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Proem

When I examine the relationships between health communities and researchers, I become curious about the power dynamics involved. Strong, equitable relationships depend on a balance of power. But what exactly are communities, and what does a power balance look like? The communities I picture are intentional, voluntary groups of people working together to achieve common goals—such as seeking, fixing, networking, championing, lobbying, or communicating for best health for each other. These groups can meet in person or virtually, and can be local or dispersed. A healthy power balance involves mutual respect, participatory decision-making, active listening, and a willingness to adapt and grow.

I always listen closely for connections between communities and health researchers. Connections that foster a learning culture, regardless of their perceived success. Please meet Lacy Fabian and Kirk Knestis, who have firsthand experience in building and maintaining equitable relationships, with whom I spoke in mid-September.

This transcript has been edited for clarity with help from Grammarly.



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<u>Lacy Fabian</u>, PhD, is the founder of <u>Make It Matter Program Consulting and Resources</u>. She partners with non-profit, government, and federal organizations using evidence and storytelling to demonstrate impact and improve program results.

<u>Kirk Knestis</u> is an expert in data use planning, design, and capacity building. As Executive Director of a startup community nonprofit and founding principal of Evaluand LLC. He specializes in research, evaluation, and organizational data analysis for complex questions.

1. Introductions & Career Transitions

Kirk Knestis: My name's Kirk Knestis. Until just a few weeks ago, I ran a research and evaluation consulting firm, Evaluand LLC, outside Washington, DC. I'm in the process of transitioning to a new gig. I've started a non-profit here in Northern Virginia to provide mobile wheelchair and scooter service. Probably my last project, I suspect.

Health Hats: Your last thing, meaning you're retiring.

Kirk Knestis: Yeah, it's most of my work in the consulting gig was funded by federal programs, the National Science Foundation, the Department of Ed, the National Institutes of Health, and funding for most of the programs that I was working on through grantees has been pretty substantially curtailed in the last few months.

Rather than looking for a new research and evaluation gig, we've decided this is going to be something I can taper off and give back to the community a bit. Try something new and different, and keep me out of trouble.

Health Hats: Yeah, good luck with the latter. Lacy, introduce yourself, please.

Lacy Fabian: Hi, Lacy Fabian. Not very dissimilar from Kirk, I've made a change in the last few months. I worked at a large nonprofit for nearly 11 years, serving the Department of Health and Human Services. But now I am solo, working to consult with nonprofits and donors. The idea is that I would be their extra brain power when they need it.

It's hard to find funding, grow, and do all the things nonprofits do without a bit of help now and then. I'm looking to provide that in a new chapter, a new career focus.

Health Hats: Why is this conversation happening now? Both Kirk and Lacy are going through significant changes as they move away from traditional grant-funded research and nonprofit hierarchies. They're learning firsthand what doesn't work and considering what might work instead—this isn't just theory—it's lived experience.

2. The Catalyst: Why This Conversation Matters

Health Hats: Lacy, we caught up after several years of working together on several projects. I'm really interested in community research partnerships. I'm interested in it because I think the research questions come from the communities rather than the researchers. It's a fraught relationship between communities and researchers, often driven by power dynamics. I'm very interested in how to balance those dynamics. And I see some of this: a time of changing priorities and people looking at their gigs



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differently —what are the opportunities in this time of kind of chaos, and what are the significant social changes that often happen in times like this?

3. The Ideal State: Restoring Human Connection

Health Hats: In your experience, especially given all the recent transitions, what do you see as the ideal relationship between communities and researchers? What would an ideal state look like?

Lacy Fabian: One thing I was thinking about during my walk or run today, as I prepared for this conversation about equitable relationships and the power dynamics in this unique situation we're in, is that I feel like we often romanticize the past instead of learning from it.

I believe learning from the past is very important. When I think about an ideal scenario, I feel like we're moving further away from human solidarity and genuine connection. So, when considering those equitable relationships, it seems to me that it's become harder to build genuine connections and stay true to our humanness. From a learning perspective, without romanticizing the past, one example I thought of is that, at least in the last 50 years, we've seen exponential growth in the amount of information available. That's a concrete example we can point to. And I think that we, as a society, have many points where we could potentially connect. But recent research shows that's not actually the case. Instead, we're becoming more disconnected and finding it harder to connect. I believe that for our communities, even knowing how to engage with programs like what Kirk is working on is difficult.

Or even in my position, trying to identify programs that truly want to do right, take that pause, and make sure they aim to be equitable—particularly on the funder side—and not just engage in transactions or give less generously than they intend if they're supporting programs.

But there are strings attached. I think all of this happens because we stop seeing each other as human beings; we lose those touchpoints. So, when I think about an ideal situation, I believe it involves restoring those connections, while more clearly and openly acknowledging the power dynamics we introduce and the different roles we assume in the ecosystem. We can't expect those dynamics to be the same, or to neutralize their impact.

However, we can discuss these issues more openly and consistently and acknowledge that they might influence outcomes. So, in an ideal scenario, these are the kinds of things we should be working toward.

4. The Localization Opportunity

Health Hats: So Kirk, it strikes me listening to Lacy talk that there's, in a way, the increased localization of this kind of work could lead to more relationships in the dynamic, whereas before, maybe it was. Things were too global. It was at an academic medical center and of national rather than local interest. What are your thoughts about any of that?

Kirk Knestis: Yeah, that's an excellent question. First, I want to make sure I acknowledge Lacy's description philosophically, from a value standpoint. I couldn't put it any better myself. Certainly, that's



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got to be at the core of this. Lacy and I know each other because we both served on the board of the Professional Evaluation Society on the East Coast of the United States, and practice of evaluation, evaluating policies and programs, and use of resources, and all the other things that we can look at with evidence, the root of that word is value, right? And by making the values that drive whatever we're doing explicit, we're much more likely to connect. At levels in, way, in ways that are actually valuable, a human being level, not a technician level. But to your question, Danny, a couple of things immediately leap out at me. One is that there was always. I was primarily federally funded, indirectly; there's always been a real drive for highly rigorous, high-quality evaluation.

And what that oftentimes gets interpreted to mean is generalizable evaluation research. And so that tends to drive us toward quasi-experimental kinds of studies that require lots and lots of participants, validated instrumentation, and quantitative data. All of those things compromise our ability to really understand what's going on for the people, right? For the real-life human stakeholders.

One thing that strikes me is that we could be as funding gets picked up. I'm being optimistic here that funding will be picked up by other sources, but let's say the nonprofits get more involved programs that in the past and in the purview of the feds, we're going to be freed of some of that, I hope, and be able to be more subjective, more mixed methods, more on the ground and kind of maturein the, dirt down and dirty out on the streets, learning what's going on for real humans. As opposed to saying, "Nope, sorry, we can't even ask whether this program works or how it works until we've got thousands and thousands of participants and we can do math about the outcomes." So that's one way I think that things might be changing.

5. Evidence + Story = Impact

One of the big elements I like to focus on is the evidence—the kind of, so what the program is doing—but also the story. Making sure both of those things are combined to share the impact.

And one of the things that I think we aren't great about, which kind of circles back to the whole topic about equitable relationships. I don't often think we're really great at acknowledging. Who our report outs are for

6. The Funder Issue: Who Is This Truly Benefiting?

Health Hats: Yes, who's the audience?

Lacy Fabian: Describing the kind of traditional format, I'm going to have thousands of participants, and then I'm going to be able to start to do really fancy math. That audience is a particular player who's our funder. And they have different needs and different goals. So so many times, but that's not the same as the people we're actually trying to help. I think part of actually having equity in practice is pushing our funders to acknowledge that those reports are really just for them.

And what else are we doing for our other audiences, and how can we better uphold that with our limited resources? Do we really need that super fancy report that's going to go on a shelf? And we talk about it a lot, but I think that's the point. We're still talking about it. And maybe now that our funding is



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shifting, it's an excellent catalyst to start being smarter about who our audience is, what they need, and what's best to share with them.

7. Dissemination, Implementation & Vested Interest

Health Hats: So, in a way, that's not only do we need to think about who the work is for. How do we get it to those people? So how do we disseminate to those people? And then, what are the motivations for implementation? And it seems to me that if I have a vested interest in the answer to the question, I am more likely to share it and to try to figure out what the habits are—the changing habits that the research guides. What are some examples of this that you've, in your experience, that either you feel like you hit it like this, worked, or where you felt like we didn't quite get there? So, what are your thoughts about some practical examples of that?

Kirk Knestis: I was laughing because I don't have so many examples of the former. I've got lots of examples of the latter.

Health Hats: So start there.

8. Data Parties – The Concrete Solution

Kirk Knestis: A good example of how I've done that in the past is when clients are willing to tolerate it. We call them different things over the years, like a data party. What we do is convene folks. We used to do it in person, face-to-face, but now that we're dealing with people spread out across the country and connected virtually, these meetings can be done online. Instead of creating a report that just sits on a shelf or a thumb drive, I prefer to spend that time gathering and organizing the information we collect into a usable form for our audiences. This acts as a formative feedback process rather than just a summative benchmark. Here's what we've learned. You share the information with those who contributed to it and benefit from it, and you ask for their thoughts. We're observing that this line follows a certain path. Let's discuss what that means or review all the feedback we received from this stakeholder group. It's quite different from what we've heard from other stakeholders. What do you think is happening there? And let them help add value to the information as it moves from evidence to results.

Health Hats: This is the solution to the funder problem. Instead of writing reports for funders, Kirk brings together the actual stakeholders—the people who provided data and benefit from the program. They assist in interpreting the findings in real-time. It's formative, not summative. It's immediate, not shelved.

9. No Strings Attached: Reimagining Funder Relationships

Health Hats: I think it's interesting that a thread through this is the role of the funder and the initiative's governance. I remember that we worked on a couple of projects. I felt like the funder's expectations were paramount, and the lessons we learned in the process were less important, which aligns with what we didn't show. Publication bias or something. Sometimes in these initiatives, what's most interesting is what didn't work —and that's not so, anyway. So how? So now that you're looking forward to working



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with organizations that are trying to have questions answered, how is that shaping how you're coaching about governance of these initiatives?

Like, where does that come in?

Lacy Fabian: Yeah. I think, if we're talking about an ideal state, there are models, and it will be interesting to see how many organizations really want to consider it, but the idea of no-strings-attached funding. Doesn't that sound nice, Kirk? The idea being that if you are the funding organization and you have the money, you have the power, you're going to call the shots. In that way, is it really fair for you to come into an organization like something that Kirk has and start dictating the terms of that money? So, Kirk has to start jumping through the hoops of the final report and put together specific monthly sendins for that funder. And he has to start doing these things well for that funder. What if we considered a situation where the funder even paid for support to do that for themselves? Maybe they have somebody who comes in, meets with Kirk, or just follows around, shadows the organization for a day or so, collects some information, and then reports it back.

But the idea is that the burden and the onus aren't on Kirk and his staff. Because they're trying to repair wheelchairs and imagining the types of models we've shifted. We've also left the power with Kirk and his organization, so they know how to serve their community best.

Again, we've put the onus back on the funder to answer their own questions that are their needs. I think that's the part that we're trying to tease out in the equity: who is this really serving? And if I'm giving to you, but I'm saying you have to provide me with this in return. Again, who's that for, and is that really helping? Who needs their wheelchair service? And I think that's the part we need to work harder at unpacking and asking ourselves. When we have these meetings, put out these funding notices, or consider donating to programs, those are the things we have to ask ourselves about and feel are part of our expectations.

10. Balancing Accountability and Flexibility

Health Hats: Wow. What's going through my mind is, I'm thinking, okay, I'm with PCORI. What do we do? We want valuable results. We do have expectations and parameters. Is there an ideal state? Those tensions are real and not going away. But there's the question of how to structure it to maximize the value of the tension. Oh, man, I'm talking abstractly. I need help thinking about the people who are listening to this. How does somebody use this?

So let's start with: for the researcher? What's the mindset that's a change for the researcher? What's the mindset shift for the people, and for the funder? Let's start with the researcher. Either of you pick that up. What do you think a researcher needs to do differently?

Kirk Knestis: I don't mind having opinions about this. That's a fascinating question, and I want to sort of preface what I'm getting ready to say. With this, I don't think it's necessary to assume that, to achieve the valuable things Lacy just described, we must completely abrogate all responsibility. I think it would be possible for someone to say, money, no strings attached. We're never going to get the board/taxpayer/or whoever, for that. Importantly, too, is to clarify a couple of functions. I found that



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there are a couple of primary roles that are served by the evaluation or research of social services or health programs, for example. The first and simplest is the accountability layer. Did you do what you said you were going to do? That's operational. That doesn't take much time or energy, and it doesn't place a heavy burden on program stakeholders. Put the burden on the program's managers to track what's happening and be accountable for what got done.

Health Hats: So like milestones along the way?

Kirk Knestis: Yes. But there are other ways, other dimensions to consider when we think about implementation. It's not just the number of deliveries but also getting qualitative feedback from the folks receiving the services. So, you can say, yeah, we were on time, we had well-staffed facilities, and we provided the resources they needed. So that's the second tier. The set of questions we have a lot more flexibility with at the next level. The so-what kind of questions, in turn, where we go from looking at this term bugs me, but I'll use it anyway.

We're looking at outputs—delivery measures of quantities and qualities—and we start talking about outcomes: persistent changes for the stakeholders of whatever is being delivered. Attitudes, understandings. Now, for health outcomes—whatever the measures are—we have much more latitude. Focus on answering questions about how we can improve delivery quality and quantity so that folks get the most immediate and largest benefit from it. And the only way we can really do that is with a short cycle. So do it, test it, measure it, improve it. Try it again, repeat, right? So that formative feedback, developmental kind of loop, we can spend a lot of time operating there, where we generally don't, because we get distracted by the funder who says, "I need this level of evidence that the thing works, that it scales."

Or that it demonstrates efficacy or effectiveness on a larger scale to prove it. I keep wanting to make quotas, right, to prove that it works well. How about focusing on helping it work for the people who are using it right now as a primary goal? And that can be done with no strings attached because it doesn't require anything to be returned to the funder. It doesn't require that deliverable. My last thought, and I'll shut up.

11. Where the Money Actually Goes

Kirk Knestis: A study ages ago, and I wish I could find it again, Lacy. It was in one of the national publications, probably 30 years ago.

Health Hats: I am sure Lacy's going to remember that.

Kirk Knestis: A pie chart illustrated how funds are allocated in a typical program evaluation, with about a third going to data collection and analysis, which adds value. Another third covers indirect costs, such as keeping the organization running, computers, and related expenses. The remaining third is used to generate reports, transforming the initial data into a tangible deliverable. If you take that third use much more wisely, I think you can accomplish the kind of things Lacy's describing without, with, and still maintain accountability.



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Health Hats: This is GOLD. The 1/3: 1/3 breakdown is memorable, concrete, and makes the problem quantifiable. Once again, 1/3 each for data collection and analysis, keeping the organization alive, and writing reports.

12. The Pendulum Swings

Lacy Fabian: And if I could add on to what Kirk had said, I think one of the things that comes up a lot in the human services research space where I am is this idea of the pendulum swing. It's not as though we want to go from a space where there are a lot of expectations for the dollars, then swing over to one where there are none. That's not the idea. Can we make sure we're thinking about it intentionally and still providing the accountability? So, like Kirk said, it's that pause: do we really need the reports, and do we really need the requirements that the funder has dictated that aren't contributing to the organization's mission?

In fact, we could argue that in many cases, they're detracting from it. Do we really need that? Or could we change those expectations, or even talk to our funder, as per the Fundee, to see how they might better use this money if they were given more freedom, not to have to submit these reports or jump through these hoops?

And I believe that's the part that restores that equity, too, because it's not the funder coming in and dictating how things will go or how the money will be used. It's about having a relational conversation, being intentional about what we're asking for and how we're using the resources and then being open to making adjustments.

And sometimes it's just that experimentation: I think of it as, we're going to try something different this time, we're going to see if it works. If it doesn't work, it probably won't be the end of the world. If it does, we'll probably learn something that will be helpful for next time. And I think there's a lot of value in that as well.

Health Hats: Lacy's 'pendulum swing' wisdom: not anarchy, but intentional. Not 'no accountability' but 'accountability without burden-shifting.' The move is from the funder dictating requirements to relational conversation. And crucially: willingness to experiment.

13. The Three Relationships: Funder, Researcher, Community

Health Hats: Back to the beginning—relationships. So, in a way, we haven't really —what we've talked about is the relationship with funders.

Lacy Fabian: True.

Health Hats: What is the relationship between researchers and the community seeking answers? We're considering three different types of relationships. I find it interesting that people call me about their frustrations with the process, and I ask, "Have you spoken with the program officer?" Have you discussed the struggles you're facing? Often, they haven't or simply don't think to. What do you think they're paid for? They're there to collaborate with you. What about the relationships between those



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seeking answers and those studying them—the communities and the researchers? How does that fit into this?

Kirk Knestis: I'd like to hear from Lacy first on this one, because she's much more tied into the community than the communities I have been in my recent practices.

14. Maintaining Agency

Health Hats: I want to wrap up, and so if. Thinking about people listening to this conversation, what do you think is key that people should take away from this that'll, in, in either of the three groups we've been talking about, what is a lesson that would be helpful for them to take away from this conversation?

Lacy Fabian: I think that it's important for the individual always to remember their agency. In their engagements. And so I know when I'm a person in the audience, listening to these types of things, it can feel very overwhelming again to figure out what's enough, where to start, and how to do it without making a big mistake. I think that all of those things are valid. Most of us in our professional lives who are likely listening to this, we show up at meetings, we take notes. We're chatting with people, engaging with professional colleagues, or connecting with the community. And I think that we can continue to be intentional with those engagements and take that reflective pause before them to think about what we're bringing. So if we're coming into that program with our research hat on, or with our funder hat on, what are we bringing to the table that might make it hard for the person on the other side to have an equitable conversation with us? If you're worried about whether you'll be able to keep your program alive and get that check, that's not a balanced conversation. And so if you are the funder coming in, what can you do to put that at ease or acknowledge it? Suppose you are the person in the community who goes into someone's home and sees them in a really vulnerable position, with limited access to healthcare services or the things they need. What can you do to center that person, still like in their humanity, and not just this one problem space? And that they're just this problem because that's, I think, where we go astray and we lose ourselves and lose our solidarity and connection.

So I would just ask that people think about those moments as much as they can. Obviously, things are busy and we get caught up, but finding those moments to pause, and I think it can have that snowball effect in a good way, where it builds and we see those opportunities, and other people see it and they go, Huh, that was a neat way to do it. Maybe I'll try that too.

15. Listen and Learn

Health Hats: Thank you. Kirk.

Kirk Knestis: Yeah. A hundred percent. I'm having a tough time finding anything to disagree with what Lacy is sharing. And so I'm tempted just to say, "Yeah, what Lacy said." But I think it's important that, in addition to owning one's agency and taking responsibility for one's own self, one stands up for one's own interests.

At the same time, that person has to acknowledge that everybody else knows that the three legs of that stool I described earlier have to do the same thing, right? Yeah. So, it's about a complicated social



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contract among all those different groups. When the researchers talk to the program participant, they must acknowledge the value of each person's role in the conversation.

And when I, as the new nonprofit manager, am talking to funders, I've got to make sure I understand that I've got an equal obligation to stand up for my program, my stakeholders, and the ideals that are driving what I'm doing. But at the same time, similarly, respecting the commitment obligation that the funder has made. Because it never stops. The web gets bigger and bigger, right? I had a lovely conversation with a development professional at a community foundation today. And they helped me remember that they are reflecting the interests and wishes of different donor groups or individuals, and there's got to be a lot of back-and-forth at the end of the day.

I keep coming back to communication and just the importance of being able to say, okay, we're talking about, in our case, mobility. That means this. Are we clear? Everybody's on the same page. Okay, good. Why is that important? We think that if that gets better, these things will, too. Oh, have you thought about this thing over here? Yeah, but that's not really our deal, right? So having those conversations so that everybody is using the same lingo and pulling in the same direction, I think, could have a significant effect on all of those relationships.

Health Hats: Here's my list from the listening agency, fear, mistake, tolerance, grace, continual Learning, communication, transparency.

Kirk Knestis: and equal dollops of tolerance for ambiguity and distrust of ambiguity. Yes, there you go. I think that's a pretty good list, Danny.

Lacy Fabian: It's a good list to live by.

Health Hats: Thank you. I appreciate this.

Reflection

Everyone in a relationship faces power dynamics – who's in control and who's not? These dynamics affect trust and the relationship's overall value, and they can shift from moment to moment. Changing dynamics takes mindfulness and intention. The community wanting answers, the researcher seeking evidence-based answers, and those funding the studies, have a complex relationship. Before this conversation, I focused on the community-research partnership, forgetting it was a triad, not a dyad.

The Central Paradox: We have exponentially more information at our disposal for research, yet we're becoming more disconnected. Lacy identifies this as the core problem: we've stopped seeing each other as human beings and lost the touchpoints that enable genuine collaboration—when connection matters most. This is true for any relationship.

The Hidden Cost Structure Kirk's 1/3:1/3:1/3 breakdown is golden—one-third for data collection and analysis (adds value), one-third for organizational operations, and one-third for reports (mostly shelfware). The key takeaway: we're allocating one-third of resources to deliverables that don't directly



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benefit the people we're trying to help. Perhaps more of the pie could be spent on sharing and using results.

Three Different "Utilities" Are Competing Kirk explains what most evaluation frameworks hide: funder utility (accountability), research utility (understanding models), and community utility (immediate benefit) are fundamentally different. Until you specify which one you're serving, you're likely to disappoint two of the three audiences.

Data Parties Solve the Funder Problem Pragmatically. Rather than choosing between accountability and flexibility, data parties and face-to-face analysis let stakeholders interpret findings in real time – the data party. I love that visual. It's formative, not summative. It's relational, not transactional.

The Funding Question Reverses the Power Dynamic. Currently, funders place the burden of proving impact on programs through monthly reports and compliance documentation. Lacy's alternative is simpler: what if the funder hired someone to observe the program, gather the information, and report back? This allows the program to stay focused on its mission while the funder gains the accountability they need. But the *structure* shifts—the program no longer reports to the funder; instead, the funder learns from the program. That's the difference between equity as a theory and equity as built-in.

