

“WHAT EXACTLY DO YOU MEAN BY THRIVE?”

A PARTNERSHIP THAT DIGS DEEP TO LIFT
PITTSBURGH KIDS | BY GAVIN JENKINS

PHOTOGRAPHY | AIMEE OBIDZINSKI/
UNIVERSITY OF PITTSBURGH, EXCEPT WHERE NOTED

Reverend Paul Abernathy has heard the story so many times that he can tell it as though he'd been there: Many years ago, a team of researchers studied the effects of adverse childhood experiences among Black residents in Pittsburgh, and they presented their results at a crowded church. Excited to share their work, the researchers delivered a slide presentation with graphs and charts that explained the consequences of childhood trauma.

However, the researchers hadn't engaged deeply with members of the community while gathering the data. For most of the Black people in the crowd, this was the first time they had seen these White academics, who were uttering words about their children like “at risk” and “mental health problems” and “juvenile justice system.”

As Abernathy tells it, at the end of the presentation, a woman raised her hand and said: “So, you're saying we're all messed up.”

That's how the presentation came off, says Abernathy. “It was: ‘You people have been through so much trauma that you're all screwed up.’”

Abernathy, who leads the congregation at Saint Moses the Black Orthodox Christian Mission in Pittsburgh's Hill District, says this anecdote is widely shared in the city. And it demonstrates that how researchers approach a study can undermine efforts to help a community.



Reverend Paul Abernathy (left) runs the Neighborhood Resilience Project, one of several local nonprofits that are part of the Pittsburgh Study.



The Pittsburgh Study is 20-year effort that will enroll 25,000 Pittsburghers, from right before birth to adolescence, and collect a broad range of data to determine the most important biological, social and community influences to childhood health and thriving. More than 100 investigators from the University of Pittsburgh and from the community are shaping the scientific questions that will lead to developmentally appropriate interventions.

Cohort study designs include experimental studies of parent-child interventions and randomized trials of community-designed programs in schools and neighborhoods, as well as longitudinal surveys and other tools.

Five years into this collective impact initiative, study organizers expect to see a 25% increase in youth's future orientation (a predictor of young adult health and well-being) and an overall increase in high school graduation rates. The big goal: Find out what factors help children thrive in Allegheny County and address root causes of inequality.



A student leads the class in morning activity in a first-grade class at Beechwood Elementary School. (Photo by Jay Manning/ PublicSource)

Val Chavis has been instrumental in shaping the Pittsburgh Study.



The Pittsburgh Study, which aims to find out what factors help children thrive in Allegheny County and address root causes of inequality, has been structured to avoid the mistakes of past research projects. The team consists of well over 100 community members and 73 academics, with cooperation from 16 area school districts and several nonprofit organizations like the Neighborhood Resilience Project (which Abernathy leads), as well as support from Children's Hospital of Pittsburgh Foundation, the Grable Foundation, the Heinz Endowments, PNC, the University of Pittsburgh and the Shear Family Foundation.

Initiated by Terence Dermody, Vira I. Heinz Distinguished Professor and Chair of Pediatrics, and Elizabeth Miller, Edmund R. McCluskey Professor of Pediatric Medical Education, the Pittsburgh Study plans to recruit between 20,000 and 25,000 participants from Allegheny County in the next two decades.

It's the largest community-partnered intervention study following children (and their families) from before birth to adulthood. The study develops and tests interventions at various developmental stages.

Studies of this variety often receive feedback through community advisory boards, but that kind of engagement doesn't go far enough, says Miller, who also serves as director of the Division of Adolescent and Young Adult Medicine at Pitt and UPMC Children's Hospital of Pittsburgh.

"We wanted community members engaged in the science," Miller says. "We flipped the script and invited people who would have been community advisors to be citizen scientists."

Dermody, physician in chief and scientific director at Children's, chose Miller to lead the study from the academic side because she has more than 20 years of experience in community-partnered research. She's an international expert in this field, he says. "Her work with young men to prevent intimate partner violence has been copied all over the country."

Miller asked Val Chavis, with whom she had collaborated previously, to colead from the community side.

At the time, Chavis was the project director of the Urban League of Greater Pittsburgh East Hills Family Support Center. She'd also taught

Pitt Med and Public Health students about how racism permeates health care, eroding wellness.

Chavis joined and influenced the study immediately. In August 2018, Chavis, Dermody, Miller and several other researchers were meeting at Children's to discuss how to get the study started.

Chavis sat next to Dermody at a long, wooden table in a conference room and listened as he explained how the study would identify the most important determinants of a child's thriving.

Chavis interrupted: "Why did you use the word 'thriving'? And what exactly do you mean by 'thriving'?" She suspected that the meaning of the word probably differs from household to household.

"We went from talking about the word 'thriving,'" Chavis recalls, "to talking about taking it to the communities and asking people, what does 'thriving' mean for their family? Their community? For Allegheny County?"

Miller calls it a powerful moment. "It really opened up the possibility to host listening sessions using a pretty systematic approach."

Chavis and Miller visited groups of people in the East Hills, Sheraden and Hazelwood—geographically distinct neighborhoods with concentrated poverty—to examine the definition of thriving.

It helped the study organizers enormously, says Miller: "We really started to think about what we need to measure."

Published in *Academic Pediatrics*, the results were called the Child Thriving Matrix, a framework for understanding child thriving, using the words of community members. Participants included 91 community members, health care and social service professionals, and researchers.

When children are comfortable in their own skin. When they have someone to talk to. When they have pride in themselves and a strong sense of self-worth. These attributes and more were seen as key to whether a child would thrive. (See sidebar for full list of clusters the participants identified.)

The Child Thriving Matrix served as a guide for how Miller and Chavis structured

the Pittsburgh Study and built its team. The study is organized into two types of collaboratives: age-based collaboratives and cross-cutting collaboratives. The age-based side of the study focuses on five stages of development: pregnancy, early childhood, early school age, middle childhood and adolescence. The adolescent stage has two sub-cohorts: middle school and high school. Like the overall study, each cohort has an academic coleader and a community coleader.

The cross-cutting collaboratives examine what actions can be taken to improve lives. Those cohorts investigate a wide range of questions including, Why aren't Black children receiving the same health care as other children? How can that be made equitable? And how can we best share relevant data with the public?

In 2019, Chavis was recruited as the service and outreach coordinator for Pitt's Center for Parents and Children. She continues to work on the Pittsburgh Study. Felicia Savage Friedman—founder of YogaRoots on Location, based in Pittsburgh's East Liberty neighborhood—has replaced Chavis as the Pittsburgh Study's community codirector.

REVISE, REFINE

Working iteratively and collaboratively has been a common theme for the Pittsburgh Study.

For instance, at the beginning of the pandemic, leaders of the Pittsburgh Study Early Childhood Collaborative got together and composed drafts of a consent form and questionnaires to begin recruitment.

Chavis says with the assistance of community members, the collaborative learned that the proposed consents and questionnaires were too long and had words that might not even be understood. "People would read it, see certain words and then think, 'I'm not answering that question.'"

Sometimes, the way the question was framed would completely throw people off, says Chavis. “We even had to take a look at the length of the consents and questionnaires and how this may impact new mothers.” They realized that some might conclude, “I have a newborn; I don’t have 30 minutes to sit here and do this,” Chavis adds.

Also, the surveys that were intended for new mothers missed something. The first thing the researchers should do is acknowledge the major life event of welcoming a child into the family, Chavis says. The community cohort members urged their academic counterparts: “Be nice and congratulate them.”

Between navigating the survey revisions and inspiring the Child Thriving Matrix, Chavis seemed like “an angel who descended from God in heaven to help us with this work,” says Dermody.

Chavis credits Miller and Dermody for creating a comfortable environment where everyone feels heard. “It’s really a conversation that most people would never have with doctors, scientists and researchers.”

to a triangle: Researchers and the data they collect are in one corner; the members of the community and what they need to thrive are in another; policymakers are in the other corner.

“Very rarely do they work together,” Bey says. And that’s one reason he’s hopeful about the Pittsburgh Study.

He’d like to see the Pittsburgh Study

answer the question, “How do we have a broad conversation to shift the focus from short-term thinking on single issues to thinking about the connectivity of all these issues?”

Dermody is optimistic. “Everyone in the country will know about the Pittsburgh Study when we’re done,” he says. “We’re excited about working together to help children thrive.” ■



Elizabeth Miller (in glasses): “Historically, the focus has been on educating communities—‘fixing’ their mistrust—as opposed to turning the mirror onto ourselves [as professional scientists] and saying, ‘What is it that we need to do to be more trustworthy?’” (Photo courtesy UPMC.)

WHAT’S THE MESSAGE?

The episode in the church that Abernathy shares shows how researchers can send the wrong messages to communities.

Researchers want to contribute to a canon of knowledge that helps people, according to Jamil Bey, founder of the UrbanKind Institute, but that may not be what gets remembered. He says, “Very often it looks like you’re the bad guy for being a poor person in that neighborhood. ‘Here’s what you do. You’re the problem; we’re studying you.’”

Bey, who has a PhD in geography and is community colead for the Policy and Place collaborative and on the leadership team of the Pittsburgh Study, wants to see action fueled by research. His team is focusing on the policies and institutions that can improve the welfare of children so that they achieve their academic goals.

He says community studies often boil down

BRAIN CHILD

For many days and nights, in many online sessions, nearly 100 health care and social service professionals, researchers and members of overburdened Pittsburgh communities came together to help chart the course of the Pittsburgh Study. In a series of brainstorming sessions, they sorted and rated interpretations of what it means for a child to thrive, coming up with eight distinct clusters associated with the word:

safety * strong minds and bodies * positive identity and self-worth * healthy environments * vibrant communities * caring family and positive relationships * fun and happiness * racial justice, equity and inclusion

Community members were more likely to name “safety” as a prerequisite for thriving than researchers were. They also ranked “fun and happiness” as more important to child thriving than did researchers.

Pitt’s Anna Ettinger, a PhD research assistant professor of psychology, Val Chavis, Elizabeth Miller and others published the results in the January/February 2021 issue of *Academic Pediatrics*; the researchers refer to their findings as the Child Thriving Matrix. The matrix and the associated measures of thriving will serve as touchstones as the researchers continue to partner with community members to figure out how to help get families and kids the support they need to thrive. —GJ