"Disability Data for Advocacy and Awareness"
Lillie Greiman
RTC:Rural
Mental Health Symposium 2022
Friday, May 13

[2022/05/13 12:59] Carolyn Carillon: Hello everyone.
Today's presentation is being transcribed so those without audio or who require text only can participate in real time.
The speakers may be using a text teleprompter tool for some or all of their presentation.
Transcriptionists will fill in any gaps and support the Question & Answer section at the end.
A little explanation about this service.
Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.
Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.
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Transcription is provided by Virtual Ability, Inc.
The transcriptionists are:
Elektra Panthar
Carolyn Carillon
The speakers will be identified by initials as they speak.
The following initials in the transcription record will identify the speakers:
LG: Lillie Greiman

[2022/05/13 12:59] Carolyn Carillon: <<transcription begins>>

[2022/05/13 12:59] Tori Landau: Hello everyone and welcome to Virtual Ability's 2022 Mental Health Symposium.
I'm Tori Landau, I live in Northern Ireland and I have Systemic Lupus Erythematosus .
Fourteen years ago I joined Second Life and I enjoy being a DJ, building things, volunteering and being able to do activities that I am unable to do in real life.
In real life I'm a qualified Environmental Scientist, Computer Based Learning educator, musician and I've been a carer to several family members.
Today I'd like to introduce Lillie Greiman who is the project director of the Research and Training Center on Disability in Rural Communities (RTC: Rural) at the University of Montana.
Lillie has been with the center since 2012, working to improve the lives of people with disabilities in rural communities.
Lillie's presentation today is "Disability Data for Advocacy and Awareness".
The presentation will showcase how the data focused tools RTC:Rural has developed have been used by their partners and also the work that RTC:Rural does to support disabled advocates, researchers and consumers.
Please remember to wait until the end before typing comments and questions otherwise it will interrupt Lillie's talk.

Welcome, Lillie. The floor is yours.

[2022/05/13 13:03] Elektra Panthar: LG: Thank you
Hello everyone, can you see me and my slides?
Thank you Tory and thank everyone for attending
I'm honored to be here, it's my first time in SL and I'm enjoying it a lot

[2022/05/13 13:05] luluruthy Resident: Slide 1 “Disability Data for Advocacy and Awareness”
Research & Training Center on Disability in Rural Communities
Prepared by Lillie Greiman, Ari Lissau and Arin Leopold
Funded by: National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)

Slide 2 “Introduction and Presentation overview”
Lillie Greiman (she/her)- RTC:Rural project director and data nerd
In this presentation we will:
•learn about RTC:Rural data tools
•learn about current/ongoing disability data advocacy efforts
•explore how you can get involved!
Please hold your questions and comments until the Q&A at the end.
[2022/05/13 13:06] Elektra Panthar: LG: I didn't know I was a data nerd until I started this job!

[2022/05/13 13:06] luluruthy Resident: Slide 3 “Why Data Matters”
There is power in data.
• Who gets represented and how?
• What questions get asked and why?
Data systems can be used to marginalize and exclude as much as they can be used to include and understand.
• Good data, bad data, no data
• Inclusion and representation
[2022/05/13 13:07] Elektra Panthar: LG: later we can discuss how anyone who is interested can get involved
Inclusion is very important especially in this world that is so focused on data
We have whole communities that are left out of the decision making process
[2022/05/13 13:08] luluruthy Resident: e.g., nursing homes, licensed and unlicensed group homes, detention facilities, prisons, jails,
detention centers, and other carceral facilities, intermediate care facilities, long-term care facilities, regional centers, state hospitals, acute care hospitals,
rehabilitation hospitals, psychiatric hospitals, veteran’s hospitals, hospice facilities, assisted living facilities without individual rooms, residential treatment centers, and other congregate shelters
[2022/05/13 13:08] Elektra Panthar: LG: we'll identify what those data gaps are
We coalesced when we noticed how COVID-19 was impacting people differently based on their conditions
Congregate settings: where people leave together and probably have limited access to what they actually need - nursing homes, prisons, etc

[2022/05/13 13:11] luluruthy Resident: People with disabilities disproportionately reside across all types of congregate settings but the data reporting systems and structures across these settings generally do not reflect this, forcing advocates and researchers into silos.

Slide 4 “Why Data Matters”
The ability to access, understand and use data is critical to supporting the public health needs of any community.
Disabled people are often made invisible across federal policy through the lack of data collection and representation leading to a disability data inequity.

- In congregate settings
- In intersectional spaces/identities

Slide 5 “Increasing data access”
The ability to access, understand and use data is critical to supporting the public health needs of any community.
Many federal and state data systems require a base level technical expertise or even specialized software to access and analyze these data
Here at RTC:Rural, we have been working to improve data accessibility and usability across several projects and with a range of community based partners.
In this presentation we will present the tools we have developed to increase access to disability data at the county level through accessible technology and GIS mapping.

Slide 6 “Disability Map Series”
Our Disability Map Series is one example of how different data visualization methods can improve access and usability of disability data.
Using 5-year (2013-2017) American Community Survey estimates provided by the U S Census Bureau, we have produced a series of more than 700 thematic maps displaying rates of disability and other important variables at the county level.
[2022/05/13 13:14] Elektra Panthar: LG: I say it's important to focus on a county level because rural areas are also areas that are impacted negatively about access
My background is in geography so I've always loved maps, about human interactions with spaces
[2022/05/13 13:14] luluruthy Resident: These variables include disability status by gender, disability type (such as mobility and cognitive difficulties), and employment, poverty, and veteran statuses.
We mapped these variables at both the state and national levels, and have also produced other specialty maps related to national response efforts to crises.
The image on this page is a snapshot of where this work can be accessed, and below it is the web address to this page:
https://www.umt.edu/rural-institute/rtc/focus-areas/maps/default.php
The next few slides will be displaying examples from each of these map series.
[2022/05/13 13:16] Elektra Panthar: LG: over 500 maps, high quality, accessible for screen readers
I hope we can update it soon and improve on it

[2022/05/13 13:17] luluruthy Resident: Slide 7 “Disability in America: People with Disabilities in Poverty (2017)”
Here is one example from our national map series.
This map displays rates of people living in poverty with a disability at the county level across the United States.

Rates have been broken into 4 categories, with the lightest shade representing the lowest rates of disability and the darkest shade showing where rates are highest.

Slide 8 “Veterans with a Disability: South Carolina” and “People Employed with a Disability: Iowa”
Here are two examples from our State Map Series, where we have mapped each of the 14 variables for all 50 states and Puerto Rico.
For these maps, we included a point layer of the 5 most populous cities for each state to sort of show some of the urban-rural disparities that we often see here in the US.
The map of South Carolina shows rates of veterans living with a disability across each county within the state.
Next to that we have map of the rates of employed people living with a disability in each county in the state of Iowa.

[2022/05/13 13:19] lululuthy Resident: Slide 9 “Informing national emergency preparation & response”
In addition to our state and national map series, we have used these ACS data to map disability rates in areas that have been impacted by natural disasters and other crises.
For example, in 2020, RTC:Rural mapped disability counts and rates in the pathway of Hurricane Laura.
On the left is the count of people with disabilities, on the right is the disability rate for each county.
It is important to note, while counts are highly concentrated in urban areas, we can see that rates of disability at the county level tend to be higher in rural counties.
Maps like these can be used to inform efforts around disaster relief and planning and other national crises.
[2022/05/13 13:21] Elektra Panthar: LG: We've been able to do maps like these for a few hurricanes, and hope to keep doing it - unfortunately they're getting worse, so this is becoming more and more important for emergency preparation and response

[2022/05/13 13:21] lululuthy Resident: Slide 10 “Disability Counts: Data Lookup”
Another data accessibility tool that we have created here at RTC:Rural using ACS estimates on disability rates is the Disability Counts tool.
This easy-to-use tool is screen reader friendly and allows users to access ready-to-use disability data for any state and county in the United States.
We have recently updated this data access tool with the most recent 2015-2019 American Community Survey data as made available by the US Census.
The variables available include the same variables used to create the map series, with the addition of race and metropolitan status (urban rural count classifications)
These datasets can be viewed on a webpage or downloaded in ready-to-use CSV format, and include all 14 disability variables, with the addition of race and metropolitan status.
The webpage URL is: http://rtc.ruralinstitute.umt.edu/geography/
[2022/05/13 13:23] Elektra Panthar: LG: we've updated it to the 2016-2020 data
You can select the states and counties you are interested in , choose the variables and give you a file you can download with access to the data
You can also compare the data
This is accessible to screen readers
We wanted to simplify the process to access the data

[2022/05/13 13:24] lululuthy Resident: Slide 11 “Coming soon: Disability data dashboards”

[2022/05/13 13:25] Elektra Panthar: LG: sign up for our newsletter or write me an email for when this tool will become available
The dashboard can give you an interactive view of the data I mentioned
We added one about institutional population as well

[2022/05/13 13:25] luluruthy Resident: Slide 12 “DisDATA and Pandemic Response”
DisDATA (Disability Advocates Taking Action) formed in Fall of 2020 in response to the countless disabled lives lost to the COVID-19 pandemic, particularly in institutions and congregate settings.
Our national inability to count those lives and prevent their loss exposes a long-standing issue that disabled people are missing from data design, collection, and decision-making.
[2022/05/13 13:28] Elektra Panthar: LG: hopefully we'll inform better where people in more need of help live, and which areas have more concentration of sick people to help in case of pandemic
[2022/05/13 13:27] luluruthy Resident: This problem is preventable through collective action.
Aim to work in solidarity with all disabled people, disability led organizations and other groups of people who are systemically marginalized
due to structural ableism and racism to collect the data needed to advocate for and affect change
DisDATA seeks data equity for disability justice.
Improved disability representation across all levels of data collection
• How questions are asked
• How surveys are implemented
• How/which data are used to inform policy

Slide 13 “DisDATA: Data in action”
Supported CILs in state and national advocacy efforts
- Communicated state level disproportionate impact to secure funding streams for emergency transitions pilot programs
- increased community awareness of the pandemic's effect on congregate settings to support current and future advocacy efforts to increase access to HCBS services and housing

Identified major data limitations and discrepancies
- Identified major disparities between CDC, CMS, and state data; discounts validity and trustworthiness of data accuracy
- lack of consistency between definitions of congregate setting types across data sets

Slide 14 – “COVID-19 Cases in CMS Nursing Facilities since July 5th, 2021”
This video graphic illustrates the change in weekly COVID 19 deaths in CMS Nursing facilities, by county, over a period of 10 weeks from July 5th to September 19th 2021.
[2022/05/13 13:33] Elektra Panthar: LG: most data we had access to was in federally supported nursing homes, there was little data in detention facilities and almost none in psychiatric institutions, so those deaths were not figured in the federal numbers
[2022/05/13 13:32] luluruthy Resident: Counties are shaded from white, to light orange, to red, on a scale from 0 to 59.
White or light orange counties have fewer deaths and red counties have more deaths.
Counties for which we don’t have data or where there are no nursing facilities are shaded grey.

The first map represents the week of July 5th and a vast majority of counties across the US are white or light orange, with zero or 1 cases.

Slide 14a
Over time clusters of counties across the country grow progressively darker until the final week of Sept 13th shows considerably more of the country in darker red,
with red counties in every state and some counties reaching levels up to 59 new weekly deaths.
Over the course of these ten weeks a total of 3,394 new COVID-19 deaths in nursing homes were reported across the United States.
[2022/05/13 13:35] Elektra Panthar: LG: from 1200 to 36000 cases in 10 weeks

[2022/05/13 13:36] luluruthy Resident: Slide 15 “How you can get involved!”
Provide feedback on data projects and tools
Email: Lillie.Greiman@umontana.edu
Visit our website: https://www.umt.edu/rural-institute/rtc/
Join DisDATA
Email: DisDATA@mso.umt.edu
Questions and comments?
[2022/05/13 13:37] Elektra Panthar: LG: people can reach out!

[2022/05/13 13:37] Shaerken Changeheart (ChangeheartShaerken Resident): /me whamps paws in appreciation
[2022/05/13 13:37] Zzri Avian (Zri Portal): /me claps talons!
[2022/05/13 13:37] Eme Capalini: Great job!!!
[2022/05/13 13:37] Anansi Jones (JeffGutie Resident): Great job!
[2022/05/13 13:37] Lyr Lobo: Great session! *cheers*
[2022/05/13 13:36] James Atlloud (Lloud Laffer): Really interesting @luluruthy - my day job is at www.countyhealthrankings.org - the challenges with this work are huge!
[2022/05/13 13:37] Eme Capalini: yay
[2022/05/13 13:37] Tori Herbit Landau (Tori Landau): Thank you Lillie
[2022/05/13 13:37] cipsen Resident: Super great data and session Lillie
[2022/05/13 13:37] luluruthy Resident: Thanks all!