

Community-Defined Evidence: A Bottom-Up Behavioral Health Approach to Measure What Works in Communities of Color

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This article describes the rationale for and components of the Community Defined Evidence Project (CDEP), which offers an important and exciting opportunity to advance the current body of knowledge on community-based practices that “work” for populations of color and to address behavioral health disparities in these communities. By developing an evidence base that uses cultural and/or community indices, the project seeks to evaluate the implementation and effectiveness of innovative community-based practices in Latino/Hispanic communities to reduce disparities and improve availability, quality, and outcomes of behavioral health care for all individuals and families.

Addressing Disparities in Communities of Color With Evidence-Based Practices

In continuing efforts to address growing behavioral health disparities and to ensure that individuals—including children, youth, and families in need of mental health services—receive the best treatment available, policymakers, researchers, and funders have promoted the use of evidence-based practices (EBPs; see Huang, 2002; Juszczak et al., 2003; Novins et al., 2000; U.S. Department of Health and Human Services, 2001; Walkup et al., 2000; Wang et al., 2000). In the literature, EBPs usually refer to well-defined, manualized interventions and treatments that show evidence of positive impact in randomized controlled trials (RCTs). Implicit in

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this framework is an emphasis on *empirical* support, which limits the definition of “evidence” and restricts the epistemology or worldview within which “evidence” is conceived to a strict form of empiricism.

The problem with relying solely on empirical evidence is twofold. First, empiricism itself is culturally rooted, and although empiricism may be compatible with the worldview of a substantial number of European Americans and Western Europeans, it is often not compatible with the worldview of many indigenous (e.g., Native American) and non-Western groups around the world.

Second, a reliance on empiricism often excludes the use of other forms of evidence in defining “evidence-based practices.” For example, indigenous, non-Western

for or appropriately standardized on populations of color. Therefore, these should not be used or promulgated for use in Latino communities without additional culturally appropriate and informed standardization, testing, or adaptation.

There are some empirically supported treatments that have been adapted or designed for specific cultural communities. For instance, Guiando a Niños Activos (GANA) is an adaptation of Parent Child Interaction Therapy (PCIT) for Mexican-American children (McCabe et al., 2005). McCabe used a sophisticated approach that included studying and documenting the values, customs, and beliefs of Mexican-American families so as to incorporate them into a PCIT adaptation that would

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European, and even some “nontraditional” European American and Western European practitioners, rely on other forms of “evidence” to support their use of treatments that are based on epistemologies that are not as compatible with empirical approaches to establishing evidence. More important, some scholars have expressed concern that an over-reliance on empirically supported interventions has the potential to become “an ideological and economic monopoly” in its advocacy for the sole use of empiricism and its methods (Slife et al., 2005).

Predominant methods for conducting research and defining evidence pose a problem for Latinos, currently the largest ethnic group in the country, as well as other diverse groups, in a number of ways. Traditionally, Latinos and other diverse populations have not been adequately included as subjects in services research (Miranda et al., 2005). They are typically not asked to participate in the conceptualization and design of treatments and interventions. As a result, the vast majority of EBPs were not designed

be fundamentally based on the culture and values that are relevant and authentic to Mexican-American families.

Modification and adaptation of EBPs typically, but not always, focuses on incorporating the service user’s values; on ethnic matching of providers and consumers; and on the incorporation of family, community and/or other informal support resources within a cultural community (Griner & Smith, 2006; Isaacs et al., 2008; Jackson-Gilfort et al., 2001; Martínez & Eddy, 2005). Some “adaptations” rely only on translations that are insufficient to qualify as adaptations because they do not fundamentally address the core values, beliefs, traditions, rituals, and historical contexts of the diverse populations they are meant to serve.

Recent evaluations of research on culturally adapted EBPs suggest promising results with regard to efficacy and effectiveness of interventions (Griner & Smith, 2006; Miranda et al., 2005). However, a number of questions still remain, including whether the adaptation of a practice compromises the fidelity of a

particular intervention (Isaacs et al., 2008). Other concerns include the degree to which researchers and practitioners adapting EBPs consider specific ethnic/cultural factors relevant to subgroups within heterogeneous populations such as Latinos (Dumka et al., 2002), as well as the continued exclusion of traditional, spiritual, or other culturally relevant practices used within communities of color (Espiritu, 2003; Isaacs et al., 2008).

Looking beyond culturally adapted EBPs, there have been a few interventions that were designed specifically for, and normed on, a specific ethnic population such as Latinos. Two notable examples are the Family Effectiveness Training program (FET; Szapocznik et al., 1989) and Brief Strategic

EBP, an alternative intervention based on the family's context and prioritized needs may be a better option.

Practice-Based Evidence. As a result of growing concern over repeated calls on the part of funding agencies and policymakers for exclusive use of EBPs in behavioral health, the concept of "practice-based evidence" (PBE) has emerged in the research literature. Isaacs, Huang, Hernandez, and Echo-Hawk (2005) defined PBE as "a range of treatment approaches and supports that are derived from, and supportive of, the positive cultural attributes of the local society and traditions." Results associated with the use of culturally specific community-based interventions, including traditional healing practices, are a

practices, including those considered culturally related or not. Community-defined evidence is a response to the growing need to recognize and test community-based practices, culture specific or not, that "work" and the need to establish a means for documenting their positive effects using culturally appropriate and accepted methods of investigation. Community-defined evidence not only seeks to refine the concept and definition of PBE, it also seeks to provide a validating research model to determine "evidence" from the community perspective.

Community-defined evidence is the knowledge accumulated through the ongoing successful implementation and/or evaluation of practices developed locally with significant community input. The working definition of community-defined evidence to date has been that:

[Community-defined evidence is] a set of practices that communities have used and determined to yield positive results as determined by community consensus over time and which may or may not have been measured empirically but have reached a level of acceptance by the community (Martinez, 2008a).

Whereas there may be no consensus that "evidence" is defined as a set of practices, evidence in community-defined evidence supports the identification of specific practices by highlighting practices the community finds to be successful, rates highly, or speaks highly of, or that the community has assisted to develop or discover. Community-defined evidence emphasizes the critical role of a particular "service user community" (consumer) in determining whether a practice "works" for the community through acceptance and continued utilization of the practice, as well as evidence for demonstrating positive outcomes as defined by the service user within her or his cultural context.

In this working definition of community-defined evidence, "community" has purposely not been specifically defined because every population group, entity, or geographic area defines itself differently and should be properly defined by the group itself. Examples of "community" might include the neighborhood/barrio, the ethnic community in a city, the community-based organization, and the community it serves. "Community consensus" has also not been specifically defined because communities may have varying ways of measuring success, based upon

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Family Therapy (BSFT; Szapocznik & Williams, 2000). Both FET and BSFT were designed for, standardized on, and replicated with Latino families in Florida. Since then, both practices have been studied for use with other populations such as African-American and white youth and families. FET and BSFT are, however, unusual examples; it is not common to find an EBP that has been designed, standardized, and replicated with youth and families of color.

Alternatives to Evidence-Based Practices

With the growing emphasis on EBPs by policymakers and funders of services, some community-based providers have felt the pressure to abandon practices that have been viewed as effective but that have not been formally established as EBPs. Although accountability is essential, forcing providers to abandon practices that have worked for children, youth, and families can have negative effects, including reliance on practices that may be inappropriate or irrelevant to the needs or priorities of families and youth of color. In addition, family and youth "voice and choice" is a critical element to consider (Osher, 2003). Even if a practice or set of practices meets the "gold standard" of being an established

common example of PBE. Such practices typically lack empirical support through formal research and are created and improved through the experiences of an organization actually offering the practice to the community (Isaacs et al., 2008). Over time, the term "practice-based evidence" has come to signify the "practice to science" complement to the "science to practice" paradigm, both of which were endorsed by the President's New Freedom Commission (2003). Over the past decade, however, PBE has come to mean many things. There are now attempts to further refine it as a concept and model that can be used to generate "evidence" of what works in communities (Martínez, 2008b).

Community-Defined Evidence. Practice-based evidence is probably the most widely recognized term used to describe the need to look beyond traditional empirically based models of examining practice effectiveness and to consider models that value the role of culture in determining effectiveness. Community-defined evidence (CDE) is a further refinement of the original PBE concept. Community-defined evidence emphasizes the inherent knowledge, experience, and expertise of communities themselves, based upon their history, prior success, and community-sanctioned use of certain

their particular parameters and priorities of what constitutes success.

A basic tenet of community-defined evidence is that people in the service user community themselves have knowledge based upon life experience and learned expertise that is rarely tapped to inform scientific study, especially in developing behavioral health practices. People in communities know who they are, the historical roots from which they come and the trauma that may be related to that history, and, many times, what works for them. Community-defined evidence is a paradigm that includes and values this knowledge in the discovery and study of those practices that have never, and may never, be studied through a controlled trial, yet are essential to include in our practice repertoire.

The Community Defined Evidence Project

The CDEP was initiated in response to the growing concern for increased recognition and acceptance of community-based practices and the need to establish a means for documenting their positive effects within communities of color by using culturally relevant, appropriate, and accepted methods of investigation. The CDEP is a partnership between the National Latino Behavioral Health Association and the National Network to Eliminate Disparities, and aims to discover and develop a model for establishing an evidence base using cultural and/or community indices that identify community-defined and based practices that “work.” Community-defined evidence can encompass, in addition to treatments, a broad array of practices that include effective outreach and engagement strategies that increase retention and use of services, as well as multi-service assistance such as legal aid, housing, employment, and nutrition services. The CDEP focuses on identifying and documenting such practices within Latino/Hispanic communities across the country in order to develop a framework that might later be used with other cultural communities.

CDEP Design and Methodology

To study practices that might constitute community-defined evidence, the following criteria for selecting practices for the project were developed.

Clear Articulation of Practice(s) Used. Practices that were accepted for possible inclusion should be clearly articulated and include a description of the development

and implementation process. Service providers/agency staff should be able to:

- Clearly articulate the practice and how it is used with the population of focus;
- Articulate how practices were arrived at, developed for, and/or adapted, to meet the needs of particular segments in the community; and

focus—such information may range from anecdotal information and traditional or indigenous knowledge generated over time to experimental studies, if applicable and available;

- Identify factors, where available, that are associated with outcomes such as outreach, engagement, and other practices

In clinical work with victims, an effort is made to raise consciousness regarding their rights, abilities, and potential, as well as awareness about the impact of domestic violence on all of society.

- Indicate whether the identified practice(s) derives from traditional or other culturally indigenous practices within the community.

Demonstrated Knowledge of the Population(s) Served. Service providers/agency staff should be able to:

- Clearly describe the population(s) of focus;
- Identify key demographic and/or cultural indicators; and
- Provide data (anecdotal or empirical) related to the proportion of service users who use Latino-focused practice(s).

Utilization of Specific Practice(s) by and for the Latino/Hispanic Community. Practices should demonstrate some evidence, anecdotal or otherwise, that consumers were indeed using these practices. Service providers/agency staff should be able to:

- Provide information related to utilization and retention rates associated with the identified practice(s); and
- Indicate how utilization helps, if rates are measured, to shape development, refinement, or implementation of the identified practice(s).

Potential for Demonstrating Outcomes. Service providers/agency staff should be able to:

- Provide information indicating whether the population(s) of focus value and are satisfied with the identified practice(s) and/or other services provided;
- Provide, where available, information on the effects of using the identified practice(s) among the population of

that can support continued use of practices or services; and

- Provide other data that indicate the practice(s) “works” with Latino service users.

Potential for Sustainability of Practice(s). Service providers/agency staff should be able to:

- Describe how the identified practice(s) is sustained by their agency;
- Identify whether they have specific funding sources for the identified practice(s); and
- Provide information, where available, about whether practices have been replicated with different populations and the process they used.

A nomination and review process identified organizations and programs that use innovative practices successfully with Latino and Hispanic communities across the country. A total of 56 organizations and programs and their practices were nominated (through a self- and third-party nomination process), representing 27 states. Nominated sites were then asked to participate in a one-hour screening interview designed to elicit information on key site characteristics (e.g., access indicators, outreach strategies, practice utilization, program and satisfaction evaluations, and clinical outcome measures that focus on functional and relational behavioral health and well-being outcomes), as well as the degree to which consumers and family members were involved in the development, implementation, and/or evaluation of an identified practice. Interview responses were then reviewed separately by two researchers

using a scoring sheet that calculated a total score given the degree to which consumers' input was incorporated at every stage of practice development. A mean score was then calculated for each site and these were ordered from highest to lowest. The 16 practices with highest scores were selected to participate in the study.

Data collection for the 16 sites consisted of in-depth interviews with a cross-section of each organization's stakeholders, including consumers, family members, providers, and community partners. Each site was also asked to submit demographic information for the practice of focus, as well as perceptions of community needs and barriers to mental health services. A total of 246 interviews were completed and are undergoing analysis to document the essential components of practices and factors important to their continued successful implementation.

and comprehensive approach to addressing domestic violence among Latinas in the community by emphasizing these women as political beings. In clinical work with victims, an effort is made to raise consciousness regarding their rights, abilities, and potential, as well as awareness about the impact of domestic violence on all of society.

Practices That Increase Service Accessibility. Practices that increase service accessibility focus specifically on increasing access to services for children, youth, and families. An example is a community partnership working to increase access to a wide range of services and changing the way services are delivered to families in a southeastern state through a network of local providers, community health workers, and a grassroots community resident organization that identifies community needs and concerns and feeds these back through the network.

Community Outreach Practices. Community outreach practices focus on reaching out to the potential consumers in a variety of ways, to increase service reach, identify needs, or provide follow-up services. An example is a mental health clinic in the U.S. Midwest that works to "integrate immigrant and refugee families into the American society" through the services the clinic provides. The clinic conducts a great deal of outreach by relying on home visitors to develop relationships of trust with consumers, especially with the undocumented population.

Organizational Infrastructure Practices. Organizational infrastructure practices are implemented within organizations to enhance their administrative functions and/or other aspects of their organizational infrastructure in support of a program developed specifically for the local Latino/Hispanic population. An example is a multicultural relational approach that has been developed by a community-based mental health organization in a northeastern state to recognize, explore, and ascertain consumers' expectations with regard to treatment, to develop culturally relevant treatment methods, and to diminish cultural misunderstandings in the development of programs.

Interventions and Treatments. Locally developed interventions or therapies have been developed specifically to address the behavioral health needs in local Latino/Hispanic populations. An example is a therapeutic drumming approach that has been developed by a community-based mental health treatment center in California to address anger management and violence in adolescent males.

Locally Adapted Evidence-Based Practices. Local adaptations of EBPs have been modified to address behavioral health needs in local Latino/Hispanic communities. An example is a local adaptation of Cognitive Behavioral Therapy (CBT) in a U.S.-Mexico border community in Texas to address the mental health needs of a largely Mexican immigrant population.

Implications for the Field

Community-defined evidence can be viewed as a complementary option in a growing tool box of epistemologies and methodologies to define "evidence," especially in diverse communities. The knowledge gained through the CDEP can contribute to the field by documenting the way in which the traditional or indigenous knowledge that exists within communities has been used to develop and implement

Community-defined evidence would supplement EBPs that are already being used effectively with populations of color, therefore improving access by having more culturally appropriate and relevant options.

Cross-site findings will be used to further refine the parameters for defining and identifying community-defined evidence through distilling the "essential elements" that the sites have in common and that have been deemed critical to their success as defined by the local communities in which they are implemented.

Examples of Innovative Practices Selected for Study

Practices that were identified for in-depth study were categorized for the purposes of analysis. These categories are identified and defined below, and an example is provided for each.

Practices That Build Capacity and Consciousness in Local Communities. Generally, the practices identified in this category focused on building community capacity and/or raising the political consciousness of individuals (in various age groups) to prevent negative behaviors or improve behavioral health or well-being. An example is a domestic violence program in the U.S. Southwest that provides a holistic

Practices That Raise Awareness About Mental Health. These practices focus on raising awareness within Latino communities about a range of mental health issues and services in formats that are widely available and culturally relevant. An example is an association affiliated with a county mental health department in a southeastern state that promotes information and education about mental health and available services specifically for Latinas. The association provides community workshops and has produced educational brochures and a CD series addressing mental health issues specifically for local Latina women.

Innovative Engagement Practices. Innovative engagement practices focus on engaging Latino consumers to establish rapport and increase provider acknowledgement of consumer values and preferences. An example is a health education and prevention organization in a western state that uses an engagement technique that incorporates art and storytelling to allow each consumer to express her or his individual identity and consider how it relates to health and well-being.

successful practices for the residents of these communities. Community-defined evidence is not meant as a substitute for evidence-based practices that have benefited from the “gold standard” of controlled research. It is offered as an alternative model to describe how evidence can be defined from another paradigm, and as a method for including and validating practices that have emanated from communities from years of outcomes deemed successful by the community—a bottom-up approach. Although the empirical model seeks to confirm or disconfirm hypotheses using methods such as randomized control trials, and then accumulate knowledge of interventions from research conducted under such controlled conditions, community-defined evidence is predicated on the community members as a whole providing information about what works and what does not work in the community. Within this paradigm, worldview, cultural context, and personal interpretation are critical to the success or failure of an intervention or practice.

Community-defined evidence is more likely to take into consideration several critical variables that many times are not addressed when the intended population comes from an ethnic or racial group, including:

- Historical trauma;
- Current trauma related to racism/ethnocentrism/white privilege;
- Worldview;
- Immigration status;
- Generation in the United States;
- Preferred language;
- Socioeconomic status; and
- The presence and practice of traditional beliefs, values, and rituals, including spirituality and communication styles.

These variables contribute to the success or failure of any intervention or practice because they influence the ways in which children, youth, and families interpret them.

Whereas the CDEP studied practices in the Latino community as a start to define the “essential elements” that would constitute community-defined evidence, the long-term goal is to share the knowledge gained to determine its application to other major populations of color. Community-defined evidence would supplement EBPs that are already being used effectively with populations of color, therefore improving access by having more culturally appropriate and relevant options. It would also improve

quality by using what has been shown, although maybe not documented by methods such as randomized clinical trials, to work in diverse communities.

From a practical perspective, community-defined evidence seeks to positively influence academicians/researchers, governmental entities, and public and private funders to include the use of appropriate culturally and community-defined evidence criteria when addressing the needs of populations of color. Examples include using CDE criteria alongside EBPs in requests for proposals (RFPs) and contract language so that funders/policymakers give grantees the option of using practices supported by community-defined evidence as well as practices tested in randomized controlled trials in their service delivery repertoire.

funding agencies has been promoted as a solution to the poor outcomes that ethnically/racially diverse populations have encountered in the behavioral health system. However, a number of limitations with regard to the use of EBPs with ethnically/racially diverse populations have been raised within the research literature (Bernal & Scharrón-del-Río, 2001; Isaacs et al., 2008; Manderscheid, 2006; Mays & Albee, 1992; Miranda et al., 2005). Specifically, these limitations relate to the lack of participation from communities of color in the development and testing of EBPs, as well as the degree of cultural relevance their outcomes may have for ethnic and racial communities (Isaacs et al., 2008; Miranda et al., 2003, 2005; Nagayama Hall, 2001; Sue, 1998). Further, as Isaacs et al. (2008, p. 622–623) note:

EBPs could therefore exacerbate and deepen existing inequities if they are implemented without sufficient attention to factors that may differ between specific communities.

The intention is to support development of knowledge and expertise of communities of color and to expand our knowledge of and study of existing community practices with populations of color that are perceived to be of value to the community. An additional aim is to influence future legislative and policy efforts so that funding is prioritized for culturally based research on racial/ethnic behavioral health disparities and to advocate for practice “effectiveness” measures that are culturally and community appropriate.

A research and evaluation agenda for the implementation and use of community-developed and based practices as well as EBPs that are effective with populations of color is essential. A long-term goal of defining a paradigm such as community-defined evidence is the elimination of disparities in behavioral health. Research conducted using the community-defined evidence model represents one major step toward achieving that goal by discovering and developing measurement criteria by which to assess what really works with populations of color within the context of their own communities and culture.

Conclusion

The wide support for EBPs on the part of policymakers and key behavioral health

[Theory development is] stymied by the complexity of the relationships between culture and mental health, as well as the many important related factors that would need to be considered (e.g., acculturation, language, socioeconomic status, regional effects, family variables, community variables).

So the question is: By what method do we define “evidence” for a cultural community? The hegemonic paradigm suggests evidence should be collected by external researchers using an empirical epistemology. This approach negates alternative forms of “knowing” that may exist in communities of color and ill-prepares interventions for implementation within their communities (Zayas et al., 2004). EBPs could therefore exacerbate and deepen existing inequities if they are implemented without sufficient attention to factors that may differ between specific communities. Native American communities, in particular, have expressed concern that government mandates requiring use of EBPs not only ignore the impact of traditional spiritual ceremonies or rituals in behavioral health, but may also constitute “another form of oppression” (Isaacs et al., 2008, p. 623).

There is contemporary evidence of many effective and culturally appropriate

practices in diverse communities that have never been formally measured empirically or documented in any manner (Callejas et al., 2009). The CDE paradigm is an important opportunity to advance the current body of knowledge of community-defined and community-based practices that “work” for populations of color and to increase knowledge and awareness of these innovative practices among researchers, policymakers, and funding agencies. By developing an evidence base that uses cultural and/or community indices of success, the goal is to influence the research and evaluation agenda, as well as policymakers and funders, to implement and use community-defined and community-based practices to reduce disparities and improve availability, quality, and outcomes of behavioral health care for all individuals and families.

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