How-To Guide
Finding and Using Data for Advocacy

In this guide, you will learn how to:

- Find data to use in policy change advocacy

- Determine if data is from a trusted source

- Use data to support testimony

What is data? Why use it?

Data are information, facts, or statistics that have been collected, measured, and analyzed and can help people make decisions and plan changes in policy at the local, state and national levels.

For example, data is used to:

- Allocate funding and resources to state and local service providers

- Determine the distribution of congressional seats and legislative districts

- Help decide where a new bus stop should go

- Help decide where to place curb cuts

Data can influence policy changes that promote community participation and independent living. Because data is used to make decisions that affect the quality of life in our communities for groups and individuals, accurate data is essential. Learning to use data to support testimony is an important skill for effective advocacy.

Using data in public testimony

Providing examples and stories in public testimony is an important aspect of advocacy and policy change. When these stories are supported with facts from data sources, the stories have more influence. Data helps decision makers understand how issues affect the community and provides a larger context for individual experience. When used correctly, data lends your voice credibility.

Using data correctly

When using data for advocacy it's important to use it correctly or it could hurt your cause. Always cite the source of your data so that decision makers can access it themselves. Never make a claim that the data doesn't support.

Sources and types of data

There is a lot of data available to the public online, and it can be found and accessed by searching the internet. However, not all data is accurate and reliable. Some data sources are more reliable than others.

Trust your data source

Before using data, make sure it's from a trustworthy organization. If your data is from a primary source, meaning you are using data from a government department or a research institute or university who has actually collected and analyzed the data you are using, the data is probably trustworthy.

If you are gathering data from a secondary source (not the agency or institution that collected the data directly), check to see where the data came from and make sure the organization is reliable and not politically biased.

It is usually best to use data from a primary source if it is available. The **Data Resources** section at the end of this guide contain links to many reliable primary sources.

Even if the data you want to use comes from a trustworthy source, decide for yourself if it makes sense. If the data seems wrong or confusing, contact the source and ask for more information. If you use data from an untrustworthy source, it can make your audience discount, or not listen to or trust, what you have to say.

Tips for when you're searching for data:

- Consider the URL, or the ending of the website.
  - If a site ends in **.gov**, it is probably a government website, which is usually a good source for objective reports and primary data.

o If a site ends in **.edu** is most likely an educational institution, like a university. However, you still need to make sure they are not politically biased.
o If a site ends in **.org**, it is usually a non-profit organization. Some .org's are good sources, and others are not. You'll have to do some research on the organization and see if they have an agenda or political bias.

Understanding data and its limitations

When data is collected, it isn't gathered from every individual in a given population, so the data is really an estimate, or a **sample**. A sample is a small part of the whole that is meant to show what the whole is like, because it would be impossible to survey every single person in a population.

Government departments and research units that gather and analyze data will include the data's **margin of error**. The margin of error reflects how reliable the results of the survey are. The larger the margin of error, the less reliable the data. However, if the survey is done correctly, the data sample should be representative of the group surveyed.

Making inaccurate claims

Always make sure you understand exactly what the data is reporting. If you're unsure, ask. Also, make sure that you clearly explain what type of data you are using. If a decision maker finds that you have used the data incorrectly or if they don't understand the data you're presenting, your voice will lose credibility and you may not be able to influence change in your community.

Example:

If your data reports that 90% of the housing in your county is inaccessible, it would be inaccurate to say that nine out of ten houses in your community have entries that cannot be accessed by people who use wheelchairs. In this case, the data does not specify that inaccessibility refers to wheelchair accessibility. There are many different things that make a house inaccessible, not only wheelchair accessibility. In this case, you need to make sure that you clearly define what type of accessibility you are talking about.

US Census Data

One excellent and reliable source of data is the US Census Bureau. The US Census Bureau conducts over 130 surveys per year, which collect economic and demographic data for the United States. The data from these surveys are useful for many kinds of advocacy when you need information on poverty, gender, race, income, and disability to influence policy change in your community. See the **Data Resources** at the end of this guide for more information and links to US Census Bureau surveys as well as other reliable data sources.

Finding data that meets your needs

The first step in finding data that meet your needs is to clearly define the issue or problem you want to explore and what you want to do with the data once you've found it. If you want to find data to apply for grant funding, or to demonstrate a need for community investment in particular services, you'll want to find data that is relevant to those who use, or would use, that service.

For example, if you want to increase accessible housing in your community, it would be useful to find data on the following:

- The number of people with disabilities in your community
- The number of people with disabilities in public housing
- The number of people with disabilities with a Housing Choice Voucher

As you search for data, you may find that it's useful to gather data from a few sources, including national data sets as well as local statistics. Local service organizations who receive grant funding are required to gather data on their services and can provide information on the demographics of their service population and numbers served. Using data from a few reliable sources can help compare local and national numbers and create a more complete picture of the issue you're researching.

For example, if you're looking for data on accessible housing, you may get data from:

- Disability Counts Data Finder
- American Fact Finder
- Community & Work Disparities (ADA-PARC)
- Your local Housing Authority office

*See the **Data Resources** at the end of this guide for more information on these data sources.*

<u>Get Started: Finding Data for Your Advocacy</u>

What issue do you want to research?

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What kind of data would be most helpful to highlight the importance of this issue?

- o Disability
- o Income
- o Housing
- o Healthcare
- o Other?

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What local, state or national resources could you use to find data? Use the resource guide at the back of this publication to help you.

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Constructing your message

Clear messages address the **Who, What, Where, When, How and Why** of an issue. In order to make the best decision possible, decision makers need to know the specifics.

Read the **Sample Testimony** on the next page to see how the data and story combine to address the Who, What, Where, When, How and Why. Decide whether you think the Sample Testimony would be effective in creating change.

Sample Testimony

Hello, my name is Anyperson Jones. I am the Executive Director of the Town & County Center for Independent Living. Our center provides independent living services to over 2000 people in our community per year and today I would like to speak about the current community development plan, in which there is a proposal to build 250 new housing units over the next two years.

At the Town & County Center, we serve individuals from both rural areas as well as people who live in the city. Over the years, we have seen accessible housing become more available within the city limits, but in rural communities, most housing remains inaccessible. While the Town & County Center for Independent Living supports community development and recognizes the need for additional housing in our community, we are concerned that the plan doesn't include information about the number of units that will be built outside the city as well as how many units will be built in accordance with universally accessible design standards.

Using data from the 2011 American Housing Survey, researchers at the University of Kansas Research and Training Center on Independent Living report that, nationwide, 27% of rentals in rural communities are up one flight of stairs with no elevator. This means that once a person moves in, and is transported into the unit with assistance, they remain homebound and unable to participate in community life. Additionally, 17% of rental units in rural communities don't have an entry level bathroom and cannot be accessed by individuals who are unable to use stairs. 29% don't have an entry-level bedroom.

In our own community, we hear from people each day who are trapped in their homes. In January of this year, we received a call from an individual who lives in an apartment with a two-step entrance. She uses a wheelchair and is unable to enter or exit her home without help. She relies on Meals-on-Wheels in order to eat regularly and, once a month, a relative who lives in another community brings her groceries. The food rarely lasts the month and she has been unable to find additional assistance. As a result, she often goes hungry. If she could get into and out of her apartment herself, she would be able to wheel to the grocery store only two blocks away. She has tried to find an accessible apartment in her community but has been unable to do so as there are very few available rentals and, because most of the housing stock predates the ADA, very few rentals are accessible.

Each day we receive calls like this from individuals who, because their homes are inaccessible, are unable to do any of the things they want and need to do outside the home. Because of the isolation, they are unable to meet their needs and suffer unnecessarily from treatable health problems, hunger, loneliness, and despair.

Plans for community development are exciting and energizing and have the potential to make our cities and towns more enjoyable for everyone, but in order to fully and fairly realize this vision, development must be accessible. The Town & County Center for Independent Living would like you to appoint an accessibility committee to address the shortfall in the community development plan. We would be willing to serve on the committee as well as recommend accessibility experts who could help ensure the new housing units, as well as other development projects, are inclusive of all members of our community.

Constructing Your Testimony

Who are you, who do you represent, who does the issue affect?

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What is the issue you want to testify about?

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Where is your community affected by this decision? City? Rural? Neighborhood? Organization?

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When will the decision take effect?

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How does this issue affect you, those you represent and your community?

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Why is it important to your community?

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What action do you want the decision makers to take?

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Draft the story you want to combine with data

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Research and Training Center on Disability in Rural Communities | rtc.ruralinstitute.umt.edu
Rural Institute for Inclusive Communities at the University of Montana

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Data Resources

Disability Counts Data Finder

RTC:Rural developed the **Disability Counts Data Finder** webpage to provide accessible data about disability in rural areas in the US. The site uses data from the American Community Survey (one of the US Census Bureau surveys) matched with information about rural definitions to provide a one-stop shop for downloading disability data for every county across the US and Puerto Rico.

American Fact Finder

The **American FactFinder** provides US Census data in a searchable website gathered from the American Community Survey, the American Housing Survey, Annual Economics surveys, Population surveys and more. The tool is designed to help individuals and organizations gain easy access to the information and data they need.

For step-by-step instructions on how to access disability data using the American Fact Finder, visit RTC:Rural's ***A Step by Step Guide to Accessing Disability Data***.

Users of the American FactFinder need to be aware that there are some accessibility issues with the website. If you encounter access problems obtaining the information you need, contact them directly for assistance: 301-763-INFO (4636), 800-923-8282, or by submitting a request at https://ask.census.gov.

Community & Work Disparities (Americans with Disabilities Act- Participatory Action Research Consortium)

The Community & Work Disparities (ADA-PARC) website is a collection of public data sets that provide data on the status of people with disabilities in local communities. The data include national, state, county, and city data, presented by state and then at county and city level, if available.

There is data on **Community Living** (where people live, programs and spending), **Community Participation** (health coverage, community-based subsidized housing, access to community resources, transit usage, community crime rates, educational attainment), **Work & Economics** (employment, economic status, housing affordability), and **Demographics** (age, racial/ethnic background, type of disability).

State-level data

- **Disability Statistics**

  - Disability Statistics offers a user-friendly way to access disability data by state using data from the American Community Survey, the Current Population Survey, and the Equal Employment and Opportunity Commission.

County-level data

- **County Health Rankings**

  - County Health Rankings offers information on health behaviors, healthcare, environmental factors that affect health, and socioeconomics at the state and county level.

Data from the US Census by individual survey

These data sets are typically used by researchers, and may not be easy for you to use. Some of these sites have fact sheets that summarize segments of the data they have gathered, but to find more usable data use RTC:Rural's Disability Counts Data Finder or the American Fact Finder.

- **American Community Survey (ACS)**

  - The American Community Survey collects data on demographic variables such as age, sex, race, ethnicity, income, employment, disability, education, transportation, household size, housing tenure, and utilities.
  - However, ACS data has limitations, especially in regards to rural areas. See Rural Matters: The Geography of Disability in Rural America, a Research Findings page on the RTC:Rural website, for more information.

Data from the Centers for Disease Control and Prevention (CDC)

- **Centers for Disease Control and Prevention (CDC)**

  - The Centers for Disease Control and Prevention provides comprehensive data and statistics on a variety of health and wellness issues as well as tools and resources to help you find the information you need.

- **Behavioral Risk Factor Surveillance System (BRFSS)**

  - The Behavioral Risk Factor Surveillance System collects state data about health-related risk behaviors, chronic conditions, and use of preventative services. They collect data at the state and local level, and the website provides access to data and data analysis tools, publications and resources, and fact sheets.

- **Disability and Health Data System (DHDS)**
    - The [Disability and Health Data System](#) is an interactive data tool to find information about the health and wellness of adults with disabilities. There is data on more than 30 health topics, as well as information on five functional disability types: cognitive, mobility, vision, self-care, and independent living. Data can be viewed by state or region. DHDS can be used to identify data patterns across the country, download PDFs, maps, and customized data tables to use for presentations or reports, and to gather state-specific data to inform decision-makers.

- **Healthy People 2020**
    - [Healthy People 2020](#) is a 10-year agenda for improving the health of people in the US. It includes over 1,200 objectives, organized into 42 topic areas, to monitor and improve the health of all Americans. You can use their data search tool to search by key word, topic, and data source.

- **National Health Interview Survey (NHIS)**
    - The [National Health Interview Survey](#) is a household health survey that collects accurate and current statistical information on the amount, distribution, and effects of illness and disability in the US. The results track health status, health care access, and progress toward national health objectives. The survey covers things like medical conditions, health insurance, doctor visits, physical activity, and other health behaviors. It does not include data on people who are institutionalized, such as those who live in long-term care facilities.

Data from the US Department of Agriculture (USDA)

- **Economic Research Service (ERS) Rural and Agricultural data**
    - The USDA's [Economic Research Service](#)'s mission is to collect data on agriculture, food, the environment, and rural America so that people can make well-informed decisions about things in the public and private sectors. ERS research covers a variety of topics, including rural economy and population, which includes business and industry, employment and education, rural poverty and wellbeing, and population and migration.

- **Atlas of Rural and Small-Town America**
    - The [Atlas of Rural and Small-Town America](#) is a map that shows data about people (demographic data including population, education, age, race and ethnicity, and more), jobs, county classifications (such as rural and urban classifications), and veterans. You can look at the data at the country, state, and county levels. The maps and the data can be downloaded, saved, and printed.

Additional resources

- **Google Public Data Explorer**
  - Google Public Data Explorer makes charts and maps of public-interest datasets, such as data from the US Census Bureau, the US Bureau of Economic Analysis, and the CDC. Note that Google does not provide any of the data, so you still need to make sure the data comes from a reliable, unbiased source.

- **Data.gov**
  - On Data.gov, you can search through US government open data. You can search by topic, such as Health, Local Government, Public Safety, or Finance, as well as by keyword. The site has over 194,263 datasets you can search.