

Out of the Ivory Tower, Into the Real World

Examples of Street-Smart Community Health Research

Dramatic medical advances have created effective approaches to reducing the burden of many chronic health problems. But in many cases, the clinical know-how developed in academic and research institutions hasn't reached the streets—particularly when those streets are located in poor and minority neighborhoods. In too many communities across the nation, better research hasn't resulted in better health. Such research suffers from a “greenhouse effect”: Interventions that work well on paper or even in controlled trials do not work well in the often chaotic community settings for which they are intended.

A key approach to transferring the promise of evidence-based research into the communities that can most benefit from it is community-based participatory research (CBPR). CBPR reflects a continuum of approaches that emphasize community involvement in research:

- At one end of the spectrum is research conducted in community settings but without the direct or formal involvement of the community in decisionmaking—what could best be described as *community-placed* research.
- At the other end of the spectrum is *community-driven* research, in which community leaders seek out research and other partners to help implement and advocate for programs and activities they believe to be necessary and important.
- Somewhere in the middle of the spectrum is *community-partnered* work, in which research institutions and community organizations and representatives come together as equals to identify opportunities, conceptualize research and action-oriented agendas, design and implement research, analyze findings, and work together to ensure that those findings are appropriately disseminated and ultimately produce desired change.

Abstract

This research highlight documents examples of RAND Health's community-based participatory research—an approach to transfer the promise of evidence-based research into communities that can most benefit from it. Such examples include *Witness for Wellness*, which addresses depression in underserved minority communities in Los Angeles; *Cognitive Behavioral Intervention for Trauma in Schools*, which addresses trauma in Los Angeles schools; *Alianza Contra el Asma*, a community-centered coalition to address asthma disparities in Puerto Rico; and innovative work with community partners to develop improved, culturally appropriate mental health services in New Orleans.

The middle of this spectrum is where RAND's community-partnered work has focused; such work strives for an equal relationship in which academic and community partners enjoy a balanced partnership in various aspects of research, including program development, research design, implementation, and analysis. Although the approach to leadership and participation may differ for different phases or activities within such work, the ultimate goal is to produce solutions that will have a more powerful impact on communities and that will give communities a sense of confidence to advocate more effectively on their own behalf.

This research highlight presents three examples of RAND's community-partnered work:

- *Witness for Wellness*—a proven, successful model for academic-community partnering.
- *Cognitive Behavioral Intervention for Trauma in Schools (CBITS)*—a program to help children cope with violence, CBITS focuses on continuing efforts to further

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transfer the proven benefits of evidence-based RAND-partnered research within a community setting

- Alianza Contra el Asma—a community-centered coalition to address asthma disparities in Puerto Rico.

We conclude by discussing some of RAND’s newest community-partnered work, including efforts to improve mental health in the New Orleans area.

Witness for Wellness: Treating Depression in Underserved Minorities in Los Angeles

Although the potential benefits of quality improvement interventions for treating depression exist, achieving those benefits in a community setting has proven difficult. Witness for Wellness (W4W) is a multistakeholder, academic-community partnership initiative that strives to combine principles from evidence-based research on depression with community expertise and direction in historically underserved minority communities in Los Angeles. W4W is rooted in a partnership between RAND researchers, the University of California, Los Angeles, and Healthy African-American Families (HAAF)—a unique organization that serves as a bridge to promote effective interactions between the grassroots community in Los Angeles, community-based organizations, the Los Angeles Department of Health Services,

health care providers, and research organizations. More than 500 participants from a variety of racial, ethnic, educational, and religious backgrounds attended an initial conference on depression, out of which emerged the W4W mandate and its three working groups of community and academic members.

Figure 1 shows W4W’s project logo, which highlights its guiding principles, the approaches that W4W uses (shown on the road), and (on the right side of the road) the three working groups that focus on improving community awareness of depression and reducing stigma around mental illness (Talking Wellness), improving quality and outreach of services (Building Wellness), and addressing key policy barriers to care while supporting advocacy to protect vulnerable populations (Supporting Wellness).

Talking Wellness. One key barrier to implementing interventions to treat depression is overcoming the stigma attached to actually talking about depression within ethnic minority populations. The Talking Wellness working group conceived of a series of outreach events through the use of the arts—comedy/poetry, documentary film, and photography—to improve the community’s ability to discuss depression. An existing educational intervention—a public service announcement—was also used for comparison purposes. The community’s responses to these events were obtained through audience surveys and discussion groups, leading to data that were collaboratively analyzed, with feedback provided to community members and scientific audiences.

Part of the give-and-take between community members and academics involved decisions about how to evaluate the events in a way that was rigorous enough for researchers but still sensitive to the needs of participants—for example, using surveys to measure change but being careful to reduce the burden on community recipients by controlling the number of questions included, the length of the survey, and the literacy level. Such give-and-take has led to a two-sided education process. For example, researchers wanted to use questions as worded in previous surveys to allow for comparability with those surveys, whereas community members wanted more user-friendly wording, which, from a researcher perspective, meant sacrificing comparability.

Designing interventions and collecting the data from them within the participatory framework yielded numerous

Figure 1. Witness for Wellness: A Grassroots Intervention to Treat Depression



SOURCE: W4W project (Bluthenthal et al., 2006), used with permission of the W4W executive committee.

advantages, including substantial community input into both the qualitative and quantitative research designs and a better understanding on the part of the community about the requirements for collecting data. The process also revealed some challenges, including the need to juxtapose academic research deadlines with a participatory process.

Building Wellness. Overcoming the stigma attached to depression—being able to talk about it—is only one step toward treating it. It is equally important to improve the ability of community agencies to recognize depression and provide those in need with referrals to appropriate care.

With this goal, the Building Wellness working group—despite competing priorities—narrowed its focus to how communities can get access to quality help, who needs help, and how community service providers can provide outreach effectively and in a culturally sensitive manner. The working group chose to develop and implement a Web site to support providers in identifying depression and educating and referring depressed clients to specialty services in the community.

Developing the Web site to help meet unmet need for depression services helped focus the community-academic partnership. The centerpiece of the Web site is a case worker tool kit for facilitating depression identification, education, and referral. The working group also secured funding for an initial feasibility trial that began in 2008.

The process also identified a significant community concern: ensuring access to services when depression is identified. This concern led to a formalized memorandum of understanding between two community agencies to ensure access to care for people identified with depression—a very real change and an impressive victory for the Building Wellness team.

Supporting Wellness. A key part of treating depression in a community setting is to ensure that a support structure is in place to work with the community in fostering policy change and advocating to protect the community's vulnerable populations. This has been the focus of the third working group. Much like the other working groups, the Supporting Wellness group began with a series of action items and narrowed its focus to activities aimed at educating members about policy, building connections with the community, and determining the community's wants, needs, and priorities.

Of the three groups, the Supporting Wellness group had to work hardest to identify opportunities to make a difference from a policy perspective and to familiarize both community and academic members with what the options were locally in terms of advocating for vulnerable populations. One of the group's major accomplishments was to obtain a position on a countywide stakeholder committee that recommended priorities for mental health spending and development of new outreach programs to the county. That effort

contributed to the funding of a participatory planning grant to improve community mental health services for persons of African descent in South Los Angeles.

The W4W work has led not only to a broad community planning process and set of products but to a new community-partnered participatory research initiative, Community Partners in Care (or CPIC), funded by the National Institute of Mental Health. CPIC is seeking to determine whether community action and coalition development efforts improve the implementation of evidence-based programs to improve the quality of depression care in underserved communities relative to a more "standard," or time-limited, approach to orient individual community agencies to these evidence-based programs. In other words, does "building a village" of agencies that work together to improve depression care offer a better solution than targeted help to similar agencies in the same neighborhood, without the added efforts to support coalition building or extensively tailor services to local populations? To help answer this question, RAND and its academic and community partners are conducting an innovative, group-level, randomized controlled trial, with randomization at the level of the agency site—social service, primary care, mental health specialty, and other trusted community organizations, such as churches—in several Los Angeles neighborhoods, including South Los Angeles and Hollywood.

The intervention sites will receive support for an innovative, community-engagement and network capacity-building intervention to develop a community-wide plan to implement the evidence-based depression programs, while the comparison sites will receive an initial training conference and access to support materials for their own use in implementation. Like the Witness for Wellness program, the entire study is being designed and implemented under a community-partnered participatory research model with joint leadership through community and academic lead institutions. The study will also support a collaborative analysis that determines which of the two interventions is most feasible and effective in terms of improving depression care and outcomes—considering impacts for agencies, providers, and clients—and will support the implementation of that intervention in study sites once the trial is completed. This effort represents the first large-scale randomized controlled trial of a community-partnered participatory research approach to implementing evidence-based depression care.

CBITS: A School-Based Program to Help Children Cope with the Impact of Violence

In addition to depression, communities—and, in particular, the children living within them—are also vulnerable to the mental health effects of violence. Somewhere between 20 and 50 percent of children in the United States are affected

by violence, either because they are victims of it directly or, more likely, because they are witnesses to it. The post-traumatic stress disorder symptoms that children experience as a result of exposure to violence include depression itself as well as increases in behavioral problems and in problems with performance in school.

While all racial, ethnic, and economic groups are affected by violence, the burden falls more heavily on children in minority neighborhoods, who are least likely to have their mental health needs met in the first place. Schools are a good entry point in communities to intervene, but what actually works, and can it work in a school setting?

For the past decade, the Los Angeles Unified School District (LAUSD) has been working with RAND on one such intervention. LAUSD was one of the first school districts in the country with a child mental health service unit (since 1933) and district crisis intervention services (since 1984). The work originated when LAUSD designated funding to help recent immigrants with their education and focused on violence exposure among this group. LAUSD turned to RAND for help in designing an intervention for students exposed to violence, hoping to develop a program that would be feasible for the school setting but that would also draw from what the scientific literature has shown to be effective. What started as an internal district program expanded to include the trauma experienced by all inner-city youth in their own homes, schools, or neighborhoods.

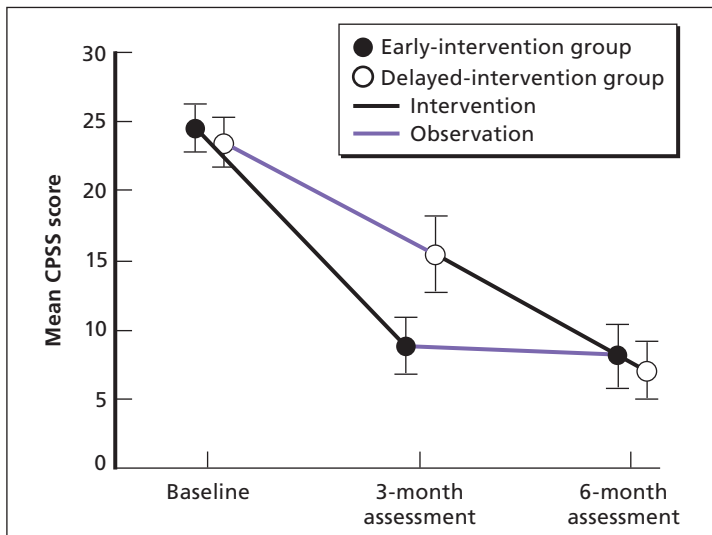
This work ultimately led to developing, implementing, and evaluating a practical, evidence-based intervention called Cognitive Behavioral Intervention for Trauma in Schools.

CBITS was developed in close collaboration with mental health clinicians at LAUSD and consists of 10 group sessions designed for a multicultural population. It includes activities that train children in relaxation, dealing with negative thoughts, solving real-life problems, approaching anxiety-provoking situations, and coping with the violent event through talking, drawing pictures, and writing. The program is also designed to build both peer and parental support.

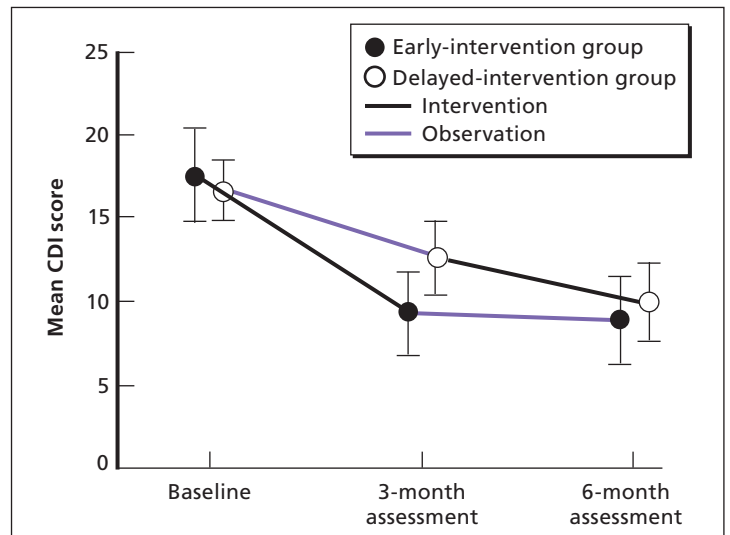
Modifications driven by the partnership with bilingual, multicultural psychiatric social workers included reducing the time of each session to allow it to be delivered during a single school period, developing examples that were culturally appropriate and relevant for recent immigrants, and developing a consensus on how to handle certain cultural issues.

After this initial step, LAUSD conducted a randomized controlled trial of the program in partnership with RAND, involving an early intervention group and a delayed intervention group. This study showed that CBITS significantly helped students cope with the devastating effects of violence. The side-by-side figures compare the scores for the two groups on the Child Post-Traumatic Stress Symptom (CPSS) scale and the Children's Depression Inventory (CDI). The left figure shows that the early-intervention students substantially improved: The magnitude of the difference between the two groups means that 86 percent of the early-intervention group reported less severe post-traumatic stress symptoms than would have been expected without the intervention. The rightmost figure shows depression symptom scores: The magnitude of the difference between the two groups means

Post-Traumatic Stress Symptoms at Baseline, Three Months, and Six Months



Depressive Symptoms at Baseline, Three Months, and Six Months



SOURCE: Stein BD, Jaycox LH, Kataoka SH, Wong M, Tu W, Elliott MN, Fink A. A Mental Health Intervention for School Children Exposed to Violence, *Journal of the American Medical Association*, Vol. 290, No. 6, August 6, 2003, pp. 603-611. Copyright © 2003, American Medical Association. All rights reserved.

that 67 percent of the early-intervention group reported less severe symptoms than would have been expected without the intervention. In addition, parents of students in the early-intervention group reported that their children were functioning significantly better.

To date, this collaboration has produced almost 25 peer-reviewed journal articles that are either in print or press, 10 grants, and an intense dissemination effort that has spanned the United States and reached as far as Israel, Japan, and Australia.

Achieving the kinds of results shown in the program evaluations requires that CBITS be implemented as intended. But one of the key barriers to implementing CBITS in schools is that doing so requires trained clinicians to administer it—a resource that many school systems do not have access to. To overcome this barrier, RAND and its academic partners have been working to “push” CBITS further down into the school community as a school program—an intervention referred to as Support for Students Exposed to Trauma (SSET).

Key to this effort has been working with teachers and school counselors unfamiliar with CBITS, mental health clinicians who are, and national experts on school-based programs to adapt and modify CBITS so that it can be delivered effectively by non-mental health professionals.

This collaborative and participatory process has yielded some significant changes in what has become SSET. These included using a “lesson plan” format that teachers are more comfortable with, rather than a treatment manual. More substantively, some aspects of the original CBITS program/manual needed to be “unpacked” so that a nonclinician could use them; some clinical elements had to be modified to make them viable to nonclinicians; and other elements, such as individual training sessions with students to “process” their traumatic experiences, had to be dropped altogether because they required clinical training to administer properly.

With SSET modified, attention turned to developing tool kits to actually deliver it in schools, such as flexible implementation support and consultation so the program can be tailored to specific school needs. For example, if schools want to screen children for referral, they need simple screening materials and instructions. As of fall 2008, SSET is being pilot-tested to determine how it performs relative to CBITS and what needs to be improved before rolling it out more broadly within schools.

Alianza Contra el Asma Pediátrica en Puerto Rico: A Community-Based Intervention

Childhood asthma is a significant problem in the United States; according to the most recent estimates, more than 23

million Americans have asthma, including nearly 7 million children under age 18, and costs to deal with it are nearly \$20 billion annually. Asthma is also a very complex disease, with risk factors that include genetic predisposition, environmental exposures, poverty, and inadequate health care services. This means that effective interventions for reducing the disease must address multiple fronts, integrating health care and physical and environmental components that are community-focused. In response to the problem, RAND Health assembled a nationally recognized set of experts in the field and developed a “blueprint for policy action” that included 11 policy recommendations to help improve childhood asthma outcomes in the United States by promoting asthma-friendly communities nationwide.

Research indicates that some populations, such as Latino populations, have a greater predisposition to asthma, especially Puerto Rico populations in the mainland United States. (See the publications by Homa and Lara included in reference section.) A similar, perhaps more severe pattern is present among persons living on the island of Puerto Rico. Thus, with funding from The Robert Wood Johnson Foundation, a program called Alianza Contra el Asma Pediátrica en Puerto Rico was instituted to provide a unique opportunity to apply some of the recommendations from the blueprint in a real-world community setting.

Over five years, Alianza focused on establishing a model health services community program in Puerto Rico to improve the quality of life of children with asthma and their families. A community-centered interagency collaboration developed agreements and intervention strategies, with the following goals: Develop a pilot model in the Luis Lloréns Torres Housing Project in San Juan, Puerto Rico, prepare this community for sustaining services after the five years, and develop strategies for disseminating the model in Puerto Rico and for working with other communities. Alianza formed a coalition of more than 20 organizations composed of local housing project leaders and organizations; island-wide organizations with expertise on and a commitment to asthma, high-risk communities, and/or coalition work; health care providers and systems; and university and research institutions. This community-based coalition was one of seven nationwide that formed part of The Robert Wood Johnson Foundation’s Allies Against Asthma program.

Activities have included empowering children with asthma and their families by conducting multiple asthma-education programs for children and families in different community settings and employing community residents to work as community health workers. Increasing community awareness and knowledge about asthma was another focus, including sponsoring a wide range of community-based educational and recruitment activities, such as large health

fairs, summer camps, a community-wide asthma-control poster campaign, and a school asthma poster contest.

To improve access, quality, and financing of health care services, the effort worked with the local managed care company (Medical Card Systems, or MCS) to formally institute an improved insurance coverage policy for all children participating in the pilot program (all medications and needed equipment were covered directly by MCS, not deducted from the local clinic's capitation) and successfully implemented a clinical coordinator program at the local Luis Lloréns clinic.

As is true of all community work—such as that of W4W and CBITS—Alianza faced a series of challenges. For example, building the coalition took time, as did performing a community needs assessment to understand better the burden of asthma and the related health care and other barriers experienced by the community. These data helped in the design of the interventions and provided evidence of need that was important for continued funding. A joint academic-community team developed, piloted, and implemented the Puerto Rico Childhood Asthma Survey in more than 2,200 households in the intervention community (Luis Lloréns Torres Housing Project) and the control community (Manuel A. Pérez Housing Project) combined. The survey showed that the lifetime prevalence of childhood asthma was over 40 percent in both communities.

Another fundamental challenge was how difficult it was to implement in the “real world” what on paper appeared to be the ideal pilot insurance coverage and care coordination program. Although universal insurance exists in Puerto Rico, the local clinic alone presented many infrastructure barriers that were completely unrelated to insurance coverage. For example, in the process of care coordination for asthma, many times charts could not be accessed, medications obtained, and doctors consulted because of multiple “red

tape” barriers, as well as an initial lack of desire for change among some of the clinic providers.

Despite such challenges, the efforts appear to be associated with improved asthma control and system change in the intervention community of Luis Lloréns Torres. Many of the coalition members have stated that the effort made a difference for the targeted population and helped reduce the high burden of asthma that the community was experiencing. For example, the local clinic's medical director conducted an audit of all childhood asthma emergency department visits for asthma before and during the implementation of the clinical care coordination intervention and showed that such visits for childhood asthma decreased considerably during the intervention.

At the “state” level, project staff participated in island-wide efforts to advocate for improved public policies for asthma in Puerto Rico. For example, the project's coordinator chaired the public policy workgroup of the Puerto Rico Department of Health's State Asthma Plan Committee. A tangible result of this group's advocacy efforts was the passage of Puerto Rico Public Law 56 in February 2006, legislating a child's right to take asthma medication at school.

Based on these results, efforts to continue and adapt some of the interventions begun by Alianza in the Luis Lloréns Torres Housing Project are continuing in a grant through the year 2009 from the Merck Childhood Asthma Network (MCAN) Program. Funding will allow for selected interventions to be extended to another community (the control community for the Alianza project) and will identify ways to make the program sustainable.

CBPR: A Growing and Continuing RAND Health Focus

While CBPR work in W4W, CBITS, and Puerto Rico is ongoing, RAND Health continues to forge ahead with new efforts. One of those efforts is in New Orleans. In the years since Hurricane Katrina and the levee failures swamped New Orleans, the prevalence of mental illness has more than doubled in the city, with one-third of residents exhibiting symptoms of depression or post-traumatic stress disorder. Half of those cases qualify as moderate to severe. This concern has led to a Robert Wood Johnson Foundation-funded project awarded to RAND on behalf of REACH NOLA, a community-based participatory research and action partnership working to improve community health and access to quality health care in post-Katrina New Orleans. From its New Orleans office, RAND is working as one of the REACH NOLA partners to develop improved, culturally appropriate mental health services in New Orleans.

One part of that effort involves developing centers with community organizations to improve access to mental health and resilience services in the region, while another effort



Advertising for a health fair at the Luis Lloréns Torres Housing Project in San Juan, Puerto Rico

(supported by the American Red Cross) involves supporting those and other centers in evidence-based training for direct mental health services delivery. Going beyond the usual focus on health care settings, these projects—like the examples discussed above—are establishing broad, community-based partnerships to learn how to share the responsibilities for developing, implementing, and evaluating strategies for and with local populations.

Building on these efforts to develop partnered research as a way to build capacity to improve local health services and outcomes and to document these efforts through research, RAND is a key partner with other academic and community agencies in the newly funded National Institute of Mental Health Partnered Research Center for Quality Care. This center is unique—not only is it about partnered research, but its entire infrastructure is based on CBPR principles. The full

center and each of its components are co-led by community and academic leaders, and each sponsored project is implemented under a similar model. The center uses innovative approaches to evaluate partnership networks for research and to fit study priorities and designs to partner and community needs, priorities, and strengths. The research is co-conducted, and products are collaborative projects to build a broad partnered research capacity that should help stimulate a sustainable focus on partnered, participatory research in mental health for RAND and its partners over the next 5–10 years.

This center may serve as a unique national resource for sharing lessons about what can be achieved through partnered research, building on the examples of W4W, CPIC, CBITS, and the innovative work in New Orleans through the REACH NOLA partnership. ■

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