

Podcast Interview Transcript

Hae-Ran Han, Christina Nicolaidis, Dora Raymaker

Welcome to Progress in Community Health Partnerships' latest episode of our Beyond the Manuscript podcast. In each volume of the Journal, the editors select one article for our Beyond the Manuscript post-study interview with the authors. Beyond the Manuscript provides the authors the opportunity to tell listeners what they would want to know about the project beyond what went into the final manuscript. The Associate Editor who handles the featured article conducts our Beyond the Manuscript interview. In this episode of Beyond the Manuscript, Associate Editor Haera Han interviews Christina Nicolaidis and Dora Raymaker, authors of "Community based participatory research to adapt health and violence measures for use by people with developmental disabilities."

Hae-Ra Han: Dr. Nicolaidis, thank you for your time today. We also have another author of this paper, Dr. Raymaker, in queue. To give our audience an orientation to your project, can you please provide a brief summary of the project, perhaps highlighting its purpose and the main points you address in the paper?

Christina Nicolaidis: Okay. So this paper addresses a part of a larger project. Our partners at the University of Montana, and Portland State University, and our various community partners, we worked together to conduct a survey about violence against people with developmental disabilities. The part that this paper addresses is how we used community-based participatory research (CBPR) to actually make it be possible. The issue is that people with developmental disabilities often get excluded from research because there can be a number of different challenges in terms of including them as research participants, and when you get to something as sensitive as an issue around violence against people with developmental disabilities, it's really important that we get the information from participants themselves. It doesn't really make sense to ask a proxy about the violence that they either don't know about or may have perpetrated. It just doesn't make any sense.

Hae-Ra Han: Right.

Christina Nicolaidis: So we had to find a way to be able to actually get, you know, reliable, valid, useful information directly from people with developmental disabilities. We also had to do it in a way that would not necessitate mandatory reporting, because they're a protected group and so we had to find a way to do it anonymously.

So this paper is really talking about how we use the CBPR process to adapt currently existing measures to be more accessible to people with developmental disabilities, and then some of the psychometric testing we did to make sure that it was actually okay.

- Hae-Ra Han:* Sure. So when I was reading the paper, I read it with much interest and I was intrigued by the paper in that it really offers this community perspective, which has not been well-addressed in the literature. You just talked about some of these challenges and the uniqueness of the population. So I wonder if you could tell us about how the health partnership described in the paper was started in the community.
- Christina Nicolaidis:* Well, so this particular project was a little bit different than many of the other CBPR projects that I've been involved with or that Dora's been involved with. This one—actually, the CDC [Centers for Disease Control and Prevention] put out a call asking for research around the association between violence, health, and disability in people with developmental disabilities. We thought it was a very important topic and the CDC call didn't say anything about CBPR.
- Hae-Ra Han:* Right.
- Christina Nicolaidis:* We said, you know, really this can best be done using a CBPR approach. In fact, I really believe it's the only way to do this is to use a CBPR approach. So the academic partners, we'd all had various connections in the past with each other, we started talking about how this would be an interesting possibility, and we each had longstanding relationships with community organizations that work with people with developmental disabilities outside of this project. So we were able to go to our community partners that we'd known from other work and basically say, "Hey, is this something you're interested in?" And this was something that we heard from the disability communities was a very high priority. So they partnered with us and they joined in as we were writing the proposal to partners throughout the project.
- Hae-Ra Han:* I see. So –
- Dora Raymaker:* There is a bit of intersectionality with the academics too in that some of the people in the more academic roles also identify as members of disability-related communities.
- Hae-Ra Han:* So I wonder, for Dr. Raymaker, if you can address this question: If there was any type of work that the partners needed to have to prepare them for this project? Was there anything that the partners needed to do to prepare them for this project, such as educating them about the research process in general, survey methods, all these types of things that you needed to?
- Dora Raymaker:* So, yes, but not before. We tend to weave those things into the work that we're doing, so at one of our very first meetings we were talking and wanted to look at all of the various instruments that we might use and collaboratively decide which ones we were going to use and which ones we weren't going to use, and also about the constructs that we said that we were going to measure in the grant. So we actually had a conversation about what is a construct. What has the CDC told us we were going to measure for constructs, and then what might we want to get at that isn't in there, and are there things that have been left out that they feel are important? So we sort of would weave the scientific ideas in with the actual work that we were doing to make it more concrete, because otherwise you're just dumping a bunch of like concepts people don't care about on them.
- Hae-Ra Han:* Right.
- Dora Raymaker:* That didn't quite answer exactly the question. I didn't think of it as preparation so much as a necessary part of the process.

- Hae-Ra Han:* I see. Even when there is a strong partnership already there, I can imagine any project can be faced with challenges. So just to dig in deeper a little bit, I wonder if there were any particular challenges to getting any of the partners involved in the partnership that you created along the way.
- Christina Nicolaidis:* There were lots of challenges. I don't know so much that it was in getting people involved.
- Hae-Ra Han:* Okay.
- Christina Nicolaidis:* Because as I said, first, we had longstanding—not for this project, but we had longstanding relationships with—there were four community-based organizations that partnered on the project and there were academic partners, who had longstanding relationships with each of them –
- Hae-Ra Han:* Yeah.
- Christina Nicolaidis:* I might not have had them with all four, but I had a strong working relationship with the Autistic Self Advocacy Network and other partners. So it wasn't so much of an issue of getting people involved, especially because this is a topic that had pretty high resonance. In general, people immediately said, "Oh yes, this is something we care about." This wasn't something we had to convince anybody was an important issue.
- There were plenty of challenges. This was a 3-year grant. And it's now been 4 or 5 years and we're still writing papers on it. There were plenty of challenges along the way. I think there were some challenges that were inherent in it and we kind of needed to work through, and there were some challenges that we just kind of were like, "Oh, we didn't think that through very well. We should have done this differently and we didn't."
- Hae-Ra Han:* What were some of those unexpected challenges?
- Christina Nicolaidis:* So the biggest challenge was that we had been used to working remotely, but in different ways. For example, I work very closely with Dora and with others in the autistic community, and we work remotely, but we work through mostly instant messenger chat and text-based chat forms, because for many of our autistic partners it's much more comfortable to communicate through written word. We knew right off that that wasn't going to be possible for many of our other partners, who have greater difficulty with written communication or with typing quickly or anything like that. So we had nixed the idea of communicating through text-based forms right off, but we thought we might be able to make it work going through communicating via telephone, and that just didn't. It just turned out that it really wasn't—even though we put in a fair amount of accommodations—it really wasn't as accessible as it needed to be for the members of the steering committee.
- I should back track. We have a steering committee that was across sites between Montana and Oregon, and then we had community advisory boards at both sites that were in person. The in-person –
- Dora Raymaker:* The steering committees, the community members on those were representatives of the community-based organizations that were involved in the project. So the leadership was in the steering committees.

Christina Nicolaidis:

Okay. So at the local level, at the community advisory board level, things went great. It was just so exciting to be in that room. It felt like in some ways it was like the United Nations of disabilities. I mean it was just there were so many different people with different types of disabilities. It was just really very lovely, very just exhilarating to have those community advisory board meetings.

That didn't hold true for the steering committees. The steering committee was the leadership and it was the three academic partners and the four representatives from the community-based organizations. That's what we were trying to do over the telephone and it turned out that many of the partners from the community-based organizations really weren't getting their voice heard well over the telephone, because they were having different accessibility issues, but ultimately, it wasn't really working and that was when we had to stand back and go, "Yes, it makes sense in the big picture to have one group that leads the entire project, but it's more important that the community partners have a strong voice, and that's not happening." So we split up and we ended up having the Oregon steering committee meet in person, and the Montana steering committee meet in person, and then the project staff and the academic partners kind of made sure that we were communicating between the two sites.

I think we didn't set it up that way to begin with because we didn't want it to be the academic partners communicating with each other. On the other hand, it was so much better in the long run to have really good, valuable discussions in person that weren't happening over the telephone.

Hae-Ra Han:

I see. It's a very interesting reflection on the working process overall and somewhat related to my next question, because my next question has to do with the working style of the partnership. I wonder if you can share any approaches you took by the partnership overall to make sure that all partners' viewpoints were heard, other than the technical issues, perhaps, that you just described, and then any viewpoints that were heard and taken into consideration to ensure the participation of all partners throughout the project?

Dora Raymaker:

One community partner, spontaneously said that he liked our group because we had shared leadership. So I think that one of the things that emerged pretty early was that everybody kind of had each other's back. There are lots of things that you can do to help a partnership, but also the people themselves and who they are, I think, matters. We had a group of people who, even if they didn't know each other at the start, were actually very caring and considerate of each other. So if somebody noticed that somebody else wasn't being heard, they would speak up. We all had a way that we monitored each other and shared that kind of leadership and facilitation to make sure everybody got heard. So that's one thing that I think was important and actually delightful about that group.

Another thing is that we had a lot of feedback mechanisms built into how we worked together. So I come from system science, not from health services, and I'm always very interested in dynamics and sort of larger structures and how things played out. We had a keep-change exercise at the end of every group. We had guidelines that we co-created that we then went back to yearly and said, "Okay, are these still the guidelines that we want," and made adjustments. We had a lot of processes for continual adjustment and it was through that that people would speak up and say things like, "You guys were going way too fast. I got completely lost."

Dora Raymaker: “Okay. So for next meetings, we need to slow down and do smaller chunks.” So I think the internal feedback processes is another piece that I think was really important, but I don’t think that would be as good if we didn’t have such a caring group of people.

A lot of people in the group also had more than one type of disability, so we got really good over time at learning how to support each other.

Christina Nicolaidis: One of the fun things that we really got to observe in some way is how much over time we all got better at predicting other people’s needs and preferences. All of the work happened at the actual community advisory boards, and those were made up of four people with developmental disabilities, a parent, a disability services worker, and then the academic partners were in the room. As Dora said, there was a lot of overlap of disabilities, but almost all of our community partners had at least—had either an intellectual disability, or were on the autism spectrum, or then on top of that, may have had other disabilities. At first, there were some competing accommodations at times, in that some of the things that the autistic partners needed to make language more precise and concrete made it harder for the partners with intellectual disabilities and vice versa. The partners with intellectual disabilities wanted things that were written in more plain language, but that actually made it harder for the autistic partners to understand.

And at first it was just so frustrating, because like I said, from the academic side we really wanted this to work and we wanted to make as many accommodations as we possibly could, but it felt like, “Wait a second, if I accommodate this person’s”—you know—

Hae-Ra Han: The other person feels—

Christina Nicolaidis: I’m hurting this person. It was just so frustrating. We’d get into a lot of impasses. They weren’t—it wasn’t like we were mad at each other, but it would just—people would get tired.

Hae-Ra Han: Challenging. Yeah.

Christina Nicolaidis: As time went on, I think we all—the community partners, the academic partners—ended up starting to kind of realize, “if I do that, that’s going to make the language more imprecise, or if I do that, that’s going to add extra words. How can I make it more precise without adding five extra words?”

So it got to the point that there was a lot of learning among the group. We think of co-learning as academics learning from community and community learning from academics, but this was a much more complex co-learning that ended up having such an easier time just throwing out possible solutions that actually worked for people than it was in the beginning.

Hae-Ra Han: Sure. I think in a way that’s why that having an open feedback loop for anyone to provide feedback was important, and I wonder how that process through which you provide feedback was created. Was that just part of natural evolution of your conversation or was it a deliberate effort to make that process as part of the research process?

Christina Nicolaidis:

We were pretty deliberate. Many of the members of the team, both on the academic side and on the community side, had experience doing CBPR in other contexts. So we didn't come into this with this blank slate. We deliberately built in change exercises and external evaluators were included from the beginning of the grant process. We had already done a fair amount of work around how we chunk things out and how we're going to have kind of clear agendas and what we were going to do. So this wasn't, oh, we just happened upon it, but then every project you do, you end up refining and learning a little bit more.

Hae-Ra Han:

Right. I think one of the biggest values that I see in your work that's presented in the paper is actually you were able to present sort of before and after the changes were made as a result of all of the CBPR processes in your survey items, in the words, languages you used in your survey questions. So to the listeners, who are listening to this podcast, I think you would appreciate the tables that are presented in the paper. In relation to that, I wonder what do you see as the main value, as the biggest value of your work.

Christina Nicolaidis:

I think for this particular paper I think the value—I guess it's actually just showing the value of a CBPR approach in making survey instruments more accessible. We often think of CBPR for qualitative research. I use CBPR for a lot of qualitative research.

Hae-Ra Han:

Yeah. Right.

Christina Nicolaidis:

But I think we underutilize CBPR in terms of just having quantitative survey research being more valid. I think in this case this is a good example, where I really think that we wouldn't have been able to even get the information if we hadn't used a CBPR approach. So I think outside of this particular project there is—I would love to see other groups also using a CBPR approach to make research more accessible to people with disabilities, people with different communication styles, people who otherwise might not be able to participate in research.

Hae-Ra Han:

How about Dr. Raymaker?

Dora Raymaker:

So, that was very concrete and practical and I'm going to get big and idealistic. For me, the main value of this work is the of larger connections between science and broader systems change in that I think that involving people, who have not been given voice in research, and giving them control over research that impacts their own lives creates another feedback loop that changes things. I mean it's not just the direct changes to—you know, any empowerment that might come out of the process or that kind of thing, but I think that the more we can show researchers that they can do this the more researchers will start involving populations with their studies instead of just as subjects, which starts a chain reaction of having studies that are more community relevant and then that community relevance means that the discourse that's going out into the world might be one that the community favors over what the experts think the dialogue should be.

So I think that to me the greatest value is the connection between this in a much longer game, and changing the dynamics between researchers, community members, and then the message that society gets what researchers are saying, because they're going to listen. You know, society in general is going to listen to some expert researcher well before they listen to some random, autistic woman, who they think can't communicate right. So that would be my big, idealistic answer.

- Hae-Ra Han:* So, in response to Dr. Raymaker's comments, I was raising another question in terms of the sustainability of the program, if there were any active plans to sustain the program, because when I was listening, the point was really that this is one of the first steps toward this line of research, so I was curious to learn if there is any active plan on your end to sustain the program, and if there is, if you would like to share with the audience?
- Christina Nicolaidis:* The larger picture that Dora was talking about is actually probably broader than this particular study or even this particular partnership. As we said, many of the people involved in this particular study had longstanding relationships and now we have even stronger relationships—
- Dora Raymaker:* True.
- Christina Nicolaidis:* There are quite a number of projects that have continued with various members of the group. For example, many of the people that were involved on the Oregon side of the project now have received a grant from the NIH [National Institutes of Health] to develop pregnancy-related resources for women with intellectual disabilities and women on the autism spectrum, so many of our community partners, many of the academic partners are part of that project. Dora and I co-lead an organization called AASPIRE, it's the Academic Autism Spectrum Partnership in Research and Education. We have a series of studies we have been doing that are all CBPR studies there too. They're all CBPR studies in terms of working on topics that are of importance to autistic adults.
- And then some of the members from the Montana group I know have continued working together on some projects. So this has spawned many things and is continuing in many ways. The project itself was a very specific observational study that, again, was actually called for by the CDC. I would love to, at some point, see some more intervention work that we might end up doing around violence against people with developmental disabilities, but in the meantime, there's quite a lot of continuation of, again, those same relationships in some of the history of working together and figuring out what works for the group.
- Hae-Ra Han:* Very exciting. So we're getting to the final question and I wonder if there is any other additional thought you'd like to share with us about the project?
- Dora Raymaker:* I found it to be a very satisfying project.
- Hae-Ra Han:* Okay.
- Dora Raymaker:* So I don't know what I'd do differently. I think that a lot of the earlier lessons learned got applied into this.
- Hae-Ra Han:* And then you were able to respond and then modify the process as needed, I think?
- Christina Nicolaidis:* Yeah. I think ultimately most everyone involved in the project felt that they had (A) really contributed to something that was important and (B) learned and grown. We may have taken different things from it, but I think we all really left the project feeling like we really had personally grown a lot from it.
- That being said, I wish the project could have continued. I wish that it came with us as an intervention study that wasn't immediate. Again, as I said, we've kept those relationships and we're all still working in the area, but now we're still writing papers. Even though the grant

funding has ended, we still have plenty of papers we're writing, so we keep in communication around the papers and every time I send something around the papers it's always like, "I miss you guys." You know? So yes, I wish there were a quicker, more immediate next step.

Hae-Ra Han:

That's right.

Christina Nicolaidis:

But we're working on it.

Hae-Ra Han:

Yeah. Yeah. I hear very satisfying—

Dora Raymaker:

I think my greatest hope for this paper is that anyone reading it who doesn't already know, that it will change what they think that people with developmental disabilities can do, particularly in terms of self-report as research participants, and as co-researchers within the research process. I think there's an idea that we can't do that type of work, but we can and I hope that people see that.

Hae-Ra Han:

That's a great point and I have to say that we do look forward to receiving more of your—and reviewing—more of your papers along the line. So thank you so much, Dr. Nicolaidis and Dr. Raymaker, for sharing your additional thoughts and experiences about the project. It's been a great pleasure talking to you both.

Christina Nicolaidis:

Thank you.

Hae-Ra Han:

Thank you so much.