

NARRATOR:

The Disability & Philanthropy Forum presents Gabriel San Emeterio, LMSW, Co-founder and Senior Fellow at Strategies for High Impact / Long COVID Justice.

GABRIEL SAN EMETERIO:

Meaningful patient involvement, both in peer support, creating research protocols, standards of care, listening to people's experiences is important, doing the advocacy. But all of it takes resources.

And in order to get the government moving, we need to get the people the tools and the funds to really organize and create that people's power. With the ailments and long and associated diseases, for instance, we need to change our culture. If we used to have one person doing one task and burning them to the ground doing that one task, maybe we need to have three people that can share that task so that people can step in and step back. It's a re-imagining of how work is done and providing the resources needed so that people can do that work. So that befalls on funders as much as government, but funders I guess can do that faster. Government's a little slower to respond.

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