

Title: Cultivating a Teachable Spirit: A First Step Toward Co-Creation

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On April 22, 2021, [All In: Data for Community Health](#) kicked off the Developing Meaningful Measures by Centering Community Voices Affinity Group with subject matter experts from the [American Institutes for Research \(AIR\)](#) and [Patient Family Centered Care \(PFCC\) Partners](#). The launch of this Affinity Group was filled with so much enthusiasm, as approximately 100 participants from across the nation gathered virtually. This kickoff was one of six sessions created for people to share best practices on how to build and sustain trusting relationships with people who have diverse lived experiences and to co-create measurement that is driven by and focused on what communities know matters most to their health and well-being. The ultimate goal is to elevate community power in data sharing efforts and advance health equity.

The design of this Affinity Group is rooted in AIR work funded by the Robert Wood Johnson Foundation focused on how to use measurement to drive transformative, meaningful, and sustainable change. For more than five years, AIR and PFCCpartners have collaborated together on a project focused on patient-centered measurement, that is, health care measurement driven by patients' and caregivers' expressed preferences, needs, and values. This project showed that the key to making measurement patient-centered is for measurement teams, patients, and their caregivers to do measurement work together as equal partners. Equal partnership is when patients, families, and community members co-create, or decide together what metrics to measure, how to measure them, who should get the results, and how to use those results.

Members of the DASH National Program Office team sat down with the lead facilitators, Karen Frazier of AIR and Libby Hoy of PFCCpartners, to learn more about how their partnership mirrors what they are teaching in the *Developing Meaningful Measures* Affinity Group. At AIR, Karen's work focuses on how centering people and communities in measurement can lead to systems change. Libby got started in this line of work as a mother of three sons with mitochondrial disease, who each had a total of six specialists. After many long nights in the hospital, Libby realized that in the culturally diverse city of Long Beach, California not everyone who entered the hospital had the same opportunity to partner and set a team approach to care. It was extremely helpful for Libby and her family to have a pathway to care that was in direct alignment with their values. As a result, partnership has been at the core of PFCCpartners's work. Libby noted, "This is really interesting too is that [w]e came from two different perspectives, obviously lived experience and professional but also, you [Karen] looked at systems first and I was in the middle of a system and never saw the system," said Libby of PFCCpartners.

AIR's work in patient-centered measurement alongside PFCCpartners's lived experience is a dynamic duo. Together, PFCC and AIR co-create the Affinity Group meetings. This requires them to



trust, listen to one another, and be both flexible and ready to change plans. When asked, what trust looks like in their partnership, they stated that it is essential to have an open space for people to talk where others are ready to listen, hear, and understand other perspectives, and then take action on what is heard. Karen added, “all partners should be treated and valued as equal members of the team. They should have access to all the same information as other team members, they should be included in the team’s activities, and their ideas should be acted upon.” It is important for organizations entering into partnerships with community members to be authentic, humble, and ready to learn, recognizing what they do not know. According to Libby, “when building authentic relationships; we must be prepared to be incompetent.”

This Affinity Group is focused on partnering with community members around measurement because measurement is directly connected to power! Karen points out that traditionally, “measurement is used by those in power to set goals, define success, and determine resource allocation.” An important part of changing systems and making them more equitable is changing how those systems use measurement. Re-centering *measurement* around people and communities—especially those who have been excluded and marginalized—helps to recenter *systems* around people and communities. Karen describes that by co-creating measurement with patients, families, and communities, we can “focus on what they care about, center their voices in the decisions that impact them, realign power structures, and build equity into systems as opposed to reinforcing inequities.” Measurement also provides an outlet for patients, families, and communities to act on the sense of urgency that they feel in the face of an inequitable system. Libby mentions that “measurement activities are complicated, but they give us, community members, an informed path forward. We cannot fix a problem that we cannot see because it hasn’t been measured.”

When asked what they have in store for this Affinity Group, Libby informed us that they are sticking to co-creation - to decide together with the participants what topics to cover. Karen and Libby’s greatest hope for participants is that when they walk away from the sessions, they have cultivated what Libby refers to as a “teachable spirit.” This means that when partners approach measurement work together they are prepared to build and sustain trusting relationships by recognizing that there is a lot that they do not know. It means decentering themselves and listening, hearing, and valuing their partners as equals when identifying shared goals and co-creating measurement. It means having humility! Humility is at the heart of every meaningful partnership centered around measurement, as it has the potential to contribute to more equitable systems that reflect the needs and priorities of communities. This Affinity Group will continue to engage organizations and individuals from across the country, who are interested in leaning into meaningful partnerships to do measurement work.

This Affinity Group has not only been well received, but has given DASH awardees an opportunity to learn, connect with peers, and gain insights on how to advance the field through measurement and community partnership. It is not too late to join this Affinity Group which meets virtually, every 4th Thursday at 11:00 a.m. central standard time. [Click here](#) to learn more about the



Developing Meaningful Measures by Centering Community Voice Affinity Group and a listing of other Affinity groups on our webpage.