

Jill Harrison, PhD:

Hi, this is Jill Harrison, executive director of the National Institute on Aging IMPACT Collaboratory at Brown University. Welcome to the IMPACT Collaboratory Grand Rounds podcast. We're here to give you some extra time with our speakers and ask them the interesting questions that you want to hear most. If you haven't already, we hope you'll watch the full Grand Rounds webinar recording to learn more. All of the companion Grand Rounds content can be found at impactcollaboratory.org. Thanks for joining.

Vince Mor, PhD:

Thank you very much for joining us on this morning's podcast. We are speaking with Sheryl Zimmerman, Ellen McCreedy, and Tina Sadarangani, who gave a wonderful Grand Rounds yesterday about conducting embedded pragmatic clinical trials in community-based organizations and what it means to establish relationships with those organizations and get those organizations involved in research and engagement. So to introduce my members, I'm going to ask Sheryl Zimmerman briefly to introduce herself and then Ellen and Tina.

Sheryl Zimmerman, PhD:

Yeah, thanks very much, Vince. Sheryl Zimmerman. I'm a university distinguished professor at UNC Chapel Hill and I co-direct the Program on Aging, Chronic Illness, and Long-Term Care at the Sheps Center for Health Services Research. And I'm executive director of the National Center for Excellence in Assisted Living.

Ellen McCreedy, PhD:

Morning, my name is Ellen McCreedy. I'm an assistant professor at Brown University Center for Gerontology and Healthcare Research, and I'm going to be talking today about some trials in the assisted living setting.

Tina Sadarangani, PhD, RN:

Hi, my name is Tina Sadarangani. I'm an assistant professor at the NYU Rory Meyers College of Nursing, and I'm focused on adult day services and expanding access and reach to older adults from diverse communities.

Vince Mor, PhD:

Great, thank you very much. So Sheryl, I'm going to ask you a question that I asked yesterday on the Grand Rounds, but you spent a lot of time talking about assisted living, it's focus and its breadth across the country and also other community-based organizations such as adult day services programs across the country. Could you comment on whether there exists a comprehensive, complete sampling frame that is available for researchers who are interested in this world?

Sheryl Zimmerman, PhD:

No, there does not currently exist a complete sampling frame that is available to researchers to do research. I know a question was asked about the CDC because the CDC does do large national surveys, the National Post-acute and Long-term Care Survey, and they release their data I believe every two years. It's a wonderful, wonderful resource. If people don't have it, and Vince, maybe I'll just put a link somewhere in our Collaboratory so people can get access to all of their reports, but that is not a publicly available sampling frame.

So what best practices are, at least in my experience and what my colleagues do, is just the good old-fashioned way, you roll up your sleeves, you go to the states, you contact the states, you get their lists of licensed communities and work from there. So it takes time, it takes effort. And years ago we also used to talk about assisted living that wasn't licensed. I know the word came up when Tina did her presentation about shadow centers and services. Those exist in assisted living, but we don't really focus on them as much anymore because regulation has become, obviously, across all states, we can get very large lists which weren't available before.

Vince Mor, PhD:

Great, thank you very much. That's very helpful. So there was a wonderful question which we didn't get to in yesterday's Grand Rounds and it came from one of the attendees who asked, can you speak to the relationship building phase of your work? The questioner asked what you could offer, the home and community-based service prior to funding or in early stages is really limited. What worked for you to get in the door and establish these relationships? And Tina and Ellen, I know both of you have spent time doing this, would you want to each comment on that?

Tina Sadarangani, PhD, RN:

Sure, I'd love to Vince. I'm really passionate about this topic and I, like the person asking the question said, I started doing this work and establishing these relationships as a postdoctoral fellow. At the time all my postdoc gave me was a \$1,500 award to do any aspect of my research and I used that \$1,500 to go attend the annual meeting of the National Adult Day Services Association. And I just sat there as a listener, but I spent a lot of time, several days there just trying to immerse myself and understand the challenges that they were facing. And with that I was introduced to several people in the field who had done community-led projects. They were collecting data and they were seeking people to help evaluate their work. So a lot of people in these settings are collecting data. They are trying to improve quality in their settings and they may have readily available access for you to go help them with the research and evaluative component in which case you both are benefiting without a tremendous dollar amount of support going into that.

But I think going there and spending some time, using resources to do that, to understand their priorities and then trying to say, well, what work have you been doing? What data are you collecting? And starting with that, I would say my first project in this space was for evaluation of a statewide program in the state of California called the Community-Based Health Home Project, which the California Association of Adult Day Services started, and they embedded registered nurse navigators in a bunch of adult day centers using a grant that they had gotten, and they needed somebody to evaluate the results of having these extra nurses navigate care across community settings.

And so I was that evaluator. I did that work remotely. And then once I successfully did that, that became the basis of my understanding of how we can use adult day centers to integrate care across community settings and how do we do that in the absence of a registered nurse, which wasn't a scalable project and that's actually how the formation of my app came about. So, I think there's a lot you can do with very little, but if you can invest that time in your heart in supporting them and understanding their needs, you will be very successful.

Ellen McCreedy, PhD:

I would echo everything Tina said. If you want to do this kind of research and if you're passionate about this kind of research, I think that you just accept that there's a certain amount of in-kind work to build and maintain relationships that won't be funded. Having said that, there are some opportunities, and I

think the Collaboratory is an example of how we're trying to fund earlier phase work. I know at the Q&I center where at Brown where I do a lot of work, we also have a philosophy that we go in and we do some listening sessions with a new partner and figure out one kind of tangible, small, low-hanging fruit priority that we could help them evaluate that would get our foot in the door both for the data and for the relationship.

And usually we can find funding internally within the university or the pilots through the Collaboratory have been a great mechanism. But I think just taking something and working with that, figuring out, okay, what's one program you have going on right now that you would really like to see some more rigorous evaluation or some support in evaluating and starting there and then letting the agenda unfold. But certainly I think everyone in this space realizes that there's a lot of in-kind work in maintaining the relationship, but I think people who do this kind of work also really value those relationships. And for me it's one of the more rewarding parts of research.

Sheryl Zimmerman, PhD:

And I know this question wasn't directed towards me, but I would just love to add to that point, is that what you both just described, if we really ultimately want to be changing care practices, improving care and outcomes, hopefully impacting widespread practice and policy, we've got to start with the true and deep understanding of what's happening on the ground in the field, the NIH stage model, which directs us how to go through those different components. But if we don't start, just the way you said, if we don't do that, if we don't make the relationships and understand what is actually happening, then our pragmatic trials, they may be pragmatic as we're conducting them and give us information, but the likelihood of it going anywhere beyond there is going to be very slim, if we've not created interventions and tested interventions that can actually have traction going forward.

Vince Mor, PhD:

That was a beautiful summary. Thank you very much, Sheryl. I really appreciate it. So another question, it's actually very curious to me. So what's been your experience in working with these kinds of companies, your partners who participate in research with respect to their commitment and ability to sustain implementation of an intervention?

Ellen McCreedy, PhD:

Well, I can speak to Bluestone, the partnership with the physician service organization I spoke about yesterday in the Grand Rounds, and I feel that they have been a very engaged partner. Now the second part of your question is sustaining. So for the implementation side, they have several examples of how they have really stepped up in the implementation for projects that are prioritized by the organization. That's the key to all of this, this is what Sheryl is pointing to and also Tina in her comments is, we really need to figure out what the priorities are of the organization, which programs they really care about, where they're going strategically and support those programs, both in the implementation and clinical expertise, but also in the evaluation support.

Once you find that alignment, there's high buy-in, this goes back to the RAPT tool that I know the Collaboratory has supported, but that buy-in is so critical for getting the implementation completed and getting the evaluation completed. Sustainability is tricky because then priorities also may shift or just because we have new initiatives going in in the same organizations and there's a limited bandwidth to what can be maintained. So I don't know that even with high prioritized projects and strategies that their sustainment is still another whole can of worms in my mind. But I do think you get a long way with

buy-in or I've seen a lot of community buy-in and community partnership buy-in really tackling the few high priority items within the organization.

Vince Mor, PhD:

Thank you very much. Tina?

Tina Sadarangani, PhD, RN:

The question of sustainability has really come at the forefront of my work. And what I've learned most recently is that, and this may sound a bit callous for someone who's very passionate about community-based work, but money is at the center of it, right? All of these organizations that we're partnering with want to keep their doors open, they need to have a sustainable source of revenue and they are constantly, they recognize the need to innovate and come up with new programs and market themselves. And I think that is always going to be a priority to them. And I have increasingly found with my research that if you can explain to them that engaging in research, continuing to use these innovative interventions, like for the app I created, or entering data into this new database that they're doing so that they have more outcome information about adult day services, the more they do that, the more likely they are to be able to leverage additional funding streams to draw additional participants.

And I'll just say as an example, I tell these centers, there aren't many adult day programs that have an app where they're telling you, "Oh, your father did this today," or "He ate well," or "He had a great day at the center today." There's a real wall that exists between family members and these programs and there's a lack of transparency. And so when I talk to these centers, I say to them, you will have more people coming to your doors, most likely coming through here if you can say, you know what, I'm also going to share with you about your dad's day today and I'm going to be an active member of your care team and innovations like CareMobi and others help do that.

So I think from a sustainability standpoint, I've increasingly learned that their biggest priority is revenue to keep their doors open. And while research and engaging in research does, no matter what, require an investment of resources on a center's part, or community-based settings part, if you can help them understand how it benefits them in the long run in keeping their doors open, I think they are more likely to sustain engagement in that work.

Vince Mor, PhD:

Great. Thank you very much. That's great, great responses and leads right into the next question. What has been your experience with your partner's willingness and comfort with this whole idea of random assignment?

Tina Sadarangani, PhD, RN:

We have not gotten to that point yet, and I think that that's going to be a big question in adult day. I will say that any sort of thing that's kind of like an inequitable, that feels to them inequitable is going to be somewhat problematic. However, I also think that centers recognize the need for strong good science in this space. So we're not there yet and I would love to hear what the others have to say, but I do sense that it may be something that is going to be a piece that requires considerable education, discussion, collaboration to make it feel like whatever we're introducing into the center is something equitable that everyone can benefit from.

Vince Mor, PhD:

Great. So Ellen, why don't you talk about your experience so far?

Ellen McCree, PhD:

So I've done randomization in a couple of trials with our community-based partner, and I think it takes some education and some understanding their priorities. One of the things I was going to echo what Tina mentioned is the cost-effectiveness. We don't always do cost-effectiveness rigorously, but with the community-based partners and probably all our work, it's increasingly important to do that. And I think that as long as everyone's getting it and there's some wonderful designs in the pragmatic trial space where everyone gets the intervention, they just get staggered when they get it. That seems to be a palatable model, especially when you're going to show whether there's cost savings related to implementing this new intervention as part of the usual care practice.

So I think that combination of using a model with a staggered start, a stepped wedge or just a staggered parallel, really, as long as they understand that everyone in their community will get it, that feels equitable and in exchange for getting some good, not just patient-centered outcome data, which of course they're very interested in, and our partner is very interested in that data, but also showing some cost savings associated with delivering more patient aligned care.

I think if we could get better at that and really show that, and I think the timeliness of doing it. Our partner likes to move fast and I think a lot of organizations outside of academic research institutions move quickly. So being able to implement some of this work quickly is the other barrier. And I think Collaboratory somewhat addresses that, thinking differently about the types of funding because waiting for an R01 to come through does not work when an organization feels strongly about a program and wants to roll with it. So I think thinking creatively about how to fund and get these started quickly and using the staggered designs and doing cost-effectiveness evaluation is one of the keys to getting that buy-in.

Vince Mor, PhD:

Sheryl, do you have a comment here? Because you've been at this a long time.

Sheryl Zimmerman, PhD:

Well yes, thank you, Vince. It's kind of reassuring to hear how stable things are in the world across trials. We all began many, many years ago and what's happening now, but I'd like to share two things that's happened in my experience. Years ago, often it was, we would have a placebo and we found that that really wasn't necessary. And rather than worrying about that and educating our partners, people who were engaged in the trials, about the different designs of the study, we basically now have gotten nearly down to saying something akin to, for example, "We'll either be starting the training now or we'll be starting the training in six months and having more of an extended baseline in your community." Well, we all know that what's happening behind the curtain there is that they are serving as a wait list control, we're doing the intervention in the intervention sites, that's done, and then as a wait list control, we're giving it to the other communities.

We're being totally above board about it, but we're not burdening them with all of the different considerations that went into why you're getting the intervention now and why you're getting the intervention a little while from now. And, last point about this for me is that once they've agreed to participate, they've agreed to participate. Yes, there's challenges about, are we going to be able to get all the data we wanted in a timely way, et cetera. But if they're there, they're usually there and they're willing to, in my experience, understand that this whole research process is going to unfold as it unfolds.

Vince Mor, PhD:

Great. Thank you very much. Now for Tina and Ellen, I have a big question. Both Sheryl and I are quite senior, and you guys are relatively earlier in your careers. I want to ask you about your perspective as both junior faculty and making this significant investment in a relationship and working to be able to undertake a large-scale trial, whether it's embedded or phase three or phase four, that relationship building time, which is your most precious commodity, is your own time, how does that work and how do you feel about that as junior faculty sort of struggling to make a name and a place for yourselves? Tina, you want to start first?

Tina Sadarangani, PhD, RN:

That is just the most valuable investment I have made and continue to make in my career. I think you cannot be successful with any stage three, stage four, frankly, any feasibility study without investing time in those relationships. And again, I think as an early career faculty member, I'm trying to figure out, how do I be strategic about those relationships? How do I come up with publications with my community partners? How do I engage them so they don't just feel like I'm borrowing their site, but they're actually part of this?

And I think the more time you invest in learning that, and again, there are ways to generate strategic deliverables out of that, which I've touched on earlier, the more you invest in that, the more successful I truly believe your trials will be. And one of the reasons for that is because not only is it me investing my time in building these relationships, it is these adult day practitioners, their staff, who are investing their time in me to jump on the phone to teach me about the day-to-day challenges of running a program, the day-to-day questions and problems among family caregivers that they hear about, how they use, leverage person-centered care, which they've been doing for 100 years to better address the needs of people living with dementia in their centers.

So for me, it is extremely valuable learning as a K awardee, I view it as my education from them as part of my training. And then I think that investment only makes and expedites the process of your future trial. The one thing I will say though, is as a caution to other early stage investigators, is to budget additional time. If you are doing work in these settings and you are trying to implement any type of technology or innovation, it is going to take much more time than you think, and that is something in your timeline you need to account for because these centers most often have not been historically, as Sheryl pointed out yesterday, engaged in research. Most home and community-based settings have been left out of this work.

So there is a period of education that they need in implementing this work, and you need to work with them to understand how best to do that in their setting. Because as I said yesterday, especially in adult day, if you've been to one center, you've been to one center. But if you can invest time in knowing these nuances, it will make the whole process smoother down the line.

Ellen McCreedy, PhD:

Yeah, great comments. I agree with Tina. For me, there is a tradeoff. I think that we just have to admit there's a tradeoff. It just takes longer to get the collateral that we need for promotion and academics. The papers and the grants, everything takes longer in this type of work. And I was trained in the administrative data type of work and writing papers that way, and I think I just got excited about this. It gives me something that kind of just pointing to problems, not that that isn't needed, that is needed, but it motivates me. It's something that I feel passionate about. I like to feel like I'm making a difference and not just shouting out problems. And so this type of work, just appeals to me probably more than writing

papers and doing grants, which is not great for my promotion, but I think that this is just something that makes me want to go to work every day.

And so that's the reason for me to do it. And the rest, I think probably academics could be better at aligning the promotion and finding other ways to recognize these relationships and the time that they take. But I've been very supported in doing this work where I am and hopefully other junior faculty that want to take this type of path and are passionate about it are also supported. It's not for everybody. You should pick something... I think at the end of the day, you should do, if you like doing the econometrics, you should do the econometrics. And if you like doing partnerships with communities, you should do that because that's, at the end of the day what you get up and go to work for. So, I don't know. It doesn't always align perfectly well with the incentives, but it's a lot of fun. So I will continue to do it.

Vince Mor, PhD:

Thank you very much. So Sheryl, I believe that we can begin to start the process of phasing our careers out because we have two wonderful, wonderful new people to take our place in this world focused on long-term care and home and community-based services, because Ellen and Tina are just such wonderful advocates for this kind of engaged partnership research in this world that's so very, very important. With that, I'm going to thank the three of you so very much for your time for this podcast. I think it's really very helpful and important for the listeners and for our field altogether. Sheryl, any last comments before we close it off?

Sheryl Zimmerman, PhD:

I just would say Amen to what you said about being in very, very good hands with Ellen and Tina. I cannot tell you how much I learned yesterday during the Grand Rounds and also then even today during the podcast. It's just a pleasure and I've just great, great respect for them and the accomplishments they've made and are sure to make in the future.

Vince Mor, PhD:

Great. Thank you very much, and on behalf of IMPACT Collaboratory I wish you all adieu. Thank you very much. Goodbye.

Jill Harrison, PhD:

Thank you for listening to today's IMPACT Collaboratory Grand Rounds podcast. Please be on the lookout for our next Grand Rounds and podcast next month.