Community-Responsive Behavioral Health Research: Translating Data for Public Consumption and Decision Making

Abstract

The community behavioral health field focuses on multidimensional mental health and substance abuse issues that exist in a challenging contextual environment. To make appropriate intervention choices, decision-makers must be informed about issues, the relative magnitude of the issues, and the key determinants that affect the issues. This article explains how a national project team worked with ten communities to collect and analyze primary and secondary data, and to create compelling presentations to deliver this data to community leaders. Dialogue with local community teams enabled the national project team to create and modify data visualizations that provide clear indicators and labels, as well as relevant data comparisons. Working iteratively with local teams ensured that the information shared was clear and compelling for stakeholders so that they could use it to build a broad-based consensus around community behavioral health priorities.

Keywords

Community behavioral health, Community partnerships, Data visualizations, Data reporting, Engaging stakeholders,

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**Introduction**

Government agencies spend millions of dollars annually compiling and publishing health data to inform communities about their local situation and trends. Few, however, actually know how these data are used or whether they are used at all. This article describes the process of partnering with ten pilot communities involved in a national Substance Abuse and Mental Health Services Administration (SAMHSA) and USDA National Institute of Food and Agriculture (USDA NIFA) sponsored project (2013-48765-21544). The goals of the project were to identify which information and data sources local leaders actually use to determine local behavioral health needs and priorities, and to enhance the use and utility of that data. Team members sought the most compelling ways to use graphics and data visualizations to engage a broad cross-section of community leaders in conversations about the important mental and behavioral health problems in their locales.

Often, data about mental health and substance use is produced by organizations outside of communities that take several years to collect, aggregate, clean, and finally release for general use. This creates a lag between data collection and publication. Moreover, these datasets are usually gathered at the national or state level and in yearly or multi-year intervals. This limits their usefulness to communities when leaders want to track trends and respond quickly, and when they want to assess the effectiveness of their response (e.g., for program evaluation). Data collected at the community level or by the communities themselves, however, may suffer from a lack of comparability across communities or nationally. When released, data are often in a format that does not capture the public’s imagination, yielding limited response to issues that may be hindering the community’s development path.

Community involvement is a component of research that creates meaningful improvements to community health problems (Ahmed & Palermo, 2010; Baker, Homan, & Kreuter, 1999; Dickert & Sugarman, 2005; Spoth, 2007). Involving community members in health research has led to improvements in community wellness (Cook, 2008; Lindamer et al., 2009). Engaging community partners as equal stakeholders in the research process creates respect for the issues and values surrounding health within each locale (Ahmed & Palermo, 2010), because local partners have insights into the context of local health issues and processes that conventional research approaches, including evidence-based practices, may fail to capture adequately (Kirmayer, 2012). Additionally, involving community partners in the research process can ensure that the products and outcomes of research will best fit the needs of the community (Broussard, Radkins, & Compton, 2014; Khodyakov et al., 2014; Lindamer et al., 2009; Scharff & Mathews, 2008). Research that is sensitive to the local context is increasingly common in health-oriented projects (Dickert & Sugarman, 2005), and allows for place-based perspectives that identify community health needs and local assets to address them.

Using a webinar format, the national team created a responsive research project that tailored each community’s data to their unique circumstances and context, simultaneously uplifting the Community Development Society’s (CDS) Principles of Good Practice as described herein. In this paper, we describe the overall project, data collected, data presentation, and how the national team worked with local CAPE teams to make the data most useful in the community priority setting and subsequent action around behavioral health.
Community Assessment and Education to Promote Behavioral Health Planning and Evaluation (CAPE) is a partnership between SAMHSA, USDA NIFA, and the Regional Rural Development Centers (RRDC). The project’s aim was to generate a collection of benchmark data for community behavioral health, with special attention to how local leaders obtain and use such data to establish priorities in their communities. A team from the North Central Regional Center for Rural Development (later referred to as the “national team”) – including the project investigator, two postdoctoral fellows, and a social media specialist -- led the project. A technical advisory committee was recruited to assist the national team. It included faculty and extension specialists from eight land-grant institutions.

A national request for proposals was issued to recruit pilot communities. Local teams responded to this open call for proposals to participate in the project. All teams were required to include members at land-grant university systems. Through the competitive application process, ten pilot communities (i.e., local teams) were selected by the national team. Communities were chosen based on the demonstrated capacity of local teams to complete the project, as well as geographic and demographic heterogeneity. The pilot communities were located in ten states: Nevada, New Mexico, Nebraska, Missouri, Louisiana, Tennessee, Virginia, West Virginia, Maryland, and Vermont. Each local team was made up of one to four people who were well-positioned and experienced in reaching out to the broader community.

In each pilot community, local teams worked with the national team to construct, pilot-test, and administer a behavioral health priority survey via online questionnaire. The purpose of the survey was to determine community behavioral health priorities and to find out where community leaders look for data to inform their decision-making. Respondents included a broad cross-section of community leaders including, but not limited to, hospital administrators, substance abuse/mental health treatment professionals, elected officials, law enforcement, parks and recreation administrators, and senior services administrators. Participant lists were generated by local teams, who provided contact information to the national project team. Local teams were encouraged to solicit as many local leaders as possible to complete the survey, which resulted in a variety of respondents from each community.

The survey included seventeen questions that asked leaders to identify specific community behavioral health priorities, data sources related to those priorities, and their familiarity with several national datasets. The survey instrument was reviewed by the national team, technical advisory committee, and local teams for face and content validity. The overall response rate was 44.5% (N=1,034). The survey questionnaire was distributed using Qualtrics, including automated reminders to those who did not complete the online questionnaire when originally requested. Given the population and demographic variability represented across the pilot communities, each community had a different sample size. Table 1 identifies participating communities and illustrates the response rates.

In addition to primary data collection, the national team assembled secondary data related to county- and state-level behavioral health, which included excessive alcohol consumption, alcohol-related automobile accidents and deaths, tobacco use, depression, poor mental health days, teen pregnancy, sexually transmitted diseases, and many other community behavioral health conditions. Secondary data were included to compare how closely community leaders’ perceptions of behavioral health priorities from the

<table>
<thead>
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<th>Community</th>
<th>N Contacted</th>
<th>N Responses</th>
<th>RESPONSE RATE</th>
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<td>67</td>
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<td>Pettis County, MO</td>
<td>175</td>
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<td>44.00%</td>
</tr>
</tbody>
</table>
Community Development Society

survey aligned with objective indicators about prevalence of behavioral health conditions. The published data came from sources such as County Health Rankings, the Behavioral Risk Factor Surveillance System (BRFSS), Centers for Medicaid and Medicare Services, and state departments of highway safety. Table 2 displays the full list of secondary data sources. Once the final list of data was determined, the national team created visual representations of these data to enable the local pilot teams to engage with the broader, non-academic audience of community leaders.

Unfortunately, data varies substantially among states, so some states had much more data available at the county level. One indicator from the community survey, nonmedical use of prescription drugs, was very difficult to find, while other indicators, such as child abuse, were available at the county-level for some communities and only at the state-level for others. Even when data about a topic existed for some indicators, the specific metric varied at times, meaning that two communities may not be comparable. (Example: Child abuse may be rate of child abuse per 1,000 children, or it may be number of substantiated claims of child abuse.) More information about data indicators and sources can be found at the CAPE Project website (http://www.healthbench.info).
Over the course of the project, the national team created two-page snapshot reports as well as a fifty to sixty page extended profile for each community. The snapshot reports were meant to be eye-catching so that they engage local stakeholders in conversations about mental health and substance use, whereas the extended profile reports included more comprehensive information from the survey as well as secondary data. In total, the national team created ten extended profile reports with 308 visualizations of local health indicators from both primary and secondary data, not including earlier drafts or versions that were tested for community use/approval.

The visual representations of the secondary data\(^2\) took three forms: Trend graphs, speedometer graphs, and scatterplots. The trend graphs (Figure 1) showed the level of the indicator, such as a rate or number of cases, for each year that the data were available. Community, state and national (if available) trends were depicted as well as a linear trend for the community. The speedometer graphs (Figure 2) showed how the pilot communities were faring compared to other communities in their state for each individual behavioral issue. The speedometers were in a half-doughnut shape, divided into thirds. Each third, representing the bottom, middle, and top third of rates of behavioral health indicators, was designated by a different color (red for worst third, yellow for middle third, or green for best third of counties in the state). A black needle was positioned to indicate the pilot community rate or level for the behavioral health issue in question compared to other counties or communities in the state for the most recent year available. The scatterplots (Figure 3) were four-quadrant graphs with x- and y-axes that assembled all of the available behavioral health indicators in one graph, comparing county or community rates to the state average and across time. The position of each indicator was based on the degree to which the indicator was getting better or worse over time (x-axis) and the degree to which the county or community indicator was doing better or worse than the state for the most recent year of data. Indicators in each quadrant were color-coded to display overall performance: county or community behavioral health indicators performing better than the state and getting better over time were green; those performing worse than the state and getting worse over time were red. Indicators getting better over time but still performing worse than the state, or indicators getting worse over time but better than the state were both yellow. One example of each graph is included below.

\(^2\) Visual representations were created for the secondary data to show the situation at a given point or change over time. Because the primary data were collected from only one point in time, similar visualizations were not possible. Primary data were summarized in tables and a narrative as part of the extended profile report.
Figure 1
Example trend graph using data from the Behavioral Risk Factor Surveillance System (based on 24 counties).

Number of Poor Mental Health Days in the Past Month
2008-2012

Figure 2
Example speedometer graph using data from the Behavioral Risk Factor Surveillance System (based on 24 counties).
Figure 3
Example final format scatterplot.

Doña Ana County Health Indicators:
Over Time and Compared to New Mexico

Incidence: Better than New Mexico

Drunk Driving
Crashes

Domestic Violence

Depression
(Medicare Recipients)

Smoking

Suicide

Poor Mental Health
Days

Incidence: Worse than New Mexico

STDs

Binge Drinking

Heavy Drinking

Trend: Getting Worse

Teen Pregnancy

Child Abuse

Drunk Driving
Deaths

Depression

Trend: Getting Better

Better than New Mexico and getting better
Better than New Mexico and getting worse
Worse than New Mexico and getting better
Worse than New Mexico and getting worse
Figure 4
Initial version of scatterplot for Finney County, Kansas

Figure 5
Example bar graph using data from the Behavioral Risk Factor Surveillance System (based on 24 counties).
Dialogue with Local Pilot Teams

The national CAPE team focused on making the data products useful to the individual communities by engaging in dialogue with each local team about their needs, wants, and preferences in presenting information to their communities. After creating the initial visual representations of data, the national CAPE team conducted webinar meetings with each of the pilot community teams to review their community’s data. Engaging local pilot teams with the national team about the data representations adhered to the first CDS Principle of Good Practice, promoting active participation of all local CAPE team members to create something that would engage the broader community and help to positively affect the lives of community members impacted by behavioral health issues.

The meetings were scheduled to last for one hour and took place using Adobe ConnectTM, an accessible web-based tool that allows participants to meet across distances with decreased time and expense (Loveridge, Nawyn, & Szmecko, 2013). Using an online presentation system enabled the national and local teams to review the visual presentations together in real time and to assess the effectiveness of data visualizations. The online webinar format helped the national CAPE team meet the second CDS Principle of Good Practice: engaging community members in learning about community issues and their impacts, because some of the pilot team members were unaware of behavioral health trends or had not previously seen data presented in such a fashion.

Feedback and Action

Several themes arose in feedback that the national team received. These included the need for clarity, relative comparison, and ease of interpretation. Most communities emphasized the importance of clear labels and the need for non-academic audiences to quickly understand and interpret each image. In response to suggestions offered by the local pilot teams, the national team created clearer descriptive labels for the indicators. For instance, an indicator of percentage of Medicare recipients diagnosed with depression had a shortened label “Medicare Depression” which was changed to “Depression: Medicare Recipients”; an indicator of poor mental health days in the past month was changed from “Mental Health” to “Poor Mental Health Days.”

The first iteration of the scatterplot showed bubble indicators that were sized based on the number of people impacted or experiencing the particular behavioral health issue (Figure 4). The different sized markers on the scatterplot had the unintended effect of making the image more challenging to interpret. Based on community feedback, all scatterplot indicators were edited to be a uniform size.

Comparing the initial version (Figure 4) to the final versions (Figure 3), changes made include standard indicator size, short and easily understandable labels with lines connecting labels to indicators, clear axis labels, and a descriptive legend.

Another theme from feedback was the need for data comparing the county or community situation with some broader reference group. Originally, all local data was compared only to statewide data. Some local CAPE teams felt it would be useful to also know what the national mean was for each indicator to provide a larger context. For example, Clark County, Nevada, is home to approximately 75% of the state’s population. The behavioral health trends in the county drive the state statistics, so comparisons to national statistics were important. The national team collected additional secondary data in this case to compare Clark County to all counties in the United States with a population of 900,000 or greater. Making this change is an example of how the national CAPE team adhered to the third CDS Principle of Good Practice: incorporating the interests of community members.

There was not a one-size-fits-all result for the presentation of behavioral health information across the ten pilot communities. For instance, most local teams were interested in having data about teen pregnancy. For some local teams, however, seeing teen pregnancy data parsed for different age groups such as under 15 years and 15 to 17 years was more informative. Several of the pilot communities were located in towns with major universities, leading local teams to ask whether it was possible to remove college students from data about heavy or binge drinking.

The national CAPE team made most of the requested changes to the trend graphs, speedometer graphs, and scatterplots, but in some cases was limited by the availability of data. For instance, the national CAPE team was unable to locate county-level data on illegal drug use and non-medical prescription drug use (also referred to as prescription drug abuse or recreational prescription drug use) for most of the pilot counties. Aside

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1The Behavioral Risk Factor Surveillance System (BRFSS) was our source for data about alcohol consumption. The BRFSS defines heavy drinking as regular daily consumption of more than two alcoholic beverages for men and more than one alcoholic beverage for women, whereas binge drinking is defined as consuming more than five alcoholic beverages for men or more than four alcoholic beverages for women on a single occasion. It includes adults over 18 years of age and excludes people living in group housing, such as college dorms. Thus it could possibly include college students over 18 living off campus.
from data that were wholly unavailable, some indicators had only limited data available. In these cases, the national team provided as much information as possible to each pilot community. For example, bar graphs were included in lieu of trend graphs when data for a behavioral health indicator was available for three or fewer years. An example is shown in Figure 5.

After several rounds of dialogue between the national and local CAPE teams, the data were assembled into tailored PowerPoint presentations to enable each of the local CAPE teams to present locally-relevant data and information to their community leaders and stakeholders. Local teams were encouraged to edit and revise the presentations to make them more relevant to community members. Each local CAPE team held a meeting with community leaders and stakeholders between September and October 2014. Encouraging the local CAPE teams to hold community meetings to share data and information, along with supporting local CAPE team members' presentations, helped the national CAPE team accomplish the fourth CDS Principle of Good Practice: working actively to enhance the leadership capacity of local CAPE teams as community leaders.

The national CAPE team included the trend graphs, speedometer graphs, and scatterplots as part of a compilation of data for each individual community in the form of extended profiles, which were 61 pages long on average. The national CAPE team also created a manual with instructions on how to use Excel to create the behavioral health graphics. Both the extended profiles and the manual are available on the project website (www.healthbench.info). When new data become available, the local teams will be able to replicate the graphs to provide a consistent trend series of data and determine whether progress toward improvement is occurring. Excel was selected as the program to create the trend graphs, speedometer graphs, and scatterplots because it is more easily accessible to non-academic audiences than statistical data packages such as Stata or SPSS. The instructional manual helped fulfill the fifth CDS Principle of Good Practice, of being open to a variety of action strategies to support long-term sustainability, by showing local CAPE teams how the data were assembled to create the visualizations and encouraging them to create similar graphs in the future.

The feedback from local teams highlights a number of issues related to conducting research with communities and the effectiveness of data visualization. All of the local teams were enthusiastic about sharing the secondary data and CAPE survey data with leaders as well as broader audiences in their respective communities. Some teams were concerned about the general state of data literacy among community members. This was resolved when we talked with local CAPE teams who were aware of data literacy abilities within their communities, and made visualizations more user-friendly. All of the local teams felt the trend graphs were easy for most community leaders to understand, as this type of visual representation of data was commonly reported in the media. The speedometer type graphs, although unfamiliar to some local teams, received positive responses and local teams felt they would be good tools to generate discussion among community leaders. The scatterplots were perceived by several local teams as quite complex, containing too much information to understand quickly, especially for non-academic community leaders and members who do not often deal with data. To aid in quick comprehension of the scatterplots, additional labels were added and enlarged to draw attention. For example, a plus sign on the right side of the scatterplot indicates that a trend was getting better and a minus sign on the left side of the scatterplot indicates a trend was worsening. One local team leader felt that if community members had to work too hard to understand the image, they would quickly abandon the effort. The team responded by moving the scatterplot from the beginning of the presentation (a preview of data) to the end (summary). Local team feedback indicated that moving the scatterplot to the end meant the audience had already had a chance to understand the many data sources within the chart, making it easier to understand this graph.
In a few cases, local teams asked for secondary data to be compared on a different scale (geographically smaller or larger), or to split the indicator based on a characteristic such as age or college student status. Limitations of the secondary data source meant that such changes were not always feasible. Data from secondary sources is limited in scale to community-relevant geography such as counties. Secondary data from multiple sources may not contain comparably measured and framed indicators to allow for analyses across communities and between the community and the nation. For instance, for most users, data from the BRFSS is suppressed for counties with a population under 1,000 people or where there are too few cases. As another example, child abuse and neglect data is often collected by state agencies, but it is reported in different units, e.g. per thousand versus percent of total reports.

The national CAPE team informally followed up with each of the local teams after the project had concluded to examine the impact of the project. All of the local teams held meetings with interested individuals and groups from the community to present findings and generate discussions of next steps. A sampling of those findings is presented here.

The CAPE Project had a positive impact on the local community in the New River Valley, Virginia, by allowing key community leaders to come together outside of their specific areas of work to discuss behavioral health issues broadly impacting the region. The data visualizations shared in presentations, reports, and brief publications, captured the attention of community leaders and guided robust discussions. The project's local team leaders shared the data visualizations with their networks and engaged conversations with stakeholders at the local and state level, commenting that it was useful to see the data in new ways. Using CAPE data and reports, the local team submitted a new funding application for state-supported mental health services.

Community leaders in Chittenden County, Vermont, worked together with the national CAPE team to make the final data visualizations most appropriate to the context. The model of national coordination with local on-the-ground researchers and practitioners helped the data visualizations fit the behavioral health situation in the county. Leaders in Chittenden County felt the speedometer graphs that compared the county to the data of other counties in the state effectively conveyed data to those interested in behavioral health. The findings of the CAPE Project are helping local community members work on behavioral health through collaborative projects with local organizations such as the United Way and outreach to local government officials.

Similarly, the local CAPE team in Finney County, Kansas, used the data products to enhance public awareness about behavioral health issues in their community. The CAPE project, community, survey, and data findings appeared in multiple local and regional news outlets. The data stimulated discussions among local service agencies about behavioral health issues, built cohesion among community health coalition partners, and mobilized the community to articulate broad community behavioral health priorities. The data visualizations were useful in starting conversations among community leaders and will be used by social service agencies to bolster funding applications that deal with behavioral health issues in the county.

In Garrett County, Maryland, the local team used the CAPE findings to connect with local news media, to generate conversation in the community, and to place behavioral health concerns on the broader community agenda. The local team appreciated the opportunity to provide input about which chart formats were most effective. Through the feedback process, the final versions of the data visualizations were comprehensive, easy to read, and helped provide a clear description of the behavioral health issues in the community.

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4 See footnote 2.
Limitations

One limitation of this initiative was that secondary data were not available for all of the behavioral health indicators included in the survey of community leaders, so cross-community comparisons of perceptions of priorities and prevalence or incidence data were not possible. Additionally, the secondary data were lagged by at least two years, meaning it is possible that the community leaders’ perceptions of behavioral health priorities were based on more recent developments within the community that had not yet been captured through formal survey mechanisms such as the BRFSS.

As previously mentioned, the format of the data meant it was not always possible to subdivide the secondary data into categories that would be most meaningful to the local teams. For instance, the Finney County, Kansas team was aware of the community’s concern about teen pregnancy. They requested that the national team divide the teen pregnancy indicator by age groups, but the national team was limited to the age groups provided in the secondary data as the teen pregnancy rate was not available for each year of age. For other communities, such as New River Valley, the national team was not able to parse out college-aged or college-attending students from samples of binge and heavy alcohol consumption.

Conclusion

Overall, local CAPE teams wanted methodologically sound, clear and detailed data about community behavioral health indicators to share with local leaders and community members. Through the process of presenting data to and engaging in a dialogue with community teams, the national CAPE team was able to create responsive data presentations that reflected local concerns while meeting all five CDS Principles of Good Practice\(^5\). To promote active participation for community leaders and members to influence decisions about behavioral health in their communities, the national team held webinars and attended in-person meetings to disseminate data and create dialogues around behavioral health. This process engaged community members in understanding what behavioral health issues were in their communities, and how perceptions compared to statistical evidence of behavioral health problems in their respective locales. Through an iterative process in the creation of the visualizations, the national team incorporated the diverse perspectives of community leaders and members. Preparing the visualizations for community presentations in editable format allowed community leaders to enhance their leadership capacity and share the visualizations in a relevant way. The national team remained open to using a variety of visualization techniques throughout the process to best serve each community. Drawing from the CDS Principles of Good Practice helped the project be attentive to the diverse interests of community members and to engage community leaders in multiple steps of the data gathering, visualization, and reporting process.

While the data collected and analyzed for CAPE were specific to community behavioral health issues, other community development practitioners could easily make use of the same strategies for creating data visualizations for any number of community attributes such as number of owner occupied housing units, unemployment, use of social assistance programs, or number of locally-owned businesses. As a one-time online survey, this strategy could be easily replicated in other communities that are willing to recruit participants, distribute the survey, monitor its completion, and analyze the data. Results can be analyzed in easily accessible Microsoft Excel software. That the survey was administered online provides additional confidentiality for participants. It is important that, regardless of data sources used, presentations and reports are tailored to speak to community concerns and to the nuances of local context so the data can best serve community needs moving forward.

These findings may change the way data is used nationally if the field chooses to make data more useful to local groups working toward change in behavioral health or other issues. Although this phase of the CAPE Project will not be duplicated, a new effort is underway to overcome the issue of lagging data. The new effort is currently testing a community early-warning monitoring system that draws in data that is updated on a biweekly or monthly basis to create analytic reports and signal increases in mental health and substance use indicators so that public health officials and other concerned community members may take action.

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\(^5\) The CAPE project web site (http://www.healthbench.info) includes the “how-to” manual on obtaining data and making the visual representations found in this article, as well as reports for each participating community.
References


