Video transcript

Strategic Partnership and Planning

Speaker: Rebecca Martin

Rebecca Martin: Thank you again for joining us. We're just going to talk a little bit about strategic partnership and planning mostly from the perspective of thinking about the partnerships that you've built so far and the ones that you might want to build taking your project further. A lot of this is based on reflections we got from the first cohort about their experiences and things they had wished they had considered.

So, without further ado, this talk … this will cover sort of people with disabilities as thought leaders and informants and what are the differences, whether you're connecting with a diverse group of informants and leaders, and what barriers are impeding those connections if there are any, and finally the strengths and connections you can leverage to bridge your gaps.

And connecting with people with disabilities, two ways that people have really sought to bring their … people with disabilities into their projects in, you know, well respected and information gathering kind of ways, are as informants and thought leaders. And what we kind of see is the differentiation between the two is the extent to which they can get involved and the timing.

So a thought leader, which is what we're hoping for, right, in our projects, is going to be involved in the design of the project, and they usually are brought in earlier in the project, or they might help you to realize that your project needs to pivot a bit in the way that you initially conceptualized it. So they're usually pretty early strategic partners. That's opposed to informants, who are also providing great service and providing their expertise but usually within a more limited framework.

For example, a thought leader might be brought into a project where you ask the community of people with disabilities, "what do you need presently that would make your life more inclusive, like more available for you to be part of the community." Whereas an informant you may have spoken with another service provider and thought that transportation — not that focusing on transportation is bad, I'm just using this as an example — that transportation might be something based on what you've heard around, and then you ask people well tell me just about your transportation experiences.

It's about that double checking to make sure that the things that you're focusing on are also really jibing with the community that you want to work in. And an informant is still a very important part of the process, and they inform decisions that are made by project staff, but a thought leader is often empowered to be part of that decision-making team, and so that's kind of the difference in the power there. And often informants are brought in later in the project once everything's designed. Then it's more of a feedback that you get from an informant asking, you know, how how does this work for you, what I've designed, rather than how would you design this to be most effective.

Some things about thinking about working with people with disabilities are that family members and service professionals are really important supplement to the information you can get from people with disabilities, but we should try not to think of them as a one-to-one representative of what a person with disabilities might need or want for inclusion. Sometimes, I mean even with the best of intentions as a parent, I know that sometimes what I want from my daughter has more to do with or has something to do with how I need things to be or what I'm looking for the outcome, but especially with people with disabilities who are adults, who still have a relationship in which their parents are involved in their lives in a somewhat instructive fashion, there can be a tendency for their needs also to be incorporated into that packaging.

So it's just really important to recognize that how a parent presents something might not be exactly how the person with disabilities would, and it's great to have their opinion and incorporate that in a larger whole, but you want to try not to substitute a family member or a service professional for the person with disabilities.

And then to find people who are diverse and have diverse life experiences within the people with disabilities, they really have to come from different settings within your community. A really great place to start on a lot of the projects is to find a partner and to have them help you source connection with people with disabilities, but you have to be careful that that group of people is not representing all people with disabilities for your community if your project is aiming at a larger group of individuals.

So for example, there might be people living in communities at home, and if you go through a group home situation you may not get in touch with people who are living out in the community and they may have different experiences or different needs. So these are just things to consider as you're thinking about continuing to build your networks as you move forward in your project.

Some common challenges that came up in the first year of the grant program were distrust experienced on the part of people with disabilities towards working with professionals about these policy, these PSE changes. Another one is the lack of diversity within a group, like, perhaps getting a group of people who are very similar in background, and then systemic limitations that sometimes keep us from getting the guidance that we need from people with disabilities.

So I want to talk about distrust for a moment, because distrust and mistrust are very similar, but I think it's really important that we think about this, and it can help us to think about how we experience any sort of hesitation we experience from people with disabilities. So mistrust is a lack of trust that is based on maybe bias or sense of unease or intuition, but a distrust is based on previous experiences, knowledge, and informed opinions.

I think it can be really hard for us as we're trying to engage a community that's new to us or even one that we've been involved with for a long time, that to feel distrust coming from people, and I think that there can be a frustration especially as we feel a timeline that we want to really focus on making sure that we recognize that it's the previous experiences of the people with disabilities that's really guiding this feeling or like the undercurrent of this feeling.

So what's important about that is that we can keep that in mind when we're building the relationship and really ensure that we're doing things that are going to decrease distrust with the community in the future or at least not create additional opportunities for distrust. And I think that thinking about it as distrust can really help us be patient and recognize that that relationship might take some time.

So some of the things that you could do potentially looking at a situation where people with disabilities are expressing distrust is what kind of role in the project have you given the people with disabilities. Is this something where they're going to have some agency, and are you considering them as partners who are equivalent to the groups that you're engaging?

We had one partner or one project in the first cohort where they listed individuals as partners on a survey that we did, and they were saying because this person gives us just as much information as XYZ group, and I thought it was a really interesting way of looking at the people with disabilities for informing projects as being true equal partners in this work.

How are we compensating individuals, and if we can't compensate them individually what are we giving back to the communities that they're parts of that make them feel like this isn't an extractive process but something where we're really valuing them and we want them to see that we are dedicated to making differences for them?

And then thinking about the similarities and differences between the working group and the group that you're trying to engage with, there may be opportunities, particularly if you're in a specific community that you want to work in, for hiring or working with people that are from that community and that can also help to bridge some of the barriers that might happen because some of the organizations are located in different communities or are, you know, more corporate entities or municipal entities that might feel intimidating. So how can you make a connection that's meaningful in that community and have that as a basis to build upon when you're connecting with people with disabilities?

And I think that for the long-term goals since we're all in it for the PSE change, and we're all trying to build New Jersey to be the most inclusive it can be going forward, we're looking at the campsite rule, which is always leave it better than you found it, right, so that means be sure that you are being honest because a lot of times these projects are really challenging, and we might not have full agency on what's going to happen at the outcome, and we're trying to convince parties and things. That's something that you want to communicate honestly to your participants, because you don't want them to get to the end and then something falls short in your deliverables, and then they think that it's because you don't care, right. So trying to be as transparent as possible.

How do you build connections that are meaningful and see the people with disabilities as full people not just as a person with a disability who's informing your project? But you see them as the dad, brother, person with a disability, person from a certain faith, LBGTQ status, all of these things that you want to think that make up a whole person, trying to see them that way, and communicating respect in that way.

And then finally if you're doing an intangible project, I mean it's extremely important to be doing a lot of the more capacity building and thoughtful work around long-term change, but can you come up with a proof of concept that's going to show people something tangible that you're doing to make a change?

Lack of diversity of course is a big challenge and it's really important to think about who's missing from the table. And when I say that, that could be different types of disabilities, that could be age groups, it could be racially, it could be by language of origin, immigration, LGBTQ status, but is your community of people with disabilities who are informing your project representative of the area that you're in? Does it look like your area? Because if it doesn't, then someone's opinion and someone's experiences aren't being heard.

What does your staff look like? Again, there are sometimes opportunities where we hire someone in or a consultant or a person, and are they someone who comes from the community? That's obviously a good foot in, but there's other ways, too, just to be even if you're just aware of the differences and can be comfortable in those differences that goes a long way um with bringing people in.

And who are you aligned with? We had an interesting learning, I think, for all of us with Children's Specialized Hospitals project last year, because they were aligned with some emergency response responders in the community they were working with, and then there was a big difficulty in getting people of color with disabilities to share their experiences or to feel comfortable in those spaces. And so, it's important that we're thinking about, too – and I think that all the networking we can possibly do is building a a stronger community for disability work – but being cognizant of how some of our alliances or our partnerships could impact different communities that we're trying to bring in and being thoughtful about how those power balances are being presented so that people feel comfortable and, like, they have agency.

Finally, with systemic limitations there can be some real challenges with this as you're trying to gather your information from your partners with disabilities, and I think one that we've seen is that sometimes with intellectual and developmental disabilities if people have guardianships there can be real challenges with getting buy-in from parents to allow those conversations to take place. And there can also be limitations in terms of needing to adapt our own language in those circumstances to talk with people who may communicate differently, and I think that we should think of that very much like we would with a difference in language or the need for ASL interpretation. Like there are ways to bridge some of these gaps, but it's important to try to reach people where they are.

For children a lot of times we look at, we look to their parents if we can't engage them directly, and that's a very important component. I would also say that if your project focuses mainly on children and you are trying to get opinions and learn about their experiences, another great way to do that is to think about adults with disabilities who have been through the same systems or programs or live in the same communities, because they can give a supplement to what parents can provide having the lived experience but maybe not being an age group, and together the two opinions might help to round out the information that you're gathering.

Older adults can also be challenging to engage with because of lack of access to coming to places, transportation, so thinking outside of the box about how you might engage older adults who are an important community with disabilities and a sizable community of disabilities within New Jersey.

And then finally just – and I think probably most of you think about this – but with access to the spaces where you want people to come and things, you need to think about both within the building and outside the building, like, how will people get there with mobility impairments? Are there going to be things that are going to keep people from being able to participate fully?

And so one of the really important things that Jeanne and I were recently talking about was that sometimes when people with disabilities are coming into the projects and giving of themselves and giving you all this great information, you realize that the project that you initially conceptualized doesn't necessarily fully represent what's best from the perspective of people with disabilities.

And I think it's really important from the Bloustein team to make sure that you all know that this is okay. If your project needs to pivot or change direction to be in the spirit of what this grant is intended to do, that's okay. I think it could be really stressful when you put something down on paper and then feel like you have to change it. But as Jeanne always says, this is not a gotcha zone, right. We're here to help and support, and you should definitely – if you come up against this – like, you should definitely reach out to Jeanne or Karen to talk about, you know, ways that you might want to pivot on your project.

And then again, I think I've touched on this a little bit with selecting staffing consultants, but thinking about the qualifications for this position if you think about bringing people in, in terms of, like, a new staff or consultant member, like, how are they going to be connected to people with disabilities. I think it's really, it's more common, right, to look for somebody who kind of has the same skills that you have, but in this work especially if you're not coming from a disability group you may need to supplement what you have rather than looking for someone who is more in your typical network.

So, for example, if your organization is a municipality or actually, like, is more of a corporate entity or an institution, how are you going to bring somebody that can really get into the grassroots of the community? That's the kind of thing that you're looking for. So sometimes just thinking about the qualifications, like, is it really necessary to have a doctorate in public health? Maybe it is, you know, but maybe there's something else that you need more and just kind of being critical about what you typically look for in a position.

And then finally we just wanted to talk to you a little bit about appreciative inquiry. I'm using a five dimension approach – that the typical one is four – but I really like this one because it was designed for engagement. So it has DAWN is not typically one of the stages in appreciative inquiry. But basically this is to help you kind of think through your strategy and where you're going and your work and your engagement with the people with disabilities and your coalitions who are driving your project.

So DAWN is the opportunity to build these trusting relationships with the people with whom you're building these changes and that's, you know, what I think probably most of you have been doing in this last quarter is really getting to the place where the work is going to start really blossoming soon, right. But DISCOVERY is about really taking the moment and this is very "social worky," but it's to appreciate all the strengths that your partner brings and the people with disabilities bring to your project and thinking about ways in which you can capitalize on those strengths and use what you have to create what it is that you are trying to create in your community.

DREAM is coming together to imagine what could be, and sometimes it is helpful to consider making, you know, a statement or a cohesive vision so that you can all make sure that you have this goal that you're going toward together. The DESIGN is how you're making your decisions and planning to create the actions that will bring you to where you're trying to go.

And finally DELIVERY is taking these steps but also thinking very critically about how you can build for the long term even after these projects are gone. What will be the long-term policy systems and environmental changes that are going to be sustained from this project?

So then, thank you for listening. I know that was a lot of talking, but I'd like to open it up for you all. Is there anyone who would want to talk about any challenges or successes you've had in building a shared vision for change within your program?

Jeanne Herb: Rebecca, one thing I want to emphasize, and to be honest this is something that we learned through the first cohort, is this concept that fundamentally true inclusion means that you might not know what comes out on the other end. And for funders, right, because that's the role that we play here, that's a little bit of a weird thing, because we make you complete applications and grant proposals that ask you to identify deliverables and time frames, and then, you know, and on the other side of our mouths we're saying do true inclusion and you won't know what comes on the other end. So I think what we want to emphasize is do true inclusion and talk to us if that messes up what your schedule and your products were supposed to be. And we're going to try to address this a little more systematically in the third cohort RFP. So we're learning, too. Thanks, Rebecca.

Rebecca Martin: Thank you.