

Disability Counts: An RTC:Rural tool to support accessing and using data for advocacy, reporting, and funding

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What is data?

- Values assigned to represent reality
 - Quantification of experience
 - Data can also be qualitative
- Scale matters- we collect data across scale
 - What is the unit of observation (person, household, county)?
 - Matters for interpretation
- Response rates matter
 - Who are included in these data?
- All data are imperfect representations
 - If you don't measure it, does it exist?
 - Poor data = poor representation



Why collect data?

- To measure things
 - Demographics of a place or group
 - Access to services
 - Employment rates
- To understand a process
 - Migration patterns
 - Health behaviors
 - Trends over time
- To inform change
 - Health education and promotion
 - Intervention development
 - Policy recommendations



There is power in data

- Data are used to make decisions
 - Legislative representation
 - Funding allocation
 - Service delivery
- Who has access to data?
 - Governments
 - Academics
 - Politicians
 - Too often, not the people that data are collected about...
- Questions to ask ourselves:
 - Who gets represented and how?
 - What questions get asked and why?
- Lack of access/representation = lack of power



Why does disability data matter?

- Ideally, data is used to improve our world!
- Good data
 - Identify and address inequities
 - Increase funding and improve services
 - Inform advocacy, among other efforts!
- Bad data
 - Incorrect representation of reality
 - Misinformed decisions
 - May lead to inefficient policies and services
- No data = no representation
- All have impacts on marginalized and underrepresented people



Rural data challenges

- Data issues are compounded in rural areas
- Varying definitions of “rural”
 - Over a dozen different definitions!
 - Each one can yield different results
- ACS data are aggregated across 5 years
 - Point in time trends are difficult to identify
 - Example: COVID impacts will not be as obvious
- Complex interactions at the intersections of place, disability, race, culture

How can data make disabled people invisible?

- Disabled people can be excluded and marginalized with data
- Inappropriate data collection
 - Mislabeled disability as a health condition (it's NOT!)
 - Survey questions that don't capture our lived experiences
- Data that doesn't include any information about disability
- Data that doesn't include information about where people with disabilities live
- Lack of data about congregate settings and the people who live there
- Intersectional identities and disability culture are poorly represented
 - Rural + Disability + Race + Gender + Sexual Orientation... etc.

Example: Missing data = A story we can't tell...

- The disability community is concerned about what was happening to people with disabilities in congregate settings
 - It was clear that people were dying but we struggled to tell their stories with accurate data
- Data on disabled people living in congregate settings is limited
 - By rurality
 - By setting type
- People with disabilities in congregate settings are made invisible through the lack of data



Disability Counts: Now and in the future

- A data look up tool
 - To improve access to county level disability data
 - For advocates, policy makers
- Two interactive dashboards
 - To explore the data at the national and state level
- More to come!!
 - What would you like to see integrated into this tool?



Let's get into it!


UNIVERSITY OF MONTANA

Rural Institute

DISABILITY COUNTS

RTC:Rural Disability Counts

The data dashboards and tools linked below provide access to state and county level disability data as well as data on individuals who are institutionalized in correctional facilities (i.e. prisons and jails) and nursing homes. All dashboards contain filters allowing users to focus specifically on metropolitan or nonmetropolitan counties at the national or state level.



[Disability Data Dashboard](#)

This dashboard consists of a set of interactive county and state maps displaying disability data that can be filtered by state and rural classification.

[Institutionalized Populations Dashboard](#)

This dashboard consists of a set of interactive state and county maps displaying counts of individuals living in institutional settings, specifically correctional facilities and nursing homes. The data in this dashboard represent the entire institutionalized population, not just people with disabilities and come from the 2020 Decennial Census. Data on people with disabilities who are in institutions are not available at the county level.

[Disability Data Lookup Tool](#)

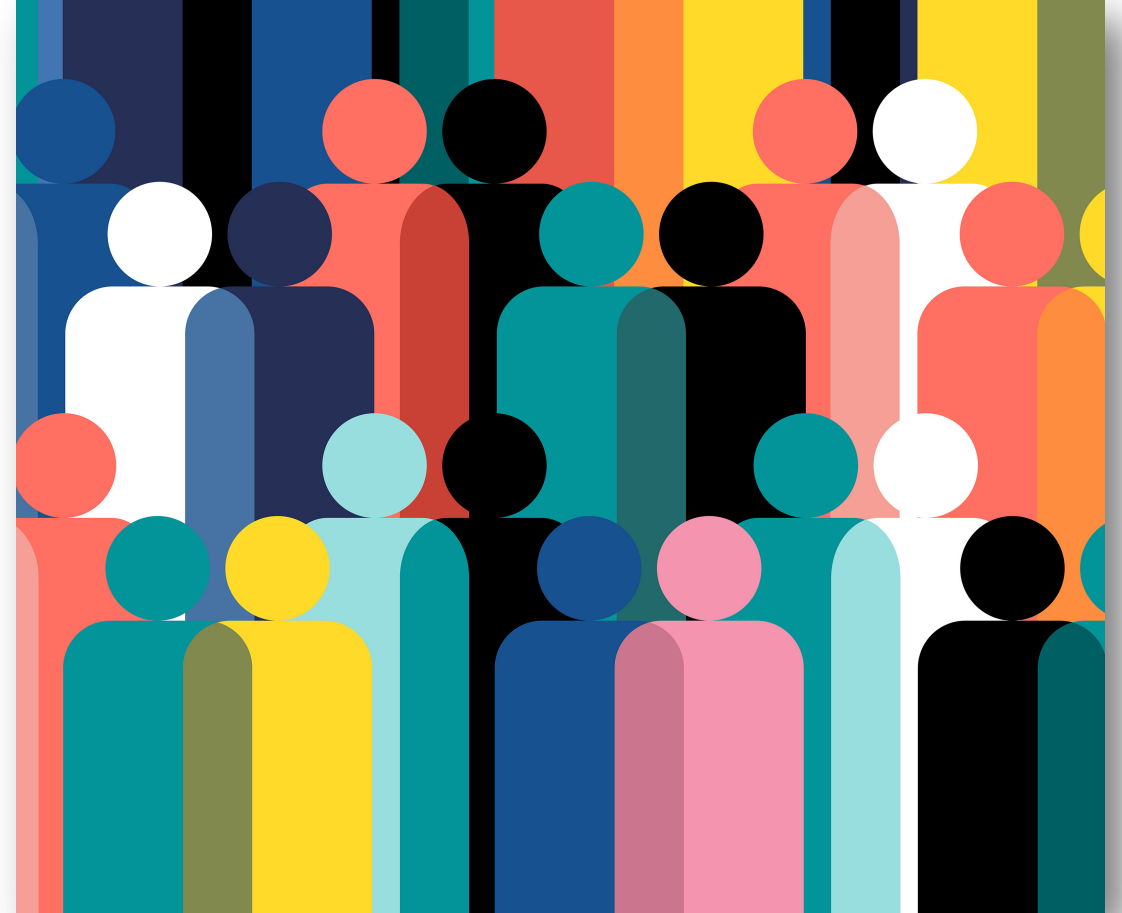
This interactive tool allows you to specify geography (i.e. states and counties) and a range of disability variables to create and download a unique dataset for the counties where you live and work.

Discussion

- Would you use this tool? If so, how?
 - What is missing from this tool?
 - What would be useful for you?
- What kind of data do you wish you had to support the work at your CIL?
- How have you used data in the past or currently?
- Do you collaborate with partners around data?

Data advocacy: Building trust through inclusion

- The solution is in the community
 - Listening to communities about what is most important to measure
- Inclusion and representation
 - Ensuring that values and experiences are reflected in the data
- Reciprocity of data collection
 - Giving power back to the communities that are being analyzed



Opportunities and contact

- Use disability counts and don't hesitate to reach out with questions or requests!
- Stay tuned to the RTC:Rural newsletter, social media and more as we get ready to host our Rural Disability Data Summit with the Urban Institute
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