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Learning How to Do Community Engagement Correctly

Kylie Mattson

Learning How to Do Community Engagement Correctly

Public health has long been a profession dedicated to helping to protect and improve the lives of the communities they serve. Over the last couple of decades, there has been countless research that has investigated the positive effects of community engagement within public health. In 1995 the Centers for Disease Control and Prevention (CDC) officially created the Committee for Community Engagement, this committee is dedicated to helping serve underrepresented communities and helping connect public health officials with the people they serve (Home | Principles of Community Engagement | ATSDR, 2018). This committee's overall goals are to build trust within communities, open up communication, build new allies, create new resources, create long-term solutions, and improve overall health outcomes. However, even with this new committee it is clear there are many inadequacies, public health officials struggle to create change and gain trust within the communities they serve today (O'Mara-Eves et al., 2013). This divide has the potential to be bridged by learning from other, stronger communities. As we've learned throughout this class the Disability community has embodied the word "community," as they have strengthened not just a small percentage but everyone within. Before understanding what community engagement looks like within the scope of public health, it's important to understand how the CDC sees community. The CDC defines community in two different ways — "those who are affected by the health issues being addressed" and by referring to "stakeholders such as academics, public health professionals, and policymakers" (Home | Principles of Community Engagement | ATSDR, 2018). With this understanding, engagement can come in many different ways. When we think about community engagement we often associate it with volunteer work,

activism, or community projects that take place within a given community. While some of this might be true regarding public health, it mainly entails working collaboratively with affected communities and their stakeholders to help create the best possible health plan for any health disparity or health behavior that needs changing. Examples of health behaviors can include getting a vaccine or quitting smoking. Working collaboratively with communities helps alleviate any power imbalances that may occur, helping public health officials create long-lasting health plans that work seamlessly within the community.

As much as community engagement has been heavily emphasized in every aspect of this field many pitfalls still occur. An example of this comes from a story I was told in class. My professor was in Kenya at the time working with the community to help with STI transmission in sex workers, while he was there another public health official with a large grant was trying to help with an influx of AIDS/HIV in a nearby area. He planned that he would give out six months of groceries to any local who was HIV positive, when he did this, he unknowingly caused a boom of cases as the community had extreme poverty issues where many could barely afford to feed their families. The people within that community purposefully contracted HIV so they could feed their families and the official left the community to deal with the consequences. He not only made a bad public health issue dire, but he also came in with all the power, no prior knowledge of the community, and no desire to engage. This, sadly, occurs far too often.

So how do we, as public health officials, learn from the disabled community on how to improve our community engagement skills? The community has largely been ignored by not just public health officials but by the world. The world does not see their needs as needing to be met or heard. “The history of disabled queer and trans people

has continually been one of creative problem-solving within a society that refuses to center our needs” (Berne, 2020, pp. 291–295). It has forced the community to create solutions together. Thus, we must look at the “10 Principles of Disability Justice” to seek the tools to make a change. Specifically, I'd like to look at four of the principles; Sustainability, Commitment to Cross-Disability Solidarity, Collective Access, and Collective Liberation (Sins Invalid, 2015). Each of these principles holds the keys to creating successful plans for community engagement.

As stated above one of our goals with community engagement is to create long-standing change, something that will work within the communities for years to come. In the “10 Principles of Disability Justice,” the principle of Sustainability is described as a way to create a pace for yourself individually and collectively to help create a sustainable guide to ongoing justice (Sins Invalid, 2015). The part I want to focus on is “creating a pace” for sustainable change this step takes patience and can be time-consuming as it rarely is a “quick fix.” There are principles of community engagement that address time constraints and express that there needs to be long-term involvement within the community, however, the implantation of this principle is always lacking (Minnesota Department of Health, 2018). An example of this is, “During the fires in Northern California, a black queer environmental justice activist with asthma went into respiratory distress and now lives with permanent brain injury” (Berne, 2020, pp. 291–295). This may not seem like an example that requires long-standing engagement, but in California, there is an understanding that forest fires are a common occurrence, especially over the last decade. There are some plans put into place if one does occur that involve evacuations and some medical help, but there is a lack of common medical supplies available for

people who may be facing medical emergencies at that time. Health plans for all matters of issues should be thought of and made sure that supplies are available to the communities years ahead.

For the principle of commitment to Cross-Disability Solidarity, Sins Invalid writes, “We honor the insights and participation of all of our community members, knowing that isolation undermines collective liberation” (Sins Invalid, 2015). In the documentary *Crip Camp*, we are told the story of how one camp was able to bring together many people with different types of disabilities, creating a safe space for people with disabilities to learn that they can accomplish tasks on their own and be able to live more independent lives. At this camp, the collective community shared their own experiences and brought in ideas that had the potential to change how others lived their lives (Netflix, 2020). With public health, it should be a similar experience. As we strive for better community engagement, we must keep our ears open to any ideas from the collective community. Our goal is not to work for the communities but to work with each other to create change. If we are unable to do this then we will not be able to meet the standards of what community engagement is and we will not be able to achieve health equity.

Collective Access is another Principle of Disability Justice that acknowledges the collective thoughts of all people, most notably the voices of those from minority backgrounds, to bring together a community of new ideas (Sins Invalid, 2015). “Black people and other negatively racialized individuals are grossly, disproportionately represented” (Harriet Tubman Collective, 2020, pp. 296–304). It is no secret that minority voices have been habitually silenced, so health officials need to acknowledge these pitfalls and work to make things better intentionally. But it’s not that easy. We can look to

ACT UP, a group of AIDS activists, who fought for medication and basic healthcare needs for people who were suffering during the AIDS epidemic. The documentary showcases the inaction of public health officials which led to millions of people dying (France, 2012). The LGBTQIA+ community still remembers that inaction and it has affected the relationships between them and public health officials. Taking accountability and sharing the power of voice with those within the communities can help strengthen not just the communities we are serving but the trust that the communities have in us. Fostering trust within the communities that we once harmed will take time and there will be tensions, but it's important to still try.

The last principle I would like to address is Collective Liberation, only by moving forward as a collective community will there be any sort of change or “revolution” (Sins Invalid, 2015). “So many disabled people live short lives, largely because of social determinants of health like lack of healthcare, inadequate housing, or unmet basic needs such as clean air and water” (Milbern, 2020, pp. 335–339). People are being left behind due to our inadequacy to come together and solve issues. Community engagement is known to help create long-lasting solutions that help bridge the gap of health disparities (O’Mara-Eves et al., 2013). We again see this in situations like ACT UP and during the 504 protests, no one was left behind in any of those situations. During the ADA and 504 protests, a large group of disabled activists settled in for multiple days to try and change laws that would create equity. During this protest we saw that the Black Panther party came in to provide them meals and others helped with other needs of people with disabilities (Netflix, 2020). In Leah Lakshmi Piepzna-Samarasinha’s poem they write “We come in packs even when we are alone” (Lakshmi Piepzna-Samarasinh, 2022). That

should be the truth with anyone helping to achieve equity. In this case, it's something that all public health officials should remember.

With there being a massive divide in health equity across communities one direction we as public health officials could take would be working with communities to co-create their individualized health plans. Health equity for all regardless of gender, race, disability, or sexuality should be what we strive for. There's no reason that in 2023 we are still lacking in this area. There's a lot of knowledge that could be shared between our communities that would propel us forward in creating better community engagement that leads to health equity.

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