very robust census page and a lot of our partners we'll be continuing this work, whether it's the census counts campaign, the ACLU, or our partners who worked on the census with us. But also, all of you have some incredible resources. I know Disability Rights California was on here, and they have a fantastic tool kit that they worked on that I believe will live on until the next 2030 census as well. So you all can definitely look at each other for that as well.

And thank you, Marsha. She dropped Eric's email in the chat. We did confirm with him knowing he will have his email shared. And of course, if there is anything you're specifically wondering from Jen or I, Eric will be able to get in touch with us. But I believe our report will provide you with a lot of good information. And I think we had a few more questions. I see a familiar name come up that asks, "Does the American Community Survey have data that would get information about the digital divide households with and without internet access?"

That is a fantastic question. They do have questions related to that in the American Community Survey. It is a very extensive survey that I can't remember off the top of my head the specific questions that are on there, but you can find that information related to the digital divide, given that the American Community Survey folks can do either via paper or they can do it online. So it's definitely important that we have both those accessibility options available to folks.

If you want specific information related to the digital divide, I recommend contacting those regional offices that Jen talked about. We had specific conversations with the Census Bureau that said we need folks to contact those regional offices. They are there to help. They're data specialist, something that I fully acknowledged. I am not. Jen is. I feel like I have seen her work, but she might have want you to think that. But she is absolutely an expert on that area, but that's what the Census Bureau is there, they want to be that resource. If you need to know specific demographics in a specific region, that's why you should contact the Census Bureau for that. That was a great question.

Jennifer Koo: And I think just very quickly adding onto that, I believe, because I looked into this as well, they tracked just internet access through asking questions about if your household has a computer. With the 2020 American Community Survey, I think a significant percentage of the population did have access to a house hold computer. And they also asked about what type of internet subscriptions that families were subscribed to. I think also they have information about age, like ages and age gaps and just populations of people who are 65 years and older, whether or not they have a computer or an access computer in their household. So again, I think the regional offices are, we keep repeating that, but I think they're a really great place to start. And they definitely have information about kind of the digital divide.

Erika Hudson: I should have just not talked, and should've just let you answer that question. And we will extend for that. So, awesome. We shared our resources and wanted to just double check if anyone has any more questions. We are nearing the hour. But if no one has any more questions, I will give it back to Jen for closing remarks today. And we'll just ask that everyone, if you can take a survey, Marsha, our fearless producer here, put it in the chat. So definitely let us know what you need to see in the future and fill out that survey for us. And we really appreciate it. So Jen, passing onto you for closing remarks.

Jennifer Koo: Thank you. I think I'll keep this brief, but I just wanted to say thank you so much to everyone for your time and engagement. And we really hope that today's discussion is as meaningful for you as it is for me and Erika. And we really believe that everyone deserves equal opportunities to be represented and included. And we'd like to encourage everyone tuning in to continue participating in these federal surveys and to also meet with your regional offices and provide them with feedback on what you need.

And also if you aren't finding what you need with the decennial census, feel free to check out our report and look at all the other options that we've outlined with the other federal agencies. I know we talked a lot about the us Census Bureau today, but there's plenty of information in our report about the other federal agencies that we mentioned. Oh, I think Ken has his [inaudible 00:56:34]? I don't know if you're able to unmute, but....

Ken: Can you hear me?

Jennifer Koo: Yes.

Ken: One question I should've asked much earlier in this session, but when you talked to the census people, did you get any sense whether there was resistance to answering the American Community Survey questions? Because that that's the survey that has the disability data and has some of the detailed data. And is there a role for the PNAs or other disability advocates interested in disability data to encourage people to, or is there a need to encourage people to answer

the American Community Survey when that's...? I mean, that's being done all the time. SO that's my question.

Jennifer Koo: I'm not sure. Erika, do you want to take that question or I can if you aren't?

Erika Hudson: I'm happy to. And thanks Ken. Ken's also one of our fearless leaders at NDRN. So super excited. And I want to thank Ken for all this work on this report too, as he definitely had an impact on this. So thank you, Ken.

And with our conversation with the Census Bureau, they do have focus groups. And the way questions are asked is very particular. And it goes through a lot of different hoops and the reasons to why questions are asked the way they are, both because of the input from people in the community, but also from the various federal agencies that rely on the disability data seen in the American Community Survey.

However, we didn't get into detail how participants feel because... And that's why they want to hear from us and disability rights activists in the community to know what is the best practice moving forward. And that relates to kind of why we don't necessarily have the question, "Do you have a disability?" On the marathon community survey, right? And why we have these six questions instead? I think, personally, depending on who you ask, they will have different opinions.

Admittedly, when I saw the survey for the first time, I was like, "Wait, why are they asking all these questions on this survey and not asking, do you have a disability? Yes or no?" And throughout those work, of course I've learned and the reasons for that, but then the question lies, what should we have all these six questions? And then also a question that says, do you have a disability? Yes or no? To see how that data perhaps differs. And that's, again, why we need to have these conversations and why the disability commuter needs to have an active role and share our input to exactly that question that 10 poses. Jen, do you have any other thoughts on that?

Jennifer Koo: I think you said it well. And I definitely think... I know with the representatives that we met with, there didn't seem to be resistance. I know, if anything, it is important to be persistent and to really advocate for what you need. And I think, from our conversations, it's actually been more informative because they've been able to enlighten us on the process of creating questions for these surveys and why it might be just... They walk us through the unintended consequences of adding certain questions that, again, like Erika said, adding an explicit question that says, do you or do you not have a disability? Because that in itself could create an opportunity for under-reporting or over-reporting, depending on how people take that question.

So I don't think we've experienced too much resistance. They do seem willing to work with us, but we would definitely just encourage you to keep having those

conversations because I think that's the only way we can really move forward and get closer to what we need.

Erika Hudson: Yeah. Thanks again. And it looks like we're at the top of the hour. So Jen, any last words on your end?

Jennifer Koo: I think I'm also... But again, thank you so much, everyone, for being here. Well, we look forward to just hearing your thoughts about the report. But that's all we have for today. So thank you so much for your time and have a great day.

Erika Hudson: Thanks, Jen. And huge thanks to Jen for all of her incredible work in this report. It's absolutely fantastic. I recommend checking it out at NDRN websites. So a huge shout out to Jennifer for all of our incredible work, and also to Marsha for producing this event with us today. And thank you again to all of you within the PNA network and everyone who joined us today. It's been absolutely a pleasure. And good luck with everything. So thank you all.