Stories of IMPACT

Community Health
Scholars Program

Community-based Participatory Research (CBPR) in health is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities.

The Community Health Scholars Program is supported by a grant from the W.K.Kellogg Foundation.

INTRODUCTION

Entering its fourth year of life, the Community Health Scholars Program is already having an impact beyond anything foreseen when the W. K. Kellogg Foundation created it in 1997. By offering postdoctoral fellowships at three training sites – the University of Michigan, the University of North Carolina and Johns Hopkins University – for the study and practice of community-based participatory research (CBPR), Kellogg hoped to increase the number of new faculty members committed to CBPR and the development of successful academic/community partnerships. That's happening, but the effects reach much further – to communities, to institutions, to federal agencies, and throughout the public health field. The broad impact speaks to the powerful force created when academic centers and community-based organizations combine their skills and resources.

The six stories in this brochure illustrate the impact of the program's projects. They also illuminate the changing research dynamic between academic institutions and community-based organizations. "Academic centers need to be grounded in community-based care, to give them a reality check on what they're writing and reading about," says Laura Gillis, director of special projects at Health Care for the Homeless in Baltimore, and a CHSP advisory board member. "It's one thing to talk about HIV rates. To sit down with a client and talk about how he accesses services for HIV, it's a whole other experience." Through these partnerships, researchers gain access and insight that they probably would not have otherwise. "You can't just sit in Ann Arbor and let your assistant go out and collect data," says Richard Lichtenstein, PhD, associate professor and training site director at U-M. "The community is not going to let you, or you aren't going to get the right answers." Community-based organizations, in turn, can avail themselves of a university's resources and expand their capacity to address health issues in their service areas. A CHSP fellow offers the time and money to get research off the ground that community-based organizations can then build programs around. Indeed, strengthening the capabilities of community-based organizations is one of the program's primary goals.

Given the collaborative nature of CBPR, many of the scholars are naturally gratified by community work, and they often feel conflicted about pursuing academic careers. Their fellowships afford an opportunity to see how both worlds may be bridged. "The program is much more of a career development tool than I thought it would be," says Eugenia Eng, DrPH, associate professor and training site director at UNC. "It shows that you can do research that's very practical." It also shows the wide variety of interests that the program can accommodate. "There isn't one template of a scholar," Eng says. Although there is at least one common characteristic: "They don't have a need to take all the credit, which is why communities like to work with them. They're not the experts." Many scholars go on to faculty positions, while others choose different routes, for example, to a federal agency. "Success isn't just defined by people going to schools of public health," says Lee Bone, MPH, associate professor and training site director at Johns Hopkins. "To me, it wouldn't be a bad thing if one our scholars went to work with a foundation. We have to be very broad."

Schools of public health have yet to widely embrace CBPR as being as worthy of time and tenure as traditional research and teaching. But there are encouraging signs. More and more grants are requiring a community-based component. And, as a result of efforts initiated by the Community Health Scholars Program, the American Public Health Association (APHA) in 2001 approved the Community-Based Public Health Caucus – mere weeks before the deadline for abstracts. Many people scrambled to pull together sessions and presentations, which attracted audiences at the annual fall conference that overflowed their rooms.

By incorporating CBPR and community/academic partnerships as fundamental career goals, the six scholars featured here – and the 18 other scholars who could have easily joined them – will continue to make a lasting impact in the communities and institutions where they work.


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Stories: Mary Jean Babic
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The photos on the cover and the opposite page show parts of a mural on a storage shed at the Ackley Acres Church and Neighbors Garden, in the South Cook Village neighborhood of Flint, Michigan. Residents created the community garden and then donated it to St. James Church. "Garden" is almost an understatement for the creation, which covers nine lots and includes a fruit tree arbor, volleyball and basketball courts, a peace garden, an amphitheater and a playground.

CBPR: The Movie

Vivian Chávez brings community-based participatory research to a video starring the people of Detroit.

The video starts with a panoramic shot of the Detroit skyline, overlaid with the opening strains of Marvin Gaye's "What's Going On?" The song fades as the shot cuts to a woman at a podium – one Wilma Brakefield-Caldwell from Community Action Against Asthma. She's objecting to negative portrayals of Detroit in the media. "Most of the people in the city of Detroit," she says, "are good people." Loving shots of Detroit landmarks follow – the Joe Louis fist, the Detroit Institute of Arts, the Ambassador Bridge, the People Mover – fittingly accompanied by classic Motown tunes.

The 32-minute documentary video, *A Bridge Between Communities*, is an introduction to a concept many people probably have never heard of: community-based participatory research (CBPR), as practiced by the Detroit Community-Academic Urban Research Center. Not the stuff of a Hollywood blockbuster, but it's no dry instructional video. From its opening shots to the final credits, *A Bridge Between Communities* focuses not only on what CBPR is but what it can achieve – healthier people and a healthier Detroit.

As a postdoctoral fellow in the Community Health Scholars Program at the University of Michigan, Vivian Chávez, DrPH, knew she would learn the art and science of community research, but she also wanted to work on a creative product that combined music, text and images. She'd had good responses presenting her dissertation findings – on violence in the lives of young women – with slides and a boom box. "The audience would actually be moved to action through empathy," she says. "I felt like I was on to something, using music, image and text; I was digging that." In terms of novelty, a video certainly trumps the more traditional paper as the product of a postdoc research project. But Chávez's work shows the legitimacy of health educators' expanding their skills into areas such as video, says Richard Lichtenstein, PhD, associate professor and training site director at U-M. He points out that *A Bridge Between Communities* has been shown to community groups across the country and used in classrooms. "Which is not true," he says, "of most papers you write."

Chávez signed up for courses in video and film production. Meanwhile, she attended meetings of the Detroit Community-Academic Urban Research Center (URC). Started in 1995 with a grant from the Centers for Disease Control, URC is a partnership among the U-M School of Public Health, the Detroit Health Department, the Henry Ford Health System, and six community organizations. Four of those organizations (Butzel Family Center, Friends Of Parkside, Kettering/Butzel Health Initiative, and Warren/Conner Development Coalition) are based on the primarily African American east side of Detroit. Two (Latino Family Services and Community Health and Social Services Center) are located in southwest Detroit, home to the largest percentage of the city's Latino population. With such a gathering of people, URC indeed bridges many communities – academic/ non-academic, east side/southwest side, and African American/ Latino. It also was a test bed for community-based participatory research. By 2000, when Chávez became involved, members wanted to produce a video so they could share their experiences with other groups interested in doing similar research.

Making a video about CBPR was itself an exercise in CBPR. Chávez cheerfully admits that at first this wasn't easy for her. "I get impatient with the participatory process, maybe because I'm a little bossy," she says. "I wanted a more artsy film. I wanted music, rhythm and action. I wanted to question," she adds, revealing her background as a Berkeley violence prevention activist. "I wanted a narrative voice that was probing and questioning of CBPR from a critical feminist perspective. I imagined that that was going to be my voice." But the community wanted a local narrator. As a non-Detroit native, Chávez sensed that she would have to defer on that point. "I'm used to something completely different from the Midwest," she says. "I learned how different I am from the Midwest. I'd be willing to push the envelope if it was my community."

The narrator role went to Maggie Floyd, who's been involved in many URC-related projects. Holed up at Chávez's house, the women drafted the script in one marathon work day.

URC members then took part in revising and finalizing the script. Chávez says Floyd was a great choice; on the finished video, she narrates with poise and presence. "You have to compromise," Chávez says. "This project truly showed me what participation looks like. Participation doesn't mean you participate, they participate. It means sometimes backing down and sometimes insisting." As she describes it, "It's not my video, but it's not not my video." Her contribution, she says, was her storytelling instinct, her sense of how to construct a compelling narrative. "How do you take 12 hours of video and make it into a piece?" she says. "The footage and the off-camera interviews were my data, the editing was my data analysis, and the production was the partnership."


In downtown Detroit, Vivian Chávez gets footage for the CBPR video.

A Bridge Between Communities describes URC's experiences with CBPR and demonstrates the connections URC has forged between Detroit's east and southwest sides. It was important to the community groups to present those aspects, says Alex J. Allen III, MA, director of the Butzel Family Center. They also wanted to be informative. The video straight-out defines CBPR, leaving this block of text on screen for several seconds: "Community-based participatory research in public health is a partnership approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process; in order to both enhance the understanding of a given phenomenon and integrate the knowledge gained with action to improve the health and well-being of the community members involved."

Voices from all sides of URC have screen time, but the video moves beyond "talking head" shots to capture the spirit of the people involved. For example, an early scene from a URC holiday party features a woman belting out what surely must be one of the most righteous renditions of Stevie Wonder's "Happy Birthday" ever committed to videotape. Community group leaders also frankly relate their dissatisfaction with past university research efforts. "Folks you're advocating for have been duped," says Beverly Lemlé, an intake supervisor at Neighborhood Service Organization. "In the past, a person has been paid $15 or $20 to tell their life story, all their personal business, only for the information to be used to say how bad the African American community is." Allen is even more blunt: "We need to make sure (research is done) in a way that doesn't rape the community."

Allen now is encouraged that growing interest in CBPR is changing research principles to benefit the communities studied, such as by sharing data that agencies can use to apply for funding. "My experience has been that some folks in academia, not all, want to do this community-based work, so this video serves as a foundation on what to expect," Allen says. "I think that's a good thing." The video, he adds, has been well-received by the community groups and academic audiences to whom URC has shown it.

Allen, too, was pleased with the participatory nature of the video's creation. "It came out a lot better than I thought it would," he says. "My brother does that kind of work, so I know that with limited funding you get a limited product. But Vivian did a good job." Lichtenstein agrees that it's not a professional video – but that's the point. "That's precisely why it's community-based participatory research," he says. Allen's brother even got in on the act, helping out with some taping during a visit to Detroit.

Now back in the Bay Area, Chávez is an assistant professor in the Department of Health Education at San Francisco State University, in the newly formed Master's in Public Health program. SFSU is primarily a teaching, undergraduate institution. A majority of students are persons of color – people from the "community," so Chávez draws on her CBPR experience every day. "You walk into the classroom, and you really have to shift how you talk about community," she says.

Her transition from activist to doctoral student to university professor is ongoing. "I have to assume a certain authority while remaining open and humble," she says. "I have to develop a new language of relating to other folks who are not community people, who are academics and scholars. I'm not completely done learning it, but (Michigan Professor) Barbara (Israel, PhD) and Rich went the extra mile to help me." She plans to keep in touch with her activist roots, even though she's now Dr. Chávez.

Recently, Dr. Chávez learned something more about community when she bumped into Israel at the American Public Health Association national conference. "Within half an hour, she was mentoring me, asking me about a grant I wrote, the articles I published, how I was navigating all that and being a good teacher," Chávez says. "It's as though the program, says, 'You belong to a group of people, and we're still looking out for you.' "

HEY BROTHA, HOW'S YOUR HEALTH?

Michael Royster teams up with Strengthening the Black Family, Inc. to improve the health of African-American men.

Among all gender, ethnic and racial groups in the United States, African-American men live the shortest lives and are at the greatest risk of dying from heart disease, cancer, HIV, homicide and other leading causes of death.

Alarmed by the trends – which are mirrored in its service area of Wake County, North Carolina – and sensing the complex social, economic and political causes beneath them, Strengthening the Black Family, Inc. (STBF) held a conference to explore the issue. Planned by a committee of men, the conference focused on cardiovascular health, diet, exercise, stress reduction and other healthy behaviors. Afterward, the men who planned and participated in the conference were motivated to develop a men's health initiative. However, STBF didn't have the staffing, research expertise or financial resources to devote to such a project, says Al Richmond, MSW, program coordinator with STBF. Talking to black men about their health concerns and then developing a program to address those concerns remained on the "wish we could do this" list.

It was, then, an opportune moment for Michael Royster, MD, MPH, to arrive at the University of North Carolina for a postdoctoral fellowship in the Community Health Scholars Program. Royster offered expertise in research and evaluation, a passion for the topic, the time to put into it, financial resources to support it and, perhaps most importantly, the commitment to community-based participatory research (CBPR) to partner with STBF in seeking solutions.

With Royster on board, STBF was able to move forward with its black men's health initiative: Hey Brotha, How's Your Health? Royster and Richmond organized a community coalition and conducted a series of focus groups to talk with African American men and identify their health concerns. (Royster used a portion of his $10,000 research budget, provided to all postdocs in the Community Health Scholars Project, to pay men for their participation in the focus groups.) It was one of those men who serendipitously christened the initiative with its catchy name. Royster explains: "He said we'd know we've been successful if, instead of saying, 'Hey, how's it going?' black men greeted each other by asking, 'Hey brotha, how's your health?' "

The phrase isn't yet heard on every street in the Raleigh area, but improving the health of black men is no quick fix. The focus groups confirmed what Richmond, Royster and others had suspected, that black men's health is affected by intertwining socioeconomic, political and psychological pressures. Male socialization, they found, is the most important factor. "There are issues of masculinity and being an African American man in a society that still has institutionalized racism," Royster says. "Black men don't want to go to the doctor or take care of their health, because they're supposed to be tough and not ask for help. That carries over into other behaviors as well – not eating right and not exercising, for example. Research shows that people with this masculine persona are more likely to drink alcohol, which leads to reckless driving, substance abuse, promiscuous sexual behavior, so that's all related." Even when men do seek healthcare, they report feeling pushed aside, as if medical personnel regarded black men as uninsured and unimportant. "Just having that perception that people don't want to see you is going to be another reason not to go," Royster says.

Other concerns are lack of good jobs, which makes it hard or impossible to get health insurance; lack of educational opportunities, which makes it hard or impossible to get good jobs with health insurance; and crime and substance abuse in neighborhoods.

Royster evaluated the data from the focus groups and compiled a report, which is guiding STBF in devising a course of action. Royster and Richmond also held press conferences to publicize their findings. National Public Radio was among the media organizations to feature reports. The attention spread the word of Hey Brotha, How's Your Health? and its three-pronged approach to the problems the focus groups identified.

Its first objective is to seek grants to recruit and support "lay health advisors," respected African American men who will be trained to promote healthy behavior among their peers. "It came out in focus groups that men were looking for guidance within their community," Royster says. "The hope is to have men think differently about what it is to be a man, and have that include taking care of your health."

A press conference announces a program to improve the health of African American men. From left: Lucille Webb, president of Strengthening the Black Family; Michael Royster; Dennis McBride of the North Carolina Institute for Public Health at UNC; and Al Richmond.

The organization also is reaching out to churches, businesses, and black fraternities to educate a wider community about the trends in black men's health and what to do to change them. The final objective is advocating for public policies that focus on black men's health. This includes working with health professionals to alert them to the perceived racism of healthcare settings and guide them on caring for black men with more sensitivity.

STBF members had worked with university researchers before, but Royster, whose background is in medicine and public health, was new to community-based participatory research. Learning took place on both sides. "They thought I had things I wanted to accomplish and their role was to be sure that I accomplished them," Royster says. "But now, since I've been here for all this time, people have gotten to know me, and they know that I don't want this to only be beneficial to me but beneficial to the whole community."

Royster's involvement has certainly been beneficial for the organization and the community, Richmond says. "If it had not been for Mike, we would not be where we are today," When community-based organizations approach foundations for funding, the first thing foundations ask for is data and research to back up requests. "That's where a lot of community-based organizations stop, because they just can't do that research," Richmond says. With Royster's help, Strengthening the Black Family now has the qualitative and quantitative data that greatly increases the likelihood of funding. "We have a nice report we can show to funders now," Richmond says. "That makes a big difference."

All the skill and time in the world, though, wouldn't have meant much without the ability to find out what's on men's minds. STBF's position in the black community opens the path for its university partners to engage in a trusting, frank relationship with members of the community, which leads to productive results. "To have access to men, to have them talk that deeply, is wonderful," says Eugenia Eng, DrPH, professor and training site director at the University of North Carolina. Until Royster and Richmond made the cognitive connection between socialization and unhealthy behaviors, the link remained a theory, she says. Now, those concerns can be acted upon.

Royster took part in other initiatives within STBF. He contributed to a successful grant application for Project SELF-Improvement, which addresses a variety of risk-factors through the Wake County black population. The $800,000 grant is the largest that STBF has ever received. STBF, in partnership with the University of North Carolina, also is applying for grants that the Centers for Disease Control is making available throughout the country for community-based research. Hey Brotha, How's Your Health? figures importantly in STBF's proposal. The CDC's requirement of a community-based component to research "speaks to the growing legitimacy of this approach," Eng says.

Beyond its better financial position, Strengthening the Black Family has grown as an organization through its history of CBPR projects, Richmond says. Going through the process of data research and evaluation has allowed STBF to document its own development and increase its capacity to address critical issues in the community.

Royster and Richmond were scheduled to co-present on their work at the 2001 American Public Health Association meeting, but Royster had to cancel because his wife was about to have their first child. Richmond presented solo, to great reviews. Co-presenting is a standard, and enjoyable, aspect of CBPR, Eng says. "It makes my talks a whole lot more interesting," she says, "and it amplifies their voice to this professional audience."

Nathan Owen Royster, born in November 2001, and his father are reported to be doing just fine and, along with many other men, looking forward to years of good health.

INTERNAL AND EXTERNAL IMPACTS

Michael Reece works to advance CBPR and strengthen the institutions that support it

In January 2001, academic researchers and community-based organizations alike cheered the news that the American Public Health Association had approved the Community-Based Public Health Caucus to promote academic/community partnerships and community-based participatory research (CBPR). The caucus brought designated presentation slots at the association's annual conference, which meant greater visibility and credibility for CBPR throughout the public health profession. There wasn't much time to celebrate, however: the deadline to submit presentations was early February, leaving only a few weeks to pull together an entire program.

Even though he had quite enough to occupy himself as a postdoctoral fellow in the Community Health Scholars Program at Johns Hopkins University, Michael Reece, PhD, MPH, recognized another learning opportunity in taking on the role of planning committee chairman. He laughs at his eagerness to volunteer for a job few wanted. "Everyone else said, 'Good, Michael's doing this, let me know when you need something.' "

It was no small endeavor. Within a week, Reece and the five other planning committee members posted a call for papers on a website. More than 150 abstracts poured in. Committee members and other volunteers reviewed the abstracts, chose those most consistent with CBPR principles, and developed a final program. Most of the abstracts submitted had to be rejected, because there simply wasn't enough space in the program. The overwhelming response to the call for papers was matched by an overwhelming attendance at the October conference: Audiences at the sessions spilled out of the rooms. Most importantly, representatives from both academic and community settings were involved at every step.

It was a watershed moment for CBPR. "Our projects had visibility," Reece says. "They had a national stage. People could see our names and our projects in print. We had some of the nation's leading public health officials wanting to get in our caucus. It invigorated people and created a whole new level of excitement for us to get some validation for doing community-based work."

Reece is low-key about his leadership – "I was the workhorse. I did the work. I can't tap into the fact that there's anything special about the way I did it." – but it's emblematic of his enthusiasm not only to do CBPR but also to strengthen the institutions that support it.

While at Johns Hopkins, Reece partnered with Health Care for the Homeless, a Baltimore agency that provides primary health care to homeless people. Taking a multidisciplinary approach, the agency has a medical team, a social work team and a mental health team. It recently added an addictions team. In Baltimore, which has the nation's highest heroin addiction rate, substance abuse is a major problem.

As the newest team added, and also because of the emerging state of their profession, the addictions team wanted a clearer picture of how its role was perceived as part of the agency's multidisciplinary approach. Laura Gillis, the agency's director of special projects, decided that an understanding of every team's role is crucial to patient care. "Without that understanding, patients may not get the correct referrals, for instance," she says. "Maybe the nurse practitioner won't think, 'Oh, the addictions team can handle this.' "

Reece met with addictions counselors and, based on those conversations, interviewed people throughout the agency – from caseworkers to the finance director to the CEO – about their perceptions of the addictions team. He compiled the responses, which showed the addictions team was more valued than it had thought, and prepared a report to present to all agency managers. Before that presentation, however, he first shared the results with the addictions counselors. "They had control over what was going to be disseminated and when," Gillis says. "They totally directed it."

Reece was experienced in community-based work, but this project was the first time he was viewed as, he says, "the academic." "Several staff members said, 'OK, we've told you enough for now. We'll tell you more when we trust you more.' That was really important for me to hear," Reece says. In fact, Gillis adds, it was necessary for an outside person to handle such a project. "When you're in an agency for a long time, it's hard to see things," she says. "Michael was a non-threatening person. He gained the trust of the addictions team. He let them understand that he would not share their confidences."


Michael Reece presents his research at a meeting of Community Health Scholars Program scholars in Ann Arbor, Michigan.

Prior to coming to Baltimore, Reece had conducted doctoral research with Positive Impact Inc. in Atlanta, which provides mental health services to low-income people with HIV. He maintained the relationship during his fellowship year, applying the CBPR insights he was gaining in Baltimore.

"We started to say, how can we take this research that we've done and use it for the maximum benefit to change the direction of this mental health clinic?" Reece says. One enormous benefit was a grant Positive Impact received from an application that incorporated the research Reece and his partners had conducted. The organization received $2 million over five years, or $400,000 a year. Previously, its entire annual budget had been $300,000. "It provided a level of stability that the organization had never had before," Reece says. "They were on a new playing field. They had new organizational pride to be one of the few agencies in the country to receive that federal funding. I don't think that would have happened if we had not incorporated our research into the application."

When Reece came to Johns Hopkins, faculty members involved in CBPR had begun regular networking meetings to generate support for community-based research. This networking group evolved into the Community-Based Research Consortium. "We discussed building an infrastructure," says Lee Bone, MPH, associate professor of public health and training site director at Johns Hopkins. "Basic sciences have labs, equipment and a cadre of individuals. Why shouldn't this area of research have equivalent components?" At the time, the school's strategic plan was undergoing review. The consortium assumed the task of building CBPR principles into the document.

Reece and Bone gathered input from faculty members and synthesized it into a draft for the strategic plan. In the process, Reece interacted with dozens of faculty and community members and took part in discussions about which projects would best illustrate CBPR. The school's senate adopted their language – the first time core CBPR values were embedded in the school's strategic plan. While no one lives or dies looking at a strategic plan, Bone says, it was important for the consortium to have an early product and coalesce around a shared purpose. "The work Michael did was important and the timing was a terrific first step," she says. Already some early results have emerged, she adds. A staff member has been assigned part-time to the consortium to help with administrative tasks.

Reece's participation gave him a preview of hurdles faculty members face in creating CBPR initiatives within their schools. His experience at Johns Hopkins imparted useful self-sufficiency and entrepreneurial skills, he says: No junior faculty member is going to walk into an academic setting with a ready-made CBPR infrastructure in place.

Now an assistant professor in the School of Health, Physical Education and Recreation at Indiana University, Reece says he's the only faculty member in his department who describes himself as a community-based researcher. He was cautioned not to talk too much about CBPR, because "people don't get tenure for that." "Most people think of doing something with communities as service, with no research outcomes," he says. "So I have to be clear that what I'm talking about is research, but it's community-based research." Meanwhile, he has funding any new professor would envy: He's continuing his work with Positive Impact, supported by the grant he helped secure; he and a colleague received a grant to study health care access of the Amish in southern Indiana; and he's begun a study of male sexuality on campus. All projects apply community-based principles in one way or another. "The skills I took out of the program," he says, "are incredibly transferable across everything I do."

What Does Your Garden Grow?

Katherine Alaimo's work in Flint, Michigan, shows how community gardens produce more than vegetables and flowers.

In 1996, Pete Hutchison had just become director of the Neighborhood Violence Prevention Collaborative (NVPC) in Flint, Michigan. NVPC's charge was to fund programs aimed at reducing crime and violence. The first year the grants were available, Hutchison was surprised to see applications from an unexpected source – community garden groups.

Hutchison had never associated gardening with violence prevention. The applications, however, persuaded him that the two were indeed connected. The green-thumb crowd had seen how gardens bring neighbors together over a shared investment, and it seemed to follow that strong neighborhood ties would discourage crime. "We were seeing all of these tremendous growth indicators in neighborhoods where gardening was taking place," says Hutchison, who has since turned his energies to being director of community ministries at Flint's First Presbyterian Church. Eventually, more than 40 percent of NVPC's grants went to groups for neighborhood beautification and were supported by Flint Urban Gardening and Land Use Corporation (FUGLUC), a citywide umbrella organization.

NVPC partnered with Thomas M. Reischl, PhD, of the University of Michigan School of Public Health to evaluate grant recipients. It had not yet evaluated the community gardens when Katherine Alaimo, PhD, arrived in Ann Arbor in 2000 for a two-year fellowship in the Community Health Scholars Program. Her doctoral research had centered on childhood hunger, and she had worked on a community farm in Ithaca, NY. She also had led an effort to bring locally grown food into Cornell University dining halls. Evaluating community gardens, then, was a natural match for her interests. "I have the best job," Alaimo says. "I get to garden and call it research."

Alaimo was the first of the program's scholars to work in Flint. She could have easily followed the path of previous scholars, who had all worked with established community partners in Detroit. Richard Lichtenstein, PhD, associate professor and training site director at U-M, says it was gutsy of Alaimo to go into, as it were, an unfurrowed field. "She showed us that opportunities were available that we didn't know were available," Lichtenstein says.

Partnering with NVPC – and, by extension, FUGLUC – was Alaimo's first experience with community-based participatory research (CBPR). She attended meetings, developed evaluation tools in cooperation with members, and plain got down in the dirt alongside gardeners. It couldn't have been more different from her previous research, which involved sitting in an office and analyzing data on a computer. "I was researching hunger in kids," she says, "but I never met any of the people I was researching."

In Flint, Alaimo organized a Storytelling Subcommittee within FUGLUC. Storytelling was central to the evaluation process. Members wanted to compile a book of personal stories and photos about how people responded to the gardens, and they also wanted to research two major points: The benefits of community gardens to neighborhoods, gardeners, young people, and other residents; and the existing barriers to and supports needed for community gardening.

"They led by saying, 'We want this,' " Alaimo says, "and I provided the structure," such as asking whom should be questioned and what they should be asked. Hutchison says Alaimo was "sometimes maddeningly insistent" on letting community members steer the project. "Which was good," he says. "It was very neighborhood-driven."

Children from the Ackley Acres Church and Neighbors Garden pose beneath a wal decorated with their handprints.

For example, Alaimo wanted to know how the gardens, by providing a free supply of fresh produce, affected residents' nutrition. But the subcommittee was interested in other things, so Alaimo didn't press the issue. Lichtenstein says Alaimo was wise to concede. "If you go into community-based work and say, 'I'm a nutrition expert, here's what I'm doing,' you're going to fail," he says.

Using four of the city's 16 community gardens as case studies, subcommittee members, including Alaimo, fanned out with tape recorders and surveys to interview gardeners, other neighborhood residents and kids. Alaimo and Reischl also completed a Flintwide telephone survey. The surveys found that gardens resulted in more social support between neighbors and increased pride in the neighborhood. Block clubs and crime watches were strengthened because of the gardens; one club chose the slogan "Bringing Good Neighbors Back."

Several gardens created youth groups, which strengthened relationships between older and younger neighbors, gave kids something to do during the summer, and even led to a few inter-generational softball and volleyball matches. Many gardens reclaimed lots that had been sites for dumping, loitering or drug use. Two garden groups, working with police, got rid of three crack houses.

Many people sensed that the gardens created a beautification impetus that radiated throughout the neighborhood. One participant noted how a once-trashy apartment building has changed: "There is not a stitch of dirt, or paper out of place; [the] entire area is cleaned up. In fact, that's turned around a hundred percent. So if [our beautification efforts] had anything to do with it, I'm extremely happy." Finally, the availability of free, fresh food drew people to the gardens – often, in fact, people other than those who actually tended the gardens. Residents, then, didn't have to work directly on the gardens in order to be affected by them.

The book of stories and photos will contain direct transcriptions of tape-recorded conversations, relating stories in residents' own words. One of Alaimo's favorites is about two young girls who always made faces and rolled their eyes at each other. Then they worked together on the garden. Now, says one, "we call each other sisters."

New to Flint, new to CBPR, new to working with African-American communities, Alaimo confronted the challenges of translating between an academic and community audience. "At the first meeting, I don't think anyone had any idea what I was talking about," she says, laughing at the memory. "I was like, blah blah blah research, blah blah CBPR." One of the FUGLUC leaders helpfully stood up and said, "Here's the deal: She's free and she wants to help." Conversely, Alaimo is learning that a community gardener who says she "spends time with her neighbors a lot more now" is described, in academic presentations, as "experiencing an increase in social capital."

Approaching gardeners with a tape recorder and consent forms also demanded the right words to establish credibility on the spot. It helped to strike a casual tone and say she was "working with Pete," who is trusted in the community. Simply interviewing gardeners, Alaimo says, may help maintain enthusiasm about the gardens. "It never occurred to me," she says, "that just by asking questions about what people are doing makes them want to do it more."

Gardening has always been alluring because it offers stewardship over small acts of transformation. In community gardens, especially in an urban area as economically distressed as Flint, those small acts of transformation multiply – as Alaimo and the Storytelling Subcommittee show – to far more than baskets of tomatoes and zucchini.

The Practice of Policy

Kaytura Felix Aaron spreads the word of community-based participatory research within the federal government.

Not long after taking a job at the Agency for Healthcare Research and Quality (AHRQ), Kaytura Felix Aaron, MD, was approached by a colleague for help in putting on a conference. The topic: How funders, community-based organizations and researchers could advance community-based participatory research (CBPR) nationally to address health disparities. As the leading federal agency responsible for research on the healthcare system, AHRQ is particularly well-poised to serve as a catalyst for change.

Felix Aaron was a natural match for the project. Fresh from a postdoctoral fellowship at Johns Hopkins University in the Community Health Scholars Program, she was eager to teach CBPR to anyone willing to listen.

Initially, Felix Aaron and her colleague considered a small, policy-oriented workshop with nineteen agency grantees working to eliminate racial and ethnic disparities. The objective was to educate them on CBPR and encourage them to partner with communities. Word of the conference got out, however, and interest flared. Additional money came in from the Kellogg Foundation, the National Institutes of Health and other sources. So much for small. The conference expanded into a two-day event that attracted ninety attendees – including leaders from community-based organizations who represent the very populations to whom federal health agencies are accountable. Felix Aaron personally contacted those organizations to bring them into the conference. Importantly, the audience also included representatives from grant-giving bodies who came to acquaint themselves with, and generate support for, CBPR.

"There was across-the-board participation in a way I've never seen before," says Helen Burstin, MD, MPH, director of the agency's Center for Primary Care Research, where Felix Aaron is based.

The first physician to complete the Community Health Scholars Program, Felix Aaron is committed to pushing boundaries between medicine and public health. Her interest in CBPR grew when, after her medical training, she entered the Robert Wood Johnson Clinical Scholars Program and worked with a community-based partnership research program to develop an evaluation tool to assess residents' satisfaction with the home-based services of community health workers. The work took her out of the clinic and into people's homes. "I was often struck by how incidental health was to other social issues," she says. The experience piqued her interest in exploring how residents organize themselves to deal with social issues, including health.

While at Johns Hopkins, Felix Aaron was mentored by public health professors as well as those with appointments in the medical and nursing schools. The multidisciplinary approach demonstrates the expanding acceptance of CBPR in disciplines beyond public health, says Lee Bone, MPH, associate public health professor and training site director at Johns Hopkins.

In addition to being the first physician in the program, Felix Aaron also took the less typical step of entering a position at a federal agency instead of a school of public health. All of this may indicate, Bone says, that "we're at the front end of a movement to integrate CBPR into the sciences and the worlds of medicine, nursing and social work, as well as public health."

Burstin hired Felix Aaron precisely for her community orientation. "If we want to study disparities in healthcare," Burstin says, "only by working with communities will we be able to study the mechanisms of disparities and how to do something about them." CBPR is partly a response to and partly an agent of the changing dynamic between researchers and the populations they study. "There's been a lot of criticism that researchers come into communities and then, we've got your data and we'll call you when we need you," Burstin says. "Some communities were saying no, if you're not going to bring something positive to my community, if you're just going to study us, we're not going to let you in." Communities that are fully engaged in research from the beginning are more likely to use the results to their benefit. Benefit to the community should itself be a research goal, Burstin says.

Successful as the conference was, it was just the first step in what Felix Aaron sees as her main objective – building a CBPR program within her agency and pushing CBPR principles throughout the Department of Health and Human Services.


Kaytura Felix Aaron, left, and Helen Burstin work together to advance community-based participatory research within federal government.

Capitalizing on the conference's momentum, she initiated more CBPR-related exchanges within AHRQ. She briefed staff members who couldn't attend the conference on the ideas that emerged from it, and she prepared a similar presentation for executive management. She's also led efforts with Interagency Work Group, which comprises various agencies within the Department of Health and Human Services, on working collaboratively on CBPR projects.

As a physician, Felix Aaron knows that CBPR is not the province only of public-health researchers but a vital concept for any medical professional or policy-maker who cares about quality of and access to healthcare. As she puts it, "It's a way of engaging, a way of working with communities." Toward that end, Felix Aaron is co-editing an upcoming issue of *The Journal of General Internal Medicine* devoted to CBPR. "That," she says, "is a new audience." She also was invited recently to join the board of Community Campus Partnerships for Health.

During her fellowship, Felix Aaron pursued her interest in exploring how community residents organize to deal with social issues. She worked with residents in the Middle East neighborhood of Baltimore, a distressed area beset by vacant buildings, drug activity and other challenges. Residents also work with its largest employer and dominant institution, the Johns Hopkins University medical school and hospital, to improve the neighborhood and what has historically been an uneasy relationship between the university and the community.

During Felix Aaron's tenure, a major concern for residents was a proposed redevelopment plan that included a Hopkins expansion into the neighborhood. As someone affiliated with Hopkins and, moreover, who lived outside the neighborhood, Felix Aaron knew it was important to be clear about her role as a scholar, not a representative of any particular institution or viewpoint. At one meeting, a resident flat-out asked her where she lived. Knowing that her answer would test her credibility – Would she lie? Would she make excuses? – Felix Aaron simply said the name of the suburb. "That's nothing like this, is it?" the questioner said. "Yes, it's nothing like this," Felix Aaron agreed. She and the man went on to become good friends. "It taught me the need to be honest and the need to engage in honest and respectful dialogue," she says. "It would have been very easy for me to assume that, because I'm African-American, I had license to that community without being sensitive or thoughtful. I think they appreciated that I was."

The neighborhood redevelopment plan called for the demolition of buildings and the relocation of some apartment tenants and homeowners. The group overseeing the redevelopment plan included members from neighborhood groups, John Hopkins, businesses and churches. Still, some Middle East residents felt their concerns weren't well represented in decisions, such as those affecting where they were moved, or if they moved at all. "They wanted development and changes," Felix Aaron says. "But at the same time, there was a lot of concern over the process of redevelopment."

Middle East residents decided to prepare their own plan to present to the redevelopment group. Felix Aaron helped them identify their needs for secure housing, children's safety, recreation and other topics. Her entire training had been in medicine and health, but Felix Aaron found herself designing housing layouts that discouraged drug activity and traffic-diverting street patterns. She tracked down information for residents and offered opinions when asked, but she describes her involvement as that of a "participant observer." "It was a very informative experience that I still carry with me, not only for the problems they faced but how communities relate to huge institutions."

After the fellowship, Felix Aaron considered going into academia. But she decided – nudged by Burstin's avid recruiting – that a federal agency would permit a rich combination of research, writing and policy-relevant work. "I see myself as someone who straddles the community and the professional," she says.

Every Thursday afternoon, Felix Aaron climbs aboard a mobile van that drives around Montgomery County, Maryland, to give low-cost or free care to people without health insurance. Working to promote CBPR among policy-setting federal agencies and other health professionals is an extension of her concern for the health of poor communities. Her job puts her precisely where she wants to be: at the intersection of policy and practice. "That's the most important thing the fellowship did," she says. "I gained clarity into where I fit in and where I want to place my flag."

Justice for Flood Survivors

In the aftermath of Hurricane Floyd, Stephanie Farquhar helped displaced residents speak up for their rights and their dignity.

On September 16, 1999, Hurricane Floyd ripped through eastern North Carolina, killing 51 people and destroying tens of thousands of homes. A year later, when Stephanie Farquhar, PhD, arrived at the University of North Carolina (UNC) for a postdoctoral fellowship in the Community Health Scholars Program, the waters had receded but the recovery was far from over. About a thousand people, most of them African American, still lived in temporary housing. Infrastructures had yet to be rebuilt. Jobs had yet to be replaced.

For Farquhar, the aftermath of Floyd presented a rich opportunity to combine academic research with her interest in environmental justice. A year after the flood, many residents, having survived the hurricane, felt victimized a second time by federal and state agencies. The relief process seemed designed to obstruct, rather than expedite, recovery. For example, agencies required papers to prove home ownership or rental agreements, but many people had lost those documents along with everything else. The Federal Emergency Management Agency (FEMA) placed an 18-month limit on temporary housing – not enough time, survivors complained, to rebuild a life. And word got out that the governor intended to use FEMA not to help the survivors but to erase the state debt.

It was clear to many that racial discrimination tainted relief efforts. Immediately after the hurricane, whites were put up at motels while blacks slept on floors in schools. One of the most serious concerns was the discovery that four hundred temporary trailers sat on top of a landfill – not a sealed landfill, but one that had been active up until the hurricane. Almost everyone housed in those trailers was African American. Some survivors faced degrading accusations of "freeloading" in temporary housing. At a meeting with flood survivors, one government official, in front of the media, told residents they should worry less about housing and more about "all the illegitimate kids your teenagers are pumping out."

Even before Hurricane Floyd, residents in eastern North Carolina faced poverty, racial discrimination, unemployment and other challenges. The hurricane worsened those problems. "They just felt like they didn't have a voice, like they had to accept what was happening," says community organizer Naeema Muhammad.

Farquhar and Muhammad met at a meeting of the Workers and Community Relief and Aid Project, a community-based coalition formed to unify and empower flood survivors. Almost at once, they were talking about how they could work together and with residents so survivors could get what they needed.

"It had been sort of anecdotal about what (survivors) had experienced," Farquhar says. "We needed to do something more systematic than coming together once a week and griping about decisions." Survivors needed, in short, to compile their experiences and present them in a digestible format to distribute among decision-making bodies and the media. They began with a survey.

In the spirit of community-based participatory research (CBPR) espoused by the Community Health Scholars Program, the flood survivors took the lead in designing and conducting their survey. First, they came up with questions they wanted answers to – on health, housing, media representation and other issues. When the key questions were settled, Farquhar made sure their wordings were scientifically sound. Then came perhaps the most important piece: Farquhar helped design materials used to train ten survivors so that they could interview other survivors themselves.

As an academic schooled in the protocols of designing and conducting surveys, Farquhar could have easily handled the whole survey project herself. But that would have undercut CBPR principles. "If I went out and collected the data, we wouldn't have trained the people most affected," she says. "It would have been me, the health professional, doing it. Now, if they want to do another survey after I've gone off, they can."

Muhammad felt equally strongly that the survey should be community owned. “The survivors weren’t sure that they could bring information forward,” she says. “We were able to show them that they could.”

A sign reflects the frustration of eastern North Carolina residents, who banded together to change the way government relief agencies treat survivors of natural disasters.

Farquhar’s work showed the need in rural areas for environmental justice, usually thought to be an urban issue, says Eugenia Eng, DrPH, associate professor and training site director at UNC. “She did a great job,” Eng says. Her background in health education was particularly valuable in training flood survivors to develop a survey and collect data.

By the time the questions were ready and the surveyors trained, it was December 2000. A March 2001 deadline loomed to vacate temporary housing. Working fast, the surveyors questioned 270 survivors in ten temporary housing sites about their experiences, frustrations and needs. Farquhar compiled a report, enlivened with photographs and quotes from survivors, detailing the injustices suffered by residents. She tapped her $10,000 research allowance to print, photocopy and mail the reports. (The money also funded training materials for the surveyors.) The report ended with survivors’ demands for improving relief efforts for Hurricane Floyd and future disasters. The demands included extending the 18-month temporary housing deadline, using FEMA money for survivors’ needs only, and involving survivors in decisions that affected them.

The survey report received media attention and led to a summit, held in February 2001. Survivors aired their grievances before government officials and the media, which gave the summit extensive television and newspaper coverage. The summit resulted in some substantial changes in flood relief policy. FEMA extended the temporary housing deadline by one year. The governor agreed to direct FEMA funds to survivors, not to eliminating the state budget deficit. He also established an advisory council to investigate recovery policies and suggest improvements. Muhammad sits on the council as a survivor representative.

Farquhar now is an assistant professor in the School of Community Health at Portland State University. In North Carolina, justice efforts for flood survivors are ongoing. Muhammad has no doubt that Farquhar’s involvement left survivors in a much better position to advocate on their own behalf. “We think there was a lot of growth amongst the survivors as a result of our work,” she says.

Coming in to her fellowship year, Farquhar says, she was “on the fence about going the academic route.” Her work with the flood survivors helped her see how she could incorporate community projects with an academic post. “It’s not just about research and publications, but bringing about some social change,” she says. “The community/university partnership strikes me as such as a necessity.” Since joining the Portland State faculty in fall 2001, she’s met with several community groups to see how she can fit in as “a university person.” Her efforts have attracted interest from her colleagues as well, who are interested in how Farquhar combines academic and community-based work. “And students really want to know about it,” she says. “They want to know that they can learn stuff in the classroom and then go out and use it.”

Perhaps one of the most important qualities an academic can bring to a partnership, Farquhar says, is humility. “Even if you bring formal skills, you have to recognize that you’re an outsider. They didn’t treat me like that (in North Carolina), but they were very gun shy about dealing with university people. So hopefully they saw that all university people aren’t bad.”

It’s true, Muhammad says, that past experiences with academic researchers made her wary of dealing with a university person, despite the potential benefits of having access to a scholar’s knowledge and the university’s resources. She addressed this concern with Farquhar up front. “We made it very clear – we need this opportunity but we won’t do it at the expense of the community,” Muhammad says. “I don’t mind a researcher coming in if people are going to gain from it. But if the community is exploited because of it, we’re not going to agree with that.”

None of her worries came to pass. “Stephanie was very humble and just so pleasant to work with. Her attitude was one of respect, as well as eagerness to learn from the survivors – not coming in with all the answers, but stepping back and giving people the space to feel what they feel.

“We all fell in love with Stephanie and we miss her,” Muhammed says. “We sure do.”

COMMUNITY HEALTH SCHOLARS PROGRAM

SCHOLARS

1998-1999

Cynthia Lanier, DrPH, RN

Diane Marie St. George, PhD

Edith Gaylord Clark Wolff, JD, MPH

Anna M. Yeakley, PhD

1999-2000

Diane C. Calleson, PhD

Vivian Chávez, DrPH

Kaytura Felix-Aaron, MD

Shannon Frattaroli, PhD,

Angela M. Odoms-Young, PhD

Sharla K. Willis, DrPH

2000-20001

Stephanie Farquhar, PhD

Michael Reece, PhD, MPH

2000-2002

Katherine Alaimo, PhD

Lisa Benz Scott, PhD

Michael Royster, MD, MPH

Yamir Salabarría-Peña, DrPH

Andriette Ward, MD, MPH

2001-2003

Precilla Belin, PhD

Scott Rhodes, PhD

Incoming 2002

Clarence Gravlee, PhD, *expected August 2002*

Derek Griffith, PhD, *expected June 2002*

Sonya Jones, PhD, *expected May 2002*

Tracey Lewis-Elligan, PhD

Michael Lindsey, PhD, *expected May 2002*

Iveris Martinez, PhD

Siobhan Maty, PhD, *expected summer 2002*

Ellen Smolker, PhD, *expected August 2002*

Deanna Williams, PhD, *expected summer 2002*

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