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Nonprofits and Data: A How-To Series #6: Using Data to Characterize Disparities Across Sub Populations/Communities, 2007

Community Research Institute-Johnson Center

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Community Research Institute

Empowering communities with quality research and data

Nonprofits and Data:
A How-To Series

6

Using Data to Characterize Disparities Across Sub Populations/Communities

Johnson Center
at Grand Valley State University

ABOUT THE COMMUNITY RESEARCH INSTITUTE

The Community Research Institute (CRI) at Grand Valley State University is a partnership between the Dorothy A. Johnson Center for Philanthropy and Nonprofit Leadership and the Grand Rapids Community Foundation.

CRI provides innovative applied research to West Michigan communities. It empowers communities with quality research and data, generates information that will improve their decision-making process, forecasts trends for effective problem solving, and measures results and reports outcomes of investments in community change.

CRI gathers, analyzes, interprets and shares national and local data through partnerships with nonprofit and neighborhood groups, and assists local and regional nonprofit leaders with decision making, grant writing, and program evaluation. This is research that makes a difference through a distinctly valuable blend of university rigor and community relevance.

For additional information visit our website at www.cridata.org or contact us directly by calling (616) 331-7585.

Research for this guide was provided by Cori Scholtens.

Nonprofits and Data: A How-To Series is available to download at no cost at www.cridata.org/publications.

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6 Using Data to Characterize Disparities Across Sub Population/Communities

INTRODUCTION

This How-To Series is designed to demonstrate six ways in which data can be used to enhance the work of nonprofit organizations and community groups. These include using data to:

1 Support Grant Applications and Other Funding Opportunities
2 Monitor Trends & Identify Emerging Problems
3 Disseminate Information to Engage Community and Policymakers
4 Evaluate Progress in Meeting Goals
5 Establish Priorities and Plan Programs
6 **Characterize Disparities Across Sub Populations/Communities**

The information contained within each guide has been developed by combining our community knowledge with that of a variety of data experts. More specifically, within each series installment, you will find an introduction to the topic, guidelines for using data to achieve the specified outcome, good practices and pitfalls with corresponding examples, and resources to find data.

WHY USE DATA TO CHARACTERIZE DISPARITIES ACROSS SUB POPULATIONS/COMMUNITIES?

A disparity is defined as "a lack of equality and similarity, especially in a way that is not fair"[i] or "the condition or fact of being unequal, as in age, rank, or degree; difference."[ii] Disparities are often based on race, ethnicity, English-proficiency, income/socioeconomic status, age, or gender. The health care field has conducted extensive research to document disparities that exist in medical treatment, health outcomes, and health care access in the United States. This body of expertise will guide much of the discussion that follows.

Why collect data to characterize disparities?

Research conducted on disparities has various goals. Some focus on identifying the existence of a disparity. Others want to understand why the disparity exists. Yet others are testing strategies to reduce disparities.[1] Collection of disparity data becomes fundamental for:

- Creating programs that work towards eliminating inequalities
- Enforcing policies that guarantee nondiscrimination
- Providing services and programs that are culturally and linguistically appropriate
- Monitoring how care and services provided are the same or different based on geography, culture, or ethnicity
- Achieving equitable access to available services
- Understanding the people served so as to provide appropriate services and remain competitive in the field
- Making informed decisions at all levels of service provision.[2]

In order to eliminate disparities across sub populations and communities, a deliberate system of data collection and analysis must be in place not only to collect data where disparities exist but to analyze and track progress towards eliminating them. Having this data system allows groups to target their efforts in priority areas or even learn where few disparities exist and use them as examples towards exemplary practice.[3] Nonprofit organizations have a responsibility to be responsive to the people living in their community. Collecting data that reflect community disparities helps them understand more about their community and more effectively address issues of concern.

Additional reasons for collecting data to characterize disparities come from the field of education. Data that measure equity and disparity helps organizations:

- Make good decisions in the interest of their clients
- Explain their various processes and practices
- Express how organizational practices reflect certain belief systems

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[i] Cambridge Advanced Learner's Dictionary from Cambridge University Press. 2006. (online)

[ii] The American Heritage® Dictionary of the English Language: Fourth Edition. 2000.

- Mobilize organizations and their communities towards action
- Monitor their progress towards eliminating disparities
- Keep organizations accountable to their intentions and goals[4]

On the grander, more systemic scheme, it is important to collect data that characterizes disparities for two additional reasons. The first is for the education of the public. Often times, the majority of Americans are not aware that issues of disparity exist. For example, a recent national study found that "more than half of all whites, Latinos, and African Americans were unaware that blacks had shorter life expectancy and higher infant mortality rates than whites."[10(p.130)] When the public does not know that a problem of disparity exists, it is not highly motivated to address it. Secondly, collecting valid and reliable disparity data creates the political feasibility to address areas of concern. Data often provide policy makers with the fuel to create political will towards change.[10]

Is collecting race and ethnicity data legal?

"The collection of data on race, ethnicity, and primary language is legal and authorized under Title VI of the Civil Rights Act of 1964. No federal statues prohibit collection of this information, although very few require it." [2(p.3)] The protection provided under Title VI is for any group that receives federal financial assistance. It does not matter if the specific program of concern has itself benefited from those funds.

What are the barriers to data collection?

While most groups agree that collecting data to combat disparities is critical, consistent and/or compatible methods are not being used across organizations to collect this data. Nonprofits face various barriers in their efforts to collect data:

- Limitations in resources
- Uncertainty on how to organize categories for data collection
- Negative response by clients towards data collection
- Barriers based on language or culture
- Little staff training
- Questions regarding validity and reliability of data
- Supposed legal barriers
- Systemic or organizational barriers[5]

The goal of this paper is to help organizations develop strategies to overcome these barriers.

GUIDELINES FOR USING DATA TO CHARACTERIZE DISPARITIES ACROSS SUB POPULATIONS/COMMUNITIES

Having access to basic data on race and ethnicity is a first step in combating disparities. It is not enough to just recognize that disparities exist. Data allows groups to determine the extent of the problem, study the causes, test interventions, and track their progress. The following strategies will help in that process.[6]

Part 1 – Steps for Researching Disparities

A "quick guide" to steps for researching disparities would include the following:

1. Start the investigation by identifying the objectives of the research and creating questions that list what needs to be learned.
2. Determine what data is needed to answer the questions written in step one, how the data will be gathered, and by whom.
3. Collect and disaggregate the data.
4. Analyze, interpret, and summarize the data.
5. Determine how to present the data to each audience.
6. Create a plan for dialogue regarding the data, including appropriate solutions and action plans.[4]

Part 2 – Tools for Researching Disparities

Research suggests three categories of data that are helpful when collecting information to characterize disparities:[6]

Administrative Data

Administrative datasets provide very basic demographic information collected about clients or a community. This information is often gathered at intake. This data is not necessarily connected to a client's presenting issues or other measures such as access status, socioeconomic condition, or client's preferences. The data may come from within the organization's existing data system or data systems shared within a particular field. In the case of emergency medicine, administrative datasets may include those of specific hospitals and those of Medicare or the Veterans Affairs. In the field of education, administrative data may come from individual schools, school districts, or state/national boards of education. These datasets usually contain a limited number of variables creating difficulty in adjusting for confounders. However, they are a good place to start in identifying prospective disparities.

Clinical Datasets

Clinical datasets provide richer detail on clients' characteristics. In the medical field, this data comes from previous or ongoing clinical trials and patient registries such as those for trauma, cancer, or other disease-specific registries. In other fields, this data may come from specific programs, intervention teams, or departments. Primary data collection may be necessary to collect clinical datasets. Data collected in this way allow the researcher to adjust for the severity of the presenting problem, care access status, education level, employment, and any number of other variables that administrative data do not. Clinical datasets allow a group to explore the presence and scale of disparities but does not clarify their causes.

Data from Surveys and Qualitative Methods

Surveys and qualitative methods allow researchers to explore the causes of disparities. Data collection comes in various forms such as interviews, focus groups, or surveys which can gather client perceptions and experiences. The attitudes and behaviors of staff can be gathered through tools including surveys or direct observation. These smaller-scale methods do not have the ability to document the presence of disparities at as large a scale as administrative and clinical datasets, but they are critical to understanding the causes and creating interventions to address them.

Part 3 – Standardizing Data Collection

While the majority agrees on the importance of having data to measure and track disparities, data collection is not uniform. Requirements for data collection and the methods used for collecting and reporting vary across organizations and fields within the nonprofit arena. Groups often find that data are missing, incomplete, not categorized consistently or of nonuniform quality. What is lacking is uniformity in standards to collect this data. It is recommended that the following five areas of data collection on disparities be standardized.

1. Who provides the information: The client or designated representative is the person most able to provide accurate information. This means the nonprofit staff member or intake personnel (a third party) should not guess the client's race, ethnicity, primary language, etc. based on observation.[2,5, 7]

2. When data are collected: Organizations need to standardize when data are collected. Some suggest collecting this at the time of admission or registration to be sure all needed information is gathered immediately upon the clients' entrance into a program.[5]

3. Which data categories are used: As an organization standardizes what data categories to include in their research, it is important to consider what standard categories are being used by the groups from which other datasets may be gathered or compared. Hospitals, for instance, may want to use the same race and ethnicity categories as the Office of Management and Budget (OMB). Other organizations may want to align with U.S. Census categories. At the same time, it is important to collect data within categories most useful to the local population being served. For example, in Omaha, Nebraska, it may be important to create different categories for American-born blacks and more recent Sudanese

immigrants. In addition, Detroit nonprofits may want to be able to differentiate between various Middle Eastern populations. This allows researchers to collect information on smaller population groups while aggregating the data when necessary. [3, 5, 8]

4. How data are stored: Data should be stored in a standard format that is compatible and comparable within the organization and across the field. It is recommended that this data system be in a private and secure electronic format.[2, 5, 7]

5. Responses to patients' concerns: Care and respect need to be taken when asking clients for personal information such as race, ethnicity, primary language, or income. A client's concerns about how the data will be used should be addressed before gathering the information. This should be in the form of a standardized response stating how and by whom the data will be used that all data collectors provide. It is suggested that this type of potentially sensitive information be asked near the end of the inquiry. Remember, individuals always have the right to withhold this information if they choose.[1, 3, 5, 7]

In order to reach the goal of decreasing disparities, it is crucial for organization leadership to be supportive and involved in data collection efforts.[5] It is also beneficial to work in collaboration with other agencies, the community, and philanthropic groups.[8] Finally, it is important to determine who in the organization is responsible for "initiating, coordinating, monitoring, and documenting policies and practices governing these data's collection" and making sure the data are accessible to the departments for which they are most useful.[2 (p.22), 3]

PITFALLS AND GOOD PRACTICES

The use of data is crucial in efforts to characterize disparities across communities and sub populations. Included below are several pitfalls to avoid as well as related good practices to keep in mind when gathering data on disparities. These tips were developed from concepts provided by numerous expert sources. After many of the pitfalls and practices, an example is provided to illustrate its potential use.

USE VALID AND RELIABLE DATA

Possible Pitfall	**Good Practice**
Data are collected without regard to data validity and reliability.	Data receive constant monitoring and evaluation for validity and reliability.

Putting it to use...

In order to make a compelling case for the characterization of disparities across a community or sub population, the data used must be valid and reliable. This occurs through the constant monitoring and evaluation of data collected and their sources. This includes assessing how data were collected, how they were applied, and the comparability of one dataset to the next.[2, 3, 5, 6]

For example…

When WellPoint of California, in collaboration with the University of California, Los Angeles (UCLA) analyzed a quality improvement project to improve childhood immunization rates, they emphasized the use of identical data gathering methodology in follow-up analysis in 2001-2002 as they had to collect baseline data in1998-1999. This was one effort used to ensure data validity and reliability. Baseline data indicated that varicella immunization rates were low compared to other immunizations and a disparity by race/ethnicity existed. Non-Hispanic white children had immunization rates of 39% while African American and Hispanic children had rates of approximately 50% and "other" children (predominantly Asian) had rates of 61%. By 2001-2002, results showed that immunization rates had risen significantly for all groups to a range of 84-92% with the disparities discovered in 1998-1999 largely eliminated.[9]

**FOR ADDITIONAL HEALTH DATA, VISIT
WWW.CRIDATA.ORG OR WWW.MICHIGAN.GOV/MDCH**

USE LOCALLY ACTIONABLE DATA

Possible Pitfall	Good Practice
Only use data that is gathered nationally and can be widely generalized.	Use both national and locally actionable disparities data to make a strong case towards action.

Putting it to use…

While large, national datasets, most often gathered from secondary sources, offer valuable generalizability and provide useful descriptions of disparities, locally actionable data helps pinpoint the causes and potential solutions of disparities. It is most often the data and actions at the local level that create the reduction of disparities. Tip O'Neil, former Speaker of the U.S. House of Representatives is recorded to have said that "all politics are local." Data can be described in the same way. The more local the data, the easier it is for the public and policy makers to see disparities across a community or sub population an issue to be dealt with "at home." National data is important. When that national data is coupled with localized data, the case for action becomes even more compelling. This concept becomes apparent in the following example.[1, 3, 9]

For example…

A survey of cardiologists found that one third felt that disparities were common in the U.S. health care system while only one in 100 believed that there were racial/ethnic disparities in care in their own practice. (Lurie 2005)[3]

FOR ADDITIONAL HEALTH CARE DISPARITIES DATA, VISIT WWW.CRIDATA.ORG OR WWW.AHRQ.GOV

PRESENT DATA WITHIN A MEANINGFUL FORUM FOR DIALOGUE AND DISCUSSION

Possible Pitfall	Good Practice
Present disparity data without a plan for productive discussion.	Present disparity data within a context of meaningful discussion.

Putting it to use…

Disparity data has the potential to evoke many emotions from people. These emotions often range the spectrum from anger to denial to just making people feel uncomfortable. Presenting disparity data without a plan for meaningful dialogue can be counterproductive. Data on disparities can lead groups to question their beliefs and practices. Without probing questions and meaningful discussion, there is the potential for data never to create action towards change. Structured questions and dialogue helps a group move forward.[4]

For example…

When presenting the conditions of disparities in schools, Ruth Johnson suggests including a discussion of the historical context. She says, “It will be necessary to bring some perspectives that are unfamiliar to many including the citation of historical and social forces that are at the root of some inequitable policies and practices in schools…it is particularly useful to include data and literature that indicate how negative conditions for students can be reversed. Literature that not only provides explanatory information but also offers hope and meaningful solutions is useful to motivate the group to move forward.”[4(p.73)]

FOR ADDITIONAL EDUCATION DATA, VISIT WWW.CRIDATA.ORG OR WWW.SCHOOLMATTERS.COM

CONTROL FOR CONFOUNDERS

Possible Pitfall	Good Practice
Fail to control for confounders, producing misleading results.	Care is taken to control for confounders, producing reliable findings.

Putting it to use...

A confounding variable decreases a researcher's ability to distinguish cause and effect. Confounding variables are two or more variables that are "confounded" (confused or baffled) when their effects on the response variable cannot be distinguished from each other. For example, a basketball coach wanted to improve the team's playing ability, so he had them start lifting weights before school. At the same time, the players decided to change their diet. In two weeks, the team's performance had noticeably improved, but the coach did not know whether it was from lifting weights or the diet change.

"Controlling for confounders is a fundamental requirement for producing high-quality research on disparities."[1(p.1166)] If you are studying disparities based on race/ethnicity, for example, understand that age distribution, income, health insurance coverage, education, employment, and other characteristics vary considerably within each racial/ethnic group. Outcomes may be based on one of these confounding variables. Failing to control for confounders can produce misleading and inaccurate findings. When data on confounders are available, they can provide useful clues about the causes of disparities.

For example…

"One study found that Hispanic children were less likely than white children to have a usual source of health care. After adjusting for parents' language of interview, however, the findings indicated something else. Hispanic children whose parents had an English-language interview were no different than white children. Those children whose parents had required a Spanish-language interview, however, were only 27% as likely as white children to have a usual source of care."[1 (p.1166)]

WHERE TO BEGIN FINDING DATA

The Community Research Institute (CRI) is working to develop a data sharehouse for the Greater Grand Rapids community. The concept or purpose of a data sharehouse is to develop a single integrated system that can support one-stop data shopping.

To begin exploring community data, visit our website at www.cridata.org. There you will find county, city, and neighborhood level data. Examples include:

- Demographic information on topics such as, population counts, poverty rates, race, housing and education from the 1990 and 2000 U.S. Census.
- Crime, housing, and voting data from the City of Grand Rapids.
- Data on regional trends including topics such as: Healthy Youth, Healthy Seniors, Education, Civic Engagement, and Community & Economic Development, Arts & Culture, Poverty, and Philanthropy.
- Various reports on topics that include: the status of women in the workplace, barriers to success for entry level healthcare workers, tobacco and smoking cessation programs, violence in Kent County, employee training needs and practices, communities of support for the aging population, and the working poor.

It should be noted that CRI has more data than we can fit on our website. If after reviewing our website, you haven't found what you're looking for contact Gustavo Rotondaro, GIS/Information Specialist for CRI, for additional data.

For more information on using data to characterize disparities across sub populations/communities, please contact Korrie Ottenwess, Research Manager for the Community Research Institute, at:

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Web:	**www.cridata.org**

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