Reaching People with Disabilities through Healthy Communities

Phase Five – Evaluation

[Karma Harris] Hello everyone! My name is Karma Harris, and I'm a public health consultant with the National Association of Chronic Disease Directors, also known as NACDD for short. I've had the privilege over the last few years of leading and managing the Reaching People with Disabilities through Healthy Communities project, which is a project funded by the Centers for Disease Control and Prevention (CDC).

This project really builds upon a previous Healthy Communities model used by NACDD and was modified to consist of six phases that really are a crucial part of the inclusive healthy community change processes that are focused on improving the health and well-being of people with disabilities. These phases are: Phase one is the Commitment phase, phase two is the Assessment and Training phase, phase three is the Prioritization and Planning phase, phase four is Implementation, phase five is Evaluation, and phase six is Communication and Dissemination.

So, for this podcast we have with us our New York State Expert Advisor, Ms. Rhonda Rosenberg, who is here with us today to talk about some of the activities involved in our phase five, which is Evaluation, and to get her perspective as a State Expert Advisor. We're also happy to welcome Mr. Yochai Eisenberg from the University of Illinois at Chicago (UIC), and also our project partners at NCHPAD, which stands for the National Center on Health, Physical Activity, and Disability, to this session to discuss some of the activities that we implemented to evaluate this project.

So, Rhonda, let's start with you. Start by telling us a little bit about your role; specifically, with the New York Department of Health, so maybe our listeners can learn a little bit about you and what you do on the disability and health side for the New York State Health Department.

[Rhonda Rosenburg] Sure. Hi Karma, I'd be happy to. And I want to say thanks for having me here today. My actual title is Project Coordinator for the Disability in Health program, or as we refer to it, the DHP. What I really do is that I work with colleagues in the DHP on projects that promote inclusion and focus on full participation of people with disabilities in health promotion programs.

I spend a lot of my time providing technical assistance and training, to both internal and external stakeholders, around tools and strategies that they can use to promote inclusion in their initiatives and projects. I also work with our bureau of marketing and creative communications to create and disseminate messaging around inclusive health promotion opportunities, inclusion strategies, and resources. And I also review social media that the bureau of marketing and creative communication has created for our entire bureau.

So, I review that messaging to make sure that it's inclusive with both its messaging and with its images. I also coordinate and convene our disability and health advisory group. And this is a group that is comprised of individuals with disabilities, their family members, and their caregivers. We have organizations and individuals, also, that work with people with disabilities and this group provides our program team with invaluable guidance on promoting statewide stakeholder collaboration, so we can

really ensure any of these changes that are made are sustainable and really do improve quality of life for people with disabilities.

And I have to say that I'm very lucky that I work with a program team that is highly committed to promoting inclusion. And we sit within a bureau that houses multiple programs, and all of these programs, and our bureau itself, is really highly committed to supporting and promoting healthy livable communities throughout New York state.

[Karma Harris] Very cool. I know I've always been a fan of the work going on at the New York Department of Health. And I love how you've integrated disability inclusion with a lot of your other programs, and this is exciting work.

Thinking about the two communities – so just as a reminder for our listeners, each of the five states brought two communities with them to the application and the New York communities were Cattaraugus County and Syracuse. And Rhonda, to be honest, these communities could not be more different. And I would love for you to give an overview for our listeners about your two communities, and just how different they are, which adds to the uniqueness of this work, I think, in the state of New York.

[Rhonda Rosenburg] Sure. Cattaraugus County is in western New York and it is really considerably rural. Syracuse is urban and it's located in the central New York region. It's really considered the economic and educational hub of the central New York region. These two communities are about a four- to five- hour driving distance apart, and each of these communities have their own really unique disparate population.

Cattaraugus County actually sits on a tribal reservation and each of the communities in Cattaraugus County are well versed with tribal cultures and norms.

Syracuse, on the other hand, has accepted more than 6,000 refugees from 40 countries in the last decade, and you may be surprised to hear that the school district in Syracuse actually speaks more than 70 languages! I would like to add here that while there's notable differences in these two communities, the one thing that these communities both had in common when we started this project, is that they both have very strong committed and really active inclusive health coalitions, and I believe that this really contributed to their ability to promote this accelerated policy systems and environmental changes.

[Karma Harris] Very nice. I couldn't agree more. I think both of these communities, while they are different, really have some of those common denominators in place, with their strong coalitions and committed community partners and really worked well to this project process. And speaking of that, in our evaluation, you're about to hear from Yochai where we really tied some of these aspects into the overall project evaluation. So next, I do want to hear from Yochai. So, Yochai, first, before we kind of dive into the evaluation discussion a little bit, tell us a little bit more about your specific role with UIC,

as well as your affiliation with NCHPAD, as sort of some background for our listeners before we dive into evaluation.

[Yochai Eisenberg] Sure, thanks Karma. So, I'm an Assistant Professor in the Department of Disability and Human Development at the University of Illinois at Chicago (UIC), and my research looks at how community design and community planning affects health for people with disabilities. As part of my work, I'm the evaluation lead for the National Center on Health Physical Activity and Disability and provide different kinds of evaluations support and technical assistance for evaluation activities for that role. And then, kind of in that role, I was linked with the work of NACDD for this project and was able and lucky enough to be able to lead the evaluation for the disability and healthy communities project.

[Karma Harris] Very cool. So, tell us a little bit about that evaluation, maybe from a high-level overview, in terms of your specific role with the project.

[Yochai Eisenberg] Yeah, for sure. So, the evaluation involved kind of a multi-level approach, being that this was a multi-level model implementation model. It required a multi-level approach for evaluation, as well. And by multi-level, what I mean is that, you know, we're looking at these national partners collaborating: the NACDD, NCHPAD, and CDC. We're looking at these State Expert at the state level who are providing this important technical assistance and training, and then we're looking at the local community-level. And then even down to persons with disabilities. And so really kind of looking across the socio-ecological model, and that's the kind of broad conceptual model that we use to help organize our evaluation.

This was a pilot project, right? So we were interested in learning about how well it worked, right? So that we could think about using it in in future work through the CDC. And because of that, you know, it's important to think about what kinds of barriers and facilitators the actual implementers of the model had. So, kind of understanding the processes used, and where there were barriers, looking at, in terms of the outcomes, you know, thinking about what was the impact of this project. We were interested in the reach and effectiveness of the policy, system, and environmental (PSE) changes that each of the communities took. And then you were also asking about, in terms of the process we used for developing this model. We took a very collaborative approach involving NCHPAD, NACDD, and CDC to really make sure that everybody's perspectives were incorporated.

[Karma Harris] And Yochai, as somebody with very limited, or amateur evaluation experience, such as myself, even though I was leading and managing this project, but knowing it's a national pilot project, and for the first time, it was intentionally bringing together public health traditional healthy community efforts with disability and health representatives, the thought of designing the right evaluation, just terrified me to be honest.

So that said, I think a lot of the state and community folks who might be listening to this segment probably felt the same way, especially if they don't feel that they are a true evaluators. So I'm really excited we're going to do a little bit of a deeper dive into this discussion because I think it could benefit them knowing, you know, if I'm not a true evaluator, you know, what kind of activity can I do to still evaluate our efforts, because we know that some activities are always better than none. And there's a lot of different things that we could think of that are doable.

And so, to that end, I would love for you to maybe detail some of the evaluation activities and things that we need to be thinking about; what we think about the word evaluation and evaluating projects like this. So, Yochai, can you sort of walk us down, take a few minutes, and walk us down our evaluation memory lane with this project?

[Yochai Eisenberg] Yeah. You know, I think that, you know, it's important not to think of, you know, being a true evaluator, or not. I think it kind of comes back to that idea of collaborative evaluation, which, you know, if you look at a lot of the CDC resources, they have really good resource documents on evaluation. That's all really about collaboration and really, it's about listening, right?

Listening to the people who are leading the project, and the people involved in implementing the project, because those are the people who know what's going to happen, and understand it, they can really inform the evaluation design. I think there's important things to consider in terms of the evaluation. Just the idea that the famous evaluation quote, that, you know, "What does not get measured, does not get accomplished." So really, is thinking about what we can measure and how we can measure it to help us answer important questions, that we think will inform the quality and outcomes of what's going on.

Also another important factor is considering the budget, in time, right? In an ideal world, we'd have a million dollars to do an evaluation, and we'd have a thousand assistants to help, in terms of data collection. But really, it's, you're kind of limited by a certain budget, as well as, you know, in some ways you don't want to overwhelm the people involved in actually carrying out the project. So those were some of the important considerations that we talked about; we don't want the actual coaches and State Experts to feel like they, all they were doing was evaluation, and not implementing anything.

And so, you know, as part of this we're still taking those into consideration, and then thinking about how to choose the right evaluation design. In this case, we leaned on the RE-AIM framework. So, the RE-AIM framework stands for: Reach; Effectiveness; Adoption, — so adoption of the tools and inclusion methods; Implementation – which in this case, is implementation of the policy, system, and environmental (PSE) changes and the model itself; and then Maintenance is the last part of the RE-AIM. So, kind of thinking about the sustainability of the intervention over time.

And so, we use that framework to help us in thinking about our objectives and our evaluation indicators and questions that really guided our activities in this process. So just to lay out our objectives, we're to look at, basically determining the implementation reach and effectiveness of the PSE changes, right? Those are really the most important kind of outcome related measures that we were looking at.

We also kind of wanted to understand, in terms of implementation, how communities used the disability and healthy communities model that was explained in earlier podcasts, even though we set up the model the same, each of the communities interpreted it in a different way, and maybe facing different barriers and facilitators to actually implementing it. So, it's important for us as evaluators to understand how did they, how did they actually implement it.

And then related to that, we wanted to understand what were those barriers and supports that influenced their work, and ultimately whether they were able to achieve the different PSE changes that they set out to accomplish. Because we know that actually being a part of the process can change an organization itself. We were also interested in understanding changes to the capacity of organizations who participated in this project, which, to us, gets to the maintenance piece, and gets to the sustainability of disability and healthy communities.

In terms of the activities themselves, you know, what this led us to, was to use a quarterly progress reports to… and that was done through online surveys. Using those to help capture some of the process and outcome measures that we were looking at and help us answer some of the questions. We also use the community action plans themselves. So, the plans that were discussed in previous podcasts, those are important data points for understanding what communities planned and how and how they created these community action plans themselves.

Some communities used the data from the CHII, Community Health Inclusion Index, very much to help inform their plan. Others maybe used a mix of the CHII, plus input from people with disabilities in the community. So, you know, these differences are important for understanding how things were implemented and what their impact was.

We also wanted to take a deeper dive, and so we also did interviews with the State Experts and the Community Coaches because that allowed us to have more informal conversations and get really stronger understanding of what were the barriers and supports, as well as how Coaches implemented the model itself. So really a mixed methods approach, quantitative and qualitative data, really helped provide a robust comprehensive evaluation to really understand how this, how this project worked and its impact.

[Karma Harris] Thanks Yochai. And thinking about all those activities that we all did as a group across each level as you explained, I really want to hear from Rhonda now, and Rhonda your specific role and vantage point as the State's Expert Advisor, talk to us a little bit about your perspective with completing some of the activities in your state expert advisor role.

[Rhonda Rosenburg] Sure. So, like yourself Karma, I really consider myself to have amateur evaluation experience. So when it, when I came on board, I was really pleased to find that the evaluation tools that were provided to both the State Expert Advisors and the community included really detailed directions and specific definitions, an example of how to document these policy, systems, and environmental (PSE) changes. So, it really made it fairly easy to update and track all of our activities.

And like Yochai mentioned, these reoccurring online progress report really kept the communities, and myself, on track with meeting our milestones.

So, this let our communities re-evaluate their action plans. Really pretty much frequently, more frequently than they would normally do, maybe, and really revise their action plans and rethink their work when it when it was necessary.

[Karma Harris] Now what was your experience like with your two communities and their activities?

[Rhonda Rosenburg] To be honest with you, we were really fortunate that both of our communities already had extensive experience with implementing PSE change and evaluation.

It really also helped that the evaluation team in this project was frequently reviewing and giving feedback on those PSE spreadsheets. So, my technical assistance activities were really rather limited during this phase. Most of my assistance activities really revolved around working with my communities, and best how to calculate the reach of specific projects in their action plan, and really ensuring that policies were written and adopted that would support the systems changes or environmental changes that had taken place, so that we could really be sure that sustainability was going to happen.

And again, as Yochai mentioned, another critical piece where I provided technical assistance was really working with my community, so that we could record any barriers or facilitators as they were working on the changes so we would have best practices recorded to reference in the future, if we wanted to work on accelerated PSE changes again.

[Karma Harris] So, Rhonda, thinking about all that, thinking about what you did as a State Expert, and hearing a little bit more about what your communities did, and how you kind of worked with them, I know one of the questions I'm asking through each of these podcast segments is, "What advice would you give to other states or communities who are listening to this about conducting this type of healthy community evaluation activities?" So, in other words, I know we've talked a little bit about what we've done, but is there any other advice you would give to our listeners that might be helpful to them?

[Rhonda Rosenburg] Sure. I'm reiterating somewhat some of the things that you and Yochai have already mentioned, but I did want to re-state, that remember, what does not get measured does not get accomplished.

So be mindful when you design your evaluation. You really want to ensure that something that's considered an incidental activity can be captured. Sometimes these really small-scale activities can really have a great impact, and with planning and collaboration your evaluation activities can truly be designed in a cost and time efficient way. Again, I can't stress enough that information from key

informant interviews should be incorporated at every stage in the process from planning and implementation to evaluation.

It's really important that you have a clear, concise, well thought-out action and evaluation plan. But, keep in mind that you need to keep it flexible, as well, as you get your feedback from your evaluation team, or local trends are happening, or your local needs change or your funding opportunity changes. You may find that you need to kind of re-scope that work in your action plan, and that's okay as long as you remain flexible.

And timing is everything. So really take a look at when your municipality, or the organization that you're working with, are scheduled to review and adopt any policy changes or ordinances. You really will achieve greater success if you propose and measure change when policies and ordinances are already going to be scheduled to be reviewed.

[Karma Harris] Yochai, in thinking about everything that Rhonda just said, what final advice would you have for state and community listeners who might be trying to embark upon inclusive healthy communities work, if you had just a final pep talk, what would you say?

[Yochai Einsenberg]

Sure. Thanks, Karma. So yes, I think Rhonda had some great points in terms of what you could follow. I guess restate what I said earlier: making this a collaborative effort and actually starting out as early as possible, so you don't want to have your project done, or midway through, and then say, "Oh, you know, we should evaluate this, we should evaluate that." You really want to start off early, start off before you implement it, as you're thinking about implementing it, involving your partners, involving those local stakeholders, bringing it to the local coalition that you formed, to make sure that the evaluation is relevant and to make sure that people with disabilities are involved too, providing local feedback and ideas.

This is some complex stuff, and you know we're still kind of working out some of the science for it, in terms of understanding how we measure and understand the impact of the PSE changes. So, you're getting a sense for how different PSEs will affect different populations in different ways and setting up that evaluation in the beginning can help make sure that you're getting that information appropriately, and that your impact is actually relevant for the local stakeholders.

And so, I think, you know, in terms of resources and funding, obviously, a lot of times there isn't those for evaluation, so you know, you do what you can, right? And I think in this case, there's some very valuable resources developed by NCHPAD and NACDD that can be used in local communities. So, the CHII was talked about, as well as some other tables and tools, and questions that can be replicated to help in terms of monitoring and evaluation overall.

So, you know, look to, look to, those resources. Look to those national centers that, that's, there. That's their role, is to help be that resource and technical assistance center for local implementation. So, seek those out. They're there, and they're there to help in terms of your evaluation, and the important piece that that plays in your project implementation.

[Karma Harris] Great, Yochai. That's really good advice. The only thing I'd like to add too is really encouraging those that might be sitting at the state level, to reach out to your state Disability and Health program if you don't currently work in that particular program.

And also, for our communities to reach out to their state Disability and Health program, if they have one. Because what we've learned is that those folks are really good resources on the Disability and Health side, but also are really good at providing state-based resources, and serving as a state liaison, sometimes between these national groups and the local-level work. So, I think that's important to consider. And as we bring this discussion to an end, I just want to thank Ms. Rhonda Rosenberg, who is our State Expert Advisor for New York, and our Project Evaluator, Mr. Yochai Eisenberg, for sharing both of your expertise and insights regarding evaluation.

I also want to thank our listeners for tuning into our conversation today about our Phase Five, Evaluation. As your time allows, just be sure to check out the next conversation where we talk about Phase Six, Communication Dissemination. We have our Iowa State Expert Adviser, as well as our project partners at NCHPAD, really doing a deeper dive into some communication techniques that we all need to learn about.