**DisData Transcript**

0:01

thank you so much all right i am just going to share my screen

0:07

and get us going all right hello and welcome to disability

0:14

advocates data disability advocates taking action or dis data ask questions

0:20

get get data and take action

0:25

i'm going to go to the next slide so just really quick we'll start with some introductions and i'm gonna go a

0:32

little bit over kind of what the goals are or our goals are for um the workshop today

0:39

um my name is lily gryman i use she her pronouns i'm a project director at the

0:45

research and training center on disability in rural communities and i am a white woman who wears glasses

0:51

in my mid-30s i'm going to turn it over to aaron who's going to also be presenting

0:56

a little bit with me later going over some of the amazing maps and graphics that we've been able to pull together

1:03

through this project so i'm going to let aaron introduce himself really quick

1:08

and then get back to the get to the workshop

1:15

hi everybody my name is aaron leopold i am a

1:20

i use he him pronouns i have brown hair a short brown beard

1:27

i'm wearing a black quarter zip i also work at the rural institute and i'm very excited to be here

1:38

yay and we are so excited that everyone is joining us it looks like we have a good number of people here

1:44

um so again welcome i hope we hope that in this presentation

1:49

today that you will learn about our new uh collaborative disability data

1:56

advocates taking action gosh i've said that so much in the past year and here i am stumbling over it um

2:04

also some information about how you can get involved to start asking questions and getting access to data and

2:10

advocating for disability data justice

2:16

we're going to share a little bit about the advocacy efforts and the work that we've done over the last year um as a

2:23

collaborative and then i'm hoping that at the end of this can start thinking about data differently um and really

2:31

recognizing that we are all data people um you don't have to be a data nerd

2:37

maybe like aaron or i or anyone can be a data nerd it doesn't

2:42

require any special knowledge or training and we are really here hoping to

2:48

make disability data uh more transparent um accessible

2:53

advocate for those things and advocate for representation across

2:58

data sets and within data systems so welcome that's a those are broad

3:04

goals i don't know that we'll achieve all of them but perhaps at some point

3:10

all right i'm gonna go to slide three so what is this data well

3:16

this data formed in the fall of 2020 in response to the countless disabled lives

3:22

lost to the covid19 pandemic particularly those in institutions and

3:27

congregate settings our national inability to count those lives and prevent their loss exposes a

3:33

long-standing issue that disabled people are missing from data design collection

3:39

and decision-making this problem is preventable through collective action so we are across

3:46

disability national collaborative and we are really committed to making data about

3:52

disability equitable actionable and transparent and one of our main goals

3:57

from this group is also to start building a national network of uh people

4:02

with disabilities service providers researchers like myself and some and other folks at research and training

4:08

centers across the country and at used um to really uh

4:14

ask the questions and define define the variables the measures that

4:19

are really valuable to people in the field and people living their lives in the community or not in the community in institutions and

4:27

how can we um really advocate for ourselves

4:32

in that way all right slide four so again who are we

4:40

mostly we're a community of people with shared values about justice equity and

4:46

compassion um we're people who really care about this work um and data can sometimes be a

4:53

little unfeeling or perceived as unfeeling but it really matters and people's lives are

4:59

at stake when we talk about data and so primarily we are a group of

5:04

individuals who have a passion for this we are advocates and activists service

5:11

providers researchers community members and people with and without disabilities

5:17

we aim to work in solidarity with all disabled people disability-led organizations and other groups of people

5:24

who are systematically marginalized due to structural ableism and racism to

5:30

collect the data needed to advocate for and affect change

5:41

so why data why does data matter um really

5:47

data matters because there is power in data um i think this is something that

5:53

we've really seen over the course of the pandemic um

5:58

that as as we've all been relying on data i think in a new way maybe over the last

6:05

18 months data has come to mean a lot of different things different people and it has been pretty um

6:13

powerful and i honestly think somewhat disturbing perhaps when you're looking at data and

6:18

recognizing that these data that we see all the time really represent individual lives and

6:24

we're making decisions based on based on these numbers that we see that

6:30

are real whole human beings behind them and that also some of that data is

6:35

missing right so not only do these these kind of cold seeming numbers actually represent human beings

6:43

we are not effectively or we are not counting everyone equally

6:48

and that really matters and so we we recognize that that the power in data

6:54

really we're asking that question of who is getting represented in data systems

7:00

and then why why are some people being marginalized and excluded um what questions are being asked of

7:08

data in these data sets and of what questions are being asked um

7:14

in the world and who gets to ask those questions and why um

7:20

and this is really to reinforce these questions are really about how data systems data sets data policy

7:27

can be used to marginalize and exclude as much as it can be used to include and

7:33

understand so really there's this idea of good data bad data no data

7:39

bad data is just as bad if maybe not worse than no data

7:45

who gets to define what good data is um who's asking the questions and defining

7:52

the questions that get asked are are the people who are being represented in those data systems the ones who are

7:59

able to make the decisions about how those questions are asked of whom and why

8:05

um the answer for a lot of years um has has been like like old able-bodied white men

8:13

usually uh now there's some white ladies in there too uh and i think uh really

8:20

we as uh as researchers for me speaking of as a researcher and then as this

8:25

broader collective group that cares about this really have a role to play and starting

8:31

to change that so really what we've seen through kovid

8:36

is that disabled people are made invisible we knew this before but was really highlighted

8:42

the disabled people are made invisible across federal policy through the lack of data collection and representation

8:48

leading to a disability data inequity this is particularly true

8:54

in congregate settings um and i think it's important i want to take a minute here to really talk about

9:01

our definition of congregate setting um which which is not is still pretty loose

9:07

honestly we are still a very loose collective we want everyone who's attending here to join and ask questions

9:13

um and help us define all of these things and and do this

9:19

together collectively but really the best way that we've come to define congregate settings now is

9:26

just a very long list of examples so i'm going to read them now so for disability

9:33

this data we define congregate settings as nursing homes licensed and unlicensed group

9:41

homes detention facilities prisons jails detention centers other

9:47

carceral facilities intermediate care facilities long-term care facilities

9:54

regional centers state hospitals acute care hospitals rehabilitation hospitals

10:00

psychiatric hospitals veterans hospitals hospice facilities assisted living facilities without

10:06

individual rooms residential treatment centers and then other congregate settings

10:12

because there are more um and really i think having that broad definition is important because people

10:18

with disabilities are disproportionately represented across all of these settings

10:25

and yet the data reporting systems and structures across these settings generally don't reflect

10:31

kind of that shared experience and it forces us into data silos where we're

10:36

unable to talk about this shared disability experience across all of these congregate settings

10:43

um and then additionally and this has been a little bit more talked about

10:49

um we have seen that disabled people are made invisible in intersectional spaces

10:55

and identities through data so data doesn't a lot of the data that is available particularly around the

11:02

impacts of the pandemic prevent you from looking across multiple

11:08

groups of demographic identifiers or identities so looking at um the the

11:14

intersection of race and disability or of various disability types has

11:20

become is nearly impossible and that also forces

11:26

groups with shared experiences kind of into data silos

11:32

so really we are seeking data equity for disability justice improved disability

11:38

representation across all levels of data collection

11:43

what we're advocating for and a lot of the work that we've done over the last year has been this

11:49

advocating for improved representation get people with disabilities disability-led organizations

11:56

at the table to assess how questions are asked how

12:01

surveys are implemented and how and which data to use to inform policy

12:07

and also ask those questions of why aren't we asking certain questions or are we asking questions in

12:14

ways that could potentially be damaging to the

12:22

community so what do we do this is where um we're gonna get into the really exciting stuff um

12:30

uh we so far as i said this is a really loose um

12:35

collaborative and we really want more folks to join and ask more questions and share their experiences

12:42

but so far we've been really advocating for disability data representation

12:47

um really getting the word out there that disabled people and disability-led organizations

12:54

must be included across all levels of data collection so two of the things that we were able

13:00

to do over the summer was super exciting um is dis data presented at the united nation

13:07

regional consultation of the committee on the rights of persons with disabilities um back in june um where we really

13:15

advocated for um that increased uh representation and visibility and

13:22

recognition of the impact that covett has had on people with disabilities in congregate settings

13:28

um we also were able to provide a public comment to the biden harris task health

13:34

equity task force um in july which was a task force focused

13:40

on a lot on data inequity actually around the pandemic and there was a huge

13:46

focus there was some focus on disability we had some good some other folks from uh the you said

13:53

other youth sides across the country presented on the disproportionate impact that covid had has had on disability

13:59

however very little was discussed around individuals in congregate settings

14:05

there was some acknowledgement of congr the impact of covid in correctional facilities

14:11

but surprisingly little on folks in nursing homes which

14:16

which almost everyone in nursing home is has a disability and

14:22

the what we've seen over the pandemic in nursing facilities has been so horrific that it's

14:28

it's disheartening but also exciting that we were able to go and say hey

14:33

this matters this is where this is how things have been really hard for us to understand what's going on and know the

14:40

true cost um of just the true loss of disabled lives over this pandemic

14:49

and i want to say thank you to mary for what she wrote in the chat

14:55

so we also um more recently have analyzed data to support local and national advocacy

15:02

efforts and again this is part of our goal as a collaborative where we want to connect

15:08

advocates with researchers and connect advocates up with the data that they need to share

15:15

their story and advocate for the things that are needed in their community and this is one way that we've been able

15:22

to do this which is super exciting so after this i'm going to turn it over to aaron to walk you through all these

15:27

amazing gifts and images and we'll do lots of rich description of them

15:34

um but what we've done is a national analysis of covid19 deaths in nursing

15:40

homes using data from the cdc and centers for medicaid services

15:46

and we've developed a research brief to communicate the impacts of covid on

15:52

people in nursing facilities and we've created these dynamic data visualizations um at both national and

15:59

state levels um we will talk a little bit more how these were

16:04

used towards the end so actually if anyone is following along on the slides slide eight has now been moved down so

16:11

we're going to get right into the maps right now and we'll talk a little bit about how centers for independent living

16:16

we're able to use some of these graphics that we've created to advocate for change um

16:23

and uh and and then ask and we'll open it up for questions then um and discussion

16:29

then about how you and your center use data for advocacy or struggle to use

16:36

data for advocacy and thank you yeah you said thank you again mary for

16:43

defining some of my acronyms university center's an excellent disability is a use

16:48

call me out please if i do that um all right i'm gonna turn it over to

16:54

aaron now to go over some of these maps that we've created talk a little bit more about the data um and play some

17:01

some visually interesting and also depressing graphics for you all

17:08

so let me turn my camera off

17:14

hello again thanks lily so as lily mentioned the data we're about to see

17:19

comes from the centers of medica for medicare and medicaid services uh nursing home covet 19 public file

17:27

this data is at the nursing home facility level the individual facility level and we aggregated it to the county

17:34

level for all of the maps we're about to see the grayed out areas are areas with no

17:39

data as lilly also mentioned limitations in data are important

17:47

when thinking about data equity an example of this specifically with this data is

17:53

that only the included facilities in the cms data are that our facilities

18:00

that receive cms funding because of that it's kind of guaranteed to be an undercount

18:05

of nursing home facilities and this data is also dependent on the

18:12

quality of reporting of each facility 494 facilities that were listed did not

18:18

report code 19 data and kind of interestingly or anecdotally

18:24

354 of the 494 facilities were in texas so

18:30

take that as you will so this graphic specifically illustrates the change in weekly covet 19 cases in

18:36

cms nursing facilities by county over a period of 10 weeks from july 5th to september 19 2021

18:44

counties are shaded from white to light orange to red on a scale from zero to 797

18:51

white or light orange counties have fewer cases and red counties have more cases counties for which we don't have

18:57

data or where there are no nursing phil facilities are shaded gray

19:03

the first map represents the week of july 5th and a majority of the counties across the us are white or light orange

19:08

with zero or one case over time the clusters of counties all across the country grow progressively

19:14

darker until the final week of september 13 shows consider considerably more of the

19:19

count country in darker red with red counties in every state and some counties reaching levels up to

19:27

797 new weekly cases over the course of these 10 weeks a total of

19:33

36 535 new cases were reported in nursing facilities across the country

19:40

and kind of while this jif keeps playing we'll spend the most time on this one i kind of wanted to rattle off some

19:45

stats that the cms had listed these stats were updated october 3rd 2021

19:52

the first is 85.3 of residents in cms facilities were fully vaccinated

19:58

with this 69.2 percent of staff were vaccinated there have been a total of hundred and

20:05

six thousand two hundred and forty eight confirmed cobit 19 resident cases

20:10

with 137 678 total resident deaths

20:16

this is compared to thousand 655 hundred and twenty eight confirmed code with nineteen staff cases with a total

20:23

of two thousand one hundred and one total staff deaths

20:29

uh we can move on to slide and i guess it would be slide nine

20:35

this graphic is similar to the last but it looks like covet 19 deaths in cms nursing facilities by county over a

20:42

period of 10 weeks from july 5th to september 19th 2021 counties are shaded

20:47

from white to light orange to red on a scale from 0 to 59.

20:52

white or light orange cases have fewer deaths and red counties have more deaths counties for which we don't have data

20:57

again are shaded gray the first map represents the week of july 5th and a vast majority of counties

21:03

across the u.s are white or lie orange with zero or one death over the time clusters of counties

21:09

across the country grow progressively darker until the final week of september 13th which shows

21:14

considerably more dark red and red counties in every state with some counties reaching

21:20

up to 59 new weekly deaths over the course of these 10 weeks a total of

21:27

3 394 deaths reported in nursing facilities across the country as a result of covet 19.

21:34

this 10-week time span was kind of chosen to illustrate the effect that maybe the delta variant was having in

21:40

cms nursing facilities as cases increased throughout the nation we can move on to the next slide it's like 10.

21:48

this is a state level map we created for pennsylvania showing pennsylvania

21:53

copenhagen cases and nursing facilities across the state starting with the week of april 26th a majority of counties are

22:00

white or light pink indicating zero or few new cases with some counties in the

22:06

southeastern part of the state reporting more cases which would be 29 to 88 cases

22:12

as the weeks pass increasing numbers of counties across the state report increasing number of cases by august

22:19

14th substantially more counties report cases in the highest category 29 to 88

22:24

cases and we can move on to slide 12. sorry slide 11.

22:35

thanks this is another graphic map of colorado counties showing the increase

22:41

in cases of coven 19 and cms funded nursing home facilities over 10 weeks from june 13th to august 28th

22:49

cases increase across counties steadily across over the weeks over these 11 weeks there are a total of

22:56

349 new covid cases in nursing facilities across colorado

23:01

so with these sort of cobin maps in mind i'd like to move on to the next slide and turn it back to lily so we can start

23:07

a discussion on using data for advocacy

23:16

thank you so much aaron um and i want to before i get in a little bit uh to

23:23

um how these maps have been used by some cils i want to just address a couple of comments i saw already in the chat and

23:31

in the questions so um we'll have uh we would love to make maths for people

23:38

if they would like them and we also have all of these maps available and these gifs as static maps and also as the

23:44

graphic image file and have a link there's a resource link in

23:50

the page or page a presentation page on the april website

23:55

that will take you to that will take you to a word doc that's just filled with a bunch of different leaks for resources

24:00

and one of them is to a google document with all of these maps and we can also send individually folks

24:07

the files if they reach out to us mary put that in the chat that's great uh also the comment about having puerto

24:13

rico in the data and i might have to have aaron back me up on this um because i'm not sure but i'm pretty sure it

24:19

would be great to have puerto rico but we don't have data for puerto rico so this is another good example of um

24:27

advocating for data access within these different data sets is that often the things that we can do are

24:32

really limited by the data that's available and so when we start identifying where is data not available

24:39

and is this a place where we can advocate for increased and improved data

24:44

that's what we're here for and that's what we want to start being able to um i identify

24:50

um so these national we were able to share and create the gif in um across

24:58

actually we have some more too for illinois in new york and washington state um and uh on the uh through that

25:05

resource link um and so we were able to support centers for independent living and state

25:10

and national advocacy efforts um where cils were able to communicate state-level disproportionate impact to

25:17

secure funding streams for emergency transitions pilot programs increased community awareness of the

25:23

pandemic's effect on congregate settings and to support current and future advocacy to increase access to hcbs home

25:31

and community-based services and housing cils used this to show the necessity of

25:37

accessing state-funded housing vouchers for emergency transitions from congregate settings

25:44

and then used to communicate state-level disproportionate impact to advocate for federal emergency funding to be used for

25:51

transitions and relocation out of facilities and this is actually specifically some of the work that misty

25:57

and dion and marcy and some others are going to be talking about this afternoon about the work that they have done in

26:04

getting reimbursed fema reimbursement for relocation emergency relocation

26:09

and i have to say we were able to present some of that data misty was

26:15

with support of this data to the national council on disability really emphasizing the barriers that that her

26:23

center faced in um accessing approval to refer fema reimbursement for emergency

26:28

transition um and i'm i'm hoping i think she'll probably be sharing some of those slides that were really powerful way to

26:35

tie data to advocacy we were also

26:41

through this process of working with this data

26:46

identified major data limitations and discrepancies between particularly between all the

26:52

different data sources that were out in the world through covid we identified disparities and

26:58

differences in covid cases and counts between cdc cms and state data

27:05

and really brings into question the validity and trustworthiness of of this data

27:12

um what we saw is that and what i can say and i think aaron i don't know if aaron

27:17

said it um is that really

27:23

this these numbers that we're looking at represent an undercount if anything um

27:30

many state level sources if you provide if you have access to that and we can help support finding some of that we

27:36

also work with a partner one a disdata member at the autistic self-advocacy network who has they have an amazing uh

27:43

database where they've been collecting and doing really digging in to get more accurate numbers

27:50

um but really there's also that discrepancy

27:56

is a real problem there are there are deaths and cases going uncounted um and

28:01

and we know that and we need to advocate for improvement around that and that's been one of our focuses

28:06

uh additionally there's lack of consistency between definitions of congregate setting types across data

28:12

sets um and that's again what aaron mentioned these are just cms funded nursing homes

28:18

there was a long list that i read earlier of other types of congregate settings where we have really limited

28:25

data we're starting to dig a little bit into disability and kovid in congregate

28:30

settings um i mean in correctional facilities but specifically those data sets are also disjointed so we're

28:36

talking about disjointed data within disjointed programs

28:43

where really i think we can come together to start saying like how can we start asking these

28:48

questions and getting the data that we want across these different groups

28:55

all right so yeah i want to have a little bit of

29:01

time here um to have a little bit of a discussion and

29:07

see if i miss anything we can pause maybe first answer any questions that are in the q a i think maybe mostly

29:14

things got got addressed there um but please put any questions that you might have

29:20

about the group or i'll switch to our next slide our last slide um

29:25

in a in in 15 minutes or so so you can be sure to get our contact information i

29:30

can put it in the actually it will put it in the chat also um about

29:36

uh how you can become involved and how you can reach out for our technical assistance if if you're interested in

29:42

but really wanted to open it up oh although i would i have i see i have

29:48

a question um this is from ty smith

29:56

uh i'm a huge data person and also a huge quality of life advocate the independent living center has been

30:02

wonderful for promoting quality of life but the behavioral health system i can't get anyone to ask any quality of life

30:08

questions my question is how can we tie in the behavioral system better to the

30:13

independent living community that is a really good question

30:18

and i actually want to open that up maybe too if there's anyone in the audience who could address any efforts

30:24

that they've had locally in many ways my response to that would

30:29

be that this is where a group joining a group like this data where we

30:35

have a lot of different brains at the table um

30:40

and identifying who are your local advocates too um who is the champion

30:47

um in do you have a champion in your behavioral health system that you can go

30:53

to and how can we also as researchers and and data experts

31:00

find out what are the questions that folks can use how where are the success stories of

31:06

communities that have been able to tie and build relationships between these two systems

31:12

i'm probably not going to have an answer for a lot of these types of questions but it's exactly the type of question we

31:18

would want to put out to the group so there's 126 people on this

31:24

call someone's got to have something right

31:29

so thank you so much tai and i'm going to put the diskdata email right now in the chat

31:35

it's diskdata meso.umt

31:41

edu and anyone who's interested in learning more getting involved can email that

31:50

email address it's also available on the links

31:55

as well that i referenced earlier so i saw some questions coming in i want

32:00

to read these discussion questions however um how does your center use data for advocacy

32:07

what data gaps have you encountered in trying to advocate for the needs of the community and i think ty's question is

32:13

right i'm lying in line with that what are the barriers that you've experienced in trying to access or use

32:19

data for advocacy and again i think that idea of competing systems and people in silos

32:25

is a huge barrier um that that i optimistically like to think that

32:32

collective action will be able to address um what are the risks associated with using

32:38

data for advocacy so as i mentioned earlier there's definitely power in data and

32:46

sometimes that can go awry right and there are definite risks in

32:53

highlighting highlighting certain types of data that can always backfire politically or

33:04

yeah ethically

33:10

um yeah so here i have something in the comment the ielts centers are cross disability as are silks when they do

33:17

survey research the number of people with disabilities and generic needs are counted but these don't get broken down

33:23

by access or type of disability i think that is an exam that is a excellent

33:28

comment and one thing that we're really hearing and when we talk about data equity across disability and

33:35

um racial and ethnic lines that being able to analyze at those intersections

33:40

of not only accessibility needs but also you know disability for people of color

33:46

who also are disabled the experience as their experiences are much different and and need to be able

33:53

to be understood right and so when we have data that doesn't allow for

33:59

that analysis and that often is because sample sizes are too small so whenever you have

34:05

a group of people that is smaller than the general population you know a small smaller subset data's data sets often do

34:13

not gather enough information to do complicated analyses and that is

34:18

something that at the biden-harris health equity task force was brought up around racial health equity um and is

34:25

something that we can advocate for as well increasing sample size novel

34:31

uh survey and analysis methods that allow us to really

34:37

um understand what those experiences are and prevent and and you know not lose them to to the

34:45

to the numbers basically

34:52

yeah this is great we've got a couple other excellent comments and aaron if you want to pop if

34:57

you want to jump in please do no pressure anyone also if they have questions and

35:02

they want to raise their hand and come on audio that's more than more than welcome um

35:11

yeah oh go ahead aaron yeah yeah how do we do that there we go uh i

35:17

can kind of jump in with the last part of ty's question which was

35:22

how do you try to do a positive data type of analysis with a weak community of support to make sure the

35:29

data is helpful instead of harmful and i think for us what's really important is that we kind of are upfront

35:34

and acknowledge all of the limitations that we encounter with our data an example of this with the cms data is

35:41

acknowledging which facilities don't report and also that this is just one kind of narrow view of congregate

35:47

settings it's not looking at a broader thing so i think we we try to be super specific we

35:52

list those limitations and we try to make people aware of those limitations and how they might be best overcome

35:59

i think that goes a long way in sort of painting the whole picture but maybe lily you could speak a little bit more

36:05

to that i could

36:14

i was muted still um yeah i think these are these are the questions i'm not sure that i honestly

36:21

can i think it's it's more that this idea of um we have someone commenting about the barrier of uh people falling into a

36:28

demographic black hole right and so um if if folks don't have a formal

36:33

diagnosis or depending on how questions are asked people may not know how to answer that question um and may not then

36:40

their experience may not be counted because the question was poorly worded that they're asked on a survey

36:45

um and then i think this i like this term a lot a demographic data black hole i kind of want to steal that whoever put

36:52

that out there um and that that can happen a lot and i think happens is much more likely to

36:58

happen when the individuals who the data represents are not involved in the process

37:04

um so you will have bad questions that will result in bad data when you do not

37:09

have representation of of everyone at the table so i think

37:15

really thinking about um about how we can collectively advocate

37:22

for improved representation and these are the exact exact kinds of questions that we need to be collecting so that we

37:29

can start to as a group identify like where are these key issues that we can really push and

37:35

wit and work with with not only service provide like local level advocates but national advocates who

37:41

will know when um and people working at um

37:46

governmental agencies policy makers knowing when you can start to push for

37:52

these changes here where is our opening and that's what's been really exciting about this group so far is that

37:58

um you know i representing kind of the researcher side of this like i love i'm

38:04

the data nerd i want to dig up what data is available i want to figure out how we can analyze it and and and create

38:09

something that individuals can use but i'm not the expert i'm not really the expert in that honestly i'm but i and

38:16

i'm also not the expert in policy or who to talk to or who is the champion or who

38:22

you know that's where this collaborative effort is going to really come um come to play

38:28

and we've got a couple other and i think actually i wanted to address tai had a comment also here around

38:35

how do you try to do positive data how do you bring data to the table to build a community of support so there are few

38:43

champions and people are exhausted in the world as we know um

38:49

i just yeah thinking about the poor public health workers of the country right now um and how do you start pulling data and

38:57

that's actually i want to promote that question i want to promote a presentation tomorrow that the rtc rural

39:04

is also doing around rural community development and that's really around identifying those strategies of how do

39:10

we identify local data local level data and local partners to really emphasize what

39:16

we do have and how great how we how um how great the community is right now but

39:23

where the places are for change right and framing it that way and there are definitely

39:29

um ways to do that generally data is right used to

39:34

highlight disparity because that's what we so often see but it doesn't have to be that way um and these and there are

39:41

lots of kind of community development strategies that focus on that positive approach so i

39:47

think that's tomorrow at 11 30 mountain time

39:53

um and i can't remember what it's called the full title but it's about rural it's about a rural community development

39:59

project and i really want to plug that so rayna i don't know if you're on or if anyone's on who's doing that put your time in the chat

40:10

all right i see another question for the data of k says for the data of

40:15

cms funding nursing homes were there any efforts to break down data by different populations living in nursing sounds

40:21

such as people with disabilities and elderly yes this is a great question actually

40:26

and it is something that if um that we are trying to take this as the research

40:32

and training center are trying to take some of our analysis to the next level and um identifying uh

40:40

specific uh demographics not only about individuals within facilities but facilities

40:46

themselves so do we see different have we seen like worse outcomes in certain types of facilities and or amongst

40:53

certain types of populations within facilities and

40:58

that is is a challenging analysis because the analysis we're working on does not have

41:05

that data so again an example of silo data sets where

41:11

data is can often i think honestly be used to

41:16

discourage you know like non-experts from analyzing it so we want to try to be here for

41:22

to try to overcome some of those barriers to start getting at those analysis and would love to hear

41:28

uh thoughts um on that

41:34

yeah okay some other great questions around i would like to hear more about different intellectual disability um

41:40

facilities uh in the area of atlanta georgia um and i think yes

41:47

ari i'm not entirely sure that i'm saying your name correctly but yes please reach out

41:52

um uh through the dis data oh i'll just go to this next slide so i don't read it so

41:58

again the email is dis data d-i-s-d-a-t-a

42:06

at umt.edu oh my gosh i think i did that wrong i think it's mso.umt.edu

42:12

ah i feel like i'll we'll get that mary just put it in the chat dis data

42:19

mso.umt.edu um because one of our

42:24

another member of disdata works at a you said a university center for excellence and disability

42:30

at the university of minnesota and they have quite a bit of data um on

42:35

intellectual and developmental disability uh resid like um they have a big survey on

42:42

uh on different uh residents i can't remember the acronym of course

42:48

this is a world of acronyms um but ari please reach out to me and i will get you connected with them um and that's

42:54

another really exciting part about this um uh project is that there are a lot of

43:02

different folks from different backgrounds and we're coming together to share um all of her all of our our shared

43:08

information um yeah oh amanda asks what's the best way

43:14

to know which data is worthy of being reported that's an extremely good question um

43:23

and i think really really challenging um i think that's where i'm

43:29

hoping that i think there's this is a group also that could potentially um we can all kind of build our data

43:36

knowledge and data um competency it's not the word i want

43:41

to use at all but um together to start understanding how do you question data

43:46

sets right how do you start to ask those questions about like is this data any good and

43:52

it's honestly going to be up to you if you look into that and you say no this question this question is no good

43:58

um you know it may be you may have to compromise and say well this is the only data but is the only

44:05

data even worth reporting it may not be um yeah and peter asks about the the

44:11

data on the maps um yes it's all for this last year 2021 um oh yeah and i see

44:18

aaron is on top of that yeah and this is another one access measures of people with environmental

44:24

hypersensitivity are not reflected in disability surveys and that's so true um and i think that's another way to

44:32

start advocating around measurements and saying there is a community out here that is completely

44:38

unrepresented and um what do we start doing and what we start doing is collectively start advocating

44:44

um join our group we're we're really we're really

44:52

not super organized right now we're getting there because we're doing this collectively and collaboratively but we are i think in the next year starting a

44:59

big push where we'll like have a website which will be great and have a format for people to join the group and some

45:08

really hopefully engaging strategies for keeping for sharing information

45:14

we have a discord actually we haven't used it that much but we would love to hear from folks

45:19

about what is the best way that you prefer to receive information is it webinars is it meetings is it conference

45:26

calls is it uh list serves is it you know slack and discord and we want to really make

45:33

this collaborative really open and accessible and inclusive

45:39

another big part you know we're really hoping to push toward not only include

45:44

disability inclusion and representation um but in you know having that inclusion

45:51

and data analysis visualization translation access data accessibility usability and transparency

45:58

um and that's something we're hoping at the rtc side of things too to help really push out and and get access

46:05

increase access to those data sets in a way that's like understandable for

46:11

anyone um because a lot of it's not uh and and then really pushing data equity

46:17

for disability justice and trying to reach outside of the disability community recognizing

46:22

that intersectional component and that we have disability represented across all sorts of

46:28

um groups and what and that there are shared uh goals and needs

46:36

across those different groups yeah and mary said this she just joined

46:42

we have a listserv or like an email chain that is there's all sorts of stuff um

46:49

and uh that gets shared on it and we would encourage everyone to just email this data and say hey i just wanna join

46:55

and i will add you to our group and you'll start getting emails that you can ignore or read when they're relevant you

47:01

know totally up to you i know emails get lost all the time but the more the better and then you

47:06

have a place to reach out for technical assistance and things like that and then another question from peter do

47:13

you have data beyond congregate settings and is it specifically focused on covid so this is actually great i kind of want

47:19

to put in um maybe or aaron do you think you could put in a link to the chat to the disability counts

47:26

uh the research and training center on disability and rural communities has a couple tools we have maps around

47:33

on disability type for every state in the country across disability type and then some subgroups

47:41

looking at poverty employment veteran status and those are available on the rtc rules

47:47

webpage and we also have a tool called disability counts

47:52

that you can access to download data

47:58

at the county level for your individual counties across those same

48:04

indicators so i think if you follow that link and then the tool is called disability counts and that's using data

48:10

from the american community survey it is a different data set um and we have some information on there

48:16

around how disability is defined it's very limited in a lot of ways as well

48:21

unfortunately as all data often is and so there's room to advocate there as well

48:27

um so yeah please check out all of those resources and i think we have them also

48:32

on our resource word doc that you can download again and then the gifts are also if you visit

48:38

the rtc world vendor table which i encourage everyone to do you can download our fact sheet on on a couple

48:44

fact sheets actually we've been looking at this for a while we have a couple fact sheets highlighting the potential risks that we we put out back in like

48:52

april of 2020 um about nursing facilities and then you

48:57

can see we have this this update of that you know everything went there and then got bad

49:03

again um and uh you can access that stuff through the vendor booth as well

49:11

lily we do have a hand raised from an attendee great mom ty smith i'm going to unmute you so that

49:18

you can ask your question

49:26

thank you and i'm i'll be quick i was just curious uh if this data is uh

49:34

more than just covert related data or if there's other things and i asked this

49:39

because i was part of a group that did some research and and i don't like this term the high end utilizes the 20

49:46

of the mental health population that uses up around 80 percent of the resources

49:52

it was uh huge uh you know about 10 years ago and then it

49:59

kind of dropped off the radar and i feel like you know as i said i'm a huge quality of life advocate i feel like we

50:06

can use that sort of data to make real good changes to help improve people's quality of life

50:12

and access appropriate uh services uh and supports

50:18

but um i can't find anyone who is interested in doing any research around

50:23

that that population again and even though it's it's very much needed

50:29

in my opinion perhaps now more than ever yeah thank you yeah

50:35

yeah ty thank you so much and no we are not and i think our goals are in the future not to be i mean we would just

50:41

want to keep growing and um and and identifying

50:46

data that's needed right any data that's needed to support the disability

50:51

community and to support quality of life for disabled people in the us um i mean internet all over maybe but you know

50:58

don't want to get too whatever um so i i think tai would love to hear more

51:05

about that is ultimately what i want to say so if you want to get together and chat or um you know email that that and

51:13

join i think that the more we get uh people involved we can have work groups

51:19

you know we're at about 50 i think we have about 50 members right now we want to grow and then

51:25

get figure out what are people's interests and advocacy and passions and get them together to start having these

51:31

conversations and saying what's been done linking up advocates with researchers who know something about that there is

51:38

there are some research organizations that i don't have on the top of my head that you know would be great to connect

51:43

you up with um and see like what are these intersections how are

51:48

um behavioral health and mental health organizations partnering with cils and

51:54

how where is that successful you know and why and how and how do you get that information

52:00

um yes and then alyssa has a really good question around data question for cils

52:07

um and that makes me think again i want alyssa i want you to reach out because we have some resources that we could

52:13

connect you up with i know that we've done something recently or have are about to put out um something around how

52:19

centers for independent living can start to collect their own data um that that's an exciting thing too beyond the data

52:25

that you get we can also help analyze like national level ppr ppe data

52:31

i don't know what that acronym stands for the 704 the report cio reporting data

52:37

um and uh i think there are there are things that

52:43

centers can do to start collecting that and defining your own measures and then you can have your own data to share and then advocate for that to be this

52:50

measure turned out to be really successful and great and this is what we learned and here's how we should incorporate it in a state level survey

52:56

or a national level survey ppr thanks mary

53:01

performance report something um so i think we're hitting the last

53:07

four minutes um i i don't know if i missed any other

53:13

um questions or comments or program performance report thanks mary

53:19

um yeah if anyone has any questions that i'm missing you can

53:24

also always um

53:31

yeah let's see i think there's some really great suggestions

53:39

around how we uh talk about access returns how we talk about disability oh my gosh there's so

53:45

many kind of quagmires and conversations also that we can get into which i think is

53:51

also really fun and exciting and super important to have those questions to have to have advocates having those

53:56

questions and then having finding our routes to taking that information um

54:01

to people in charge okay i thank you so much erin i'm going

54:08

to turn my camera off so you can say goodbye i think maybe we're kind of wrapping up soon i guess it's three minutes early so i kind of want to i

54:14

kind of don't want to i guess rush out the door but this was really really fun dis data

54:20

d-i-s-d-a-t-a at mso.u

54:26

again because i kind of can't believe i think i messed that up

54:34

oh yeah shoot good here we have a we have a good comment um uh susie when you discuss data counts

54:40

would you consider saying quote these data reflect people with specific several specific access requirements do

54:46

not but do not reflect others for example answers by people with blank were included but people whose

54:51

disabilities blank access needs were not interviewed i think that is an excellent example of the way that we can talk

54:58

about and be incredibly clear um with what data represents and that's some of

55:05

the hardest stuff actually with some of these um with some of the data sets we work with

55:10

is really understanding who is answering these questions and these are some of those really critical critical questions that

55:18

matter that that represent why disability representation matters because you have

55:24

to have people at the table when those questions are being designed to in order to understand who is

55:30

actually represented and the the truth is we don't always know we don't always have the best understanding with some of

55:36

the data sets that we work with um and yet mary just posted the evaluation

55:42

um in the chat which is awesome so yeah i think that that is that right there susie is an excellent reason to

55:49

get involved is we need to hear what are the best ways to start answering these questions and we need to engage in conversations about that um and i'm

55:56

hoping that this group at some point can be a forum for that um

56:02

and that we'll have a wide enough forum where folks with various different interests can come together and we can

56:08

share what we're learning together but also focus on the things that we're passionate um about as well that's what

56:15

we've been that's what we've been doing and what you're seeing here is kind of the results of aaron and i being geography nerds we're

56:22

both geographers and so we like to map data um and so a lot of the stuff

56:27

that we've been doing now has been focused on that but we do not want to limit it to that at all

56:34

lily and aaron thank you so much for sharing your knowledge and wisdom with us thank you to all the attendees and

56:42

please go fill out that evaluation and let lily and aaron know what a great job they did

56:48

and just a reminder that all recordings will be on the conference website so you can refer back

56:55

thank you so much