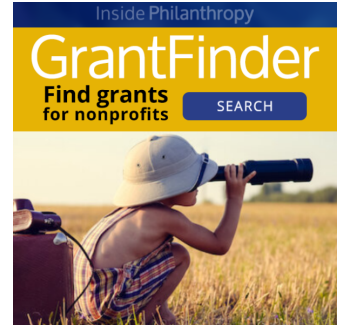


How Robert Wood Johnson's Centering Communities in Health Research

Laurie Udesky | November 27, 2024



A COMMUNITY WORK GROUP IN SAN DIEGO DELIBERATES WAYS TO REVAMP EMERGENCY RESPONSE SERVICES TO MAKE THEM SAFER AND

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A new \$20 million partnership between the [Robert Wood Johnson Foundation](#) and the American Heart Association aims to tackle health inequities by upending the way that academic research is done. It's part of RWJF's ongoing efforts to cultivate community input and [challenge traditional hierarchical dynamics in philanthropy](#), efforts that include a number of community-centered research projects.

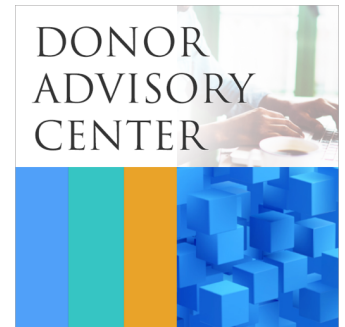
Instead of the typical top-down approach, the new initiative puts communities affected by adverse health outcomes in the driver's seat, according to Alonzo Plough, RWJF's vice president of research-evaluation-learning and chief science officer. "We're trying to be a catalyst with partners to walk that talk," Plough said.

"We hope that others at academic institutions will begin to appreciate that this model has relevance for what I think drives all of us, which is better insight on how to achieve best health for the most people," said Dr. Eduardo Sanchez, chief medical officer at the American Heart Association (AHA).

RWJF and AHA selected three projects developed by community organizations who will be working in tandem with university-based researchers. The Greenville, South Carolina-based [LiveWell Greenville](#), for example, is a coalition of community groups in Greenville County that

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work on empowering people in underfunded communities, primarily communities of color, to push the levers of power to promote “healthy eating and active living.” To that end, explained its executive director Sally Wills, the group advocates for such improvements as getting more street lights and sidewalks to make a community more walkable.

Through preliminary research, however, LiveWell Greenville came to understand that something was missing from their grassroots work. Those from the community who had stepped up to take leadership roles were well versed in the issues around health inequities and what was needed to fix them, but they had little understanding of the governmental power dynamics they were hoping to change, according to Wills.

“If you don’t even understand the pathways to start having conversations to change the environment in which you’re living, you can’t become your own advocate,” she said.

That’s where the university partner comes in. Furman University in Greenville will help review the research, working hand in hand with community members with first-hand experiences of racism and health inequities. Starting in January, LiveWell Greenville will be recruiting people from the community to sit on a research advisory board to fulfill that role. LiveWell Greenville and the community are investigating how participation in the advisory board increases its members’ knowledge about power, community organizing, how local government works, and whether their participation helps them grow their social networks around organizing. (Here’s a [link](#) to information about the other

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two projects selected by RWJF and AHA.)

“Positively disrupting research”

The notion of “positively disrupting research,” as RWJF’s Plough put it, aligns with a broader approach the foundation takes in pushing for and supporting ways to level the playing field in healthcare.

An example of ongoing work in this regard is the foundation’s [Interdisciplinary Research Leaders program](#), which assembled its first group of leaders in 2016. The idea is to have community-based advocates working with academic researchers “to address an issue that is intimately interwoven into the experience in the fabric of that community,” said Sheldon Watts, RWJF’s program officer for research, evaluation and learning. Each group or cohort has a different area of focus. In past years, groups focused on issues including early childhood, violence prevention and delivering healthcare to rural areas. The current cohort’s focus is on structural racism.

One prime example of the model in action is a group of researchers who have been working on revamping which emergency responders respond to 911 calls. The current project is building on an existing one, which was originally launched in [2020](#) by the California-based Public Health Advocates in response to community members seeking help in researching alternatives to the status quo in emergency response.

It is needed, said Dr. Kristina Gelardi, Public Health Advocates’ director of research and learning, because

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responders who showed up to calls were too often unhelpful, or even harmful. “Communities of color, queer communities and those who are unhoused were more likely to experience harm as a result of that than white communities in particular.” Gelardi’s [team](#) also includes Dr. Shani Buggs, a public health researcher at the University of California at Davis and an expert in firearm violence and injury prevention, and Dr. Susan Perez, a health services researcher at California State University, Sacramento, whose expertise is around building patient values into policy solutions.

High-profile local cases illustrate, for example, why law enforcement officers are not the best responders to many emergencies. Take the [fatal 2022 shooting](#) of Jaime Naranjo, a Sacramento County man whose family called 911 for help as Naranjo was in the midst of a mental health crisis. In fact, more than 4 out of 10 people who are injured by police shootings had been suffering from mental health or substance use problems, according to [a report](#) by the Public Policy Institute of California.

Community involvement in research of the type RWJF is attempting to foster here can also help shift opinions. In one session when the topic of mental health crises came up, for example, Perez recalled that several members of a community civic engagement group charged with weighing in on issues to inform policy said that such a crisis was solely the responsibility of the family to deal with.

A father who had a child with severe mental health problems said that belief was misguided — that his child in

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crisis could not be handled by the family without help, Perez said. “And after hearing that father’s situation, so many were swayed and had a deeper understanding.”

The conversation also served to educate other participants about the value of alternative responders. The father shared with others that police encounters with his child were fraught. “He said there were times that he had to get between police and his child,” Perez said. But he had found out about an alternative response helpline, which the family now uses. Typically, [alternative response teams](#) answering mental health crisis calls deploy clinically trained civilians who are skilled at de-escalating people experiencing mental health crises.

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Additional projects on the Gulf Coast

Other efforts RWJF is backing to put community needs at the center of research include a series of public health research projects located around the Gulf Coast, which the foundation is funding along with the National Academies of Science, Engineering and Medicine.

One project, “A Right to Be Counted,” involves researchers working with two communities to ensure that policies

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around the collection of public health data better reflect the impact of climate change, pollution and health disparities and health needs. One of the communities is in South Texas' [colonias](#), low-income communities along the Texas-Mexico border that typically have makeshift housing and lack access to fresh drinking water and sewage treatment, among other resources and services. The other community is in [Manchester](#), Texas, an area where toxic fumes billow out from nearby refineries.

“The fundamental goal of this project is to bring the voices and values of these communities into the ongoing policy discussions,” said Cason Schmit, a co-principal investigator of the project and an assistant professor at Texas A&M University’s School of Public Health. “Ultimately, we hope that future public health data systems better serve these and other communities.”

Summing up RWJF’s work in community-involved research, Plough said, “We’re trying to improve the ability of research and knowledge builders to connect the best of traditional medical and public health science and add the missing part of social, contextual, historical community experience into the mix as evidence.”

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